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Jill L. Guttormson

Marquette University, jill.guttormson@marquette.edu

Karin Lindstrom Bremmer

Minnesota State University Mankato

Rachel M. Jones

Marquette University

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“Not Being Able to Talk Was Horrid”: A Descriptive, Correlational Study of Communication During Mechanical Ventilation

Jill L. Guttormson

*College of Nursing, Marquette University
Milwaukee, WI*

Karin Lindstrom Bremer

*Minnesota State University, Mankato,
Mankato, MN*

Rachel M. Jones

*College of Nursing, Marquette University
Milwaukee, WI*

Summary

Objectives: The purpose of this *study* was to describe the patient experience of communication during mechanical ventilation.

Research methodology: *This descriptive study is a secondary analysis of data collected to study the relationship between sedation and the MV patients' recall of the ICU.* Interviews, conducted after extubation, included the Intensive Care Experience Questionnaire. Data were analysed with Spearman correlation coefficients (r_s) and content analysis.

Setting: Participants were recruited from a medical-surgical intensive care unit in the Midwest United States.

Results: Participants ($n = 31$) with a mean age of 65 ± 11.9 were on the ventilator a median of 5 days. Inability to communicate needs was associated with helplessness ($r_s = .43$). While perceived lack of information received was associated with *not feeling in control* ($r_s = .41$) and *helplessness* ($r_s = .41$). Ineffective communication impacted negatively on satisfaction with care. Participants expressed frustration with failed communication and a lack of information received. They believed receipt of information helped them cope and desired a better system of communication during mechanical ventilation.

Conclusion: Communication effectiveness impacts patients' sense of safety and well-being during mechanical ventilation. Greater emphasis needs to be placed on the development and integration of communication strategies into critical care nursing practice.

Keywords: Respiration, Artificial, Critical illness, Intensive care units, Communication. Intensive care experience questionnaire

Implications for clinical practice

- Increased emphasis needs to be placed on supporting patient communication during mechanical ventilation through integration of alternative communication strategies into practice.
- Increased frequency and repetition when providing information to mechanically ventilated patients may help improve the patient experience of mechanical ventilation.
- Provision of training for critical care nurses in how to support patient communication during mechanical ventilation and how to use alternative communication aids has potential to decrease patient distress during mechanical ventilation.

Introduction

Over 50% of patients report communication challenges during mechanical ventilation as moderately to extremely stressful (Rotondi et al., 2002 and Samuelson et al., 2007). Mechanically ventilated (MV) patients report problems not only with their inability to communicate but also with a perceived lack of information received (McKinley et al., 2002 and Wunderlich et al., 1999). Ineffective communication is consistently linked to patients' negative emotions while in an intensive care unit (ICU) including feelings of frustration (Jablonski, 1994, Johnson et al., 2006 and Logan and Jenny, 1997), fear (Jablonski, 1994 and Khalaila et al., 2011), anxiety (Engstrom et al., 2013 and Jablonski, 1994) and anger (Hafsteindottir, 1996, Johnson et al., 2006 and Khalaila et al., 2011). Frustrated patients sometimes give up trying to make their needs known or restrict communication to

only essential information (Hafsteindottir, 1996 and Patak et al., 2004).

Ineffective communication not only increases MV patients' stress but also impacts upon care during, and recovery after, ICU. Greater than one third of communication exchanges between nurses and MV patients related to pain management have been rated by researchers as unsuccessful (message not received or not understood) (Happ et al., 2011). Thirty percent of patients report being unable to communicate their needs while MV (Rattray et al., 2010). Inability to communicate needs has been associated with post-ICU anxiety, depression and distress related to ICU events (Myhren et al., 2009).

The purpose of this secondary analysis was to describe the patient experience of communication during mechanical ventilation. The two specific aims were to:

- Describe the association between the patients' report of communication during mechanical ventilation with their emotional responses in the intensive care unit (ICU) and with patients' appraisal of ICU care.
- Describe patients' experiences of communication challenges and communication exchanges during mechanical ventilation.

Methods

This descriptive study is a secondary analysis of data collected to study the relationship between sedation and the MV patients' recall of the ICU. Although communication was not one of the primary aims of the study, during initial data analysis it emerged as an important component of the patients' ICU experience.

Setting and participants

A convenience sample of patients was enrolled over 18 months from a 24-bed medical-surgical ICU in a suburban community hospital in the upper Midwest of the United States. The unit was staffed 24/7 by university affiliated intensivists. Patient to nurse staffing ratios were 2:1 or 1:1. Patients were eligible for the study if they were 18 years or older, spoke English, had an anticipated duration of mechanical

ventilation greater than 24 hours and had no documented mental incompetence. Patients on a ventilator in a long-term care unit or at home prior to ICU admission were not eligible.

Ethical approval

All aspects of this study were reviewed and approved by the first author's (J.G.) university Institutional Review Board (IRB), which serves as the IRB for the primary study site, and by the IRB for the acute care rehabilitation hospital where post-ICU interviews were also conducted. If the initial study consent was obtained from a patient's proxy, the informed consent process was repeated with patients prior to the post-ICU interview. Names used in quotations have been changed to protect the confidentiality of participants.

Data collection

Structured interviews, conducted with patients after extubation and transfer from ICU, included the Intensive Care Experience Questionnaire (ICEQ) (Rattray et al., 2005) and follow-up questions related to patients' comments during instrument completion. Interviews also included three open-ended questions: (a) do you find any of your memories of ICU distressing? (b) is there anything else you would like to share about your experience of being on the ventilator in the ICU?, and (c) can you describe anything the healthcare staff did or could have done to improve your experience of being on the ventilator? All interviews were recorded and transcribed.

The ICEQ provides a global evaluation of the patient's experience and consists of 24 items in four domains: awareness of surroundings, frequency of frightening experiences, recall of experience and satisfaction with care. Items are closed questions with a 5-point Likert response indicating level of agreement (strongly disagree to strongly agree) or measuring frequency of event (never to all of the time) (Rattray et al., 2004). Each item is scored on a 1-to-5-point scale (Rattray et al., 2005). For this analysis, seven individual ICEQ items were used. Two items assessed patients' experience of communication during MV: inability to communicate needs and perceived lack of information received. Four items assessed patients'

emotional memories of feeling unsafe, a loss of control, helpless or scared. One item assessed patients' satisfaction with care: "My care was as good as it could have been."

Data analysis

Quantitative data were analysed with SPSS version 19. Descriptive statistics were used to summarise sample characteristics and ICEQ items. Due to the non-normal distribution of ICEQ item responses, associations of communication with satisfaction with care and emotional responses were analysed with Spearman correlation coefficients (r_s) (Polit, 1996).

Patients' descriptions of communication while MV were analysed using a modification of qualitative content analysis: the interpretation of data through systematic identification of patterns or themes (Hsieh and Shannon, 2005). To begin the analysis process, all authors repeatedly read the transcripts to identify quotations related to communication (Hsieh and Shannon, 2005 and Shields and Twycross, 2008) and began open coding, developing names and early definitions for themes and identifying exemplar quotations. The authors discussed initial themes and developed an agreed upon preliminary coding scheme. Each then re-read and coded the entire transcripts (Elo and Kyngas, 2008 and Hsieh and Shannon, 2005). In the next step, the first author met with each of the co-authors to reach consensus for any areas of disagreement in coding. In the final step, the abstraction process (Elo and Kyngas, 2008), the first two authors developed subcategories based upon codes that were related, codes were then grouped (clustered) into major themes (Hsieh and Shannon, 2005). Validity was enhanced by the immersion of the three authors into the data, with a recursive process between individual readings of the transcripts with joint discussions. Final verification was done by the first author, who has 15 years of ICU nursing experience with MV patients.

Results

Sixty-nine mechanically ventilated patients were enrolled; of these 31 completed post ICU interviews, had memories of the ICU,

and were included in the analysis. Reasons patients were unable to participate in interviews included death in the ICU, post ICU confusion, or transfer to a long-term care facility directly from the ICU. Patients completing interviews with memories of ICU ($n = 31$) had a mean age of 65 ± 11.9 (range 31–87) and were 54.8% female. They were on the ventilator for a median of 5 (range: 2–26) days and in ICU a median of 8 (range: 2–34) days. ICU admission diagnoses were primarily pulmonary (pneumonia, respiratory failure, acute respiratory distress syndrome); followed by medical cardiac (myocardial infarction, cardiac arrest, heart failure). The remaining patients were admitted for severe infection/sepsis, surgical procedures or neuromuscular disease. Patients unable to complete interviews were in the ICU longer and were more likely to have been admitted with sepsis/severe infection or shock (Table 1).

Table 1. Characteristics of study sample.

	Total ($n = 69$)	Memories of ICU ($n = 31$)	Not interviewed or no memories ($n = 38$)	Test statistic	p value
Age [mean (SD)]	66.0 (12.7)	65.4 (11.9)	66.1 (13.4)	.405 ^a	.687
Female [n (%)]	39 (56.5)	17 (54.8)	22 (57.9)	.065 ^b	.799
APACHE III [mean (SD)]	73.4 (27.0)	69.1 (25.9)	76.8 (27.7)	1.18 ^a	.242
Ventilator days [median (IQR)]	6.2 (8.1)	5.1 (6.8)	8.7 (8.7)	1.69 ^c	.091
ICU days [median (IQR)]	11.4 (12.8)	8.1 (8.7)	14.4 (12.6)	2.32 ^c	.021
Mortality [n (%)]	9 (13.0)	0	9 (23.7%)	8.44 ^b	.004
Reason for ICU Admission [n (%)]				11.24 ^b	.001
Pulmonary	29 (42.0)	19 (61.3)	10 (26.3)		
Cardiac-medical	13 (18.8)	6 (19.4)	7 (18.4)		
Cardiac-surgical	4 (5.8)	2 (6.5)	2 (5.3)		
Sepsis/infection	10 (14.5)	2 (6.5)	8 (21.1)		
Other surgical	4 (5.8)	1 (3.2)	3 (7.9)		
Neuro/neuromuscular	4 (5.8)	1 (3.2)	3 (7.9)		
Shock/hypotension	2 (2.9)	0	2 (5.3)		
Other ^d	3 (4.3)	0	3 (7.9)		
Hispanic	0	0	0		n/a
Race [n (%)]				.672 ^b	.412
White	65 (94.2)	30 (96.8)	35 (92.1)		
African American	4 (5.8)	1 (3.2)	3 (7.9)		

^a t -value.

b Chi-square.

c z-value.

d Nose bleed, lower extremity ischaemia, renal failure; APACHE: acute physiology and chronic health evaluation; IQR: interquartile range; SD standard deviations.

Communication and emotional responses to ICU

Communication while mechanically ventilated in the ICU was one of the most challenging aspects of the experience for these participants. This 64-year-old female participant, who had been on the ventilator for 9 days, expressed the intensity of the experience of not being able to talk.

“Being on the ventilator wasn’t the worst thing in the world, but not being able to talk was horrid. So when they finally capped it [the tracheostomy], that was a good day. That was the worst, not being able to talk” (Participant 33).

Almost 30% of participants agreed or strongly agreed that they were unable to let people know what they wanted while on the ventilator and over a third of participants (35%) did not recall being given information they could understand during MV.

An inability to communicate needs was associated with more frequent feelings of helplessness ($r_s = .43, p = .028$) while MV. Feeling scared, unsafe or a lack of control were not significantly correlated with inability to communicate. A perceived lack of receiving understandable information was associated with more frequent feelings of helplessness ($r_s = .41, p = .039$) and not feeling in control ($r_s = .41, p = .039$) while in the ICU, but was not associated with feeling scared nor significantly associated with feeling unsafe ($r_s = .38, p = .06$). Inability to communicate needs and a perceived lack of information received were negatively associated with satisfaction ($r_s = -.39, p = .043$ and $r_s = -.42, p = .035$ respectively).

Communication challenges and exchanges

Mirroring the quantitative analysis, participants addressed both their frustration with failed attempts at communication while MV and with a perceived lack of information received from healthcare providers about their condition and procedures. Additionally, participants

addressed both global and concrete benefits of receiving information from staff. Finally, participants described communication methods, challenges of communication and ways in which they believed communication could be facilitated during mechanical ventilation.

Failed communication

Failed communication (the inability to successfully communicate a message) impacted participants' well-being, safety and comfort. A 76-year-old participant on the ventilator for 1.5 days described being unable to communicate that his dentures had dislodged and he felt he was in danger of swallowing them (Participant 43). While another participant described being unable to call for help or communicate the reason for her distress.

Participant: "I think my concern was that I wasn't able to call anybody to help. You know, when I had felt that I was in distress and I wasn't really sure what was going on, and..."

Interviewer: "And you didn't know how to call anybody..."

Participant: "No, no... I wasn't familiar with the controls on the bed or the control for calling the nurse or anything like that. And then, when they'd try to come in and they'd say, well, 'what's going on', it's like, 'I can't very well sit here and have a conversation with you and tell you.' But, you know... I think, at that point, I tried to ask [significant other] for something to write on" (Participant 58: 50-year-old female on ventilator 1.5 days with asthma exacerbation).

In another example of failed communication, a participant with a history of back pain described how difficult it was to try to explain his needs regarding this pre-existing condition.

-Participant: "Again, the fact I had to be in one position all the time, you know. I didn't realise, at the point, how weak I was... But, you know, a couple of times, if I could have just rolled on one side and slept on one side for half the night, had done something like that, which, of course, I couldn't..."

-Interviewer: "And you really couldn't help with positioning, so it was hard to get in a comfortable position?"

-Participant: "Right, right. Hard to explain to them... which way I wanted to go or move" (Participant 39: 53-year-old male on ventilator more than 30 days with pneumonia).

When communication attempts failed, participants often perceived this as a lack of response by the staff or being disregarded by the staff. In one participant's words: "There would be times I would be flailing for somebody and they'd say, 'I'll be right back.' And you're like, 'No, you don't understand. I can't breathe right. You need to help me right now'" (Participant 58).

Participants also reported moments of a failure of communication they interpreted as misinterpretation or lack of understanding of their wishes by the staff. "A lot of anxiety comes from continuing to voice the same concern and questions and not have it understood" (Participant 45). A 61-year-old male admitted with heart failure relayed a situation involving one of his family members, and how the nurse misunderstood the point of his message.

"I could hear her [the nurse] talking to Sue just out of my earshot. I couldn't hear what she was saying to Sue. And so I... said, 'Talk to me, don't talk to Sue.' And so I knew immediately I had made a mistake there, because the last thing I wanted Sue to do was leave. And so she went right back over to Sue and said, 'He doesn't want me talking to you.'... I called her back over and said, 'No, no, no. Talk to me and Sue'" (Participant 41).

It was very important that the nurse talk to him and not just about him, but at the same time not exclude his family; the nurse had difficulty in understanding and granting his wishes.

Participants also perceived failed communication as being disregarded by staff. When asked if he was able to let people know what he wanted, the participant 45 replied: "It didn't make any difference. They were going to hear what they wanted to hear." Similar incidents were brought up by multiple participants, including an unfulfilled request for a bedpan and refusal to remove a urinary catheter that was causing discomfort. Participants perceived that all of these requests were understood by the staff yet either went unheeded or were rejected. One participant captured the feelings related to

perceived disregard: "There was no control. I felt I had no control. And that is scary" (Participant 2: 63-year-old female on ventilator for 8 days).

Receipt of information

Participants described both a perceived lack of information from staff and benefits to receiving information about medical treatments or their health conditions. Participant 58 felt that information was only provided on a "need to know basis," while a 61-year-old man on the ventilator for 2.5 days described this lack of information as follows:

"Out there I don't think there was any time for communication made. I had to demand any that I got, anything I got. No one came to sit down next to me and say, 'Okay,... here's what's happening.'... In fact, I had to suck information... out of everybody" (Participant 41).

Participants had a general consensus that more information would be beneficial. When she was asked if she would have liked to receive more information, this 50-year-old female replied "Right. I think more information... just kind of, it helps. They just kind of settle your own mind, as to what it is you can expect is going to happen next" (Participant 58). Her perceptions of the value of information were even more forcefully stated by another participant:

"When somebody asks you a question and how silly it seems to you to answer their question, because... no matter how menial it might seem, it might help save their life... It really, really is important" (Participant 22: 50-year-old female admitted with pneumonia).

Participants described a number of circumstances in which the information they received from nursing staff was essential to helping them tolerate and cope with their illness, treatments and the ICU environment. Participant 44, a 53-year-old female, described what was helpful to her while on the ventilator: "Well, you know, they were explaining, 'All right, the next thing we're going to do is this and this.' So at least they let you know what the next thing is."

Two participants spoke of the value of information in common experiences of mechanically ventilated patients: restraints and feelings of breathlessness. When the first author asked Participant 9 how she felt when she realised that she was restrained the participant responded, "Well, I remember them telling me it was so I wouldn't pull out something. And then I was ok with it."

Participant 39 gave a detailed illustration of how helpful information from the nursing staff was to help him tolerate the ventilator:

Interviewer: "You said fighting the thing that was making you breathe."

Participant: "Yeah... finally, one of the nurses over there straightened me out, said 'You're working this too hard. Just relax. It will breathe when you want to'... I'm a kind of hands-on, technical guy. I want to know some of the details, because it helps me to figure out better what's going on... It would have been nice for somebody to come back and gone through, 'Okay, here's what happened. Here's what's going on. This is why you're on the breather,' you know. Like I said, until that guy [the nurse] told me to quit fighting the machine, I thought I was doing the right thing with it."

Intuitively, the nurses knew just what is needed in some situations, such as teaching the patient how to use the ventilator effectively. In other communication exchanges, patients needed the use of communication aids to assist the process.

Communication methods

Participants gave many suggestions for alternative communication aids—equipment (electronic or non-electronic) or methods used to transmit messages when the patient cannot verbally communicate (Hurtig and Downey, 2009). Participants described aids that they either utilised to help them communicate or suggested would be helpful in their communication with staff. Attempted communication methods mentioned by participants included: alphabet boards, picture boards, writing, gestures, pointing, hand signals and the assistance of family members. While the aids were described as useful, participants

also articulately described the challenges of communication attempts with some of these alternative communication aids. With both communication/alphabet boards and writing participants described getting frustrated at not being able to complete their entire message.

“Well, I had a board that I could point to. But even simple words, some people are better at it. The one thing that was frustrating is that I’d start a word, and they’d jump the gun and say, oh, a different word... And that was both nursing staff and family... I’d start in to a question or I want something or, you know, whatever, and they’d kind of presume where I was going” (Participant 39).

While he described staff and family jumping the gun, Participant 41 used a different analogy to describe a similar scenario:

“Because I kept writing things and she [nurse] didn’t answer the question. It was like a wife that tries to guess what you’re going to say before you say it. So she wouldn’t let me finish my writing. So I wrote in big letters. I said, LISTEN.”

Participants also described having difficulty writing legibly. One Participant (41) recalled the staff took away the writing board when he was unable to write clearly and attributed difficulty writing in part to “all these drugs.” That same participant offered a solution to the problem he was having holding a traditional ballpoint pen.

“They had just a piece of typing paper on clipboard, and the clip... as I recall, didn’t clip. And so what you really had was just a loose piece of paper on a board. And are you ready for this? A ball point pen... You know... if I’m doing something like that, I want a fricking [sic] felt tip Sharpie... I want the big one, you know... Something larger handled, you know, where you could write.”

In response to the interviewer's query about what could be done to make the experience of mechanical ventilation better, Participant 45 eloquently addressed the importance of establishing a method of communication.

“I think overall the biggest improvement that could be made in this whole thing [ICU experience] is to develop a system of communication between staff and patient. You know, when you

can't talk and if we could come up with something like that we would get really, really rich."

Discussion

The purpose of this secondary analysis was to describe the patient experience of communication during mechanical ventilation. Participants reported difficulty with communicating needs and a lack of information received. Both contributed to negative emotions during ICU and impacted patient satisfaction with care. Thirty percent of participants in this study recalled being unable to let people know what they wanted, similar to findings by Rattray et al. (2010). However this percentage is lower than reported in other studies in which 40–62% of patients reported communication as stressful or difficult (Granja et al., 2005, Happ et al., 2011 and Patak et al., 2004). This discrepancy may in part be due to the wording of the communication item in the ICEQ that asks participants to rate how often they were able to let people know what they wanted, a measure of effectiveness of communication rather than the stress related to communication.

The inability to communicate was associated with feeling helpless and negatively impacted satisfaction with care. This is similar to previous findings where problems with communication were associated with panic, frustration (Engstrom et al., 2013) and anger (Khalaila et al., 2011). The frustration experienced by participants surrounding communication was clearly evident during content analysis. Difficulty in communicating was described by participants as horrid, scary, the worst part and anxiety provoking. Participants often felt disregarded, misinterpreted or perceived a lack of response to their needs.

The impact of ineffective or stressful communication can be both immediate and long term. Similar to results of the current study in which participants could not successfully communicate needs, in an observational study, researchers found that communications about pain with mechanically ventilated patients were unsuccessful (defined as the message not being received or understood) over one-third of the time (Happ et al., 2011). This inability to express needs is associated with higher impact of events scores, perceived anxiety and depression post ICU (Myhren et al., 2009). Findings from the current

and previous studies highlight the need to increase emphasis on supporting patients' ability to communicate.

Similar to previous qualitative studies (McKinley et al., 2002 and Wunderlich et al., 1999), communication difficulties were not only related to the participants' inability to communicate their needs but also to their receipt of information. Over a third of participants in our study reported a lack of information received. Although this finding could be related to the amount of information provided by ICU staff, it could also be due to the participants' inability to understand or recall information. The current study did not differentiate between these two options. Participants described their attempts to gain more information as 'pulling' or 'sucking' information out of their health care providers. They felt that only with persistence were they given the information that they believed was necessary. Not surprisingly, perceived lack of receiving understandable information was associated with feeling helpless and not in control and negatively impacted patients' satisfaction with care.

Participants also spoke of the benefits of information. Information helped reassure participants, relieve anxiety and 'settle the mind.' Participants gave specific examples where information from staff helped them to understand and therefore more easily tolerate treatments including the ventilator and physical restraints.

Attempted modes of alternative communication (AC) mentioned by participants included: alphabet/picture boards, writing, gestures, pointing, hand signals and the use of family members. As has been identified in other work—the idea that communication aids would be helpful during mechanical ventilation (Patak et al., 2006)—our participants expressed a need and desire for an established "system of communication." Unfortunately, despite their potential value for improving patients' ability to communicate, even low tech AC aids such as picture boards are rarely utilised (Happ et al., 2011). Barriers to the use of AC aids during mechanical ventilation need to be identified and overcome. Our participants identified some of the problems they encountered when using AC including problems with equipment and with their communication partners.

Participants encountered problems with the writing materials and implements available. For many reasons, including the prevalence of ICU acquired weakness (Fan et al., 2009), MV patients may have difficulty writing. Adaptive writing devices may be one solution. Additionally, other options that still allow patients to communicate novel messages, such as touch screen devices, are a potential alternative.

Participants also experienced challenges during message construction with alphabet/picture boards including misinterpretation by staff or family because they 'jumped the gun' and tried to complete patients' messages for them. This highlights that merely having AC aids available may not be enough. Nurses, as the MV patients' primary communication partner, need to have the knowledge and skill to support communication and the use of AC strategies. Nurse-identified barriers to effective communication with MV patients including time, difficulty lip reading and frustration at being unable to understand the patient (Bergbom-Engberg and Haljamae, 1993 and Leathart, 1994). Many of these barriers can be linked to the lack of formal training in communication techniques (Finke et al., 2008) that leaves nurses to learn communication strategies through trial and error or observation of peers (Leathart, 1994 and Magnus and Turkington, 2006). Training nurses in AC strategies *has been found to* enhance nurse-patient communication resulting in decreased patient anxiety and increased nurses' skill and confidence supporting MV patient communication (Radtke et al., 2012). The effectiveness of such training programmes needs to be evaluated in other ICU settings. Additionally, increased collaboration with Speech Language Pathologists, experts in AC, would serve as an invaluable resource for support of patients' communication during mechanical ventilation.

There are limitations to this study. The primary limitation is that this was a secondary analysis; the original study was not focused on communication. However, the frequency with which participants volunteered additional details about communication challenges highlighted the importance of this issue for MV patients. Participants provided rich descriptions of their experiences and challenges with communication, as well as insightful suggestions of how communication could be improved between ICU staff and MV patients. Sample size is another limitation. Although the sample is appropriate

for content analysis, it is small for estimation of correlations which may have impacted quantitative results.

Conclusion

Consistent with previous qualitative studies, communication effectiveness impacts patients' well-being during mechanical ventilation and their satisfaction with care. This study highlights the impact—through the patients' own words—of communication challenges during mechanical ventilation. Nurses, the patients' primary communication partner, play an integral role in facilitating effective communication during mechanical ventilation. Greater emphasis needs to be placed on the development of communication skills and the implementation of communication strategies into critical care nursing practice.

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Corresponding author. Tel.: +1 414 288 3819; fax: +1 414 288 1939.