Patient experiences during awake mechanical ventilation

Danille Prime, MD1*, Paul Arkless, MD2, Jonathan Fine, MD1, Stephen Winter, MD1, Dorothy B. Wakefield, MS, PStat3 and Robyn Scatena, MD1

1Section of Pulmonary and Critical Care Medicine, Norwalk Hospital, Norwalk, CT, USA; 2Geisinger Health System, Danville, PA, USA; 3Center for Public Health and Health Policy, University of Connecticut Health Center, Farmington, CT, USA

Background: Sedation practices in an ICU have shifted significantly in the past 20 years toward the use of minimizing sedation in mechanically ventilated patients. While minimizing sedation is clearly in the best interest of patients, data are lacking about how this approach affects patients’ experiences.

Methods: We interviewed mechanically ventilated patients receiving minimal sedation, over a 6-month period in an ICU, in order to explore their emotional, comfort, and communication experiences. Their responses were compared with the responses of their available family members regarding their attitudes and perceptions of the patients’ experiences.

Results: Seventy-five percent of the patients agreed or strongly agreed that they experienced pain, and 50% agreed or strongly agreed that they were comfortable. Half of the patients agreed or strongly agreed that they preferred to be kept awake. Five patients (31%) indicated that they were frustrated while 17 relatives (89%) agreed or strongly agreed that the patients were frustrated. When controlling for age and gender of respondents, family members perceived higher levels of patient pain (least square [LS] mean [95% CI]: 4.2 [3.7, 4.7] vs. 3.1 [2.5, 3.8]; \( p = 0.022 \)), frustration (LS mean [95% CI]: 4.2 [3.7, 4.6] vs. 3.2 [2.6, 3.9]; \( p = 0.031 \)), and adequate communication with nurses and doctors (LS mean [95% CI]: 3.9 [3.5, 4.4] vs. 3.1 [2.4, 3.7]; \( p = 0.046 \)) than the patients themselves.

Conclusion: Patients tolerated minimal sedation without significant frustration while mechanically ventilated despite experiencing discomfort. Patient and family member perceptions of the patient experience may differ, especially in regards to pain and frustration. The use of a communication tool can facilitate understanding of patient experiences and preferences.

Keywords: patient experience; family perceptions; minimal sedation; patient comfort; communication experiences

*Correspondence to: Danille Prime, Department of Medicine, Norwalk Hospital, 34 Maple Street, Norwalk, CT 06854, USA, Email: dinprime@gmail.com

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Sedation practices in an ICU have shifted significantly in the past 20 years (1, 2). Current guidelines call for daily interruption of sedation with the goal of treating pain and anxiety but minimizing delirium (1, 3). These guidelines are based on numerous studies demonstrating improved outcomes with targeted, minimal sedation and daily sedation holidays paired with spontaneous breathing trials. Benefits of this approach include decreased length of ICU and hospital stay, fewer days on mechanical ventilation, fewer days of delirium, and improved mortality. While minimizing sedation is clearly in the best interest of our patients, we lack good data about how this approach affects patients’ experiences. Retrospective studies in which survivors were interviewed after extubation have shown that patients have largely negative memories, commonly attributed to tube discomfort and anxiety as a result of their inability to communicate while intubated (4). Some of these results may be attributable to misremembering and delirium. This bias was evident in a pilot study in which patients’ post-extubation responses differed significantly from responses while intubated (5).

In this study, we interviewed mechanically ventilated patients receiving minimal sedation in order to explore their emotional, comfort, and communication experiences. We also interviewed their available family members regarding their attitudes and perceptions of the patients’ experiences in order to compare their responses with the patients’ answers. As there is no validated tool for interviewing mechanically ventilated patients, we developed a questionnaire based on the ‘Quality of Dying and Death’ questionnaire (6). We developed one version for patients and one version for family members and
used the questionnaires to assess and compare experiences and perceptions.

Methods

Subjects and setting

This study was a prospective observational investigation using quantitative and qualitative questionnaires to survey patients and family members regarding their experiences while the patient was intubated and mechanically ventilated. This investigation was conducted over a 6-month period in an ICU, after review and approval by the institutional review board. Adult patients were included in the study if they were more than 18 years old, intubated and mechanically ventilated for medical or surgical reasons for more than 24 hours, confusion assessment method (CAM-ICU) negative, and without history of cognitive impairment. These patients were awake and able to communicate by gesture, writing, or pointing to letters on an alphabet board while ventilated. Consent was obtained from patients, who were interviewed separately from family members.

Patients were excluded based on the following: those with cognitive deficits impairing their ability to answer questions appropriately, and those who required continuous use of sedatives based on their underlying clinical conditions (i.e., status epilepticus, increased intracranial pressures, hypothermia after cardiac arrest, or severe alcohol withdrawal).

The following categories were surveyed using a 24-response questionnaire in the patient survey and a 19-response questionnaire in the family survey: emotions, boredom, communication, family experiences, and sedation preference (Figs. 1 and 2) (6). In the patient questionnaire, four questions were open-ended with the remaining 20 based on a 5 point Likert scale (1 = strongly disagree; 5 = strongly agree). Open-ended questions inquired about patient’s boredom, concerns, and frustrations. The family questionnaire also focused on the aforementioned categories with 14-point Likert scale-based questions and four open-ended questions. The latter inquired about why family members thought patients were afraid and frustrated, how having a loved one in the ICU affected the same family members, and what emotions family members thought the patients were feeling.

Statistical analysis

Data were analyzed using SAS version 9.3 (Cary, NC, USA). Descriptive (means, standard deviation, frequencies) statistics were computed for the demographic characteristics. Chi-square analyses examined differences in patient responses by gender and overall differences in responses between family members and patients. Linear regression models were used to examine response differences between patients and family members; covariates were age and gender of the respondent. Wordle.net was used to create word clouds showing free text responses of family members.

Results

A total of 18 patients were eligible to participate in the study, of whom 16 completed the interview. The remaining two patients declined to participate. Most patients were male (56%, n = 9) with mean ± SD age of 68 ± 10.9 years. Demographic variables of patients and their family members are listed in Table 1.
Of 16 patients, 11 had family members who were interviewed. And 6 of the 11 had more than one family member interviewed, for a total of 19.

Seventy-five percent of the patients agreed or strongly agreed with the statement that they experienced pain, and 50% agreed or strongly agreed that they were comfortable. Two-thirds of the patients (69%) agreed or strongly agreed that communication with the staff was appropriate. Half of the patients agreed or strongly agreed that they preferred to be kept awake and only two (12.5%) patients indicated that they did not want to be awake.

Five patients (31%) indicated that they were frustrated. Of these, two patients did not elaborate on the source of their frustrations. The other three patients experienced frustration from prolonged immobilization, subjective difficulty with breathing, lack of mental clarity, the desire to be home, and days without coffee or tobacco. Of the seven patients (43%) who experienced boredom, listening to music and company of their friends and family were listed as the primary comfort measures that relieved their boredom (Fig. 3).

Most relatives (89%) agreed or strongly agreed that patients were frustrated, citing communication issues most commonly in their comments (Fig. 4). Ten relatives (53%) felt that their loved ones were afraid because of their inability to communicate effectively and the gravity of their illness. When asked how they were affected by the critical illness of their loved one, relatives identified a number of emotions including sadness, apprehension, fear, anxiety, and stress. Relatives felt that patients experienced a variety of emotions, the most common being frustration, anxiety, and fear (Fig. 5). Family members significantly differed from patients in their perception of patient frustration (89% vs. 31%, p = 0.0004). There were no significant differences across all other categories between the responses of all patients and family members (Fig. 6).

Five (31%) patients did not have relatives available to interview.

**Table 1.** Characteristics of patients and family members

|                      | Patients n = 16 | Relatives n = 19a |
|----------------------|----------------|-----------------|
| Age, mean ± SD       | 67.5 ± 10.9    | 54.7 ± 14.6     |
| Male, n (%)          | 9 (56%)        | 7 (37%)         |
| Relative, n (%)      |                |                 |
| Spouse               | 5 (26%)        |                 |
| Adult child          | 6 (32%)        |                 |
| Sibling              | 5 (26%)        |                 |
| In law               | 3 (16%)        |                 |

Fig. 2. Family questionnaire derived from the ‘Quality of Dying and Death’ questionnaire.

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Fig. 3. Patients’ preferences of things to do if they stated they were bored (n = 8).
In the multivariate regression models controlling for age and gender of respondents, family members perceived higher levels of patient pain (least square [LS] mean [95% CI]: 4.2 [3.7, 4.7] vs. 3.1 [2.5, 3.8]; \( p = 0.022 \)), frustration (LS mean [95% CI]: 4.2 [3.7, 4.6] vs. 3.2 [2.6, 3.9]; \( p = 0.031 \)), and adequate communication with nurses and doctors (LS mean [95% CI]: 3.9 [3.5, 4.4] vs. 3.1 [2.4, 3.7]; \( p = 0.046 \)) than the patients themselves. Older respondents reported higher scores for pain (\( p = 0.006 \)), and females reported significantly higher scores than males for adequate communication (LS means [95% CI]: 4.1 [3.6, 4.5] vs. 3.0 [2.4, 3.6]; \( p = 0.006 \)). There were no significant differences in all other categories.

Discussion

Our findings suggest that patients may be inclined to tolerate a degree of pain and discomfort in order to maintain communication and wakefulness. Most of these responsive patients who were mechanically ventilated with minimal sedation agreed that they were having pain and only half reported that they were comfortable. The majority of patients felt that they could communicate well with staff and most also preferred or did not mind being awake. Indeed, less than one-third of the patients indicated that they felt frustrated.

Family members do not uniformly share the patients’ perceptions of their experiences. In particular, relatives tended to perceive the patients as more frustrated than the patients themselves reported. This measured difference in perceived frustration persisted after controlling for gender and age. The family members admitted to high levels of stress, which they may have projected onto the patient.

Most patients felt that their communication was adequate with staff members. This observation is consistent with the finding by Happ et al. that nurses were
likely to have frequent communication with patients who were more responsive (7). In terms of gender, female patients have been shown to be more willing than males to report pain (8). This tendency may, at least in part, account for our finding in the multivariate analysis that female patients rated communication higher than male patients.

Our research delves into a novel area of critical care medicine as it explores communication with patients on mechanical ventilation with little to no sedation. It also demonstrates the feasibility of obtaining real-time information about the patients’ and families’ impressions and preferences while intubated in the ICU. By using real-time reporting, we have eliminated the need to rely upon memory of ICU experiences. This is significant because previous investigations using recall by survivors found that 33–54% of patients did not remember the intubation experience (4, 5). Furthermore, investigators have expressed concern that survivors may misremember their ICU experiences (4).

The ability to communicate with patients will have many applications including the opportunity to address ventilated patients’ comfort levels, pain, and satisfaction as well as enabling appropriate sedation titration. Keeping patients more awake and minimizing sedative use and resultant delirium should reduce post-ICU posttraumatic stress disorder and cognitive decline (9, 10). Direct communication with the patient, moreover, helps to balance the perceptions of patients’ family members, which may not match up with those of the patients.

There are many limitations of this study. It was a descriptive study with a small sample size, the results of which are difficult to generalize. There are also incomplete demographics obtained for each patient and family member involved. The study is not controlled for socioeconomic status, disease severity, prior illness, and baseline neuropsychiatric diagnoses.

Further studies should use a larger sample size with multiple centers and also make note of patient and family responses post-extubation for comparison to responses while intubated and minimally sedated or awake. Our results provide a starting point for better understanding of the patient and family experiences during minimally sedated mechanical ventilation.

**Conclusions**

Our prospective study demonstrates that patients tolerated minimal sedation without significant frustration while mechanically ventilated, and that the use of a communication tool can facilitate understanding of patient experiences and preferences. Our results, nonetheless, provide a starting point for better understanding of the patient and family experiences during minimally sedated mechanical ventilation.

**Conflict of interest and funding**

None of the authors have a conflict of interest and funding. All authors had access to the data and a role in writing the manuscript.

**References**

1. Girard TD, Kress JP, Fuchs BD, Thomason JW, Schweickert WD, Pun BT, et al. Efficacy and safety of a paired sedation and ventilator weaning protocol for mechanically ventilated patients...
in intensive care (Awakening and Breathing Controlled trial): A randomized controlled trial. Lancet 2008; 371: 126–34.

2. Kress JP, Pohlman AS, O’Connor M, Hall JB. Daily interruption of sedative infusions in critically ill patients undergoing mechanical ventilation. N Engl J Med 2000; 342: 1471–7.

3. Mehta S, Burry L, Cook D, Fergusson D, Steinberg M, Granton J, et al. Daily sedation interruption in mechanically ventilated critically ill patients cared for with a sedation protocol: A randomized controlled trial. JAMA 2012; 308: 1985–92.

4. Menzel L. A comparison of patients’ communication-related responses during intubation and after extubation. Heart Lung 1997; 26: 363–71.

5. Rotondi AJ, Chelluri L, Sirio C, Mendelsohn A, Schulz R, Belle S, et al. Patients’ recollections of stressful experiences while receiving prolonged mechanical ventilation in an intensive care unit. Crit Care Med 2002; 30: 746–52.

6. Downey L, Randall C, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death (QODD) questionnaire: Empirical domains and theoretical perspectives. J Pain Symptom Manage 2010; 39: 9–22.

7. Happ MB, Tuite P, Dobbin K, DiVirgilio-Thomas D, Kitutu J. Communication ability, method, and content among nonspeaking nonsurviving patients treated with mechanical ventilation in the intensive care unit. Am J Care 2004; 13: 210–18.

8. Wandner LD, Scipio CD, Hirsh AT, Torres CA, Robinson ME. The perception of pain in others: How gender, race, and age influence pain expectations. J Pain 2012; 13: 220–7.

9. Weinert CR, Sprenkle M. Post-ICU consequences of patient wakefulness and sedative exposure during mechanical ventilation. Intensive Care Med 2008; 34: 82–90.

10. Pandharipande PP, Girard TD, Jackson JC, Morandi A, Thompson JL, Pun BT, et al. Long-term cognitive impairment after critical illness. N Engl J Med 2013; 369: 1306–16.