

The Centre of Bioethics

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Editorial

Dear friends, in this our second issue we are looking at a topic which has traditionally been titled “breaking bad news” or “truth telling”. Breaking news has a different connotation in this age of 24- hour news channels, where everything is dramatized for the sake of effect and shock value. I remember switching on the TV one day in the peak of summer to be confronted with the breaking news flashing on screen, “Ice falls in New Delhi!” I had to wait a good 15 minutes before learning the truth of the News break – an ice cube falling off a bicycle in one of the streets of New Delhi! As Dr MC Mathew suggests in his article, it is time we called this topic by a different name, maybe “briefing about illness” or “sharing health details”.

What we seek to offer in this bulletin are a variety of articles by medical people from different disciplines and situations – one speaks from the background of years of dealing with families of developmentally challenged children, another from her considerable experience with terminally ill patients who are on palliative care, yet another looks at this issue from his perspective of having worked among the rural and “uneducated” population of our country. We add the viewpoints of a theologian, a young doctor still in training, and an excellent academic article by a bioethicist. These articles will help you appreciate the complexity of the issues involved and why a simple matter like sharing health details with a patient or family can be wrought with ethical dilemmas and be so challenging. As physicians we have a lot of emphasis placed on our training in the science of clinical knowledge and skills but precious little in the art of communication. The Bible exhorts us to always speak the truth in love. Sharing difficult news to our patients and their families becomes an occasion to give flesh to what this means where it really matters– grappling with the ‘what, why and how’ of it. We really look forward to hearing your thoughts and resonances as you engage with this topic.

Satish Thomas

Sharing Information with empathy- the heart of ‘briefing about an Illness’

M.C.Mathew

I was brought one evening in May, 1982, to the Christian Medical College, Vellore with a fracture in my right leg, which I sustained at Chennai, while riding pillion on a friend’s scooter. I was given first aid at the Madras Medical College and transferred to the emergency unit of CMC Vellore. The Orthopaedic specialist on call arranged for an X-ray and admitted me in the S ward. Late that evening, professor Selvapandian and his team

came to examine me. Seeing my hugely swollen knee joint and the shortening of the leg due to the fracture, they decided to give me a posterior slab and apply traction. Dr. Selvapandian turned to me and said, 'Sorry, M.C. you seem to have a fracture and some blood in the knee joint. We will offer you some pain relief and decide tomorrow about the treatment plan. We hope we can do something to fix it'.

The next morning, with more X-rays taken, Dr. Selvapandian and the team spent a long time discussing my condition, outside my room. There was gloom in their face, which made me feel that they too were anxious. After further clinical examination, Dr. Selvapandian, said, 'M.C. it is a bad fracture which extends into the joint with multiple pieces of the upper end of tibia. We will wait for the swelling to subside and then decide about the next step. We will keep you pain free as much as possible and I hope we can find a way forward'. Five days later, Dr. Selvapandian ordered for more X-rays and consulted each of his colleagues to make up a plan. When he came for the morning rounds, he said, 'you have made some progress, and we are hopeful. We will keep you on traction for the time being. It will hopefully bring the fractured pieces together'.

As I look back, I am amazed the way, Dr. Selvapandian 'broke the news' little by little, mixing facts with hope in a good balance. It was a bad fracture and residual disability of limited range of movement of the knee joint was almost certain. Every time he came for rounds in the first week, he conveyed optimism and caution. He spoke gently and thoughtfully. He even had a sense of humour. One day, seeing me sitting up in the bed and reading the newspaper, Dr. Selvapandian said, 'I hope you would not decide to stand up'. Everything, Anna and I needed to know medically, he conveyed on different occasions with sympathy, understanding assuring us of the best possible help. Each time he visited me, he would want to hear from me and wait for my questions or comments. During the next two months, till I was ready to go back home, Dr. Selvapandian communicated his keen interest in my full recovery.

I was already a consultant in Paediatrics for four years by then and had no idea of what it means to 'break the news'. This was a firsthand experience of some guidelines about 'breaking the news' of a medical condition, outcome of treatment, complications or adverse outcome. Let me list five guidelines for us to consider while 'breaking the news'.

1. The Content

In one sense, the phrase, 'breaking the news' is a misnomer. I wish, we use phrases such as, 'briefing about an illness' or 'sharing the health details', etc. The visual media has sensationalised the phrase, 'breaking the news' with stories and photos, which to me adds stress, anxiety and humiliation in most instances. The intent of 'briefing about an illness' is to bring comfort, clarity and direction to the patient and relatives and reduce the level of fear and anxiety. Let me suggest that the phrase. 'breaking the news' has outlived its use and it is necessary for us to have another phrase to express its intent and content.

The content of what we intend to share with a patient or the family is central and need to be defined. The content will vary according to the gravity of the illness and the immediate implications. When a patient is brought unconscious following a road traffic accident, there is some uncertainty about the course of illness and the outcome. The family needs to know about the prognosis and the several immediate measures needed to revive the patient. If Leukaemia is diagnosed in a young healthy asymptomatic adult, the family will be in a state of shock and grief, in which case, the facts about the diagnosis and its implications would need to be shared in stages and in portions that the family can comprehend and respond to. In such situations, grief counselling will be part of the initial briefing about an illness. If a new born is acutely ill, following the birth, the content of the discussion with the family would involve the immediate and distant implications of the illness. In such a situation, the family has many pressures weighing on them, such as mother's health, care of other siblings at home, etc. that, briefing about the illness ought to be just enough for the family to be aware of the progress or decline in the health of the baby.

A senior doctor is the best person to define the content of this briefing, which in consultation with the team needs to be communicated in a manner the team decides to do. It is necessary that briefing about an illness is done by the designated member of the team, preferably a person with experience and full knowledge of the state of health of the patient. The disclosure would elicit questions from the family, which would need appropriate and contextual responses.

There is sometimes a question, how much of details need to be included in the briefing! Some families need lot of details and others are content with just enough information. In some situations, families may have questions or confusion about the benefits of treatment. It is for this reason, at every stage of a new treatment plan, the consent of the family or the patient is needed.

Having worked with families, who have children with neuro-developmental needs, for the last thirty-five years, the challenge that I often faced was to define the content of the briefing. When the parents come with their baby of few months of age with definite indications of neurological insult, they would have had

previous consultations and investigations. They are often in a state of shock or denial. In such situations, I have found it more useful to listen to them and help them to pursue their thinking by directing them with relevant questions. It is easier if they find answers to their questions on their own. This form of briefing about an illness needs more time, patience and rapport with the family. The families may know the facts, but they would need an affirming setting to internalise them and respond to the challenges emotionally and responsibly.

The content is central while briefing about an illness, but the setting determines its effectiveness.

2. The setting

The physical setting of a quiet and airy room is a desirable facility. A room with good seating arrangements, with wall pictures and text can make the room homely. It is necessary to have low decibels of noise in the vicinity and in the room. It is important to welcome the representatives of the family, two or three with whom confidential matters can be discussed. The privacy and rights of the patient need to be protected, and we want to avoid any loose talk about the patient and his or her illness. One or two professionals need to facilitate the conversation, out of which one person ought to be the senior member of the team. In some instances, especially when a patient is terminally ill or family is in distress, it is important to have a chaplain in the room to continue being in touch with the family and patient.

It is a good practice to begin by getting to know the members of the family and sensing their state of anxiety. Similarly the professionals need to disclose their identity. So the time of introduction is most valuable. Following this, the current state of the health of the patient needs to be presented in brief. It is good to let the family ask questions rather than give an exhaustive coverage of the treatment details. The details would get drowned in the emotional upheaval that the family may go through, while listening to all that is happening to the patient.

The setting is often emotionally charged as any information about the patient does arouse concern and anxiety. There has to be pauses in between the conversations to allow the family to take in and feel the issues discussed. Occasionally it may push a member of the family into a state of grief or anguish, which needs to be received with understanding and support.

It is one occasion, when the professionals need to show availability and openness without indicating rush or hurry. The pauses of silence need to be welcome as they are a means for emotional recovery and an opportunity for the family to come to terms with the reality.

The closure of this time has to be planned in advance. Let the professionals decide before hand the time allotted for this briefing. Avoid prolonging the time, even if the family seems to seek for more time. It is good to plan for another occasion to meet, as such times are intense in attention and listening and prolonging it can become demanding on the professionals. It s good to greet each other while closing, and agree to meet with the family again.

3. The Attitude

The briefing time about the illness is one occasion, when families would expect sympathy and understanding. One way of communicating it, is through the modulated tone of the voice, which befits the occasion. We can convey confidence and nearness to the family by synchronising the voice and the body language.

Families are comfortable if we can use non-technical language while communicating with them. It may be better to use the phrase ‘swelling all over the body’ rather than the phrase *ana sarca* while describing the clinical condition of a patient with liver or renal or heart failure. It is good to use short sentences with pauses in between to allow enough time for the family to take in and giving them permission to interrupt with questions if they so desire.

I remember one occasion, when a senior colleague called the family aside and bluntly told that their nine years old daughter was about to die and disappeared back into the ICU. It was an abrupt communication without a prelude or postlude. Later talking to me about the hospital experience after one month of the child’s demise, the family referred to this incident with much regret and remorse.

For some reason or other, people assume that doctors and nurses would be kind, courteous and thoughtful. This is expected to be our natural temperament. It is for this reason, families are most uncomfortable when we get angry, shout, or show arrogance. A hospital is also a place of hospitality, which calls for utmost understanding of the needs and aspirations of people, who come for medical attention.

Let me suggest that as health care professionals, we are engaged in knowledge pursuit. This privilege can make some of us self-sufficient and condescending in our attitude. ‘I am the doctor; I know what I am doing; you listen to what I am saying’. This attitude towards patients and families would hurt them.

Instead, if we have an enquiring and considerate attitude, we would be able to keep in touch with the families and patients during the time of their need. They would turn to us to confide and to find direction in their lives when they are overcome by sorrow or bereavement. A doctor or a nurse is a companion to patients and families and not just a provider of treatment.

Most patients and families would need life style changes and order in their lives economically, socially and spiritually when they confront a serious illness in the family. The time of briefing about an illness is the starting point to build relationships.

A few weeks back when I was admitted to a hospital for a major surgery, the senior surgeon introduced us to his team and mentioned about what would happen during and after the surgery. I thought for a moment, that he almost trivialized my medical condition by speaking about it as just another ordinary illness, in an attempt to take away my fear and anxiety about the surgery. Looking back, I realized that his welcome, approach and friendly ambience helped me to look forward to the coming weeks with ease and expectation.

The professionals sometimes deliberately keep a distance from the patient and family emotionally, so as to safeguard their professional status. This contradicts the very character of health care, when we are supposed to engage in alleviating suffering and offering wellbeing, 'physically, emotionally, socially and spiritually'. There is a humane dimension to health care, about which late Dr. K. N. Nambudiripad, professor of neurosurgery and Director of the Christian Medical College, Ludhiana used to refer to as 'compassion - an adjunct to therapeutics'

4. The Dialogue

Every communication becomes useful if it creates opportunities for dialogue. The briefing about an illness to the family is an important occasion to prepare them to make several decisions. There are treatment options; there is the economics of the treatment; a choice of the hospital for treatment; outcome of the treatment; and for some families, the option may be not to choose any radical treatment, but only palliative care.

One of the rights of a patient, according to the Geneva Convention is autonomy and right to choose. Even in an emergency situation, the relatives are bestowed with the right to choose the nature and the extent of treatment, for which a detailed presentation of facts and implications need to be made to the family. It would appear to be easier, if the medical team, 'who know best' was the sole decision makers! However, with the Internet offering all kinds of information, most families would have come with some thoughts

and choices. It is for this reason, all decision making is arrived at, after dialogue with families. The prescriptive approach we are more comfortable with, in decision-making, is non-conducive to developing rapport with patient and families.

One family with their twelve-year daughter came for consultation for intractable seizure because of which, she discontinued attending the school for the last six months. They have been to a few well known centres and had brought reports, treatment schedule and multiple prescriptions of medicines. I refrained from looking at them till I heard their story. Their story of 11 years of coping with the frequently occurring seizures in their daughter did take a toll emotionally, financially and socially. While I requested my psychology colleague to have conversation with the girl, I allowed the family to continue with the narration of their story. After one hour, they were still ventilating their disappointments with doctors, hospitals and teachers who according to them had not supported them during their difficult times. The girl narrated her story of loneliness, tiredness with treatment and emotional weariness over the reduced social life she lives at home. For fear of having a convulsion, she cannot accompany her family for shopping.

What the family needed was for someone to listen and understand their struggles. I offered them another time to discuss about the treatment options. The parents and the daughter looked comfortable to return for further discussion. I realize from several such experiences, it is necessary for me to create time to listen. I find, when we listen, we get to know many deeper issues, which are linked to the illness, treatment or long-term implications. When we listen, we affirm the family and open the door of dialogue, including searching for options that they had hitherto overlooked. In case of this family, at the end of the third consultation, they seemed ready to look at the option of epilepsy surgery. Although this was already told to them, five years back by different consultants, they ignored it. I heard recently that she is free of convulsions after the surgery.

When a patient is in critical care, or in an emergency situation, or facing complications, the dialogue will often be brief. But while planning for organ transplant, cancer therapy, assisted reproduction, HIV counseling, etc. a detailed dialogue is central and crucial for optimum therapeutic outcome.

5. The difficulties

Most professionals may not have had any format training in briefing the family about an illness. This is a challenging issue in itself. Even now, this has not become part of the formal medical training. Most doctors pick up some precepts and practice from what they see and hear from their senior colleagues.

We are still not conditioned to respect the autonomy of the patients adequately. This is because we are not introduced adequately to the foundations of medical ethics, during our undergraduate or postgraduate training period. The professionals seem to exert authority over their patients by virtue of their skills and position.

Engaging the family or the patient for briefing about an illness consumes time, attention and need openness to revise our approach based on the choice a family may make. Most hospitals do not have designated space for briefing the family about an illness or to offer counseling to the family.

We are in a fast changing scene in health care in India. There are commercial interests in health care. The Insurance sector is breaking the service pathways into tangible components, each of which is charged separately. The consumer forum is active to find out if there was neglect or omission in the service provided to a patient. The professionals are attempting more risky surgery or interventions for treating complicated illnesses. All of these and the increasing consciousness the public has about the rights of a patient, should make the professionals consider how they are using 'briefing about illness' as an opportunity to build rapport with patients and families.

It is necessary to conduct training programmes to help the health care professionals in the art of 'briefing about an illness'. This needs to be introduced to the interns and postgraduate trainees at the beginning of their programme with refresher training programme during their training period. The consultants and senior members of the team would need advanced training to help them to be equipped to face difficult situations.

A hospital is a place to communicate to patients and families. Let it be so always!

M.C.Mathew, M.D (Paed); PhD (Neuro); D.N.B.(MCH); D.C.B.R. (Lon); D.P.H; D.A.D.R; D.F.D.R. is a developmental Neurologist, currently working as professor of child Neurology and Developmental Paediatrics at MOSC Medical College, Kolenchery, Kerala.

Dilemmas in sharing difficult news

- Mathew Santhosh Thomas

It was in year 1999. He was about 30 years old. He was brought in by his father, wife and accompanied by a few young children and many other villagers. He was unconscious and was not responding to call or stimuli. Making a clinical diagnosis of "Meningo-Encephalitis", I admitted him into the rural 40 bedded hospital and started investigating for the cause.

After the routine investigations, since there was a clinical suspicion of “immune-compromised” stage I wanted to do a HIV test. Having been trained in HIV well, and holding on the ideals of “pre-test counseling” and “confidentiality”, I called the father aside since the patient was unconscious and started sharing about HIV, the need for testing and the dangers of a positive test. I was not sure if I should talk to the father or wife or other spokespeople from the village. Wife seemed to have no presence of mind to listen. So decided, father would be better. His one rejoinder was – “Aap sub jante hei, Jo karna kareeye.” “You know what is best, please do what is required”. Being an illiterate farmer from a village in Eastern UP, I do not think he understood much of my pre-test counseling, nor wanted to think more than get going!

I struggled with the issue – how do I hold on to my ideals of “Informed consent” and “confidentiality” when the family had no interest or inclination to listen or discuss this much? I went ahead and asked for HIV testing hoping that it will be negative. It came positive. The next question was, how do you now break this news to an illiterate family, who only wanted to know – “Dik ho jayega”? (Will everything be ok?) Who is the family in this context? – All are illiterate, wife is probably already infected but is in no mood to listen or comprehend. The villagers wanted to know but are they the best to communicate to? Wife might get thrown out of the house if she is positive and the blame might go to her for infecting husband? How does shared confidentiality work in the context of communicating such news? What do you do when all what the family wants is cure and not a diagnosis?

I did what I thought I should do – treated with whatever I could without doing much post-test counseling and soon was forced to send the patient home since they were not willing to treat an incurable illness.

Dr Mathew Santhosh Thomas, a physician, has been with the Emmanuel Hospital Association in their mission hospitals located in the rural parts of North India for more than 2 decades. Currently he is the Executive Director of EHA and Treasurer of TCB

Communicating Difficult News with Realism and Hope in Palliative Medicine

Ann Thyle

Giving bad news is stressful for clinicians and hearing bad news is difficult for patients. Yet, honest communication is an ethical priority for the truly compassionate clinician. Talking about sad, bad, and difficult things with patients and their families is an inevitable part of medical work, but few receive sufficient help or training.¹

Efforts to protect patients from uncomfortable and distressing facts frequently results in censoring information in the mistaken belief that not knowing will be less harmful. Most attempts to protect patients from the truth create further problems for them and their relatives. A patient with a shortened or uncertain future needs time and space to reorganize and adapt life towards the attainment of achievable goals. Realistic hopes and aspirations can only be generated from honest disclosure.²

It is possible to give bad news in a way that creates trust & strengthens the clinician-patient relationship.

A. Reviewing the evidence³

What do patients want to know? A variety of studies indicate that in most developed countries patients want a full discussion of their medical condition. But emphasis is placed on the importance of individualizing the information based on each patient's needs.

An important point to remember is that patient ethnicity can influence how and even if patients want to know about bad news. In a study of 800 patients in the Los Angeles area; 200 patients were in each four ethnic groups.⁴ The researchers asked each person: "Should a patient be told of a diagnosis of cancer?" The African-American and European-American respondents felt that telling the diagnosis was important. But Mexican-American and Korean-American respondents largely did not want to be told.

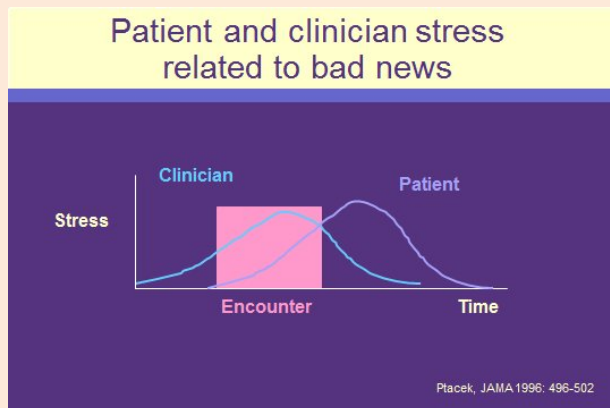
In some cultures, people believe that just discussing death can make it more likely to happen or can cause emotional harm. Some feel that if a patient is told they are dying, they will give up hope and will not fight their illness. In other cultures, one of the roles of a clinician or healthcare worker is to speak in a positive way. This does not mean these patients are "in denial" about their illness. It just illustrates a different perspective on dealing with illness.

A useful question that may help to clarify a patient's perspective about hearing bad news is, "If someone in your family was seriously ill, how do you want the doctors to handle it? Do you think they should be told?"

2. How do patients experience bad news?

The definition of bad information is that which results in a behavioral or emotional deficit in the person receiving the news and that these deficits persist. Some emotions are shock, fright, sadness, fear and even acceptance. Clinicians can't change the news itself, but the way they give it can shape the experience for the patient. They can make the news worse by adding to patient confusion or anxiety, or they can help give patients realistic hopes.

3. How competent are physicians in giving bad news?



A common complicating factor is when doctors use medical and technical terminology that patients don't understand. This causes confusion & increases their distress. Physicians are inaccurate in detecting distress, because while giving bad news they too are under stress. About 20% of physicians in a study said they had strong emotions if they had to disclose that a medical condition would lead to death.

The clinician's stress peaks during the encounter, when the bad news is delivered. The patient's stress peaks after the meeting, when the consequences of the bad news are experienced. This mismatch in stress and distress is important to be aware of in being with a patient who receives bad news.

Does how bad news is given actually make a difference?

Studies show that adjustment to receiving bad news can be correlated with three factors⁵:

- 1) The physician's behavior during the interview
- 2) A history of psychiatric illness
- 3) Other life stressors

An important finding is that patients who are dissatisfied with how they were given their diagnosis are twice as likely to become depressed or anxious. How we give bad news will impact patient mental health and adjustment to illness.

How should physicians give bad news?

Prepare well; know the facts; allocate enough time; have a quiet space; use nonverbal cues such as sitting at a comfortable distance at eye level, turning towards the patient and using an open posture.

• Find out what they already know

This step can seem awkward, but can be very helpful especially if you are concerned about cultural beliefs. A helpful way to ask is: "what do you know about your illness?" And then, "Do you want to know all the details?" In India these questions usually have to be put to the family first. They often have to be urged to allow disclosure to the patient. Relatives are concerned about their patient's well-being and feel that hearing the about the seriousness of the illness will shatter the patient. Moreover, most relatives in India consider it their responsibility to look after the patient's physical and psychological well-being and hence may not grant autonomy in decision making to the patient.

• Share the information

Firing a warning shot gives the patient a chance to prepare to receive bad news: "I have some bad news about the results of your blood test that we need to discuss."

• Use understandable language

Use language at the same level as the patient and be straight forward. You might say something like "I have an x-ray finding to share with you." Give time to absorb this information and ask questions.

• Check the understanding by saying, "Did that make sense to you?" or by asking to repeat the news back to you in his/her own words. This is a good time, if the patient is ready, to go over treatment options, prognosis etc. Remember to balance honesty with sensitivity.

• Respond to the patient's emotion

• After sharing the news, be prepared to respond to emotions. The person may be shocked

and speechless, or very matter of fact and unconcerned. Showing that you are sensitive to the response demonstrates that you are paying attention to the person's reactions.

d. Negotiate a concrete follow-up step

It is important to make a follow-up plan after the conversation. Sometimes people go into shock when they hear bad news and don't start processing it until after they have left the meeting. They might have lots of questions or concerns that they did not think to bring up during the conversation. Giving the patient permission to call or providing another resource for information is one way to deal with this. Or a meeting can be set up in the near future.

Summary:

1. Giving bad news is a fundamental communication skill.
2. How bad news is delivered can affect how patients adjust to the illness.
3. Exploring cultural beliefs can help clinicians adapt the giving of bad news to the needs of each patient.

¹ Fallowfield, L. and Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine; Lancet, 363 (9405), 312-9

² Fallowfield L, Oxford Textbook of Palliative Medicine 2010, Communication with the Patient and Family in Palliative Medicine

³ Back A, Curtis, JR, Petracca F, Stevens L, Center for Palliative Care Education, University of Washington, Copyright 2003

⁴ Kagawa-Singer, JAMA 2001; 286:2993

⁵ Blackhall, JAMA, 1995; 274:820

Dr Ann Thyle is a Consultant in Pain & Palliative Care with the Emmanuel Hospital Association. She has established Home based palliative care in seven locations in EHA. She conducts Basic course in palliative care in partnership with The Indian association of Palliative care, National Cancer Centre, Singapore and CAIRDEAF, Scotland.

Looking beyond the bad news

Rev. Prakash George

News about death, impending death, terminal illness and failures are generally considered bad news. Nobody likes to hear them. It is also very difficult to convey this news to the person concerned. One reason being, we are not sure how the person will accept the news and what his or her reactions will be. Nevertheless we have to convey the "bad" news, because it is the truth. How do we do it?

Sometimes we are tempted to play down the seriousness of the "bad" news and only share what the people like to hear. This is not helpful. People need to hear the whole truth. The Bible is not all about Good news. There is also bad news. The prophet in Ezekiel 18: 20 says, "The soul who sins shall die". The prophets had to constantly warn the people of Israel with bad news, especially of impending judgement involving various calamities and death. We read in Daniel 4: 19 when Daniel heard the dream of Nebuchadnezzar "he was perplexed for a time, and his thoughts terrified him". Nevertheless he told the king the interpretation of the

dream. As we share the bad news we need to give hope to people. All is not lost. In Ezekiel 18, God asks the people of Israel, “Do I take any pleasure in the death of the wicked?” declares the Sovereign Lord. Rather, am I not pleased when they turn from their ways and live?” (Ez.18: 23). “For I take no pleasure in the death of anyone, declares the Sovereign Lord. Repent and live.” (Ez.18: 32).

When Jesus was at the grave of Lazarus, and seeing Martha in a situation where she had lost hope, he told her “your brother will rise again” and “I am the resurrection and the life”. He who believes in me will live, even though he dies; and whoever lives and believes in me will never die. Do you believe this?” (John 11: 23 & 25).

As Christians we have the glorious message of the resurrection and the new life. Life does not end with this world. In Christ alone we have hope. People who have to hear the bad news also need to hear this good news of hope which is in the gospel of Jesus Christ. As we tell the bad news we also need to empathize with the person(s) receiving the news. The prophet Jeremiah wept over the impending bad news regarding the people of Judah. Jesus wept over Jerusalem and at the grave of Lazarus. And as we empathize, let us not shirk our responsibility of sharing the Gospel.

Rev. Prakash George co-ordinated spiritual and leadership development in Emmanuel Hospital Association

Relying on the Master Physician

Sneha Anna Joy

A frequently heard joke goes like this -the surgeon coming out of the Operation theatre says, “I have good news and bad; the operation was a success, but the patient died.” This probably is the easiest way to break bad news- to the point, distracting with a bit of humour and definitely emphasizing that it was not the surgeon’s fault. But this probably is also the most crude and callous way to go about it.

Quite early in the medical profession we come to realize that there are a million things that could possibly go wrong any day. It’s a surprise that most of us are healthy most of the days considering the number of microbes in the atmosphere, mutation causing toxins and radiation in the environment and the delicate balance between multiple genes and gene interactions, enzymes and hormones, cell differentiation and cell death, electrical impulses and chemical messengers involved in life. Anything could go wrong at any time. And the fact everything happens in perfect timing without anything amiss in most individuals definitely tells us that there is a higher Being in charge who is orchestrating everything with absolute precision. 5 years of training in medical school teaches us that it is indeed a miracle to be alive.

But what happens when this balance topples, when the mother with a perfect ANC record has a sudden IUD, when the perfectly stable patient develops an MI post operatively, when the baby with regular immunization and check up at the Well-Baby clinic suddenly aspirates and dies in the cradle? And when we as young doctors start our careers, how do we, who have no prior training in counseling suddenly handle these difficult and emotionally charged moments? How do we break the bad news?

I would like to talk about three different patients that I've had in these early years as a doctor. Mr Raju ran into casualty with a bundle of rags in his arms early on a Sunday morning. He could hardly speak. He laid the bundle with trepidation onto a casualty bed and opened it to reveal a beautiful baby girl- a couple of months old. Her skin was pale, her lips dusky and her hands and feet icy cold. There was no point trying CPR. She was long gone. The father knew it but he hoped against hope and looked towards me- I checked for pulses, auscultated for heart sounds and told him that I was very sorry. He held her close to his chest and went off wailing.

Mrs Rani, a young primigravida had had regular ANC check-ups at our small mission hospital. In her late third trimester one day when the sole gynaecologist in our hospital was on leave she presented to the hospital with high BP records and one episode of seizures. Till then her BP had remained normal. I was the attending doctor and after consulting with the gynaecologist over the telephone it was decided to give immediate care to the lady and to refer her to a medical college for further management. I explained to the relatives regarding the situation, the prognosis with respect to the mother and baby and the likely need to terminate the pregnancy and for high quality neonatal care for the preterm baby after delivery. I also explained to them how it could have happened to anyone and could not have been anticipated. The relatives were obviously upset and worried. When something goes wrong one needs someone to blame it on. And the doctor is usually the one chosen. So though they heard and understood what I said, they still continued to be mad at me and the hospital. But slowly they understood and accepted what had happened and I personally accompanied her to the medical college in the ambulance and spoke to the gynaecologist at the medical college. In the end the relatives were grateful to me.

Mr Santosh was brought to casualty with a history of headache and fall along with loss of consciousness. On examination his BP was 200/110 and was stuporose. CT Head revealed a massive supratentorial, intracerebral and intraventricular bleed. For prognostication his ICH score was calculated and was 4 which gave a 97% chance of mortality. To explain to his son that most probably his dad would not live till next day and that even if he did live, he would have gross neurological deficit was very difficult. But I gave them the figures and slowly explained it to them. Luckily or unluckily Santosh was in the 3% that survived.

So what did I learn from this and the many other similar situations I faced. First of all, break the news slowly allowing facts to sink in separately and speak to the relatives multiple times each time letting them know a bit more until finally they get the entire picture. Never hide anything from them, they deserve to know the entire truth however bad that may be. Tell them and let them see that you care and are genuinely concerned for the patient. Empathise with them and strengthen them if possible. Assure them that all that could possibly be done by a doctor has been done. Tell them that it is ultimately God the creator who gives and takes life and that you are only an instrument in His hands. Also ensure that after seeing multiple deaths you do not regard death and calamity as an everyday occurrence to be treated casually and that you have not become immune to death's sting. As a Christian doctor, I always pray to the Master Physician before sharing the bad news to give me the right words and the right tone. And I must say that this simple prayer goes a long way.

Sneha Anna Joy is a 2nd year Post Graduate Resident in General Medicine at Christian Medical College, Ludhiana

Disclosure & Veracity

Jameela George

Over the years there has been a change from physician – centred (paternalism) to patient- centred physician-patient (partnership) relationships. In countries such as ours, family paternalism is an important entity. Patients normally assume that their healthcare provider is telling them the truth about a diagnosis, the results of a test, or in recommending treatment options. However, it's easy for doctors and nurses to be bold when the news is good, but more difficult when it's not. In cases such as cancer, physicians face the dilemma of whether or not to tell the whole truth. Truth could be classified as absolute objective truth, partial truth or desired truth (what the patient wants to know). In the exploration of options and in giving of truth, what is revealed, held back, or distorted, has a profound effect on wellbeing of the patient.

Physicians have a duty to disclose information to patients about their diagnoses, prognosis, and the risks and benefits of any proposed therapies that might guide their decisions about further course of action or inaction. As full disclosure may be devastating, physicians could withhold some information, thus striking a balance. The information should be communicated in a manner that is meaningful to patients/ relatives. This could involve breaking information down into parts, or revisiting information at different visits. Competency, defined as "the capacity to weigh, to reason, and to make reasonable decisions about the risks and benefits of treatment should also be taken into consideration. In situations where the competency of the patient / family is compromised, it will be necessary to communicate only very vital information. In addition to the above-mentioned, cultural sensitivity is essential in disclosing truth – who should disclose the truth and to whom.

Arguments against disclosure

Therapeutic Privilege: Some physicians believe that they are entitled to withhold information from patients if they believe that the information will have devastating effects. This voluntary withholding is sometimes called the 'therapeutic privilege.' But withholding information could lead to loss of trust.

More harm than good: According to this, disclosing accurate information is more likely to harm the patients than to benefit them. The reaction could be shock, distress, depression etc.

Right not to know: Patients/relatives have the right not to know the complete truth about the conditions. If patient does not want to know, that view should be respected and the information regarding treatment, prognosis etc. could be withheld.

Cultural element: Often families will ask the physician to withhold a terminal or serious diagnosis or prognosis from the patient. This is to prevent the patient being pained as a result of hearing difficult facts.

No duty to disclose: Doctors do not have a duty to disclose everything about a patient's medical condition, as this could confuse the patient. The degree of disclosure could be proportional to what the patient is able to understand and wants to know.

Confidentiality: The physician is under no obligation to disclose confidential medical information to the patient's relatives.

Moral arguments in favour of disclosure

Disclosure is intrinsically good: One view is that there is something intrinsically good about respecting people and disclosing the truth. According to this, providing relevant information and empowering patients is in itself a moral good, irrespective of the consequences.

Beneficence: In making these disclosures, the ethical principle of beneficence suggests that physicians should disclose information in a way that benefits and does not harm patients.

More good than harm: Another view is that though telling the truth could initially cause distress, it could be beneficial in the long run as it contributes to appropriate decision making.

Right to know: Patients are entitled to all relevant information that might guide their decisions about what kind of therapy – if any – to pursue. If patients are unable to make medical decisions for them, their surrogate decision-makers are entitled to this information.

Necessary for informed consent: In order to get informed consent the physician has to disclose all relevant information to enable the patient/relative to make informed decisions.

Malpractice: In some countries, physicians who withhold information from a patient, even for humanitarian reasons, put themselves at risk of malpractice suits if that information is necessary to patients as they make informed decisions about their medical treatment. As a matter of both ethics and law, patients are ordinarily entitled to full disclosure in regard to their diseases and disorders.

Ethical guidelines to disclosure:

There are two ethical guidelines to be observed in regard to disclosure namely, appropriate degree of information and humane behaviour. Because most patients do not have backgrounds in medicine, physicians should disclose in patient's own terms. This might mean finding help with translations, breaking information down into parts, or revisiting information at different visits. When it comes to proposed treatments, a

Physician might find it useful to turn to informational pamphlets or support groups as a way to help patients. Some medical information is easier to disclose than others. When disclosing hurtful news, it is important that physicians communicate with patients in humane and respectful ways.

Principle of veracity:

While dealing with the terminally ill, veracity is essential in order to provide holistic care. Veracity refers to the comprehensiveness, accuracy, and objectivity with which information is handled. It is also the manner in which understanding about the condition is fostered in the relationship between the patient and the health care provider.

In order to follow the principle of veracity, it is essential to know the broad truth of the disease/ treatment options/ prognosis etc. and the competency and desire of patient/ relative to know the facts. By developing a good relationship, exploring potential options, telling the truth in a progressive manner from the beginning, getting cues and using “truth telling windows” of opportunities with sensitivity, truth telling could be possible.

Conclusion:

One of the most difficult ethical dilemmas facing health care professionals is whether, when, how and how much truth should be communicated to patients with terminal illnesses about their diagnosis and prognosis. Keeping the best interest of the patient, appropriate degree of information should be disclosed with veracity and humane manner fully aware of the fact that even when cure cannot be expected, medical care will go a long way in the lives of the terminally ill.

Dr. Jameela George is Member secretary of EHA Research Committee and is currently the Executive Director of TCB. She has a Masters in International Research Bioethics from Monash University, Australia

Aims & Objectives of TCB

- To be a Christian voice on ethical issues based on Biblical values
- To analyze, interpret and engage with the existing and emerging bioethical issues pertaining to health care and research
- To facilitate upholding the sanctity of life and dignity of humans in medical practice and research
- To promote ethical medical practice
- To build leadership in the field of Bioethics, in the areas of Medical education, Medical practice and Medical research

Prayer support:

TCB needs constant prayer support of churches and individuals alike for the success of its mission and we request all our like-minded believers to kindly uphold us in prayers for God's leading and wisdom. We will appreciate you being in touch with us through face book, website, email or post.

Contacts:

Dr. Jameela George
Executive Director
The Centre of Bioethics, India
Mobile: +91-9312795987
Email: jameelageorge@eha-health.org

Dr. Satish Thomas
Editor, Bioethics Bulletin
Professor of Ophthalmology
Christian Medical College, Ludhiana
Mobile: +91-9646001314
Email: ashusatish.thomas@gmail.com