

Lip-reading and the ventilated patient*

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Objective: To present a clinical ethics case report that illustrates the benefits of using lip-reading interpreters for ventilated patients who are capable of mouthing words.

Design: Case report.

Setting: The burn unit of a university teaching hospital in New York City.

Patient: A 75-yr-old man was admitted to the burn unit with 50% total body surface area burns. He was awake, alert, ventilator-dependent via a tracheostomy, and able to mouth words.

Interventions: A deaf lip-reading interpreter and a hearing American sign language interpreter worked together in a circuit formation to provide verbal voice for the patient.

Conclusion: For the ventilated patient who can mouth words, lip-reading interpretation offers an opportunity for communication. It is time we routinely provide lip-reading interpreters as well as recognize the need for prospective studies examining the role of lip-reading in medical settings. (Crit Care Med 2012; 40: 1529–1531)

KEY WORDS: burns; communication; end-of-life care; intubation; lip-reading; medical ethics; tracheostomy

For intubated patients or ones with tracheostomies, the ventilatory support that is life-sustaining can have the deleterious side effect of impeding communication. In intensive care settings, where life-altering decisions are made, the awake capacitated individual may be left with little hope for self-determination. We present a clinical ethics case that illustrates the benefits of lip-reading interpreters as invaluable members of the patient care team.

CASE REPORT

A 75-yr-old homeless man living in local airports was admitted to the burn unit with 50% total body surface area burns after his shirt caught on fire. After nearly 1 yr of treatment, multiple operations, and a course complicated by sepsis from a migrated gastric feeding tube, he remained with nonhealing wounds secondary to failed skin grafts and severe contractures of his upper extremities bilaterally. He had no family members and

no healthcare agent or surrogate could be located to assist with medical decision-making. The surgical team believed multiple operations were still required to address his burns, but given the extent of his injuries, it was thought he was unlikely to survive even with these operations. When asked about pursuing additional skin grafts, the patient adamantly refused. At that time he was awake and clinically stable, although psychiatry determined that he lacked capacity. Given the unclear efficacy of surgery, the inability to locate any family or friends who might serve as a surrogate decision-maker, and the patient's clear desire to be left alone, the team respected his wishes to forgo further operations and discussed palliative options with him.

In the absence of surgery, his health began to decline and he was soon ventilator-dependent via a tracheostomy. In this setting, he requested that the care team feed him coffee and donuts. The burn unit team hesitated to accede to the request, because he had failed swallowing studies and the coffee and donuts posed a significant risk of aspiration. However, the team was conflicted by their desire to bring some comfort to a dying man asking for the pleasure of eating his favorite foods.

A medical ethics consult was requested to assist with deciding the best course of action. Ethics recommended a court-appointed surrogate be sought; however, given that the process was prohibitively slow and that the patient was gravely ill, this was not attempted. Ethics

also recommended another psychiatric interview to assess whether the patient had decision-making capacity and if he truly understood the risks associated with eating. Because the patient was now ventilated and had significant contractures, he could only mouth words to express himself. The Passy-Muir valve was attempted, but this was not tolerated and did not enhance communication. Influenced by his own experience with a relative who had been intubated, the burn surgeon requested the services of a lip-reading interpreter to facilitate discourse with the patient. With the assistance of two trained interpreters, the patient expressed that he wanted to live, but not undergo the surgical and physical therapy necessary to survive. In addition, the patient requested that he be allowed to eat and denied any risk of aspiration. Furthermore, he suggested that the team could avoid any harm by extracting aspirated food and treating him with antibiotics.

With the help of the lip-reading interpreters, psychiatry determined the patient still lacked capacity to make an informed decision to eat; he had poor insight into his medical situation and could not articulate the negative consequences of eating, namely aspiration and risk of death. The clinical team remained ambivalent about denying him coffee and donuts. Ultimately, it was agreed upon that in the absence of the patient having the capacity to understand the risks associated with eating, or even a surrogate to draw on his previous wishes and help

*See also p. 1672.

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with the decision-making process, our duty as clinicians ethically prevented us from “doing harm” and feeding him.

The patient continued to speak with the team through the intercession of his lip-readers, who obtained critical social history about a difficult life, a happier childhood, a devotion to the Catholic faith, and sequestered knowledge about a family burial plot in Long Island that held his parents. After nearly 1 yr of treatment and months of “conversation,” the patient finally died from his wounds. His wishes to have a Catholic funeral mass and to be buried with his family were honored by the burn unit team, who served as his pallbearers.

DISCUSSION

The advent of technology revolutionizing the care provided to the critically ill has created an environment in which barriers to communication are ubiquitous. Patients dependent on ventilators or with tracheostomies are often unable to effectively communicate with the healthcare team and their loved ones. This can lead to feelings of social isolation, confusion, and depression (1). The Joint Commission has made communication a national imperative, recommending that individuals be reassessed throughout their hospital stay for communication needs (2). Patients who are awake and alert while ventilated are in a remarkable position of having the potential to actively contribute to healthcare decisions, preserving their autonomy and rights of self-determination as expressed through their preferences for care. However, communicating with a patient who is ventilated or who has a tracheostomy presents unique challenges.

Historically, nurses can be credited for advancements in developing strategies to communicate with ventilated patients. Literature in this domain stresses the significant bond between nurse and patient in intensive care settings (3–5). In fact, nurses are often responsible for creatively finding solutions to this dilemma of communication (3, 4). Modes of communication can be categorized into those requiring fine motor skills and those using oral motor skills (6). Using communication boards, writing, tracing letters on a caregiver’s hand, blinking, and gesturing all can be considered examples of modes of communication that require fine motor skills; mouthing words utilizes oral motor skills.

For patients in the intensive care unit, writing and tracing letters requires that individuals be able to move the hands. In studies, nurses note significant limitations to these methods, namely that handwriting is illegible and the processes are time-consuming (1, 4). Using communication boards, patients express themselves by picking out words and letters or by working with a communication partner who picks options (the patient then indicates assent or dissent). This, too, can be time-consuming and is potentially not feasible for visually impaired patients (4). Some patients, when instructed on how to use a communication board before a planned intubation, have reported satisfaction with this method of communication (7).

Mouthing words may be preferable for some patients. This communication technique uses oral motor skills and has been suggested as easier and less physically taxing (8). When patients vented via a tracheostomy can mouth words with sufficient motor strength, an electronic larynx positioned at the neck or connected to a small tube inserted into the mouth may be helpful in transmitting sound (9). When this option is not available, mouthing words and lip-reading may serve as an effective form of communication. The term “lip-reading” refers to the act of recognizing speech using visual signals (10). There is a relative paucity of recent literature on communication in intensive care settings and, in particular, lip-reading as a method of communicating with patients who are ventilated or have tracheostomies. Thus, we have extrapolated from research on communicating with deaf individuals in healthcare settings.

Experts recommend respecting a patient’s preference when determining modes of communication (11). When the patient’s preference is mouthing, i.e., requiring lip-reading by hospital staff, listeners watch the speaker’s face to understand what is being said (12). Seeing the speaker helps listeners recognize language by providing information about the production of sounds and the structure of statements, both of which help listeners identify word and clause segments (13–15). Even with a trained lip-reader, only 30%–45% of spoken English words can be interpreted (16). To maximize communication efforts, trained lip-readers must be available. In one study, a lip-reading expert grossly outperformed controls in lip-reading tasks, correctly identifying both lower-order phonetic structures (e.g., single vowels) and full sentences (17). Other studies demonstrate that over time, an individual’s words can become more easily recognizable to a lip-reader, suggesting that continuity with an interpreter is beneficial to patients requiring this service (1, 5). Perhaps it is time we routinely offer lip-reading interpretation and recognize the need for prospective studies examining the role of lip-reading in medical settings.

For patients on ventilators or with tracheostomies who are limited in their ability to use fine motor skills to communicate (our patient had contractures) or who have a preference for mouthing words, we recommend using trained lip-reading interpreters. It should be noted that some deaf people are not schooled in traditional American sign language; rather, they communicate through mouthing words, gesturing, and lip-reading.

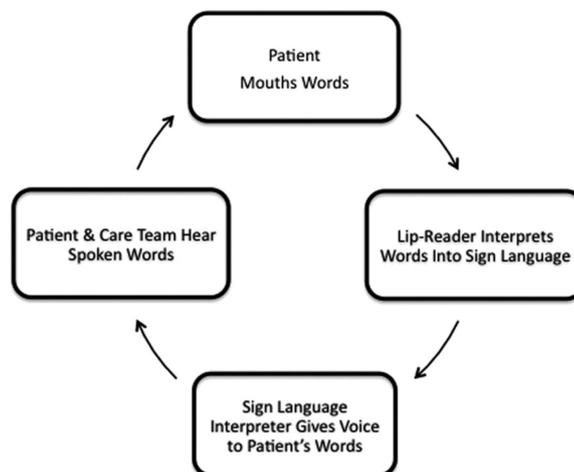


Figure 1. Lip-reading interpretation. A circuit formation.

Our hospital had a system established for communicating with this special population of deaf people through the use of two interpreters. This special skill set of advanced lip-reading was applied to our patient. The first interpreter, who actually performed the lip-reading, was a deaf individual who was trained as a lip-reader. She watched the patient mouth words and then used American sign language to communicate what he said to a second interpreter, who was a sign language interpreter and not hearing impaired. The sign language interpreter then gave verbal voice to what the patient had mouthed. The patient, who was not hearing-impaired, listened to what the sign language interpreter said and clarified anything that was not accurately interpreted. (Fig. 1.)

American sign language interpreters are not required to be skilled in lip-reading interpretation, thus this method of using two interpreters may need to be considered more frequently for lip-reading. The lip-reading interpreter available to us was hearing-impaired and not able to give voice to the patient's words; hence, sign language served as an intermediary in the interpretation process. To enhance their comprehension of what he was mouthing, our interpreters did not limit sessions to when the medical team needed their skills; rather, they worked with the patient routinely. These nonacute sessions increased the speed and fluency of the transaction and proved useful in building trust among the triad. In general, the interpreters' services would be requested by the burn unit team 1 to 2 days in advance of any discussion of depth, a visit from psychiatry, or an interview to assess capacity. In the absence of these interpreters, the patient could indicate a yes or no response to questions to communicate his needs, and the staff did not put forth the expectation of constant interpreter services.

We emphasize the importance of lip-reading interpretation for this patient and the central role that it played in his case to highlight what, in retrospect, seems to be a routine and unreflected-on omission. There is an annual projected incidence of 2.7 episodes of mechanical ventilation per 1000 population, with approximately 0.26% of hospitalized patients

requiring mechanical ventilation annually (18). The Joint Commission and other normative standards call for obligate interpretation services and, according to a survey of 83 public and private institutions from the National Public Health and Hospital Institute, approximately 11% of patients need a medical interpreter (19). However, the need for lip-reading interpretation has not been previously recognized in the same way as interpreting from Spanish to English (2). Fundamentally and ethically, lip-reading is as much an interpretation mode as that which occurs between languages, because it gives voice to patients and provides them with an opportunity for self-determination.

In writing about what interpretation does for patients, one should not overlook what it accomplishes for the clinical staff charged with caring for individuals with barriers to communication. Interpretation reduces isolation, helps to articulate preferences, and provides guidance for patient care. In the presented case, the provision of voice helped to connect an isolated, decision-incapacitated patient to the staff in a way that fostered concern and compassion. It turned his charred body into a suffering person who needed to be spoken with, comforted, heard, and acknowledged. For a homeless man who had lived for years in local airports, the last days of his life brought spiritual and physical closure; his parents were located and he was going home.

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