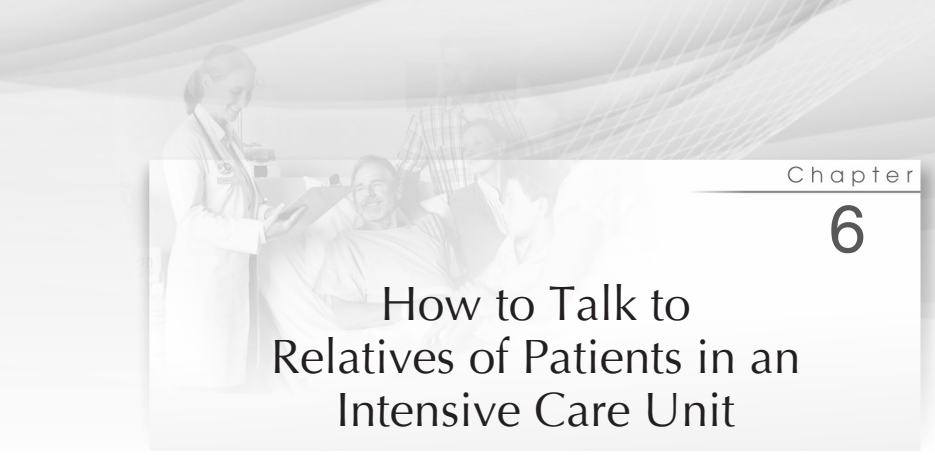

Chapter

6

How to Talk to Relatives of Patients in an Intensive Care Unit

In the world of hospital scenario, the Intensive Care Unit (ICU) is a world within a world.

A patient is usually admitted to ICU for one of the following three reasons.

First, the patient may be physiologically unstable, requiring advanced clinical judgments by the interventionist to bring back stability.

Second, the patient may be at risk of serious complications and require frequent and intensive assessment.

Third, the patient may require complicated Intensive care support. For example, serious conditions such as respiratory distress, major cardiac surgeries, and myocardial ischemic or infarction, may require continuous observation and immediate assessment and for that, the patient is admitted to ICU.

The attitude, behavior, and pattern of communication in the ICU are different from other sections of the hospital.

In the ICU, communication plays a vital role. Multiple professional societies, including the American Thoracic Society and the Society of Critical Care Medicine, define communication with families as a key component of high-quality critical care. Effective physician-patient communication improves measurable outcomes including decreased ICU stay and may reduce distress among patients' families. Studies suggest that family members view communication skills as equally, if not more, important than the clinical skills of the healthcare providers in the ICU.

At the ICU, most patients are not in a position to make independent decisions. Since critically ill patients are often unable to make decisions for themselves, their family represents their interests. The ICU team must communicate information regarding the patient's diagnosis, prognosis, and treatment and even engage family members as surrogate decision-makers for their sick or injured relative. Often, communication with families involves difficult discussions, including end-of-life issues or organ donations.

The decision maker present at the spot is usually a young person. The family identifies the young person for the job because the family believes that a young person can sustain the physical strain of staying by the side of a patient continuously and will be able to take decisions with updated information. He may be able to discuss with a doctor more 'scientifically'. However, that is not always the case.

The decision-makers are guided by several factors. They are:

A. Social Factors

a. Hierarchy Structure

In most Indian families, there is an elderly person who takes the final decision for every matter. In most cases, this person will be a senior citizen. He may visit the ICU very rarely. However, all information related to the patient reaches him and he takes the decision. So, even though the attendants of the patient remain at the bedside, if the person is asked by the ICU team to give an opinion on the line of treatment, he only responds after consulting the actual senior decision maker at home. This creates delay, confusion, and lapses in proper communication.

b. Social Environment

Unfortunately, in India and many countries of the world, society guides the attendant about the opinion to be informed to the ICU team. Take the example of a couple, ostracised by society for inter-caste marriage and heavily assaulted physically. The relative attending the two in ICU will be scared to give an opinion to the ICU team without approval from the village chieftain.

c. Cultural and Social Background

At times there are major impeding social factors that hinder treatment. For instance, there is apathy in certain families to continue treating females newborns in ICU care. Unfortunately, the social attitude towards the female child makes the family negatively oriented. The attendant shows the least interest in helping the ICU team in reviving the baby.

In many societies, for religious or cultural reasons, injection is taboo. The effort of the ICU team in treating the patient is resisted by his attendants in all possible ways.

Inheritance of property is also a factor in a certain class of people. It may so happen that the demise of the patient will make them relatively richer in terms of property. That thought goes on playing subconsciously while making decisions.

d. Illiteracy

Education helps a person to think rationally. With education, they become aware of the concept of intensive care. Unfortunately, many patients and their relatives are not properly educated and have mental blocks. Their thinking may even go to the extremes like 'Why that machine (ventilator)? Keeping a flower on the feet of our deity in the temple will cure the patient!'. They refuse to understand that the Almighty will give blessings through some media. Maybe the ventilator is the media.

e. Over Literate

This is a novel problem for about a decade. The relatives gather knowledge from social media and web search engines. Gaining knowledge is good. Unfortunately, they gather only the information that suits their line of thinking. Subsequently, they confront the ICU team at every step of treatment, refusing to understand the logic given by the ICU team.

f. Financial Capability

This is a major factor. The expenditure involved in ICU care is enormous. Having worked in several large hospitals for many years, I find the cost involved is justified in the majority of cases. However, the expenditure in most cases exceeds the

capacity of the patient's family. Every opinion sought by the ICU team from the patient relatives, makes them think about the cost involved.

B. Emotional Factors

The relatives of the patient have several emotional factors playing in their minds. Most of the emotions generate negative thoughts, perhaps owing to the circumstances. Many a time, a person in this psychological state of mind finds decision-making difficult. The commonest factors playing in their minds are:

a. Sense of Guilt

Several thoughts of guilt play in the relative's mind when near and dear ones get admitted to the ICU. Below are some examples of the relative's thought process:

Probably we have neglected the patient when he was otherwise normal resulting in aggravation of complications. We have neglected the patient.

Maybe we did not realize the seriousness of resulting in a delay in rushing the patient to the hospital. We are responsible. We brought him here thinking that this hospital has the best facilities. We should have gotten him admitted to another hospital.

b. Anger

So many people in the world are healthy. Why my relative, who is a good person, is suffering? Why God is so unkind to him?

My work routine is getting disturbed because of hospital visits and that will lead to serious consequences for my career prospect.

c. Depression

My mother is now bedridden. I cannot bear to see her comatose state. She used to run after me with my lunch and feed me when I was a kid. Now, she is fed through tubes. Her sparkling eyes are expressionless. How can I bear all these pains?

My brother had a massive heart attack. He was the only financial support for the family. How can we run the household in case he is not able to work anymore?

d. Mental Pressure to Do the Best

With my financial capacity, this is the best I can do for my father. However, probably, if I sell my house, I can take him to a better hospital but my family will have no roof over their heads. What do I do? Continue here or sell my house and move him to another hospital? Again, to my knowledge, in this city, this is the best hospital. Moving to another hospital means, I have to temporarily settle in the bigger city until he is cured. What do I do?

C. Mistrust in the Healthcare Industry

The gap between the patient and the ICU team is increasing with every passing day. The reasons are medical, social, and communication-related.

The mistrust of the patient and their relative towards the healthcare professionals (HCP) leads to their loss of faith, increased lawsuits of medical negligence filed in the court of law, and fodder for gossip for the news-hungry media. The causes of this gap are multifarious. They are:

- Medical
- Social
- Communicative

I. Medical reasons

Suspicion of human trial

With the advancement in the field of medicine and regular research on various drugs, mistrust of HCP is creeping in fast. The relatives think that their patient is made a guinea pig for a medical trial. They are not aware that medical trial has to be approved after clearing stringent checklists and it can be done only after unambiguous consent from the patient and relatives.

Short supply of new technology

Large multi-facility hospitals can afford to purchase several high-end pieces of equipment, which can be simultaneously used on many deserving patients at the same time.

Unfortunately, due to various constraints, many hospitals can afford to procure a lesser number of such high-end equipment.

As a result, high-end equipment is used on patients deserving it most. Another patient, who probably would have benefited gets deprived. In the event of such an unfortunate outcome, the relative thinks that his patient suffered because the ICU team deprived his relative of the appropriate equipment.

Transplant

Organ transplant is an important cause of mistrust. Relatives of the patient in a deep coma start thinking that the ICU team is strategically taking less care of their patient. They feel that in the event of the death of the patient, the ICU team will try 'brain washing' them to donate organs.

Withdrawing life support

The condition of patients in the ICU is always unpredictable. A patient who is on the path of recovery may suddenly deteriorate and immediate care has to be restarted to revive the case. A patient, say on ventilator support, may improve and the ICU team may decide to discontinue the support. However, soon after the withdrawal, the patient may deteriorate again and may have to be put back on ventilator support again. This stark reality may be accepted by all except the relatives of a few patients. They think that the ventilator was discontinued to be used for some other patient, thereby depriving their patient of proper care.

Doctors are strangers

Mainly doctors in the ICU are responsible for such mistrust. Mistrust develops only in those ICU Units where the doctors rarely meet the patient's relatives. In addition, on many occasions, the doctor who meets the relatives may have a change in his duty hours and some other doctor interacts with the patient. The relatives get confused about who their primary doctor is.

However, it is an additional responsibility of the ICU team to step forward and try to bridge the gap.

All these issues leading to mistrust can be overcome by regular meetings in a structured way. The details of the way forward are described later in this chapter.

II. Social reasons

Loss of faith—a global phenomenon

Loss of faith is a global phenomenon now. In every sphere of life, mutual trust is diminishing. Healthcare services cannot be an exception.

Increase in codification and rights

In the past, doctors were treated as next to God. The faith of the patient in the doctor was unshakable. Such a relationship is a thing of the past. Now, providing treatment comes under a service provider and consumer agreement. doctors are now liable for an action for medical negligence. Once a patient is critically ill, relatives assume that it is their additional responsibility to find out even an iota of 'fault' in treatment. The moment they are dissatisfied, they create an issue. Thus, for anything the ICU team opines about the patient, the relatives try to find fault instead of believing it.

Moral pluralism

Moral pluralism is not a cause of mistrust but it creates a dilemma in the minds of caregiving relatives. This results in confusion in the decision-making process about the patient. As an example, consider a patient who has developed paralysis of all limbs and slipped into a coma. The ICU team opines that the patient will recover from the coma but will stay completely paralyzed for the rest of his life. The caregiver's relatives get into a moral dilemma about whether the recovery will be a boon or a bane. They get confused.

Social media and Internet search engines

Fire, if used properly is a boon to society. If not, it causes disaster. Social networking and internet search engines are like fire. Unfortunately, as far as medical science is concerned, the information gathered from the internet by non-medical people leads to more mistrust, and more misunderstandings, thereby increasing the gap in doctor-patient relationships. If the doctor finds that the patient or the relative is arguing based on wrong knowledge then point it out to them and advise them to gather correct information from trusted sites. If possible, the doctor

can name some trusted sites. Advise the patient that gaining knowledge is good but not for self-diagnosis and the gathered knowledge should, in no way, come in the way of doctor-patient mutual trust and should not hamper the treatment process.

III. Communication-related

Insufficient contact and rapport with HCP

With advancements in science, changes in lifestyle patterns, and heavy dependency on equipment-oriented patient monitoring patterns, the ICU team has very little contact with the patient. A real connection is absent. It is worth remembering that apart from medical treatment, the patient and caregiver relative give equal importance to kind words, cheerful greetings, and the sympathetic approach of the ICU team. Unfortunately, in many cases, healthcare professionals lack giving a human touch to the patient.

This mental distance can be overcome if the ICU team is proactive. The details on this point are described later under the appropriate heading.

Insufficient discussion with HCP

Care in the ICU is usually a team approach. Apart from the intensivist, there may be a cardiologist, neurologist, pulmonologist, and others. The caregiver relative gets lost about whom to approach and when. The solution to this is also elaborated later under the appropriate heading.

WAYS TO BUILD RAPPORT AND CONNECTION WITH PATIENTS AND RELATIVES

ICUs are fast-paced, unpredictable, and complex places and the environment may inadvertently create opportunities for disrespect. It is so crammed with technology that it is easy to get distracted. This is a primary reason why the ICU team should make an additional effort to stay connected with the patient. The HCP should understand that the patient and the caregiving relative want to stay connected to the human element of treatment. The patient also should be made aware that the machine is not treating the patient. It is the human

brain which is controlling the technology and deciding on the course of treatment. So, despite the beep sounds and blinking lights of machines in the ICU, the human touch and the human decision are treating the patient.

The ICU team should remember that the environment in the ICU does not lend itself to being a naturally compassionate place.

A few suggested ways for incorporating the human element are:

1. Treat Every Patient Equally

The ICU team should have respect for all the persons under their care. Respectful treatment honors the patients and their families. As professional healthcare team members, it is their job to focus on creating an environment that imparts the best possible care to every category of patients. Under no circumstances, should the ICU Team be judgmental.

2. Remember basic Courtesies

Greet the patient and the relatives. Stay calm even if the ICU situation is stressful. I was once advised by a senior intensivist that even in a very emergency situation in the ICU, where needed, one has to walk fast but never run. The moment the HCP runs to fetch something, the patient gets panicky.

3. Be there for your Patient

To the extent possible, the members of the ICU team should spend some time with the patient or caregiving relative so that their anxiety gets allayed.

4. Get Acquainted

The ICU team should know and honor patients, and families and respect their beliefs, values, and cultural preferences. Enquire about the patient's food preferences. Ask about their inclination on the spiritual aspect. Enquire who will be the decision maker in case the patient is not in a position to make it.

Prioritize knowing patients as persons, not diseases or injuries, or bed numbers.

5. Understand the Patient's Perspective

Educate the patient about the plan of care and make sure they are part of the decision. Performing procedures like Lumbar Puncture, venesection, etc. should not come as a shock to them. These should be done in a respectful manner. We should remember that the patient is the sick person in the ICU and their relatives are extremely stressed.

6. Communicate with Respect and in Nonmedical Terminology

The ICU team should communicate in a way the patient or relatives understand. After communicating, it is necessary to confirm that they have understood it properly. Open-ended questions may be asked and doubts clarified.

It is believed that the ICU doctor, even if unconscious, should be talked to and given empathy. It transmits positive energy.

Even for a sedated or comatose patient, the team should focus not only on the equipment and monitors but also on the patient.

7. Treat the Patient with Respect even During an Internal Conversation

Many times, the ICU team uses internal codes to refer to a patient like 'nagging patient', 'short-tempered irritating old man', etc.

During the casual talk, the patient or the caregiver may overhear it and that would spoil the relationship.

In many hospitals, these types of patients are coded by some secret code which is tagged as a flyer on the case sheet. For example, the secret code may be HWC meaning 'Handle with care'. These types of codes don't remain secret for long.

8. Maintain Dignity

The patient may be unconscious but that does not mean that sponging, changing, etc. can be done without drawing the screen. The dignity of the patient is important irrespective of his level of consciousness.

9. Keep the Personal Conversation of the Team out of the Range of Hearing of the Doctor

Laughing and joking in the ICU workstation within hearing of an acutely ill patient can be seen as disrespectful. Noise and voices should be kept to a minimum inside the ICU.

10. Healthy Work Environment

A hygienic work atmosphere must be maintained. Apart from the advantage that it heightens reputation if the hospital is neat and clean, the more important plus point is that it prevents infection and helps faster recovery of the patients. The patient also gains peace of mind which will speed up the cure.

11. Make Personal Safety Way a of Life

One can extend help, and support only if one is fit and healthy. Before reaching out to the patient, the ICU team must ensure they are in full gear of Personal Protective Equipment. With this, the patient also gains confidence that the ICU team is not spreading infection. Remember you can help others only if you are safe.

The way forward—frequent structured meetings between the ICU team and the patient (or the patient's responsible relative).

As discussed, one of the important reasons for the mistrust of patients and their caregivers towards the ICU team is the lack of rapport inside the ICU and insufficient communication from the ICU team. With several specialists and other technologists in the caregiving scenario, the patient and his attendant are confused about whom to contact. Ideally, the intensivist treating the patient should be the primary point of contact during rounds.

However, the team should meet the relative frequently on prefixed dates and times to clarify their doubts. The meeting should not be casual. It should be well structured. If possible, the full discussion must be recorded after keeping the relatives informed about it.

Involve the relatives to the maximum extent possible. It should be the aim of the ICU team to conduct the meeting to make shared/informed decisions about patient care.

Step one: Plan a meeting

Schedule a meeting with a relative of the patient. Inform the relative of the patient that it should not be a large group. Two to three responsible relatives and friends who can take the decision and give consent about the further course of action by the hospital on the patient should represent the patient. Preferably the same people should attend future meetings as well.

All concerned specialists who were involved in treating the patient should attend. They should schedule the day's routine in such a way that they can attend the meeting undisturbed. The nursing charge of the ICU can attend the meeting if any questions about nursing care are apprehended.

The venue should have a comfortable seating arrangement. The room should have a projector facility in case the treating doctors feel that some sort of audio-visual explanation about the disease is necessary to update on the patient's condition.

The venue should have a video recording facility and one person from the ICU team should be assigned to minute the meeting.

Step two: Pre-meeting preparation

Before the meeting starts, the ICU team who is to attend the meeting should get thoroughly acquainted with the case and case sheet. They should internally discuss possible questions from the relatives and decide on the response. Schedule other works in such a way that the participating HCP team does not get disturbed during the meeting (except for acute emergency calls).

The intensivist should lead the team and should also be the moderator of the meeting.

In case the patient or relatives speak a different language, arrange for an interpreter.

Step three: Mental preparation of the ICU team before attending the meeting and what should be the attitude of the doctor toward the patient during a meeting.

The ICU team should ensure that they have the following mindset, attitude, and temperament during the meeting:

Should speak the truth with compassion

Restrict the number of people: In both the ICU team and the doctor team, the participant numbers should be restricted to lesser numbers. Only close/responsible/decision-making relatives should attend. The ICU team should include only those directly involved in the care of that patient. This will ensure better and more fruitful interaction.

Delicately inquiry on the source of finance: There are many investigations and treatment modalities that can be deferred for a later date. In case it is found that the relatives are heavily burdened financially, try to help in this way.

No anger: Once temper is lost, the discussion reaches nowhere. Try to understand the turmoil the family is undergoing and control the temper

Avoid the temptation to argue: During any meeting with people in agony and pain, there will be many occasions where arguments may crop up. There may be members of the patient team who may try to tempt the HCP team to argue. One should not fall prey to it. The ICU team should understand this and avoid the temptation to argue.

The perfect balance of hope and reality: The ICU team should remember that every word they speak, and every facial expression they make is heard/observed by the relatives with full attention.

Spirituality: Explain to the patient that the effort put in by the ICU team is as wished by Almighty and you all will put best and sincerest effort to alleviate the pain, suffering, and agony of the patient on his behalf

Reinforce your presence: Bring confidence in the patient about your team. Reinforce the belief in them that whatever the team is doing is honest, sincere, and with the fullest technical knowledge.

Never argue hope of recovery: As we all know, nothing in the world is in our full control. Do not discourage the relatives. Keep their hopes alive with guarded optimism.

Never vouch for an outcome without strong scientific evidence or backup: Never vouch for any outcome/modality

unless there is scientific evidence to prove your point. In case the statement given by you does not happen, you can quote the scientific data as the basis of the statement given.

Step Four: Introduce the team to the relatives

The moderator should introduce all team members to the relatives. The relatives should also introduce themselves including in which way they are related to the patient.

In case of video recording, inform the relatives in advance. Take written consent about video recording. In case the team feels that taking written consent is delicate then first inform relatives and turn on the video. After turning it on, inform once more (so that the voice gets recorded) that the full proceedings are getting recorded. With the rising trend of consumer unrest and medico-legal issues, this suggestion will keep the team safe.

One ICU team member should be assigned to minute the meeting.

Step five: Ask the relatives to express their concern

Ask about the concerns of the relatives. Let them explain their concern very clearly. Tell them that as the meeting proceeds, more concerns may arise and those can be discussed as and when they come up.

At this phase, do not counter, and do not get distracted (by checking messages on mobile, etc.). Listen to them with the fullest concentration and empathy.

Once the relatives voice their concerns summarise them. Categories of their concern-mental agony, social, financial, etc. Tell them that you fully understand their concern and feel it. Tell them that you are with them emotionally and will do the best possible to address it.

Step six: Enquire Patient's concerns

The thought process of the patient should also be explored and discussed.

Discuss this issue with relatives in detail like—has the patient executed any will?

Has the patient signed any wish of "Do not do active Resuscitation"?

Has a similar situation occurred with any other relatives in the family? If so, what was the patient's reaction to it?

Has the patient ever discussed lifestyle in the event of getting incapacitated? Would he have preferred a lengthy incapacitated life compared to a healthy active life?

Has he ever discussed organ transplants, etc.?

What would have been the reaction of the patient had he been present in this meeting?

Step seven: Discuss the condition of the patient so far

The intensivist, with the input of other team members, as and when required, should explain details of the patient's treatment to date. If necessary, to make the point clear, use the shield of educative images. After completing, the intensivist should ask the team members whether any point is missed out. Invite them to add it.

Step eight: Patient's understanding of the version

Once the ICU team explains the details of the patient's condition, treatment done so far, etc. the relatives should be asked to describe, in their version, what they have understood. It should be soid that this exercise is to ensure that they understood the points of the ICU team clearly. In case they are reluctant, they should be told that the team also did their bit and repeated the relative's concerns when they had described it. The reciprocal response will benefit all.

Step nine: Ask for fresh concerns (if any) to give clarity

The relatives are invited to explain openly any fresh concerns that have occurred in the course of the discussion. The ICU team must address it.

Step ten: Explain the further plan of action

Explain to the relatives how the team is planning the subsequent course of treatment of the patient. Wherever possible, explain to them why such a step must be taken. Ask them whether

they have any opinion on it. In case the future treatment plan has any high-cost item, hint it to the patient.

Step eleven: Summarise

Before concluding the meeting, the moderator should summarise the proceeds of the meeting.

As is usually the case, while all patients admitted to the hospital feels that they are in confinement, the patient in the ICU feels that they are in total isolation. They feel as if they are in a condemned prisoner cell in a jail. It is not the patient alone. The relatives of the patient also start thinking similarly. Topping up the burden is growing mistrust towards healthcare professionals. The ICU team has to bring the patient and relatives back to their comfort zone.

It is felt that if the process is followed, the major portion of probable misunderstanding between the ICU team and patient relatives can be averted.

The bottom line

All members of the ICU team should work with the following two philosophies in mind.

First—rely on science, and practice science but believe in compassion, empathy, and spirituality.

Second—the conscience of the ICU team should be clear that whatever course of treatment is given is in the best interest of the patient and nothing better is possible in the given setup.