

A Model for Humanization in Critical Care

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<http://dx.doi.org/10.7812/TPP/12-044>**Abstract**

We present a case in which narrative medicine was used to assist a patient with amyotrophic lateral sclerosis who was dependent on mechanical ventilation and prolonged hospitalization. Implementing narrative medicine led to the development of more effective communication that strengthened the therapeutic relationship, enhanced humane care practices, and resulted in greater physical and psychological comfort for the patient. Narrative medicine is a discipline that has been progressively incorporated into medical training to restore a humane and individual physician-patient relationship. The patient is viewed, not merely as a case to diagnose, but as a person with a story that evokes emotions in those who assist him or her. In fact, narrative medicine can be understood as a model of medical practice based on narrative competence, ie, the ability to acknowledge, to absorb, to interpret, and to respond to a person's story. It strengthens empathy, rescues patient individuality, and facilitates solutions to conflicts in complex settings, such as critical care units, where clinicians are constantly exposed to existential issues, both moral and ethical.

Case Report

When I (AMF) first saw Mr P, age 49 years, he was in his bed, near to me, quite still, but very active in moving his eyes and making physiognomic expressions, which were relatively subtle, of satisfaction or of discomfort. Our introduction, though possible, had not taken place. Mr P had amyotrophic lateral sclerosis (ALS) and a tracheotomy. Since his admission to the intensive care unit (ICU) 5 months earlier, he had been dependent on mechanical ventilation. He had gradually lost muscle movement and was inert except for eye movements, his only means of communication with the world.

Before I approached the patient, greeted him, and introduced myself, I was instructed by the ICU staff on the use of two small paddles that lay beside his bed. One paddle was marked "yes," and the other paddle was marked "no." Staff members were to place the paddles in his field of vision and ask yes-or-no questions, and he would answer by looking at one of the paddles.

Because I knew so little about him and his needs and desires, I thought it would be helpful to find an effective way to communicate more extensively. I knew that there were a number of communication methods for those who suffered from, for example, locked-in syndrome. The well-known case of Jean-

Dominique Bauby, whose movement was restricted to one eye after a stroke, led staff of the hospital where he was confined for 15 months to develop a code of communication by blinking.¹

The method that was used with Bauby is generally called Partner-Assisted Scanning (PAS) and uses a board with letters arranged according to their frequency in the patient's language. The letters are arranged in lines, in order from the most common letters to the least common letters, in the direction of reading.² We researched letter frequency in Portuguese, our and Mr P's primary language, and created a square table, 20 cm on each side, with 4 lines.

Mr P agreed that he would move his eyes to his right to indicate "no" and to his left to indicate "yes." Having established this basic code, we started using the letter board. First, I explained to him that using the letter board would allow him to communicate more effectively and extensively. I asked if he would like to try this method, and Mr P signaled yes. After five months of hospitalization, this would be the first time he would try to form words to directly communicate preferences.

I thought it would be best to begin by asking him about what he wanted at that moment. "Mr P, you will tell me what you want, okay? Think about what you need, what you desire at this moment, and try to summarize it in one word. Let's start this way, okay?" I asked if he understood my proposal and repeated it. I asked if he was able to see the letters on the board. I moved the board closer and farther away and repeatedly asked, "Closer, farther?" to find the distance most comfortable for him. I continued, "Is the first letter of what you want in the first line?" He moved his eyes to his left, "Yes." I confirmed that he was able to hear me, "Can you clearly hear me?" After his confirmation, I looked intently into his eyes and began to slowly name the letters, "A, E, O, S, R... ." After the letter R, he moved his eyes to the left. "R? Is it the letter R?" He again replied, "Yes." In each letter, I always asked this question at least twice, to ensure the accuracy of the procedure. In about 10 minutes, we had already formed a word, "Remedy." In approximately 15 minutes, he had formed his first sentence after 5 months in the ICU, "Remedy for throat."

The new possibility of communication with Mr P seemed to have a significant impact on his quality of life, which was so limited by the circumstances. The ability to communicate more effectively led to the most significant and profound interactions between Mr P and members of the ICU staff. First, I would ask him about desires we already knew of, and he would answer

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“yes” or “no”: if he wanted to be aspirated; if he wanted to change his position in bed; if he wanted to change the bed position; if he felt pain, nausea, thirst, hunger, sleepiness, dizziness, or sadness; if he wanted to watch television (and which channels and at what volume); if he wanted to listen to the radio, news, or music; or if he wanted to say something in particular through the letter board. After accurately understanding his desires, I would then attempt to make him comfortable. In some cases, it was very simple and basic: just move his legs, arms, or bed position.

And, in an instant, I understood: “A hug? ... Is that it, Mr P?” He smiled without blinking. He wanted a hug from his sister. She, a little hesitantly, touched and hugged him, and both wept silently.

There were many intense, emotionally charged situations marked by pain, suffering, anguish, and relief. Once, early in our meetings, I was told that Mr P had asked several times, at dawn, in previous days, for withdrawal of mechanical ventilation. I went to him to investigate the incident: “Mr P, as soon as I arrived this morning, staff members told me that you asked them at dawn to turn off the devices. Is it true? Do you confirm?” “No,” he answered—repeatedly. After confirming his negative response, I proposed the matter in another way: “Listen, what’s going on? Did you ask someone to kill you? Do you want to die? Is that it?” “Yes,” was his response, as tears streamed down his face. He wept intensely. “I understand, Mr P. You are suffering a lot, right? And for so long. Is that correct?”

More tears. Then, it became clear that turning off the devices would provoke a very painful death by suffocation. Mr P wanted to die, but in a less painful way. It was very difficult for me to hold back tears in the face of that powerful outpouring of grief and anguish. I reflected on this episode for a few days, thinking deeply about our limited existence in this world.

During a visit from his sister, who could not come frequently, he glanced at me, asking to say something. His first few letters of a new sequence were, “Ahu ...” “Ahu ... what?” And, in an instant, I understood: “A hug? ... Is that it, Mr P?” He smiled without blinking. He wanted a hug from his sister. She, a little hesitantly, touched and hugged him, and both wept silently. After a deep breath, I withdrew from the room. It was an intimate and necessary moment that also drew the attention of the entire staff.

His sister left, and then one of his sons, who looked about 14 years old, came beside his bed. Mr P repeated the same request: “A hug.” I commented: “Today is hug day. A day of intense emotions.” Such is the immense value that a hug offers in certain circumstances.

There were other profound situations, and also some witty ones. Mr P, on several occasions, dictated to me numbers he wanted to play in the lottery. He first produced the sentence “I want to play,” and I realized shortly after that he was not referring to a board game or anything similar. Sometimes, I even went to the lottery place to play for him. At other times, I passed on the dictated numbers to his mother. It was common for me to call his family, informing them of his requests: his pillow, or the “radio/CD player” with his favorite discs. We talked about several subjects: soccer matches, elections, hobbies, and other interests. This communication was extremely important in

rescuing his humanity, which had been lost in confusing mazes of muted anguish, the anguish that breathes quietly in the scary universe of an ICU.

Discussion

We used narrative medicine to assist a patient with ALS who was dependent on mechanical ventilation and prolonged hospitalization. We developed a more effective communication strategy, strengthening the therapeutic relationship and making the environment of the ICU less impersonal.

After implementing this new communication strategy, we noticed a humanizing effect that provided physical and psychological comfort to the patient within the limits imposed by his disease. We also observed increased sensitivity and empathy of staff in response to our patient’s condition and feelings. The priority given to Mr P’s care, and the improvement in his communication, contributed to more informal and interdisciplinary case discussion focused on quality of life inside our ICU. The primary goal of this report is to help readers consider ways of improving care through narrative medicine in a wide range of settings.

This case illustrates three aspects of our practice of narrative medicine: 1) we read Bauby’s story,¹ and gained understanding from his representation of his unique experience; 2) this understanding informed our approach at Mr P’s bedside, effecting change in his clinical and familial relationships and in our clinicians’ personal understanding of illness and dying; and 3) our experience with this singular patient shed light on our predicaments of illness and health care.

Relieving unnecessary and unjustified suffering is an important role of clinicians. Healing and rehabilitation are not enough; we should also consider validation (assigning or legitimizing value) of patient feelings and desires. The duality of care and action has been inherent in medical practice since antiquity.

In past decades, technologic advances in medicine and medical training based on the biomedical model have focused on technical aspects that promote loss of individuality in the physician-patient relationship. Mechanistic action results in patient care that is fragmented and impersonal. Values, fears, beliefs, weaknesses, feelings, and emotions are often viewed as secondary, leading to dehumanization in medical practice.³

In addition, therapeutic procedures in intensive care medicine have been guided by protocols established by methodical observation of population samples in large, prospective randomized studies. It is worth mentioning that the individuality of each person in these studies is dispelled by statistical methods designed to produce a representation of the sample as a whole. Study results are related to the sample (which is selected to represent the population), but not to the unique stories of each patient. Thus, there is a serious risk of regarding each individual as a mere inanimate, passive, and automatic object, and mistakenly viewing statistical summaries as unequivocal realities that do not allow exceptions. The main limitation involved in applying these evidence-based data in real-life scenarios becomes evident when the therapy approach is based only on statistical evidence and does not consider the individuality of each patient. Each case is unavoidably unique in its contexts and idiosyncrasies.⁴

To rescue the individuality of the physician-patient relation-

ship, clinicians must develop the ability to listen to stories and to understand and honor their meanings. This is narrative competence: the capacity of human beings to acknowledge, to absorb, to interpret, and to react to stories. A new discipline at Columbia University in New York, narrative medicine, is based on this approach. The curriculum is designed to develop narrative skills in clinicians.^{5,6} Narrative medicine uses patient stories as a diagnostic, therapeutic, and educational tool. These narratives are much more than mere reports of signs and symptoms; feelings of patients and physicians are often their most important aspects. The patient is not seen as merely a case of disease, but as a story that arouses feelings in those who assist him or her.^{5,6} It is precisely this thoughtful narrative of feelings that is encouraged. Thus, clinicians who are able to narrate and to reflect on their feelings can provide more conscientious, humane, and compassionate care and are more accessible, generous, and helpful to their patients.^{5,7-9} In addition, exercising explicit awareness of one's own feelings and experiences leads clinicians to be more generous with their emotions and with their peers.^{5,8,9}

Medical schools are increasingly incorporating narrative competence into their curricula. Studies have shown the benefits of using narrative medicine to improve a physician's empathy for patients and to develop clinical skills, observation, self-knowledge, ethical sensitivity, intuition, diagnostic capacity, textual skills (knowing a story's structure, embracing its multiple perspectives, and recognizing metaphors and allusions) and creative skills: narrative competence provides a broader context for developing professionalism.⁹⁻¹¹

Another important application of narrative medicine is managing dilemmas physicians experience, such as ethical conflicts in complex clinical scenarios. The reflection afforded by narrative—identifying and organizing a broad range of factors—facilitates resolution of such dilemmas.¹²

Thus, narrative medicine can be understood as a model of medical practice based on narrative skills, which are the starting point for reflection on one's own clinical experiences, for conflict resolution in complex scenarios, and a way to recover individuality in the care of sick and dying patients, in addition to

its well established role in medical education. Narrative medicine can be quite useful for physicians in ICUs in particular, because they are constantly exposed to existential, moral, ethical, legal, social, religious, and economic conflicts that directly affect their feelings, emotions, and psychological defense mechanisms. In these settings, narrative medicine promotes reflection about the complexity of the dilemma, leading to solutions that provide better holistic care and respecting each patient's unique story. ❖

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Nothing Greater

There is no greater calling than to serve your fellow men.
 There is no greater contribution than to help the weak.
 There is no greater satisfaction than to have done it well.

— Walter Reuther, 1907-1970, American labor union leader