Is My Patient Still Alive?

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Abstract

The modern-day health-care firmament is fighting one of its biggest battles of mistrust, the seeds of which have been sown over the years and the roots seem to run deep. There is a substantial misunderstanding about the complexities of intensive care treatments, especially the life support interventions. A critically ill patient on ventilator is often perceived by the families to be dead. Such misconceptions have a huge negative impact on the already friable doctor—patient relationship. The paper presents an overview of the problem and deliberates on the possible theories of such misunderstandings and chariness. An attempt is made to suggest the steps that could be taken to address this complicated issue.

Keywords: Alive, death, intensive care, trust, ventilator

A critically ill patient on ventilator is often perceived by the families to be dead. Such misconceptions have a significant negative influence on the already friable doctor—patient relationship. Open and frequent communication with complete transparency and increasing awareness about intensive care procedures and protocols will help quell such misunderstandings.

SCENARIO 1

An 80-year-old morbidly obese, diabetic female patient was brought to the emergency department with features suggestive of severe community-acquired pneumonia. She was intubated in triage and managed in the Intensive Care Unit (ICU) with mechanical ventilation and supportive care. The relatives were counseled about the severity of the disease and the guarded prognosis was updated. The family, however, appeared to doubt the explanations and requested for a second opinion. They appeared skeptical about the need and rationale, for keeping her sedated and on mechanical ventilation. She showed gradual signs of improvement, got extubated, and was discharged in a stable condition. It was later revealed by one of the family members that they were actually misguided by a Godman, who had convinced them that the patient had already expired at the time of admission.

SCENARIO 2

An advanced malignancy male patient with severe sepsis and multiorgan dysfunction was being managed in the ICU.

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Multiple detailed counseling was conducted, explaining about the poor chances of survival. The family, however, wanted all aggressive management to continue. At a subsequent family counseling session, one of the relatives argued that we were intentionally keeping the patient on life support and that he had actually passed away a long time ago. We did rationalize with the entire family explaining them about his critical clinical state, which they seemed to understand. After detailed family discussion, it was decided consensually to deescalate the vasopressors and not to add any additional therapies. The patient expired in about 30 min. To our surprise, the family members alleged that we had shown them factitious parameters and that the patient had been dead long ago.

SCENARIO 3

A critically ill patient was being taken from the ICU as leave against medical advice (LAMA). The patient was on full ventilator support and maintaining vital parameters on a stiff dose of vasopressors. The relatives were explained in detail the risks of transfer and expected risk of death and the proper documentation was done. The patient was taken to another hospital where he was declared brought dead. The resident doctor of the receiving facility passed an irresponsible

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comment saying that the patient may have been dead for hours. The relatives returned with the media and created a ruckus on the hospital premises.

NTRODUCTION

Healthcare in India has gone through a phenomenal change in the last two decades.

The corporate healthcare has especially been under the scanner and is witnessing one of its worst phases. The dark clouds of mistrust loom low and everyone seems to have serious doubts about the integrity of the noblest profession. Our fraternity, despite working hard, has lost the faith of the common man.

The ICUs are among the costliest and deal with the sickest patient in the hospital. Every intensivist would agree to have confronted the above-mentioned scenarios and the ever-increasing ire of anxious, nontrusting attendants.

"Is my patient still alive?" is the question, which my team is being routinely asked. In fact, the relatives literally mean – "We hope you are not keeping a dead patient on life supports." The question is popping up more often than not and shows the change in the perception of the general public toward our profession.

In our country, it is a common misconception that ventilator means "end of life" and a person on ventilator is almost "expected" to die sooner or later. A critically ill patient by virtue of his clinical status, further complicated by multiorgan dysfunction and use of sedatives to keep him comfortable, is often perceived by the relatives as dead and being kept on life support systems only to mint money.

The timing of such question usually coincides with the patient not improving clinically, families facing financial crunch, and unpredictability looming large over the short-term and long-term expected outcome. The bewildered relatives are seen struggling to arrange for finances to ensure continuation of care in a private hospital versus trying to arrange a bed in a government-run ICU. The presence of acquaintances with half-baked knowledge whose prime interest is to provide unsolicited advice based on their whims and fallacies further confuses the relatives.

Why are we encountering this situation so often?

The principal and most notable reason explaining the above situation is the loss of trust, which is strongly influenced by the internet, social media, and the films. The contribution of "loose talks" and "medical jousting" cannot be disregarded.

Most ICUs are closed-door units and the general public is skeptical about what goes on inside the well-guarded walls. The limitation of visiting hours and the improper communication lay the foundation of mistrust.

Public confidence in healthcare is steadily eroding, and it is a global problem.^[1] The creep of commercialism into medicine has been cited by Collier, as the most common reason for

declining trust in the medical profession as a whole. Other cited explanations include media scandals that uncover gross incompetence or the covering up of mistakes and general skepticism about the altruism of doctors.^[2]

Trust is built steadily in most situations. A recent meta-analysis by Birkhäuer *et al.* has found a positive correlation and better clinical outcomes when patients had higher trust in their health-care professional.^[3]

The intensive care admission, on the contrary, is usually a medical emergency. The rapidly deteriorating clinical status along with the burden of expenses and unpredictability of outcome thwarts the process of trust building. The family is further stressed when they are required to take desperate decision for a patient who is unable to communicate by virtue of sick state.

It is ironic that Indians rather trust the Godmen, quacks, self-proclaimed "babas" and "tantriks," and pharmacists, instead of the treating physicians.

In Scenario 1, the relatives had complete faith in a Godman and had serious doubts about the medical facts that we had put forth during each counseling session.

The easy accessibility of internet has undeniably helped us become more aware of the world around us. However, on the flip side, patients prefer to Google their clinical symptoms and therapeutic options before they even step into the hospital.

The medical fraternity is, however, concerned about potential misinformation and misinterpretation of health information available on the internet. [4]

The physicians do worry that the use of the Internet may lead to patient confusion, unrealistic expectations, and a potential increase in litigations.^[5]

It is not uncommon to find news articles where the hospital is accused of keeping a patient on ventilator even after death. [6]

The social media too is filled with health information that is actively shared and believed as the truth. Moreover, this is not a trend that the millennials are setting. The older generation that is still discovering the ways of social media and the internet is under greater danger by imposing trust in unsolicited health information floating in the digital space. The unauthenticated health applications and availability of advice from the online communities further add to the confusion.

Traditional media houses have always been on the lookout for sensationalism and the medical community serves as a soft target. [7] There are so many success stories where the patients survived their critical illness due to timely intervention of the intensivists and the use of life support. The media, however, focuses only on one mishap and paints the entire medical community in a negative light.

Actor Aamir Khan and his TV show "Satyamev Jayate" had a phenomenal success among the masses but had a devastating impact on the image of medical profession in India. The episodes deviated from its purpose of creating awareness and tainted the image of doctors in a generalized fashion. The celebrity anchor's efforts to highlight malpractices in the medical field in India did upset the medical fraternity, but the viewers concurred that the "discreditable practices" were widespread and the actor was indeed doing a great service. [8]

Considering the current embitterment with the medical profession over the last few years, most Indians would be willing to implead themselves into the cases and provide evidence in support of Aamir Khan's views.

An interesting article by Flores, nearly a decade ago, explains that movies have a powerful influence on popular culture due to their international popularity, easy accessibility, and profitability as an industry. He also scripts that the negative portrayals of doctors are on the rise, and this is adversely impacting the patient's expectations and the doctor–patient relationship.^[9,10]

"Gabbar is back," a Bollywood film, released in 2015, shows the protagonist bring in a dead man to the hospital, requesting the doctors to save his life. The hospital and its staff are shown asking for large sum of money to treat the patient and later declare him dead. The sequence may appear exaggerated, but it seems to find acceptance as a "real thing" in the minds of viewers. It being a mainstream production, the movie succeeds in manipulating the psyche of a common man and leads to the creation of a negative image of the medical fraternity. The mobbing of our hospital in Scenario 3 may have its roots tethered to such depictions.

At the other end is a movie (waiting, 2015) that is a beautiful and sensitive portrayal about the intensive care settings. [12] However, this film never enjoyed the same kind of attention despite very realistic portrayals by incredibly talented actors who deliver a truthful and very sensitive narration of what unfolds in the ICU.

The implications of casual or reckless statements made by an individual are many and have a very high likelihood of causing serious harm (Scenario 3). "Medical Jousting," a term used to describe the criticism of patient's previous doctor, is a practice that has caused irreparable damage to our profession. This practice has further forced the public to view the medical profession with suspicious eyes and worsened the already poor doctor–patient relationship.^[13,14]

How to deal with this situation?

The need of the hour is to be prepared for this question, and handle the situation with calm and patience. Evaluate the patient yourself first. Make a note of the aspects to be discussed, the evidence to be put forth and the possible questions, that may arise, and how to deal with them. The discussion is expected to be complex and not amenable to cookbook rules.

It is imperative to understand the intellect of a person one is trying to converse with. When faced with such a query, we have often asked the attendants a straight-faced question; "What do you understand by death?" We explain to them that, we label someone "dead" when a person is not responding, a person is not breathing, and the heart activity has stopped. They are further explained that their patient is unconscious by virtue of his/her sick clinical state and also due to the use of sedatives (wherever applicable). It is further clarified that although the ventilator is supporting the respiration, the patient's cardiac activity seen on the monitor is his own. The attendants are explained that a dead person would have a zero heart rate and a straight line on the monitor. One of our colleagues often makes the relatives palpate the pulse to show them the signs of life [Figures 1 and 2]. Transiently, disconnecting the ventilator to demonstrate spontaneous breathing efforts helps. If the patient is not paralyzed, pinch and show them (attendants) a grimace, a motor movement, or an eye blink. The most challenging situation is when the patient is deeply comatose by virtue of his critical clinical state. We have witnessed situations, where the relatives have even doubted the parameters shown on the monitor as simulated.

It is very difficult to change their perception of what they wish to believe, but such interactions do put some lucidity into the gibberish situation. We document the same and place it as a part of the medical records.

For a patient going LAMA, we ensure to document the status at the time of shifting from the ICU, which includes the exact vital parameters. We document that all the therapies have been continued at the time of shifting. We have recently started pasting an electrocardiography strip and an arterial blood gas report taken just before shifting the patient out of ICU.

We have also dealt with a situation when the patient had to be woken up before her being taken LAMA just to prove that she was alive.

We all talk about sedation vacation as a tool to decrease ventilator-associated pneumonia, but to me, this is the only one intervention that makes the family believe the living status of the patient. Showing the family that the patient is waking up, moving his/her limbs is the only infallible way to make them believe that their patient is alive.

7/4/17	
9:45 AM	. Family had doubts regarding
	the aline status of the patient.
,	They were explained that patient
	is on ventilatory support and
	is sedated as for now. They were
	shown vitale on the monitor
	HR-164/min, BP-132/76, SPOZ-100%
	on Froz- 60%, RR-18/min. They were
	made to palpate carotid, brachia
	and radial pulse.

Figure 1: Bedside counseling and documentation by the Intensive Care Unit team

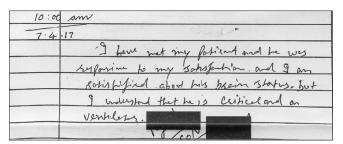


Figure 2: Endorsement of the meeting and discussion by the patient's relative

No further escalation of therapy is a safer option when compared with acute de-escalation, which results in immediate death and fortifies the ill perception of the family members (Scenario 2).

We have had sessions where we have tried to explain the family members the difference between death, brain death, and drug-induced comatose state.

Whenever we anticipate that the family members do not seem to trust us, we do give them the option of a second opinion and provide them with updated case record. We also arrange for multidisciplinary meet to address all the family members together and the minutes of the meeting are documented.

Is this situation preventable?

The patient admitted to the ICU is vulnerable and a roller coaster course is expected. Hold a family meeting early, preferably within 24 h of admission. The explanation should include the expected short-term and long-term outcomes. We discuss expected complications and need for life supports. If patient's family has reservation about any treatment option, the same needs to be documented. The institutional policy about fore-going of life support treatments should be discussed on a case merit basis. Preemptive discussion about the aggressiveness of institution of life supports and the resuscitation goal in a moribund patient saves the last minute predicament. Daily update about the clinical status does help in dealing with an unexpected deterioration. It does make sense to discuss the worst early during the course along with the proposed plan of management. Judicious identification and declaration of brain death and early discussion regarding end-of-life pathway in appropriate cases may prevent loss of trust of the aggrieved family members.[15] There are ample patient education initiatives about common medical and surgical conditions and psychological disorders, but there is a definitive paucity of information about critical care at least among the laypersons. The accessibility to awareness programs and explaining the families about what goes inside the ICU could help ward off misunderstandings. A simple explanation about the rationale of sedation may help the anxious relatives understand its significance. We have started conducting these sessions in our hospital where we try to answer their queries in as simple and straight terms as possible. We have realized that just being able to talk to intensivists outside the ICU helps families connect better with the treating team.

It is of utmost importance to be able to build the trust, especially when dealing with life-threatening situations in intensive care. Allowing the relatives to be a companion in the management of their loved ones provides powerfully important nonverbal demonstration of compassionate care and is likely to increase their trust of the treating clinicians.^[16]

CONCLUSION

We need to accept that there are no simple answers to this intricate question. When a loved one is admitted in the ICU, the family and near and dears ones are mostly in a state of denial and shock about the extent of what the admission could mean. Their psychological state oscillates between imposing 100% trust in the treating team and the bouts of doubts that come during the lows. The medical jargon is tad overwhelming for a common man. It is here that the medical fraternity could make the entire process more humane. The complexities of intensive care can be made a bit easy to understand, and families must be reassured that the medical team is doing all it could in the best interest of the ailing patient. Open and frequent communication with total transparency helps sow the seeds of trust. Although the social media can be detrimental as far as spreading the misconceptions is concerned, the same medium holds a lot of power if used correctly. The reach and reinforcement offered should be tapped too. At the institutional level, the breach created by a perception of commercialization needs to be curbed. The medical fraternity needs to align together to re-establish its integrity and to regain the dwindling trust of the community.

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