An Indian Primer of Palliative Care

For medical students and doctors

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"True listening is love in action." – ***M. Scott Peck***

COMMUNICATION SKILLS

"Communication is a vital basic need and apt communication is no less than an art."

Scenario I:

Smt. Sudha, a patient with acute exacerbation of bronchial asthma, is brought to OPD by her relatives. She is breathless on mild exertion which makes her confined to bed most of the time. She appears worried and tells the doctor,

"I am scared and not able to sleep."

Physician: "Don't worry!"

Smt. Sudha: "But I feel anxious; I stay awake throughut night."

Physician: "I know, I shall give you medicines to get good sleep. You will be alright then."

The physician prescribes anxiolytics and Sudha leaves the OPD deciding not to take the prescribed medicines.

Scenario II:

Mr. Gopal is a sixty year old man and has been having loss of appetite, pain in upper abdomen, nausea and fullness of stomach for two months. He approaches a primary care physician. The physician, after a quick examination, gives him reference letter to gastroenterologist to get an endoscopy done. Gopal, a farmer living in a rural area, is reluctant to go elsewhere and tells the physician:

"Give me some medicines to make me feel better."

The physician: "Medicines can be given later: you need to consult a specialist as early as possible."

Gopal: "That seems difficult. We are having the harvesting season and I cannot leave."

Doctor is irritated, insists and gives the note of reference to the specialist; Gopal walks away dissatisfied.

What do you feel regarding the above consultation scenarios?

Could these situations have been handled differently?

INTRODUCTION

What do we remember from the days when we or one of our loved ones were ill and admitted to a hospital? The recollections would mostly be feelings; those related to interaction with staff, nurses and doctors; how they made us feel. We often recollect with gratitude, those professionals and interactions that brought clarity to the clinical situation, helped prioritise and supported us in deciding on the next steps.

On the other hand, we may recollect the deep distress and anguish of uncertainties that we faced due to poor communication and inadequate access to information.

Good communication is a trainable skill. Proper communication is vital for the well-being of the patient and the family and for the professionals' satisfaction from work. Research in communication between the physician and the patient has consistently shown that there is room for improvement in the way physicians interact with their patients. Studies indicate that there is a major unmet communication need for information about the disease, prognosis and treatment options, intent, side effects and complications.

Learning Objectives of this Chapter

At the end of the course, the student is expected to

1. Describe why communication skills are important.
2. Identify the barriers to effective communication.
3. Recognize the do's and don'ts in communication.
4. Enumerate the steps of effective communication.
5. Describe the steps of communicating bad news.
6. Describe how to deal with extremes of emotions (crying, anger etc.)
7. Describe how to deal with collusion.

WHAT IS THE NEED FOR COMMUNICATION SKILLS?

Good clinical communication will help the patient express his needs to the treating team more effectively. It helps clarify doubts and baseless apprehensions. The therapeutic rapport that develops through effective communication supports the patient and family to handle the emotional responses to the illness and to deal with uncertainty.

Good communication enables the physician to better understand the symptoms, their trajectories and their impact on the patient's quality of life and brings clarity to the clinical condition. It can help us better understand the patient's thought process and the meaning that the patient attaches to his or her situation. Through good communication, the physician can convey the required information about the disease or plan of care to the patient in a manner which helps him/her feel supported.

Effective communication helps build trust which will sustain a long term clinical relationship. This encourages rational and shared decisions about treatment. The patient is then more likely to complete the prescribed therapeutic plan and to adopt health promoting behaviours. The physician can allow a shared and balanced decision to evolve, *based on patient's values, beliefs and priorities, yet supported by clinical evidence and rationale.*

In regular clinical practice, the crucial aspect of good communication is often by-passed more due to convention and hierarchy. This leads to misunderstandings, erroneous interpretations, inappropriate decisions, confrontations and sometimes even law suits.

Common areas where communication skills become essential

a. Responding with empathy to patients
b. Recognizing and responding to cues from patient for information and emotional support
c. Understanding the patient's priorities
d. Encouraging the patient to ask questions
e. Providing information in a supportive manner
f. Shared decision-making
g. Delivering prognostic information
h. Communicating bad news
i. Checking patient's understanding
j. Discussing transitions in goals of care from curative to palliative
k. Handling collusion

What if we fail to communicate adequately?

1. *It may lead to poor symptom control.*
2. *Patient may not comply with the plan of care as their needs/concerns/agendas have not been discussed and addressed.*
3. *Adjustment to the illness and interventions may be poor and this can lead to worsening of distress.*
4. *Conflict can escalate.*
5. *The team that does not communicate effectively may find an enquiring patient as "too demanding." This can impact the therapeutic relationship.*
6. *Medico-legal problems stem primarily from poor communication and the misperceptions and misunderstandings that ensue.*

What are communication skills?

Communication includes acknowledging and understanding the concerns of the patient and family, and responding in the most appropriate manner to bring clarity to their current situation.

Core Principles

- Respect: Treat the patient and family with respect. This is essential for a healthy relationship, which in turn, promotes good communication.
- Empathy: Empathy is the ability to try to understand another person's feelings by placing yourselves in their shoes. It helps to acknowledge the other person's suffering and helps to build a good relationship. It is very different from sympathy, which is a sense of pity that the other person may find offensive.
- Trust: Once the patient loses trust in you, you lose the ability to help him. Truth is essential for maintaining trust. Lies, for example in an effort to conceal the diagnosis, destroy trust.
- Unconditional positive regard: We have no right to be judgmental. Whether the patient is good or bad, thankful or grumbling, optimistic or pessimistic, we should try to consider him the most important person. In particular, care is needed to ensure that we do not come to a position of taking sides when there is rift within a family, particularly between a patient and a relative.

What is NOT Communication Skill?

1. Conversation is NOT necessarily adequate communication. A good conversation on general topics such as travel, politics or weather is NOT adequate communication.
2. Trying to convince the patient to follow the agenda decided unilaterally by the clinical team is NOT good communciation.
3. Conversing in a soothing and gently manner, without allowing for their participation, is NOT good communication.

Barriers to effective communication

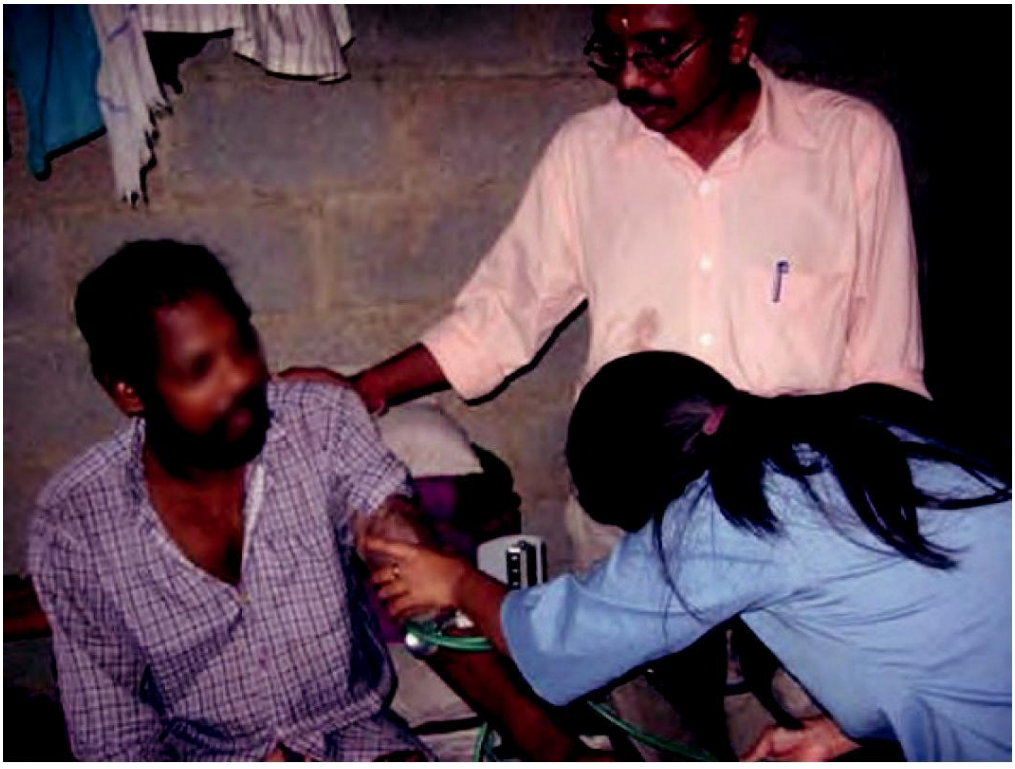

Fig 2.1: Concentrating only on physical tasks
can be a barrier for communication.

Possible barriers that may hinder the professionals:

- Too busy to spend time to understand thoughts and feelings of patient
- Worried about upsetting the patient and handling reactions
- Not having the knowledge and the skill
- Uncomfortable to enter into unpracticed area of interaction
- Unable to say - “I do not know!”
- Concentrating on physical concerns, which are easier for the doctor
- Not perceiving communication as **part of their job**
- Worried about being blamed or fear of worsening the situation
- Unfamiliar with language and dialect can be be a barrier.

Possible barriers that patients may face:

- The physician perceived as too busy
- Lack of privacy and unfamiliarity of the surroundings
- Perception that only physical problems are to be conveyed
- Fear of confirmation of bad news
- Fear of treatment being denied if they raise questions / doubts
- Fear of losing control over emotions
- Stumped by the medical jargon and technical terms
- Authoritative hierarchy of the hospital environment

Complexity of Communication Process

Every communication follows a common process from its inception to completion. A thought is conceived by the speaker → gets processed based on various mental processes, impressions and memories → put into words based on the language, mood, culture and intent, with an aligning tone of voice and body language → information conveyed.

The listener hears the words and perceives the non-verbal cues as well → these are processed based on the mental processes, impressions and memories within the listener.

The "information heard" by the listener is unique to that person and could be very different from the "intended information" conveyed by the speaker.

The original thought of the speaker will reach the receiver in its correct form only when the speaker ensures clarity at each step in the communication process. In other words, clarity is of prime importance throughout the communication cycle for effective transfer of information.

The physician should observe and process the patient's non-verbal and verbal behaviour. This process allows the physician to acknowledge any unstated or unexpressed needs and agendas that the patient may have.`

Example 1 – "I don't know much about the different treatments" – here the patient

may be lacking confidence to ask for more information on the pros and cons of each.

Example 2 – "At times, I just can't think clearly; I wonder why." – Although not a direct request, this may be a cue for help to cope emotionally.

Example 3 – During discussions on treatment options, the patient may keep introducing blocks to avoid decisions – this may be related to previous experiences of similar condition with someone known or to denial of reality. This behaviour needs to be noted and understood by the physician, and uncovered empathetically by recognising the cues.

Non-verbal Communication

We all know that communication occurs verbally and non-verbally. But we are unaware that non-verbal communication accounts for the bulk of our daily communication process. It can be the sole means of communication in young children and in people who are terminally ill, differently-abled, or emotionally overwhelmed.

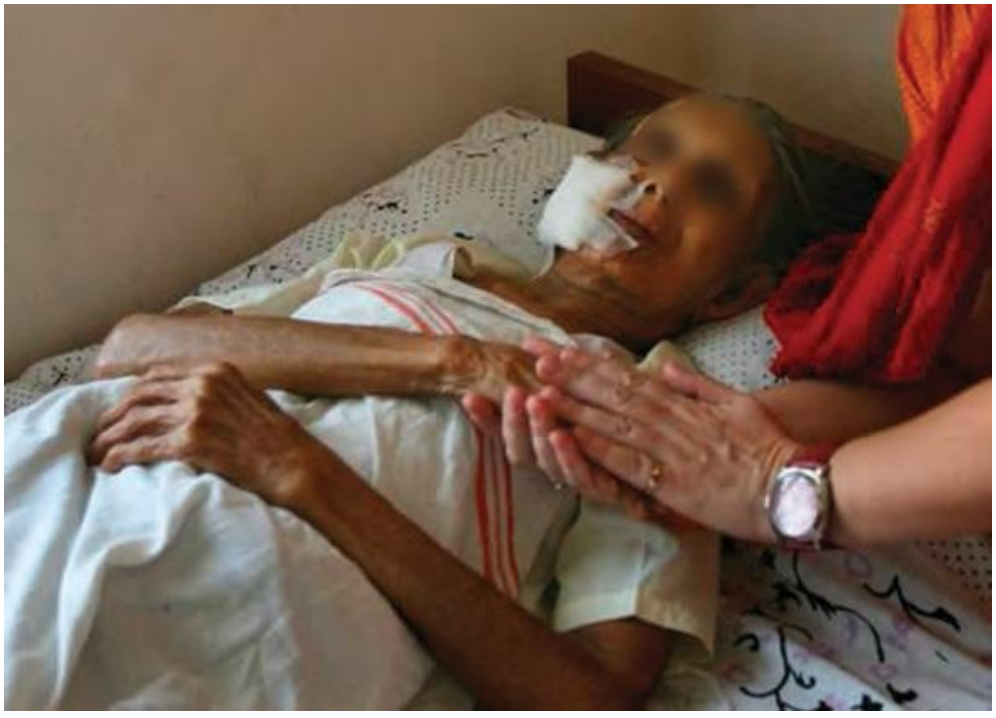

Fig 2.2: Non-verbal communication can convey loud messages.

Frequently used strategies for effective clinical consultation:

Beginning the consultation

After the greetings and introductions, begin with open-ended questions (those that cannot be answered with Yes or No) e.g. “So, how are you feeling today?” or “What brings you here today?” or “How have you been doing lately?” Such questions are not restrictive and do not pin down the discussion to a pre-decided agenda. Beginning with open-ended questions allows the consultation to be based on the patient’s agenda and can then proceed with information sharing and setting priorities.

In case of an important perceived need, the physician may declare an agenda, “Today, let us discuss the various treatment options for your current condition.”

Closing consultation

Here, it is important to check patient’s understanding e.g. “Why don’t you tell me what you have understood so far?” or “What questions do you have?”

It is also useful to summarise the discussion so as to reinforce joint decision-making e.g. “I just want to go over what we’ve been talking about. This will ensure that we are on the same page.”

Response strategies

Responding to information cues

This can begin with clarification on the patient's statement that gave you the cue ("I don't know much about the different treatments"). Once we check with the patient and confirm the need for information, we may provide a preview of options and proceed with empathy based on patient's responses. e.g. "Do you have some specific questions about the treatment?" or "When you mentioned complications of this treatment, was there anything particular that you were worried about?"

More examples are discussed below under the section on communication in advanced diseases.

It is important to avoid overload of information and medical jargon. The patient should be encouraged to ask questions, and an attempt should be made to address each of them. Here again, checking the patient's understanding is an important aspect of effective communication.

Summarizing statements like, "So, in a nutshell, we will start this medication today and then, after 3 weeks of physiotherapy, we shall review how you feel," are useful to convey that we have listened and understood their concerns, and this helps in building trust.

Responding to emotional cues

Acknowledge and validate the emotion that came across ("At times, I just can't think clearly; I wonder why."). We can do this by naming it to convey our understanding. e.g. "I note that you are feeling confused/distressed due to the ongoing events" or "It seems like this has been very tough for you to cope with."

It is useful to state it as normal under the circumstances and acknowledge the patient's efforts in coping with the situation. e.g. "It not uncommon to feel this way, under the circumstances," or "It is natural to feel tired and unable to focus on work. It would be very reasonable to take a holiday after this cycle of chemotherapy."

Silences

It is very important to permit intervals of silence during the conversation. This allows the person to gather her/his thoughts through the emotional turmoil and bring out the most significant concerns. We, as professionals, often feel compelled to fill in the silence with some extra information. This is unwarranted: our talk is often unheard and it may disturb their flow of thoughts. Also, one should avoid interruptions during the communication process, as much as is practical. You may feel overwhelmed with a need to reassure the patient with statements like, "Don't worry; everything will become alright" but this could be meaningless and premature, and may block further communication.

Responding to patient barriers

Periodic summarising helps to organise thoughts and to prepare for further discussion. e.g. "So far we have talked about… There are some more aspects that need consideration for us to reach

a decision; would you like to discuss those today?" Then, the dialogue can proceed with open questions and emphasis on shared decision-making. e.g. "Let us work together to figure out how to solve this problem," or "These are difficult decisions to make. If there is anything I can do to help you with these decisions, please let me know."

Principle	Poor communication	Good communication
Ask open questions	Is your pain better today? This is a closed question and restricts and forces the pa- tient's response.	How are you feeling? This is an open question and allows the patient to talk about what is the most im- portant issue for her / him
Be empathetic e.g. Patient: I feel very scared when I am short of breath.	Dr: Take these tablets and your breathing will improve.	Dr: Breathlessness can be very frightening; what sort of fears do you feel when you are breathless?
Balancing hope and truth	Dr: There is nothing more we can do; your disease is incurable and there is no point in continuing to stay in the hospital. Here the doctor is destroying hope irrevocably.	Dr: I am afraid there is no more treatment available to cure your disease. But we can definitely keep you comfortable with regular evaluation and medications. We are with you.
Respectful confidentiality and avoiding unhealthy curiosity e.g. Pt: I feel distressed by the fact that this cancer is the direct consequence of the abortion that I had when I was 17 years old. I have not disclosed this to anyone.	Dr: Were you not married then? This question cannot help in any way and may rein- force guilt.	Dr: I think we need to discuss this more as it is obviously a very significant reason for your distress. Be assured that everything that we discuss will be kept confi- dential.
Therapeutic relationship e.g. Poor compliance with medications	Dr: You have not taken the medicine for your pain as I advised. Don't waste my time; sorry, I cannot see you. Here the doctor is not interested in understanding reasons why the medicines were not taken and correcting them.	Dr. If you were not able to take the medicine as advised, there must be a reason. Would you like to talk about it? Did you have any trouble when you started the tablets? Do you have any questions or clarifications before using them?

Now, let us review the scenarios discussed at the beginning of this module and see how to handle them differently.

Scenario I.

Here Smt. Sudha appears really apprehensive and is not able to sleep. The physician prescribes anxiolytics to help her sleep. He has not explored the reasons behind her apprehension.

Is it because she had a relative who died from breathlessness?

Is she worried about how long her illness will continue?

Is she upset because she continues to be a burden to her family?

Eliciting and addressing these are the most important aspects of treating her insomnia. Prescribing anxiolytics without exploring her concerns will limit self-expression and will definitely not settle her symptoms

Scenario II

Why does Gopal walk away in frustration?

Here the physician insists that the patient has to meet the gastroenterologist. His suggestion is professional and with good intention. But Gopal has his own genuine reasons to refuse. Here the physician could have spent little more time with Gopal, given him proton pump inhibitors, antibiotics for H. Pylori and maybe a prokinetic for two weeks and reviewed the situation after 2 weeks. The physician can also talk to the family about his doubts, need for evaluation and discuss possibility of alternate arrangements to relieve him through his harvest commitments. Then Gopal may be more receptive to the physician's suggestion as he would feel understood and cared for. The relatives would also know the real concerns and help Gopal understand the need for evaluation.

Learning to communicate with patients with advanced and progressive diseases

Effective communication with patients facing progressive disease, with complex problems and an uncertain future is a challenge and needs skills and practice. Patients with advanced and progressive diseases have issues other than physical ones and they require compassionate listening and empathetic responses.

25-year-old Ms. Gita has come to meet the doctor. She has been diagnosed with advanced cancer of the stomach. She has not been eating much for the last 5 days. She has not been interacting with her family and has been mostly confined to her room. She has even stopped telling stories to her little niece, one of her favourite pastimes.

She wishes to speak to the doctor alone and says, "Chemotherapy is not helping

me. I cannot stand it. Doctor, please help me. I want to die."

How will you respond to Ms. Gita's request?
"Doctor, please help me. I want to die."

Do you think one of the following responses would be appropriate?

a. "You should not say such things. God gave you life. Trust him."
b. "You must chant mantra regularly for strength to endure this."
c. "Look at that man over there. He has no family; he is alone and in pain. At least be thankful that you have a loving family."
d. "Oh you poor thing; it is so sad you have to go through this terrible disease."
e. "There is nothing to be afraid of. Be brave! We shall look after you. Don't worry!"

f. "It is a squamous cell carcinoma. It is quite radiosensitive. You have a good chance of remission."

g. "Oh, so you are waiting for your final visa?! Ha, ha. But we can get your passport renewed!"

Do you think any of these responses would be caring enought to the expressed distress by Gita?

If not, why?

There is evidence to suggest that certain responses are to be avoided while communicating with sick patients.

What is not recommended during clinical communication?

1 Do not immediately reply to the patient's words. It is useful to inquire into feelings or real questions behind patient's spoken words.

e.g. To Gita's request; it may be more appropriate to respond with another question, "I can see that you are deeply distressed; would you like to share your thoughts with me?"

e.g. When a patient asks… "Doctor, how long do I have?" the implicit question could be, "Doctor…now that I have very little time left, what can I expect? How can you help me?"

2 Do not philosophise or moralise.

e.g. "You should not say such things. God gave you life. Trust in God." Such statements may hurt the patient's feelings and may act as conversation stoppers.

3 Avoid comparisons. It is insensitive to say that someone else's grief is greater and therefore, the patient has no right to grieve (disenfranchised grief). And this too is a conversation stopper. Instead we should listen to the person and allow venting of feelings. Eventually if the person herself comes to feel, "After all, my troubles are less than that person over there," that may give her some comfort.

4 Avoid meaningless words like, "There is nothing to be afraid of." They prevent further communication.

5 Avoid medical words (jargon). Technical language tends to overwhelm patients and prevents them from asking questions.

6 Avoid false reassurance. e.g. "When your general health improves, we shall try more chemotherapy. That will cure you." Any reassurance provided by this is short-lived and then it destroys trust. Reassurance is essential to maintain hope after but it must be based on truth. For example, "Even though this disease is incurable, we can help you to live as comfortably as possible. I think you may yet be able to get back to work at the office."

7 Do not make assumptions. Check the patient's insight into the diagnosis and prognosis, and what it means to her. e.g. "What made you ask that question?"

8 Avoid patronising or condescending attitude. The patient will open up to you only if you deal with her/him with respect.

9 Do not force your beliefs or convictions on the patient.

e.g. "You must chant mantra regularly for strength to endure this" is imposing your own beliefs on the patient. The person is unlikely to question you, but may not bring her problems to you any more.

10 Avoid sympathy, which is hard to bear.

e.g. "Oh you poor thing; it is so sad you have to go through this terrible disease." Instead convey empathy – an attempt to put ourselves in the patient's shoes and to try to understand what he is going through. e.g. "I can see that you are going through a lot…"

11 Avoid inappropriate humour.

e.g. "Oh, so you are waiting for your final visa?! Ha, ha".

The patient himself may use humour as a coping strategy, but coming from us it may seem insensitive and can be hurtful.

12 Avoid both lies and thoughtless honesty. Lies may not be believed, and even if believed, will destroy trust later. On the other hand, truth should not be disclosed like a bombshell. "Truth is a powerful therapeutic tool, but must be applied in the right doses at the right time."

Steps for effective communication

1. Build a relationship
2. Open the discussion
3. Gather information
4. Understand the patient's perspective
5. Share information
6. Arrive at agreement on problems and plans
7. Close discussion sensitively

1. Build a relationship
   - Set the scene. For dealing with a request like Gita's, you need the time and privacy.
   - Preferably, you could be sitting down at eye level, not too close to invade private space, but close enough to lean forward and touch the patient if the need arises.
   - Convey empathy with your expression and with a statement such as, "I see that you are very worried." The important thing is to convey that you care.
2. Open the discussion
   - Acknowledge feelings like pain or loss. In the case of Gita, it would be appropriate to say, "It looks like life is a burden for you right now." Acknowledgement of suffering makes the patient feel that she is understood.
   - Listen actively. Active listening involves eye contact, appropriate facial expression (empathy), body language (leaning forward) and verbal responses like "Yes, I see...," "and?," "hmmm," "oh..." etc. It also involves encouraging the patient by repeating her last few words and paraphrasing.
   - Listen to what is said, but also to what is not said, specifically facial expression and body language, which might indicate suffering.
3. Gather information
   - Explore and find the patient's level (What does she know? How much does she want to know?)
   - Use open questions or statements which invite responses such as:

- "What do you think might be the problem?"
- "What worries you most?"
- "That must have come as a shock to you."

4. Understand the patient's perspective
    - What does she feel about it all? What questions does she have?
    - Be prepared for an emotional reaction (sobbing, anger, silence, despair).
    - It may be necessary to facilitate sharing with words like, "Could you tell me your thoughts and how you are feeling?"
5. Share information
    - The patient decides the agenda for further discussion. In other words, what she considers important must be discussed at this stage.
    - If she wants to postpone discussion about further treatment, that should be allowed within a reasonable time frame.
    - The patient has a right to know everything, but not a duty to know. Confirm what the patient really wants to know.
    - Use common conversational language.
    - Check understanding at every stage.
6. Reach agreement on problems and plans
    - Summarise the problems brought out by the patient.
    - Suggest a course of action.
    - Answer any questions.
    - Arrive at a course of action acceptable to the patient, making it clear that this is not an iron-clad contract and that the plans are negotiable.
7. Close discussion sensitively
    - Avoid abruptness.
    - Review and summarise discussion before finishing.
    - Leave the door open to talk again.

At the end of discussion, Gita is likely to have brought out her important concerns. She would have felt that someone cares and that she is not alone. We may have found some way of encouraging communication between her and the family members. She would now have clarity about her treatment plans and might feel more in control of her life. Her prioritised physical concerns would be managed. Her unrealistic fears would have been elicited and removed and some realistic hopes of achievable targets (relief from pain and other symptoms, regular sleep, improved functionality and of course Gita spending quality time with her dear niece) might have become possible.

With all these inputs, do you think we would have responded adequately to her distressed request for death? Wasn't it actually a plea for help and support!?

Communicating Bad News

The desired outcome of consultation while breaking bad news would be "to convey threatening information in a way which promotes understanding, recall and support for the patients' emotional response and a sense of ongoing support."

When the news is really bad (the disclosure of diagnosis of cancer), the seven steps described above are very relevant. However well-communicated, bad news is still bad. It is important to understand how the patient may respond to the bad news. The aim is to minimise the impact, to remove needless fears, to instil realistic hope and to reassure the patient that he/she will not be abandoned.

Elisabeth Kubler-Ross has described different possible reactions to a bad situation.

They are:

1. Denial: "This cannot be true. This cannot be happening to me." This is usually a passing phase; but once in a while, a patient may continue in denial. For some time, it is a good coping strategy. When the person is unable to deny any more, there may be a higher emotional impact to the bad news.
2. Anger: Anger at the situation may get re-directed in the form of "shooting the messenger" - anger at the doctor or nurse. Or often, the anger may be directed at whoever is close to the patient, such as the spouse.
3. Bargaining: Bargaining may be with God, and may accompany offers to "go straight" hereafter. It may also take the form of "doctor-shopping" or "system-hopping" --trying different systems of medicine one after another.
4. Depression: It is normal to grieve when there is a bad situation, and grieving people may need help and support. Sometimes the patient may go into clinical depression, which needs to be identified and treated.
5. Acceptance: This state, when the patient says to himself, "Well, this has happened, I cannot undo it; let us see what we can do about it," is the healthiest of all.

Kubler-Ross herself was the first to admit that not everyone goes through the same stages and not in the same sequence. Our job is to find out the person's feelings, react appropriately and help the person to come to the state of acceptance.

Some examples of unhelpful communication styles:

1. **Hit and run approach**
   Doctor: "You have stomach cancer. We must start treatment by Monday."
   The patient may feel shattered.

2. **Straight answer to straight questions**
   Patient: "How much more time do I have?"
   Doctor: "Cannot say precisely. But we have seen people living up to one year!"
   The patient may feel worried and depressed.

3. **Talking only to the relative**
   Patient: "Doctor, please tell me about my condition!"
   Doctor: "Don't worry, I have explained everything to your son. He will tell you."
   The patient may feel suspicious and worried.

4. **Blunt and unfeeling**
   Patient: "I have severe pain and it kills me!"
   Doctor: "Your disease and its treatment procedures will be painful. Do understand that and cooperate with us. Otherwise it is going to be difficult."
   The patient may feel upset, lonely and abandoned.

5. **Destroying hope**
   Doctor: "It is sad, but it is my duty to speak to you. You have an advanced illness which has gone beyond the stage of cure. I can't help you further. I am sorry!"
   The patient may feel hopeless.

6. **Sad, feeling inadequate and protective about self**
   Doctor feels very upset and unprepared to speak to the mother of an ill child who will die. Here, the doctor may avoid or postpone speaking, or give the responsibility to someone else.
   The patient and mother may feel alone and desperate.

Some examples of helpful communication styles:

Sharing sadness, yet conveying truth and offering realistic hope:

Doctor: "I wish I had better news to tell you. It is sad that your child has limited time left. But we will do our best to keep him as comfortable as possible. We will be here for you."

Mother/patient may feel consoled, reassured and supported.

Flexible, based on feedback with reassurance:

Doctor: "What do you know already about your disease?" Patient: "I have an advanced form of cancer."

Doctor: "Yes, and unfortunately it is progressing (pauses, waits for response and cues to continue). We are unable to offer cure. (pauses). Here are some possible options, you can choose from. We will always be available for you."

Patient may feel concerned but reassured.

Collusion

Collusion usually occurs when the family conspires among themselves or with professionals to withhold information or lie to the patient.

It is usually well-intentioned, acting in what is believed to be the best interests of the patient, to protect the patient from emotional harm. However, this usually creates tension when the patient wants to know the truth and has the right to information.

Collusion must be addressed when it is:

- **hindering good quality care**
- **leading to futile interventions**
- **becoming harmful to the patient**

Steps to manage collusion

1. Convey to the relative that you are on their side. Do not start by trying to "convert" the relative. The approach should be, "You want the best for your mother. I too want the best for her. Let us talk about it and make plans."
2. Explore the family's understanding/insight about the illness and their reasoning.
   - Establish whether they are trying to protect themselves or the patient.
   - Recognize that they may have valid concerns about the patient's capabilities and past behaviour patterns.
   - Identify whether they have a correct understanding of the clinical situation.
3. Reassure and explain.
   - Reassure that you will not walk in and impose information.
   - Find out if the family has already felt the adverse effects of the withholding of information from the patient. Has he been anxious? Has he been in the "bargaining" phase making unrealistic demands about treatment?
   - Explore how much withholding information has affected the communication and interaction within their family.
   - Explain the consequences of keeping the diagnosis from the patient.
   - Mention that you recognize the patient's right to information, if requested.
   - Offer to facilitate the conversation between the family and patient, if they find it too difficult to handle.
   - If they are still unwilling, get conditional permission to find out what the patient already knows.
4. Share information as it becomes necessary.
   - Explore the patient's understanding, and assess their wishes for further information.

- Inform the family members about the patient's wishes.
- Share information in digestible chunks; avoid information-overload.
- Inform the family members what has been discussed with the patient.
- Encourage open communication between the family and patient.
- If the situation demands clarifications or explanations, pitch in.

Occasionally patients collude with professionals to withhold information from their family. This is more difficult as the patient has to give permission for disclosure of information, but the principles are the same as above – sensitive handling, exploration of reasoning, explanation about consequences, reassurance and offer of facilitation.

Managing Anger

Anger is a response to feelings of helplessness, distress and fear. It may also be a negative result of an ineffective communication between health care professionals and the patient/carers/ family members.

Anger is often unleashed on a person who is perceived as close (spouse, close friends, close family members) or non-threatening (usually security staff, reception staff, attendants, junior nurses and junior doctors).

Anger is often the source of medico–legal suits. A direct simple and empathetic approach helps. Have the person sit down. Acknowledge and name the emotion. Then address the need of the patient or family to be understood.

For example, "I can see that you are angry. Can we sit down and talk? Tell me what you thought went wrong. I shall try my best to help." Remember:

- The patient may direct anger at you whether or not you are the source of distress. Try to understand that the anger is directed at the situation, and not personally at you.
- Be calm, empathetic and use positive non-verbal signals throughout the conversation.
- Give the patient time to express himself; do not jump in with explanations prematurely.
- Allow the patient to express his emotions and feelings.
- Observe the nonverbal cues of the patient.
- Acknowledge the reasons for anger.
- Arrive at a consensus through "participatory decision-making."
- Summarize the conversation.
- Ask if the patient would like to add something or needs any clarification.
- Assure your continued support.
- Follow up after a stipulated time.

What can worsen anger?

Defensive responses
Indifference/dismissive attitude
Blaming the patient's behavior for what had happened
Blocking the patient's questions and leaving them feeling inadequately understood. This includes premature assurance. Passing the task on to a junior or paramedical

Managing Denial

Denial is the patient's refusal to accept the bad news. It is avoiding thoughts and feelings that are painful or difficult. It occurs to some degree in everyone who has a serious illness, though usually only briefly. It is a shock absorber that helps one bear an overwhelming situation and cope with it.

However, for some patients, denial of the illness or of its severity can cause delayed diagnosis or compromised compliance with treatment. In that event, patient and sustained efforts may be required to convey at least one part of the truth to permit treatment.

Denial can be a problem if the patient:

- does not accept the diagnosis and/or prognosis and avoids/delays treatment
- minimizes the symptoms and implications of the illness
- insists on continuing with curative treatments and other measures, even when they have been proven futile or ineffective

Denial appears to be a common defence mechanism in the majority of palliative care patients. It varies in its severity and pervasiveness. It has varying effects in the process of adaptation. In some cases, denial reduces anxiety, whereas in others, it results in excessive delay in seeking help and poor compliance to treatment.

The following questions can help gain an understanding about the degree of denial.

- What do you think about your illness?
- What is your understanding about the seriousness of your illness?
- What are your future plans?
- Do you have another plan (Plan B) if your current plan does not work?

Assessment of denial

- A cognitive evaluation is essential to rule out the possibilities of any psychiatric disorders.
- Check patient's insight–establish what he knows. This should include his understanding of the diagnosis, prognosis and the chances of success with the current treatment regime.
- Listen to the words used and observe for non-verbal signs. This might tell you how much the patient knows and how he feels about the illness.

How do we manage denial?

1. Ensure that the patient's denial is not due to lack of information, lack of understanding or lack of agreement with medical recommendations.
2. Distinguish between a fact being denied (e.g. diagnosis of cancer) and implications of the fact denied (e.g. treatment not done because of denial).
3. Assess how and when denial is used by the patient.
4. Assess the benefits and risks of denial to the patient's psychological condition and compliance to treatment.
5. If denial is expressed by minimization of illness, or lack of emotional response, it signals that the patient is frightened. Provide emotional support and discuss their concerns.
6. Adopt a non-confrontational approach. If denial is causing significant problems, direct confrontation may only reinforce the state of denial.
7. Last but not least, emphasise to patients that they will not be abandoned. They will be supported no matter which treatment plan is selected.

Conclusion

The physician should be the centre of clarity to allow shared and balanced decision-making to evolve, based on patient's values, beliefs and priorities along with clinical evidence.

Good clinical communication will help the patient understand his perceptions better, remove baseless apprehensions, find support to handle the emotional aspect of illness, deal with uncertainty and build trust that will sustain a long term clinical relationship. This encourages rational, shared decisions about treatment. The patient is more likely to complete the prescribed therapeutic plan and adopt health-promoting behaviours.

The challenge of "lack of time" invariably comes up. We should remember that good communication is more of an attitude of genuine caring and readiness to support the patient, irrespective of time. Most patients do not fall in the advanced disease category and do not require a great deal of time to complete the clinical interactions. The important starting point for the treating unit is acknowledging the fundamental role of communications on therapeutic outcomes. We should create systems to assure the regular practice of good communication through modifications in our documentation and in involving appropriately trained team members for this important task. The multidisciplinary team approach is crucial for complete caring systems to evolve.

My friend, I care
Don't tell me that you understand; don't tell me that you know;
Don't tell me that I will survive; how I will surely grow.
Don't come at me with answers; that can only come from me,
Don't tell me how my grief will pass; that I will soon be free.
Don't stand in pious judgement of the bonds I must untie
Don't tell me how to suffer and don't tell me how to cry.
My life is filled with selfishness; my pain is all I see,
But I need you; I need your love unconditionally.
Accept me in my ups and downs, I need someone to share.
..Just hold my hand and let me cry; and say… "My friend, I care."

Test your knowledge

Multiple choice questions

1. What is necessary in effective communication?
    a. Active listening
    b. Giving medical advice
    c. Normalizing
    d. Reassuring
2. Which is the most appropriate way to overcome denial?
    a. Be short and precise
    b. Involve colleagues as testimonial

c. Non-confrontational approach
d. Rational and assertive explanation

3. True or false questions
   a. Collusion makes the work for doctors easy.
   b. Sensitive truth telling is harmful for the patients.
   c. Doctors can show emotions even at the clinic; it is helpful for patients.
   d. Medical students need to be trained in good communication skills.

Ans: 1 – a; 2 – c;

True/False: 3a – F; 3b – F; 3c – T; 3d - T

Suggested Reading

1. J. Randall Curtis and Douglas B. White; Practical Guidance for Evidence- Based ICU family conferences-Chest 2008;134;835-843
2. Buckman.R1992: How to Break Bad News – Pan Books
3. Buckman R1998: 'I Don't Know What to Say – Pan Books
4. Falcon. M Neil B 2000: ABC of Palliative Care - BMJ Books
5. Faulkner A et al.1994: Breaking bad news - a flow diagram in Palliative Medicine 8:2:145-151.