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Symptom Identification in the Chronically Critically Ill

Grace B. Campbell, BSN, MSW, CRRN, CBIS and
John A. Hartford Foundation "Building Academic Geriatric Nursing Capacity" Predoctoral Scholar, University of Pittsburgh School of Nursing 336 Victoria Building 3500 Victoria Street Pittsburgh, PA 15261

Mary Beth Happ, PhD, RN, FAAN [Professor]
University of Pittsburgh School of Nursing 336 Victoria Building 3500 Victoria Street Pittsburgh, PA 15261

Abstract

Ascertaining the symptom experience of chronically critically ill (CCI) patients is difficult due to communication impairment and fluctuations in patient cognition and physiological conditions. The use of checklist self report ratings is hampered by the inability of most CCI patients to respond verbally to symptom queries. In addition to the communication problems caused by mechanical ventilation, the apparently diverse idioms of symptom expression add to the potential for miscommunication regarding symptom experience. Although patient communication impairment is a major barrier to symptom identification, symptom assessment and treatment are fundamental components of nursing care for CCI. This paper reviews and describes the unique constellation of symptoms experienced by many critically ill patients. We report our observations of symptom communication among CCI patients and nurses and discuss inconsistency in the language of symptom expression among nurses and patients. Clinically applicable strategies to improve nurse-patient symptom communication and suggestions for refinement of symptom assessment in chronic critical illness are provided.

Keywords

Symptom assessment; chronic critical illness; nonverbal communication

Introduction and Background

A symptom is defined as a "subjective experience reflecting changes in the biopsychosocial functioning, sensations or cognition of an individual." 1 (p.669) Symptom amelioration comprises an essential aspect of nursing care during prolonged critical illness, as nurses intervene to minimize the psychological and physiological effects of noxious symptoms such as pain, dyspnea, and worry. Indeed, Doran and colleagues[2] proposed that symptom frequency and severity are nurse-sensitive patient outcomes. For the chronically critically ill (CCI) patient, who is typically mechanically ventilated and thus, nonspeaking, nurses' interpretation

(corresponding author) mhapp@pitt.edu Phone: 412-624-2070 Fax: 412-383-7227.
gbc3@pitt.edu Phone: 412-417-8804

of the patient's entire symptom experience (both physical and psycho-emotional aspects) becomes key to symptom relief.

More than a protracted period of acute critical illness, chronic critical illness is a distinct syndrome of multisystem alterations that includes metabolic, neuroendocrine, neuropsychiatric, and immunologic dysfunction. The only hallmark of this syndrome is the need for prolonged mechanical ventilation at some point during its trajectory. The CCI may be cared for in a variety of settings, including inpatient respiratory care units, long term acute care hospitals, and nursing homes. Despite receiving technologically advanced care, outcomes are poor in the CCI. This population exhibits high rates of mortality, poor functional status, and reduced quality of life. In essence, the CCI are those patients who survive an acute, life threatening episode but progress to a chronic and prolonged state of multi-organ compromise with recurring complications, prolonged dependence on medical and nursing care, high symptom burden, and poor outcomes.

Because of the prolonged, symptom-laden nature of chronic critical illness,3-5 it is incumbent on nurses to fully evaluate these patients' symptom experience. Although the perception of the individual experiencing the symptom is considered to be the “gold standard” for identifying and studying symptoms,1 obtaining data on symptom experience during chronic critical illness is difficult. Symptom assessment is impeded by communication impairments secondary to respiratory tract intubation and mechanical ventilation. In addition, recall biases and fluctuations in patient cognitive and physiological status hamper accurate retrospective recall of symptoms experienced.6 In one sample of CCI patients, 75% exhibited cognitive impairment at study enrollment, and nearly 40% exhibited cognitive impairment at the end of their RCU (respiratory care unit) stay.4 Such difficulty with symptom assessment may lead to inadequately treated symptoms and high levels of untreated pain or misinterpretation of nonverbal cues.7 For example, when he had finally regained the ability to speak, a CCI patient reported to the Speech-Language Pathologist (SLP) that the nurses misinterpreted his mouthed word as “pain” when he was actually requesting a pair of pants! (Brooke Paull, SLP, personal communication July 15, 2009). In a classic study, Baer and colleagues8 found that professional caregivers (nurses, physicians, and social workers) attributed higher pain levels to patients able to verbalize their pain than to their nonverbal counterparts. The authors speculated that professionals may believe that patients experiencing pain are responsible to verbalize their symptoms to the health care team to receive treatment. In contrast, in a retrospective record review of 52 mechanically ventilated patients, investigators reported that both physicians and nurses documented observable indicators of pain such as cardiorespiratory signs, body movements, and ventilator compliance more frequently than patient self reports of pain, indicating that physicians' and nurses' interpretation of symptom experience is an important aspect of providing care to CCI patients.9 Clinicians interprete physiological and behavioral signs as indicators of pain, however, dyspnea, anxiety, or fear, are also competing explanations for the meaning of these physiological and behavioral signs. Thus, we need to better understand the process of symptom assessment and symptom identification in the care of CCI patients.

Symptom Identification

Symptom assessments often employ checklist self report ratings. Many symptom surveys, such as the Memorial Symptom Assessment Scale, were originally designed for use in outpatient cancer care and require retrospective recall about symptom presence and intensity during the preceding days or weeks.[10],[11] These tools have also been applied to other chronic health conditions such as chronic obstructive pulmonary disease and AIDS.[12] Use of assessment techniques designed for the setting and type of population is crucial, as various symptoms may occur as a result of disease process or treatments experienced during the illness trajectory.[13]

The symptom experience of the CCI is likely to be quite different than that of cancer patients in an outpatient or community setting.

Nelson and colleagues3 applied the Condensed Memorial Symptom Assessment Scale (C-MSAS)[14] to CCI patients in an RCU. Using the C-MSAS, a self-report numerical rating scale, CCI patients were asked to rate symptom distress and frequency for each of 15 symptoms, using word descriptor scales (e.g., “Never” to “Almost constantly”). Seventy-two percent of queried patients in Nelson's study were able to respond to symptom questions at least once during their period of mechanical ventilation (“responders”). The number of times patients were unable to respond to queries was not reported. Symptom assessments were performed twice a week, for an average of 3-4 weeks, yet the mean number of responses to the twice-weekly symptom queries among the participating patients was 3.6 out of the potential 6 - 8 total opportunities. Patients were unable to respond to symptom queries for a variety of reasons, including “lacking capacity,” on a number of occasions. Patients unable to communicate by verbalizing, writing, or pointing to a card, were excluded from the study.3

Nelson's study[3] was the first to focus on the symptom experience of CCI patients receiving mechanical ventilation in the post-intensive care unit (ICU) phase of illness. Importantly, the use of prospective methods in this study avoided the recall bias and exclusion of non-survivors inherent in retrospective symptom experience studies, and recognized the necessity of symptom assessment on a ‘real-time’ basis. The exclusion of patients with complex communication difficulties, and the potentially high number of nonresponses in this study, highlight the need for improving symptom assessment methods for the most seriously ill and the CCI, typically the most debilitated nonverbal and cognitively impaired patients in ICU and post-ICU settings.

Puntillo's seminal program of research elucidated the importance of assessing, documenting, and treating pain among acutely critically ill patients, including procedural pain[15–17] as well as the generalized symptom experience during acute critical illness.[18] Critically ill, mechanically ventilated patients may, however, experience a wide range of other symptoms beyond pain and dyspnea that are difficult but important to assess. In three separate studies of CCI, symptoms were prevalent in over 90% of subjects; pain was predominant in a list of symptoms that also included dyspnea, distress related to communication, fatigue, and anxiety.[3–5]

Our research team is currently studying symptom communication between nonspeaking mechanically ventilated patients and their nurses to investigate relationships between communication performance, symptom management, and clinical outcomes in the ICU (K24-NR010244, M. Happ). Most patients in our study qualify as CCI, with the average time on mechanical ventilation 23 days at the beginning of study observations. Thus, we are gaining unique insight into the symptom experience and communication about symptoms, treatments offered and enacted in the care of CCI patients.

Conceptual Model

The conceptual model informing the work upon which this article is based is an adaptation of the Revised Symptom Management Model,[1] in which symptom experience and treatment are proposed to be mediated by nurse-patient communication [Figure 1]. Difficulty, quality, and success of nurse-patient communication may impact symptom identification and treatment, in turn potentially affecting clinical outcomes such as days of mechanical ventilation, ICU length of stay, hospital length of stay, and comfort over what is usually a very protracted course in acute care settings. Further, the relationship between nurse-patient communication and symptom experience is likely bi-directional. That is, while the communication process impacts symptom interpretation and treatment, the nurse's interpretation of the CCI patient's symptom

experience may also affect subsequent nurse-patient communication. Appropriate symptom treatment is crucial, as it may impact clinical outcomes including length of ICU stay and weaning from mechanical ventilation.

When direct patient-nurse communication is difficult or impossible, symptoms experienced by nonverbal CCI patients must be interpreted by proxies (for example, family or members of the clinical teams) for treatment to occur. Research, however, has suggested that proxy symptom reports show low to moderate concordance with patient symptom self reports.5,18 Learning more about patient-nurse communication (both verbal and nonverbal) is crucial, then, to improving the accuracy of symptom assessment and treatment with CCI patients.

The remainder of this paper will discuss symptoms commonly experienced by CCI and/or mechanically ventilated patients. We include insights gleaned thus far during our study of nurse-patient symptom communication and the clinical implications for critical care nurses.

Symptom Assessment and Symptom Communication in CCI

Nelson[3] pioneered the identification of a unique set of symptoms experienced by CCI patients, which has been further expanded upon by Wiencek.[5] Li[19] conducted similar work with mechanically ventilated ICU patients. Although studies of outpatient cancer patients identified pain, nausea, depression, and fatigue as the most commonly reported distressful symptoms, [13] studies of CCI patients identify a constellation of symptoms that seem related to respiratory failure and respiratory tract intubation. The critical care studies suggest that CCI patients experience a different set of symptoms than other populations, and that this symptom set may require unique assessment and management techniques.

The most frequently noted symptoms among CCI patients in the Nelson et al. study included pain, lack of energy, difficulty communicating, thirst, dyspnea, and psychological symptoms such as sadness, nervousness, and worry.[3] Over 50% of patients reported experiencing these common physical symptoms at levels termed “quite a bit” or “very” distressing. Moreover, psychological symptoms were more prevalent in the CCI than physical symptoms. Nelson and colleagues found that 70% of the sample experienced worry on a “frequent” or “almost constant” basis, and over 60% reported a similar frequency of both sadness and nervousness. These results are congruent with a review of several studies of symptom assessment in ICU previously performed by Nelson's group in 2001,[20] in which they concluded that, in addition to pain, ICU patients frequently experience high levels of dyspnea, anxiety, and fear while being mechanically ventilated.

Li[19] noted a similar symptom constellation in a pilot study of coexisting symptoms of mechanically ventilated ICU patients in which all study patients reported some degree of dyspnea. Forty percent of the sample experienced severe thirst and moderate to severe pain, while moderately intense tiredness, hunger, generalized discomfort, and depressed feelings were experienced by more than 30% of participants. In addition, Wiencek[5] performed a secondary analysis of a CCI database in which both patients and proxies responded to the question, “What symptoms are most bothersome at this time?” Congruent with other studies' findings,[3],[19] patients were most bothered by pain, fatigue, and respiratory distress. Further, proxy respondents thought that patients were most bothered by pain, loss of independence, communication difficulty, and impaired cognition.[5]

Puntillo's18 qualitative exploration of how nurses assess and treat symptoms among nonverbal critically ill patients provides further insight into the symptom experience of acute and chronic critical illness. This study focused on the nurse's assessment process and subsequent choice of treatments for patients unable to self report. Using a series of open-ended questions, interviewers queried nurses about the approaches they used to identify symptoms and to select

treatments to alleviate those symptoms. Based on these interviews, Puntillo[18] surmised that when confronted with patient inability to self report symptoms, nurses rely on physiologic signs (e.g., heart rate, blood pressure), behavioral signs (e.g., tearfulness, restlessness), or a combination of both to identify that symptoms are present. However, similar changes in vital signs or behaviors may be associated with many different symptoms. For example, elevated heart rate, blood pressure, and respiratory rate could be signs of pain, anxiety, dyspnea, or fear. How, then, do nurses identify the specific symptom and provide appropriate treatment? One possible explanation is that nurses may use their own personal or professional experiences to find potential meaning in their observations of the patient, and provide treatment based on these personal interpretations.[18] Puntillo's study further illustrates the key role that nurses play in the assessment and interpretation of symptom manifestations in understanding and treating symptoms of the nonspeaking CCI patient. These studies demonstrate that ICU patients experience a range of symptoms that are difficult to accurately identify. The logical implication of these findings is that this range of patient symptoms continues to be under-assessed and undertreated in the ICU.

We recently conducted an extensive literature review to identify definitions of the symptoms likely to be experienced by CCI, mechanically ventilated patients. These definitions were used to identify symptoms from 356 videorecorded observations of nurse-patient communication among 89 nurse-patient dyads. These patients had been intubated an average of 23 days before enrollment in the study. Overall, the group's median length of time on mechanical ventilation was 35 days during lengthy hospital stays, ranging from 7- 297 days (median = 50 days). When applying literature-derived definitions to actual communication between nurses and CCI patients, we noted the use of inconsistent and overlapping terminology for naming and describing symptoms as well as some differences between patients and nurses in language used. Such discrepancies may contribute to a lack of congruence noted in some studies between patients and surrogates (nurses or family caregivers) when identifying symptoms.[5] Some of the differences between literature and nurse-patient terminology are shown in Table 1.[21-34] We concentrate here specifically on the set of symptoms most common among CCI patients.

Pain

Visual analog scales (VAS) or verbally administered numerical rating scales (NRS) have been used to assess pain. As with other types of self report instruments, impaired cognitive, physical, and communicative abilities may prevent adequate patient expression of symptom distress. Several published pain assessment scales have been designed for use with nonverbal patients, including the Behavioral Pain Rating Scale,35 the PAIN Algorithm,36 the Behavioral Pain Scale,37 the Nonverbal Pain Scale (NPS),38 the Pain Behavior Assessment Tool,17 and the Critical Care Pain Observation Tool.39 (See Table 2 for a synopsis of these instruments. For an in-depth discussion of these instruments, there are several reviews of interest.40-43) Some of these scales combine physiological and behavioral signs of pain with technology interface (i.e., ventilator asynchrony).[44]

Despite increasing awareness of the prevalence of pain in the CCI since early work highlighting this issue,[7] high rates of unrelieved pain remain in critical illness.[3,5,20] In our review of video recorded care episodes, we have noted that nurses often query patients regarding presence of pain, which patients may deny. Despite patients' denial of pain, the focus of conversation during the remainder of the care episode frequently involved identifying and resolving various noxious stimuli such as nasogastric or endotracheal tubes, positioning issues, room temperature, or even wrinkled linens, all of which cause great patient discomfort, if not pain. Perhaps pain represents to nurses a set of conditions related to various aspects of physical discomfort. By using a broad conceptualization of pain assessment to include various sources of discomfort, nurses may seek to decrease the perception of pain among the CCI.

Lack of Energy and Fatigue

Although lack of energy is a distinct symptom on assessment checklists such as the C-MSAS, this symptom label is not widely used in the literature, appearing in only one article.[21] Most authors refer to fatigue,[22],[23],[45],[46] and may equate fatigue with lack of energy.[45] Fatigue is defined as a "subjective, unpleasant symptom…ranging from tiredness to exhaustion" interfering with the "ability to function."23 (p.527) Inherent in these definitions is the implication that fatigue affects one's ability to perform mental and/or physical work. Some authors note that 'tiredness' implies a temporary situation of energy depletion, while 'fatigue' connotes a chronic condition.[22] This level of discrimination is difficult, and perhaps unnecessary, in sedentary, bed-ridden critically ill and CCI patients.

We found, during observations of video recorded care episodes, that several terms are used interchangeably by patients and nurses. Symptom terminology and descriptors that were not included in formal definitions of lack of energy, tiredness, and fatigue, were often used by patients and nurses to seemingly describe tiredness and lack of energy. For example, while patients do not commonly complain of lethargy, nurses frequently described patients' as "lethargic" in clinical documentation and in conversations with other team members, such as physicians and respiratory therapists. Likewise, although considered distinct in academic symptom definitions, nurses and patients often used the terms 'sleepy' or 'drowsy' when discussing patients' tiredness and lack of energy. Finally, 'weakness' is defined as objective measures of muscle strength, [21] yet patients and nurses also use the term, 'weakness,' when discussing the subjective experience of fatigue and lack of energy. In our video examples and review of nurses' clinical record documentation, nurses and patients appear to equate 'weakness' with the subjective sensation of inability to perform physical activities rather than an objective assessment of muscle strength. These findings illuminate the need for nurses caring for the CCI to be aware of the various types of fatigue or lack of energy that this population may experience. Ameliorative interventions for muscle weakness or deconditioning are different than those appropriate for sleepiness. The few extra minutes needed to delve more deeply into patients' individual experiences of lack of energy could result in greatly improved symptom management. The nurse may wish to query patients for the presence of sleepiness, muscle fatigue or weakness, and ability to participate in functional activities (such as turning, getting out of bed) in order to fully assess fatigue and determine appropriate interventions.

Thirst and Dry Mouth

Nelson's work exploring the symptoms experienced by CCI patients showed that thirst is a distinct symptom experienced at high rates among critically ill patients, and this symptom was added to the modified C-MSAS.[3] The symptom literature uses patient self-report regarding degree of distress related to dry mouth rather than describing or defining thirst. Thirst is presented as the result of a dry mouth, implying that the two often occur concomitantly and is described simply as a desire to drink fluids.[24] No conceptual work has been published to differentiate between thirst and dry mouth. Nurses and patients in our video recorded care episodes certainly used these terms interchangeably. Treatment for these two symptoms was often the same, consisting mostly of offering mouth swabs and lip moisturizer, and when appropriate, ice chips.

In contrast to CCI, the oncologic symptom literature contains numerous references to dry mouth (xerostomia), a common side effect of many cancer treatment regimens.[47] Dry mouth is also common in other populations such as renal dialysis patients48 as well as among healthy elderly people, in addition to those with chronic illnesses.47 Subjective "thirst," however, receives little attention in the chronic illness literature. CCI patients have the added "drying" insult of oral or tracheal intubation *and* may be unable to safely swallow oral fluids, causing thirst and dry mouth to be particularly distressing. Thus, thirst and dry mouth are overlapping,

interdependent symptoms among ventilator-dependent CCI patients that require frequent nursing assessment and treatment. Nurses can ask about both dry mouth and thirst in order to determine the most appropriate interventions for the patient's particular symptom experience.

Dyspnea

Most nurses are extensively trained in assessment of breathing difficulties. Objective measures of breathing effectiveness such as noting respiratory rate and character, observing for cyanosis, auscultating for adventitious breath sounds, and measuring oxygen saturation, are basic aspects of physical assessment for most patients. However, the patient's experience surrounding breathing difficulties may encompass much more than can be gleaned by observation of physiologic signs. The subjective experience of dyspnea is comprised of 3 dimensions: physiologic, functional, and psychological.[27] Physiologic aspects reflect measurable parameters such as respiratory rate and oxygenation levels. Functional aspects of dyspnea are expressions of the affect breathlessness has on the patient's ability to complete various activities of daily living. When patients discuss psychological aspects of dyspnea, they refer to emotional state(s) associated with difficulty breathing, such as feelings of suffocation, fear, or anxiety. Thus, nurses and CCI patients address various aspects of shortness of breath when communicating about their symptoms. In nonverbal patients, it is difficult to ensure that patient and nurse are discussing the same aspects of the symptom. For example, when patients in our study reported shortness of breath or feelings of difficulty breathing, especially during ventilator weaning trials, nurses would often respond: “Yes, you're tired from breathing on your own. We'll put you back on the vent now so that you can rest,” implying a functional focus. Nurses also addressed the physiologic aspects of dyspnea, for example, informing a patient who complains of shortness of breath that her “numbers” (pulse oximetry) are below the desired level, and that the weaning trial will be discontinued.

Less commonly were nurses and patients observed discussing possible feelings of fear when patients reported breathing difficulty. This may be due to the difficulty in communicating abstract emotional constructs in the presence of respiratory tract intubation. To ensure that all aspects of the experience of dyspnea are addressed, nurses could ask patients whether they are afraid when they experience breathing difficulties. When patients exhibit signs of possible anxiety, nurses should remember that, even in the absence of physiologic data indicating poor oxygenation, patients may feel a sense of dyspnea and react with anxiety or fear; asking patients whether they feel short of breath may provide an opportunity for reassurance and education and reduce the need to administer anxiolytic medications. Further, because of the multiple meanings and labels used for tiredness by both patients and nurses, it is important for nurses to fully validate patients' symptom experience through clarification whenever possible. For example, a nurse might ask, “I want to make sure I understand, are you feeling sleepy or tired from the breathing work?”

Psychological Symptoms

Emotional or psychological symptoms are often experienced by the CCI and critically ill individuals. [3,19] Sadness and depression, fear, worry, anxiety or nervousness are terms that nurses in our study used when naming these abstract constructs. As with other symptoms, we observed that clinicians and patients used terms interchangeably that the definitional literature treats as distinct constructs. For example, anxiety is defined as a somatic response characterized by a vague, generalized feeling of uneasiness or increasing tension. It may be accompanied by objective signs such as trembling, cardiovascular excitation, and motor agitation.[28,29] In contrast to generalized anxiety manifested by somatic responses, worry is described as a purely cognitive symptom in which the negative feelings have some specific object.[30,32] That is, while anxiety is generalized, worry is about something specific. In our observations, nurses and patients do not seem to make these distinctions regarding generalized versus specific origins

for the subjective feelings. Rather, worry and anxiety are used interchangeably with "nervous," and even colloquial terms. One patient reported feeling "jumpy" in several videorecorded sessions, without clear identification of cause. Nurses offered various treatments including reassurance, anxiolytic medications, and analgesia.

Communication Difficulty

Communication difficulty ranks as one of the most common, distressing symptoms of CCI. Although it is a "condition" caused by respiratory tract intubation, communication difficulty certainly meets the definition of symptom as a "subjective experience reflecting changes in the biopsychosocial functioning…of an individual." 1(p.669) Nurses may not regularly assess or document this condition; yet, it remains a frequent source of distress among ICU patients.[49] Nelson's group, the first to designate difficulty communicating as a "symptom" in chronic critical illness, found that difficulty communicating was one of the most distressing symptoms experienced by two separate samples of the mechanically ventilated, comprising 50 CCI patients[3] and 100 critically ill cancer patients,[20] respectively. This finding is corroborated by studies of perceived stressors during critical illness,[50-53] and studies of the experience of mechanical ventilation and of nurse-patient communication in the ICU.[34,54,55]

Other psychological symptoms such as anxiety, panic, frustration, anger, and sleeplessness are associated with the inability to communicate during mechanical ventilation treatment.[30,49-51] These psychobehavioral symptoms are often treated with sedating medications which can prolong treatment with mechanical ventilation and may cause or potentiate delirium, further isolating the critically ill patient from nurses and family visitors and placing them at risk for adverse sequelae of critical illness. Moreover, hospitalized patients who have a communication impairment are more likely to experience a preventable adverse event than patients without communication impairments.[56] These studies have clearly established the problem and potential consequences of communication impairment during critical illness. Yet, we have noted infrequent explicit assessment of this symptom by nurses. The literature on communication difficulty documents few nurse-initiated ameliorative interventions.[57] Nurses should maintain heightened awareness of the prevalence and serious consequences of communication difficulty among those with CCI, and should include assessment of communication difficulty in their plan of care.

In addition to involving other members of the interdisciplinary team, particularly the speech-language pathologist, to assist with evaluation of communication difficulties and initiation of appropriate interventions, the nurse can advocate with the entire care team to facilitate consistent use of recommended adaptive communication strategies during all care interactions, potentially resulting in improved symptom identification and management by all disciplines.

Clinical Implications for Critical Care Nurses

The CCI symptom research literature reviewed in this paper highlights the unique symptom burden experienced by this population. Symptoms commonly experienced include pain, lack of energy, thirst, dry mouth, psychological symptoms such as anxiety and worry, and communication difficulty. Complicating symptom identification is a lack of universally agreed-upon definitions for these distressing symptoms. Literature-based definitions, a foundation of symptom management research, may differ from the language of symptom expression used in daily practice by nurses and patients. Improving nurses' appreciation for language or naming differences and their understanding of the importance of validating the interpretation of symptom messages with nonspeaking CCI patients is essential to improving symptom management in this patient population.

The central role of communication difficulty as both symptom, and as context in which symptoms are interpreted, is critical to understanding and improving the symptom experience for CCI patients. The research literature has clearly established the problem and potential consequences of communication impairment during prolonged critical illness. Addressing communication impairments and preventing the detrimental effects of communication difficulty is a safety and quality of care concern for critical care nurses. There is a growing recognition that improved communication is essential to improve the quality and safety of healthcare in America;[58],[59] however, patient communication impairment has received little to no attention in critical care quality and safety research. Nonvocal critically ill and CCI patients are at risk for suboptimal management and high distress over a protracted course of illness. In addition to improving the patient's critical care experience, improved communication performance between the patient and nurse may reduce misunderstanding, misinterpretation, and missed communication that can be potential sources of error.

Interventions to improve patient communication in the ICU have been described and pilot tested with mixed, but promising, results.[57],[60-67] Recently, there are multiple resources for structuring patient communication interventions and improving nurse communication skills.[63],[68],[69] The speech-language pathologist can be a key member of the interdisciplinary team for CCI patients, recommending assisted communication strategies based on an assessment of the patient's motor and cognitive abilities, and providing a resource for staff, patients, and family/significant others.

Communication difficulty with nonvocal patients may discourage critical care nurses from directly asking about many symptoms, especially psychological symptoms such as sadness or worry. When patients are nonvocal, whether due to intubation or to physical or cognitive deficits, nurses essentially ‘control’ the conversation and are responsible for naming the symptoms being experienced. Treatments are based on the symptom labels assigned by the nurse. However, as Puntillo[18] noted, nurses may provide “treatments” based on observation of objective signs such as vital sign changes, without fully ascertaining patient perceptions about current symptoms. Yet these objective signs could indicate a number of potential subjective sources of distress. Symptom assessment is incomplete without explicit validation of the patient's subjectively experienced symptoms, and symptoms that are not fully assessed cannot be adequately treated. In addition, if nurses attempt to elicit self-report information about the symptom from the patient, but the communication difficulty is too great, the patient may acknowledge symptoms such as pain or dyspnea, because communicating about more subtle symptoms is simply too exhausting or too frustrating.

Nurses combine observation of signs with context and empathic interpretation of how they might feel in a similar situation[18] to identify potential symptoms. Identification, clarification, and validation of the subjective symptom(s) being manifested through the signs observed by the nurse should be accomplished using as many communication techniques as possible, including communication boards, tagged yes/no questions, or computer technologies designed to permit patient self expression.[63] While these augmentative communication techniques are not appropriate for heavily sedated or comatose patients, they can provide useful adjuncts to care for many conscious patients struggling for a way to communicate with healthcare providers and their loved ones.

Critical care nurses can further positively impact the care of the chronically critically ill by maintaining familiarity with the symptoms most commonly experienced including pain, lack of energy, thirst, dry mouth, dyspnea, psychological symptoms such as anxiety and worry, and communication difficulty. Providing appropriate treatment still depends upon accurate symptom identification by the nurse. Nurse awareness of the most frequently occurring symptoms, combined with use of easily learned communication techniques, permit healthcare

providers of all disciplines to obtain patient reports of symptoms and enabling targeted treatment of those symptoms.

Simple Techniques to Improve Symptom Communication

Commercially available communication boards or "printed" communication boards developed by nurses or SLPs can facilitate communication about symptom location (body part), intensity (visual analogue or numerical rating scales), and quality (descriptor word list). Communication board examples are available at http://www.pitt.edu/~speacs and from the CD-ROM accompanying the Beukelman, Garrett, and Yorkston text[64] or from commercial sources (see http://www.vidatak.com/).[66] Nurses can encourage the consistent use of gesture and pointing to indicate symptom location and intensity.[70] Topic communication lists for symptom identification can help narrow the focus of symptom queries.63 Establishing a clear and consistent YES – NO response with patients facilitates accurate confirmation and validation of the patient's message.34,68,[71] For patients who are sedated or have difficulties with attention and focus, tagging the end of a YES-NO question (Example: "Are you having pain – Yes (slight pause) or No?") can provide the focus necessary for the patient to complete a response.[72] At minimum, nurses should gain the CCI patient's attention before speaking, speak clearly, slowly and provide adequate time for the patient to respond 73 (For additional communication tips, go to http://hartfordign.org/uploads/File/nursing_counts/AJNFinal5_06.pdf).

Because most CCI patients have tracheostomies, they can be encouraged to mouth words in a slow, exaggerated manner while pointing to the first letter of each word as it is mouthed. This technique, "first letter spelling," can increase accuracy of lip reading when patients are cognitively intact, fairly literate, and able to point74,75 Patients who are cognitively intact and have good arm and hand coordination can be assisted with writing using clipboards, pen grips, and other adaptive writing supports.[64] Involve occupational therapy to obtain the adaptive equipment best suited to patients' abilities and consult speech language pathology for patients with complex communication needs such as those with limited upper extremity movement (e.g., spinal cord injury, Guillian Barre, myasthenia gravis, cerebral vascular accident).

Future research

Finally, further clinically-based research is needed, with collaboration between bedside nurses and researchers, to further illuminate the language of symptom experience most commonly used by the chronically critically ill. Patricia Benner[76] describes how nurses learn from patients, developing the learned information into sets of "common meanings" that "evolve over time and are shared among nurses." 76(p.6) Researchers and nurses caring for the CCI can further the development of these shared common meanings, with the goal of better understanding the symptom experience in the CCI to facilitate improved management and improved patient outcomes.

Conclusion

Accurate assessment and appropriate treatment of identified symptoms is a vital nursing role when caring for the CCI, with their high incidence of cognitive impairment and communication barriers such as sedating medications, artificial airways, prolonged mechanical ventilation, and protracted stays in acute care settings. Effective symptom management is associated with improved patient outcomes such as more ventilator-free days and shorter lengths of stay.

Mechanically ventilated critically ill adults may manifest symptoms via various behavioral and physiological signs that could be associated with a variety of symptoms. Evidence has shown that the CCI most frequently experience pain, lack of energy and fatigue, thirst and dry mouth, dyspnea, anxiety and worry, and communication difficulty. It is imperative that nurses caring

for CCI patients understand the unique symptoms likely to be experienced by their patients, and allow sufficient time for adequate assessment of these symptoms. Nurses need to educate the CCI and their families that emotional and psychological symptoms such as anxiety, fear, and worry are common, and permit patients to acknowledge these feelings. It is also incumbent upon nurses to work with the interdisciplinary team to implement appropriate communication strategies to facilitate patient communication of their symptom experience and to allow patient participation in selecting effective, timely treatment of those symptoms.

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Figure 1.
Symptom Communication, Management and Outcomes Model. (based on Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. J Adv Nur 2001; 33(5): 668-676.)
Key to abbreviations: ICU = Intensive Care Unit; LOS = length of stay; MV = mechanical ventilation

Table 1

Definitional Terms for Common Symptoms in Chronic Critical Illness.

Symptom and references	Literature-Derived Definition	Nurse-Patient Terminology
Lack of Energy[21,23]	• Fatigue • Ranges from tiredness to exhaustion that interferes with ability to function • Decreased capacity to perform physical and mental work • Physical, emotional, or cognitive tiredness	• Lethargic (rarely used by patients but often by nurses) • Tired • Weak • 'Worn out' • Sleepy • Drowsy
Thirst [24]	• Desire for fluid, especially water • The urge to drink • Often the result of dry mouth	• Asking for water • Asking for mouth care • Pantomiming drinking or mouth care (often used by nonverbal, intubated patients) • Nurse statements that patients must be thirsty because their mouths appear dry
Dry Mouth[25,26]	• Subjective complaints of dryness, burning of oral mucosa • Difficulty chewing or swallowing • Objective observations of dry, cracked lips, furrowed tongue • Presence of oral candidiasis	• Same terminology as for thirst, used by both nurses and patients
Dyspnea[27]	• Three key dimensions: • (1) Physiologic : measurable parameters (respiratory rate; oxygenation) • (2) Functional : effect of dyspnea on ability to perform activities of daily living • Psychologic : emotional states related to difficulty breathing (fear, anxiety)	• Can't catch breath • Having 'trouble' breathing • 'Numbers' or 'Oxygen' look good/bad (remarks made by nurses when patients note breathing difficulty) • Tired from breathing(usually associated with a weaning trial) • Fear, anxiety related to dyspnea less commonly discussed
Anxiety[28,29]	• Vague uneasiness or increasing sense of tension • Nonspecific state of uneasiness • A somatic, rather than cognitive, symptom	• Anxious • Nervous • Worried • Jumpy • Restless
Worry[30–32]	• Negative affect associated with perceived inability to control or obtain desired results in a future situation • A negative emotion about a specific event or object (not a vague, generalized feeling, as with anxiety) • A cognitive, rather than somatic, symptom	• Same terminology used for anxiety, by both nurses and patients

Symptom and references	Literature-Derived Definition	Nurse-Patient Terminology
	• May be the cognitive counterpart to generalized anxiety	
Communication Difficulty[30,33,34]	• Distressing communication impairment, primarily the inability to speak, understand messages, and/or be understood Inability to represent thoughts, feelings, desires and needs fully to others • Distressing problem with speech, word recall, writing and/or gesture	• Often expressed as frustration (by patients and nurses) or anger (by patients) related to communication problems

Table 2

Pain Assessment Tools for Nonverbal Patients

Assessment Tool	Features	Score Range	Advantages and Disadvantages[40]
Behavioral Pain Rating Scale [35]	• 4 behavioral domains (restlessness, tense muscles, frowning or grimacing, patient sounds)	• Each domain rated on a 3-point scale • Total score ranges from 0 (no pain) to 12 (most pain).	• Demonstrated reliability and validity only in Post-Anesthesia Care Unit patients without neurological problems or major complications, limiting generalizability to other populations • Not tested in ICU, non-ICU settings, or in CCI • Accuracy may be decreased if movement is restricted due to sedation, weakness, or restraints • Requires some vocal ability • 0-12 scoring may be difficult to understand, as many other tools use 0-10 scoring
PAIN Algorithm[36]	• 6 behavioral domains (facial expression, movement, posture, vocal sounds, pallor, perspiration) and 3 physiologic indicators (heart rate, blood pressure, respiration) • Nurse rates presence or absence of pain behavior in each domain or indicator	• Nurse appraisals of pain behaviors converted to 0-10 numeric rating scale • Score used to guide management of pain based on algorithm	• Moderate reliability and validity found in one study • Not tested in non-ICU settings or in CCI • Length of the tool may limit clinical utility • Pain behavior ratings are not standardized or defined, introducing nurse subjectivity
Behavioral Pain Scale [37]	• 3 behavioral domains (facial expression, upper limb movement, ventilator compliance) • 4 items in each domain	• Each domain rated on 4-point scale • Total score ranges from 3 (no pain) to 12 (most pain)	• Acceptable reliability and validity for use with nonspeaking ICU patients • Not tested in non-ICU settings or in CCI • Inter-rater reliability questionable • Accuracy may be low if movement is restricted due to sedation, weakness, or restraints • 3-12 score range may be difficult to understand, as many other tools use 0-10 scoring
Nonverbal Pain Scale [38]	• 3 behavioral domains (facial expression, body movement, guarding) and 4 physiologic domains (change in vital signs, change in skin color or temperature, and pupil dilation)	• Each domain rated on a 3-point scale (0-2) • Total score ranges from 0 (no pain) to 10 (most pain)	• Acceptable reliability demonstrated in 1 study in an ICU • Construct validity questionable due to inclusion of indicators such as smiling or lying in a normal position, which may not indicate presence or absence of pain • Not tested in non-ICU settings or in CCI • No rationale provided for vital sign change parameters designated as pain indicator

Assessment Tool	Features	Score Range	Advantages and Disadvantages[40]
Pain Behavior Assessment Tool 17	• 3 behavioral domains (facial expressions, body movements, verbal responses) • Varying numbers of descriptors in each domain	• Nurse marks presence of any observable descriptor in each domain • Instrument is not scored; clinical management of pain based on nursing judgment after noting presence of pain behaviors	• Moderate validity demonstrated in a large sample of hospitalized adult medical, surgical, and trauma patients in both general inpatient and ICU settings • Reliability not reported • Not tested in CCI • Simple for bedside nurses to use • Provides operational definitions to standardize behavioral observations • Pain management relies on nursing judgment due to lack of summed score to indicate increased pain severity
Critical Care Pain Observation Tool [39]	• 4 behavioral domains (facial expression, movements, muscle tension, ventilator compliance)	• Each domain rated on a 3-point scale (0-2) • Total score ranges from 0 (no pain) to 8 (most pain)	• Validity is questionable due to instrument's inability to differentiate between patients reporting pain and those not reporting pain • Inter-rater reliability high except in verbal patients; no instrument reliability data reported • Not tested in CCI