



Ian Anderson Continuing Education Program in End-of-Life Care

Module 5

COMMUNICATION WITH PATIENTS AND FAMILIES



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Case Scenario

David Hawk is a 30-year-old man who presented to your office with fatigue, weight loss, night sweats, and cervical adenopathy. He did not have any symptoms suggestive of infection. On physical exam, he has several 2-3 cm nodes in his anterior cervical chain that are hard but not fixed. He also has some axillary and inguinal adenopathy. You order a CBC that is unremarkable and his Monospot is negative. Concerned, you make arrangements for him to have a lymph node biopsy however you tell him “not to worry, its probably nothing serious”. We’ll have you up and running again in no time”

David has always been very healthy and very active. In high school he played competitive basketball and by the time he started university, he was on the national team. He recently successfully defended his PhD thesis in biochemistry and has just been hired by a well-known pharmaceutical company. He is very excited and has told you that after all his years of studying “life seems to be just beginning”. You have followed him regularly and outside of some minor ligamentous injuries, he has never required any medical treatment. He has two brothers both of whom are healthy. His parents are also your patients: his father has class II angina and his mother has mild asthma.

You are dismayed when the biopsy of his lymph node reveals Hodgkins Disease. You bring him back to the office to tell him the bad news

David: “I can’t believe this is happening. I thought you said it would not be anything serious!” They have clearly made a mistake and mixed my tests results up with someone else’s”

“Did you think it was something serious? Why didn’t you tell me??”

Introduction

Communication is fundamental to the physician-patient relationship. Currently, poor communication is a significant problem affecting the medical profession. The Royal College of Physicians and Surgeons CanMEDS 2000 project recognizes that communication is essential to the provision of “humane, high quality care” by specialists. Unfortunately, even a quick perusal of the literature reveals that physicians lack training and knowledge in how to communicate news effectively, and deal with the emotional response to such news. Even more concerning, studies show that communication skills do not improve and may even worsen in the course of training due to the perceived lack of value in effectively communicating on the part of more senior physicians, the lack of good role models and physical and emotional fatigue.

When a person is diagnosed with a serious or life-threatening illness and is nearing the end of life, good communication is crucial to convey the seriousness of the illness (as difficult and sad a task as this may be), the expected course and treatment alternatives including palliative care. Only through good communication can pain and distress be alleviated and decisions regarding treatment and advance care planning be made. Only through good communication can physicians convey their caring and empathy for dying patients and provide good quality end-of-life care.

Objectives

- ❑ Describe and demonstrate the components of effective communication in dealing with seriously ill patients and their families.
- ❑ Be able to break bad news, listen and respond to the needs (informational and emotional) of patients and their families at the end of life.
- ❑ In clear language appropriate to their level of understanding, honestly address the concerns of the patient and his/her family and ensure their comprehension of any imparted information.
- ❑ Know and understand the consequences of the language used to impart information
- ❑ Be able to communicate so as to not destroy hope or provide false hope
- ❑ Demonstrate empathy and caring using verbal and non-verbal language
- ❑ Be able to communicate and discuss end-of-life decision-making in a way that is sensitive to issues of culture and religion
- ❑ Recognize situations in which the health care provider will have difficulty in interacting with the patient and/or family and develop communication skills to overcome these difficulties

Effective Communication

- ❑ Professional communication is a skill and like any skill can and must be learned. Being a nice person does not automatically mean you know how to communicate with patients and families.
- ❑ Communication is needed to establish the therapeutic relationship, obtain relevant information about problems and discuss diagnosis, prognosis and treatment options according to the patient's goals to ensure quality end-of-life care
- ❑ If physicians are not interactive and do not respond to the patient's needs for either information or emotional support, they will not be seen as caring and, their patients will not confide in them their hopes, dreams and fears.
- ❑ Without trust, good quality of care cannot be provided since patients will not tell health care providers about any pain or distress they are experiencing, what they are worried about in the future and what is important to them.
- ❑ At the end of life, when trust is lacking, decision-making may fail to take into consideration the dying person's goals, beliefs and values and he/she may not receive treatment he/she wants or may undergo unwanted interventions

Goals of Communication at the End of Life

1. Convey respect and understanding for the patient as a person first, patient second
2. Convey information about illness, its likely course and treatment options (including resuscitation, life support and artificial nutrition)*
3. Communicate empathy and support
4. Convey appropriate hope**
5. Develop a treatment plan in context of patient's goals, values and notions of quality of life
6. Arrange for follow up meetings and reassure about ongoing care and support

* Seek to reduce unnecessary uncertainty and help with end-of-life decision-making (see [End-of-Life Decision-Making Module](#))

**Not hope for cure but hope for good quality of remaining life and/or fulfilling realistic goals and expectations

Barriers to Effective Communication

- ❑ Although key to the physician-patient relationship, many barriers to effective communication exist. Due to the emotional content of communication, these barriers are more likely to arise when the news is bad or when the patient is at the end of life.
- ❑ In their efforts to improve communication skills, consideration of these barriers may help all health care providers to discover problems that they can work to overcome.
- ❑ Barriers can be divided into those due to patients and families, due to health care providers and those due to circumstances.

Barriers due to patients and families

Misunderstanding of illness, treatment options and prognosis

Biases over the role of palliative care in society and medical profession

Lack of knowledge of social, cultural norms, roles and expectations regarding death

Re-alignment of roles within the family structure

Lack support, lack of coping mechanisms → crisis

Physical and emotional depletion

Strong emotions

Differences in values, beliefs or culture

- ❑ Patients and families may misunderstand the illness and the prognosis. These misunderstandings are more common when the news is bad and, when patients and families are physically, emotionally or psychologically stressed. Physicians should give information in small chunks, and check understanding. Even if patients and families seem to understand the news, physicians must be prepared to give repeated explanations and answer questions.
- ❑ Biases over the role of palliative care within society and the medical profession may lead patients and families to misunderstand what palliative care involves. They may perceive involvement of palliative care as implying death is imminent and fail to understand that expertise in palliative care can help improve quality of life.
- ❑ Patients and families may lack knowledge of social, cultural norms, roles and expectations regarding death. They may never have seen or had a loved one die. This confusion over what to do may result in refusal to recognize the severity of illness and prognosis, over-emphasis on treatments leading to possible cure and failure to accept palliative treatment which is seen to mean accepting death.
- ❑ Faced with the stress of illness and threatened loss, family may struggle to re-align their roles within the family community. They may lack support, may not be able to cope and may present in crisis. When in crisis, misunderstandings, confusion and conflict within family and with the health care team are more common.
- ❑ The physical and emotional depletion that accompanies severe and/or prolonged illness also decreases ability to concentrate, retain information and decreases decision-making capacity.
- ❑ Strong emotions: anger, guilt, denial over illness, threatened loss or unfulfilled dreams may consume the patient and family and result in inability or refusal to process information.
- ❑ Differences in values, beliefs or culture may make it difficult for patients and families to express their emotions, needs and goals with health care providers.

Barriers due to health care providers

Depth of the physician-patient relationship: health care provider grief over having to impart bad news to well-known patient or difficulty in imparting such news to a new patient.

Personal experiences of illness and death

Physical, emotional and psychological stress and depletion

Fears of confronting own mortality and fears of death

Lack of training and poor role models

Fears of emotional outbursts

Fears of appearing weak or unprofessional for displaying emotions

Personal beliefs and values regarding treatment, death, palliative care

Fears of being messenger

Guilt and self-blame due to iatrogenic complications resulting in poor quality of life, increased severity of illness and/or death

Unrealistic expectations of the success of life-sustaining interventions or failure to discuss the role of life-sustaining interventions in view of patient's goals, values and beliefs

Inconsistent approach to the issues, differences in language leading to confusion (perception of "mixed messages") and misunderstandings with patients and families.

- Physicians may develop strong bonds with patient and family, whether they have known them for years or just a short time. These bonds may make breaking bad news or discussing issues around end-of-life care difficult since physicians may find it difficult to contemplate losing a patient they care for deeply
- Physician's personal experiences with illness and death may affect their ability to care for a person who is at the end of life
- Physical, emotional and psychological depletion may affect ability to

communicate caring, empathy and compassion

- ❑ Caring for someone who is dying leads to physicians confronting their own mortality and fears of death
- ❑ A lack of training and role models results in poor communication skills and either a lack of awareness of patient's feelings and reactions or inability or fear of discussing these emotions
- ❑ Physicians are not taught how to show empathy and caring and may fear emotional outbursts
- ❑ Many physicians have been taught that displaying emotion is a sign of weakness or unprofessional. These physicians may have difficulty in discussing end-of-life issues for fear of feeling or displaying emotion
- ❑ Health care providers' personal beliefs and values may influence their ability to communicate and care for people at the end of life
- ❑ Physicians may fear they will be blamed for being the messenger when the nature of the news is bad and/or sad
- ❑ When illness is due to or has been exacerbated by iatrogenic complications, physicians may be consumed with self-blame and guilt which may affect their ability to consider the patient's situation, i.e., How has this iatrogenic complication affected the patient's quality of life and is the patient likely to recover?

Barriers due to circumstances

Lack of previous relationship with patient and family

Lack of privacy

Unavoidable interruptions

- ❑ If physicians have to discuss personal, difficult end-of-life issues when they just meet a patient and family, communication is often stilted and awkward
- ❑ As hospitals lose more and more beds, privacy becomes more and more difficult to obtain

- There may be unavoidable interruptions if the physician is the only one on duty in, for example, the ER or ICU

How to Communicate at the End of Life

Preparation

Review chart and test results

Discuss with other team members, the purpose of the encounter, the information that needs to be conveyed, the team's perception of the patient and family's knowledge, understanding and emotional state*

Who will be present (other team members, family)?**:

Ask whether they want to have information conveyed to them or to surrogate*** (important in non-Western cultures)

Decide with the patient when the best time to meet would be and avoid interruptions during meeting

* Discuss with other team members (when applicable) what information needs to be conveyed i.e. what are the informational goals of the encounter, what are the perceptions of other team members regarding patient or family's understanding of situation to date, what concerns have they expressed to other team members

** Ask the patient who he/she wants to be present and decide who from the health care team will go: should invite RNs and consider inviting social worker, and/or chaplain (if appropriate). Strongly encouraged to have RNs – at least – and family present when breaking bad news or discussing end-of-life issues. Allows the team to know what was said, how it was received. In this way, the team can help provide support, re-explain information if needed after the meeting and ultimately improve the quality of care.

*** Differences exist in way handle information based on race, culture, religion and socioeconomic class. Ask the patient if they want information to be conveyed to

them or to surrogate: in non-Western cultures, people may believe that bad news can cause harm and hasten death or it may be traditional that a particular family member receives the information and then decides whether and how to tell the patient.

- Patients have the ethical and legal right to decline to receive any information and to designate others both to be recipient of the information and to make decisions regarding their ongoing care

Helpful Phrases

“Would you like me to tell you what the tests show or is there someone else I should talk to?”

“Some people do not want to be told what is wrong with them, but would rather their families be told instead. What do you prefer?”

Communication at the End of Life – A 9-Step Approach

9-Step approach to end-of-life communication:

1. Start the meeting
2. Agree on the purpose of the meeting
3. What does the patient/ surrogate/family know?
4. How much do they need to know to make decisions around EOL issues?*
5. Sharing information/responding to emotions
6. Discover their goals, expectations, hopes, values and beliefs, fears
7. Address their needs
8. Develop a plan
9. Arrange follow-up

* See [End-of-Life Decision-Making Module](#) for detailed discussion

Starting the meeting:

- ❑ No matter what information needs to be conveyed, physicians should find a quiet room to allow privacy, expression of emotions and maintain confidentiality
- ❑ Avoid talking in hallways, communal waiting rooms, doorways
- ❑ Sit down: conveys interest, respect and sense that you will spend time with them and will not give information and then abandon them
- ❑ Introduce yourself to patient and family members and explain your role. Give opportunity for other team members to introduce themselves and explain their roles
- ❑ Ask the family members to introduce themselves and explain their relationship to patient



- ❑ Builds the team relationship with patient and family

Purpose

- ❑ Agree on purpose of meeting. In end-of-life communication, the purpose is generally :
 - 1. To update (from their point of view or yours)**
 - 2. To break bad news**
 - 3. To discuss a decision point**
 - 4. To provide emotional and psychological support**
- ❑ Agreeing on the purpose allows them to prepare psychologically and emotionally for what is to follow and removes anxiety generated by uncertainty of the purpose of the meeting or course of discussion
- ❑ Allows the patient an opportunity to state if he/she is prepared to discuss these issues or if another time would be better. These discussions however cannot be deferred indefinitely
- ❑ Fears that bad news will lead to depression, suicide or refusal of treatment are unsupported in the literature: most patients want to know what is happening, what their diagnosis and prognosis is, even if the news is bad.
- ❑ Whether purpose is to update, communicate bad news, provide empathy and support or decide about course of treatment, all meetings can follow the same 9 general steps
- ❑ Physicians must be flexible, attentive and responsive to the patient's needs which may be expressed verbally or non-verbally

Helpful Phrases

“I wanted to meet with you to discuss your tests results.”

“I am sorry to tell you that I have bad news. You have had a big heart attack and your heart is badly damaged.”

“We need to talk about where we go from here: as you know his kidneys are not working well. We are at the point where we need to talk about dialysis and whether, given his current situation, he would have wanted to go on dialysis...”

What do they know?

- ❑ Many patients already have thoughts and beliefs about what is wrong with them, what their illness is caused by and how serious it is
- ❑ Asking them what they already know before rushing in with explanations allows you to assess:
 1. the language they use
 2. their level of understanding
 3. any misconceptions, misinformation
 4. when they were last updated and what they retained, understood from that meeting
 5. their emotional state, coping abilities



- ❑ Send a message that what they feel and think is important ⇒ strengthens the patient-physician relationship

Helpful Phrases

“Why don’t we start by you telling me what you already know (or think is happening) and understand, and we’ll go from there?”

“ What do you understand about your illness and the tests you have had?”

“ How would you describe your health?”

“ What did the other doctors tell you about your symptoms or the tests that you have had?”

“ What did Dr. Jones tell you when she sent you here?”

“ When you first had pain what did you think it could be?”

From Buckman R., *How to Break Bad News: A Guide for Health care Professionals*, Johns Hopkins University Press Baltimore 1992

Summarize what the patient has told you  confirms that you were listening and understood what he/she said

- Check the patient’s/family’s understanding up to this point:

Helpful Phrases

“ Does everyone understand what has been happening up until this point? Do you have any questions about why we did the tests we did or what they showed up until now?”

“Are there any further questions before we proceed?”

How much information do they need?

- Even when patients are nearing the end of their lives, they will need enough information regarding treatment alternatives, their risks and benefits and how these treatments will affect their remaining quality of life in view of their goals, expectations, values and fears (see module on [End-of-Life Decision-Making](#) for a specific and detailed discussion).

- Patients and their families will need to know what the likely course of their illness will be and what is part of the normal dying process e.g. decreased appetite (see module on [The Last Hours](#))
- Discussion about where they would like to die (hospital, home, hospice) and whether resources can be put in place to fulfill this wish and ensure their comfort should occur and they will need to know how different treatment alternatives will affect their ability to die at home (see module on [Palliative Care – Standards and Models](#))

Sharing the information

- Keep it simple and clear
- Use language appropriate to their level of understanding
- Pause and wait for reactions after giving information
- Listen to their concerns, fears, hopes and expectations
- Be attuned to their emotional responses: verbal, non-verbal cues
- Address these emotions – see following sections for detailed discussion
- Show empathy and compassion – different from pity (implies they are your inferior) or sympathy (feeling you have for their response to news)
- Summarize the imparted information
- Are there any questions/concerns?

AVOID:

Talking down to patients and families

Avoid jargon and, if technical term slips out, check understanding

Avoid “Why” questions: asks for justification and promotes defensiveness

Avoid language you would use with a colleague:

“ We almost lost you”

“You almost didn’t make it”

“You had an arrest”

“ He is vegetative”

Avoid euphemisms: growth, tumor, passed away

Do NOT say:

I know what you are going through

I know this must be a shock

I know how hard this is



YOU DO NOT KNOW!!

Helpful Phrases to Convey Empathy

“I have seen many people in similar situations and while every one is different I understand something of what you are going through.”

“What are your biggest fears? Worries?”

“Even though we talked and knew this might happen, it doesn’t make it any easier.”

“Can you tell me what you are feeling?”

“I wish the news was different.”

“Is there anyone you would like for me to call?”

“How are you coping?”

Prognosis

- ❑ People want to know so expect to be asked.
- ❑ People may ask about prognosis not only to help them to make treatment decisions and plan for the future, they may also be verifying that their illness is serious and the end of their life is near (From Buckman R., *How to Break Bad News: A Guide for Health care Professionals*, Johns Hopkins University Press Baltimore 1992).
- ❑ It is better to explain prognosis in generalities: days to weeks, weeks to months, months to years. The intent is not to avoid the question but rather not to give the patient and family false expectations about the length of time remaining (From Buckman R., *How to Break Bad News: A Guide for Health care Professionals*, Johns Hopkins University Press Baltimore 1992).
- ❑ Physicians can use discussions of prognosis to lead into discussions about decision-making at the end of life. However, if goal of the meeting was to break the bad news of a fatal illness, patients and families may not be able to absorb any more information in which case further discussions regarding treatment plans and end-of-life decision-making are best deferred to another meeting (see [End-of-Life Decision-Making Module](#))

Helpful Phrases

“I would like to be able to tell you exactly how long you have left to live but I do not have the power to do so. I can tell you we are likely talking days to weeks.”

“Twenty percent of people with this illness live for 3 years but I can’t tell you whether you will live for 3 years or for a shorter or longer length of time. I can tell you, based upon what has happened to other people with this illness, what you may expect but I cannot tell you exactly what will happen to you. We can use what we know about what may happen to discuss what health care decisions we may need to make together in the future.”

We need to hope for the best but plan for the worst. We can’t predict surprises and need to plan in case something happens. We will have a better sense over time as we see how things evolve together.”

“I wish I could tell you what will happen but I would not be telling you the truth if I said I could.”

Non-Verbal Communication

Facial Movements: Do they smile, frown, blush, cry?

Gaze: Do they look at you? Look away? How often? Do they stare? Blink a lot?

Head Movements: Is their head tilted? Are they shaking it? Nodding?

Body/Hand Movements: Do they seem uncomfortable or self-conscious? Do they have difficulty sitting still? Are they wringing their hands? Playing with their purse?

Posture: Are they relaxed or uptight? Leaning forward or trying to lean away from you?

Interpersonal Distance: Do they seem to be telling you that you are too close?

Touch: Do they go to move away when you move to touch them? Do they reach out to you? Seem to look for you to touch them?

Voice: Are they having to fight for control? What emotion is expressed in timber, pitch? Are they starting to stutter? Do they have to clear their throat or pause a lot?

Adapted from Hall JA, Affective and Non-Verbal Aspects of the Medical Visit, [The Medical Interview](#), Lipkin M Jr, Putnam SM, Lazare A eds., Springer 1994 p. 499

- Observing patients and families' non-verbal responses can provide clues to their emotions and help physicians convey empathy and support in response.
- Physicians need to be conscious of the messages they convey through non-verbal communication since these can be seen to contradict verbal expressions of support and empathy. In cases of apparent contradiction, credence is given to message conveyed non-verbally.

Common Health Care Providers' Responses to Patients' and Families' Emotions – Things To Avoid

Diversion: change the topic, withdrawal

Jargon

False hopes of cure or of greater benefit than likely or possible

Inappropriate destruction of all hope: painting the prognosis, course of illness as so awful that all hope for any quality of remaining life is destroyed.

- ❑ When communicating bad, sad or unexpected news, physicians are often unprepared and dread the emotional responses of patients and families. Their dread is manifested by reverting to a language they are comfortable with (jargon to patients and families), changing the topic or diminishing the seriousness of the situation.
- ❑ When confronted by disbelief or denial, or in an effort not to provide false hope, some health care providers destroy any hope even if some uncertainty as to prognosis or course of illness exists in order to force the patient to perceive the seriousness of the situation or to decide to withhold or withdraw certain treatments
- ❑ Physicians must try to convey as accurate and realistic a picture as possible given the available information to allow patients and families to make informed decisions at end of life

Better Responses to Patient's and Families' Emotions – Things to Do

Don't be afraid of silence

Don't abandon

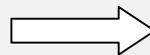
Don't make promises

Don't give false reassurances

Recognize the power of non-verbal communication

Develop a plan with patient and family

Explore goals, hopes, concerns and fears



BUILD TRUST

- To help physicians deal with the more difficult emotional responses that arise as they share information, the next section will discuss some of the possible emotions physicians will encounter and suggested ways of dealing with them.

The following has been extracted and adapted from **Robert Buckman's book *How to Break Bad News: A Guide for Health care Professionals***, Johns Hopkins University Press, Baltimore 1992 and readers are referred to it for a more detailed discussion

Patients and Families' Emotional Responses When Faced With Unexpected or Bad news

Shock
Grief
Guilt
Fear
Anxiety
Denial
Anger
Disbelief
Displacement
Depression
Bargaining
Over-dependency
Shielding

From Buckman R., *How to Break Bad News: A Guide for Healthcare Professionals*, Johns Hopkins University Press Baltimore 1992

Disbelief

- If it is unexpected, bad news is commonly met with disbelief
- When patient or a family expresses disbelief, they are usually attempting to understand the information but can't quite accept it as true
- Expressions of disbelief are not intended to be argumentative or to dispute the reality of the information and often disbelief is stated but actions, non-verbal communication show that news has been understood and accepted
- To show empathy, physicians need to respond to these difficulties in accepting such news: "I can understand that it must be very hard to accept (the seriousness of) this illness...."

Shock

- ❑ Shock is easily recognizable, even expected, but very difficult to support, respond to and help someone through
- ❑ People in shock are not able to function, they can't make decisions because they are not registering information. They may even not be aware of what they are doing because they are overwhelmed by such intense emotions
- ❑ People in shock can best be supported by staying silent to allow them time to adjust. Phrases such as "I can see this news has come as quite a shock. Is there anything I can do to help you right now?" "I can see that you are overwhelmed by this very bad news."

Denial

- ❑ Denial is a refusal to accept news, a genuine belief that it's not real or that it is somehow a mistake
- ❑ Often patients subconsciously fear and or know that the news is correct
- ❑ Patients in denial often make clearly unrealistic plans
- ❑ Denial is a subconscious defense mechanism that gives patients and families time to adjust by preventing damage to the patient's and families view of the future
- ❑ Physicians need to recognize the protective nature of denial and that it is a normal initial reaction to an overwhelming threat to the person's sense of self and well-being.
- ❑ However, denial can become prolonged and affect the ability of the patient to ask for and receive quality end-of-life care. Families may become isolated from the patient in denial if they accept the news and try to prepare for the impending loss
- ❑ Helpful approaches include asking: "What is it that makes you feel this is a mistake? We will hope that the treatment will work but we need to plan what we will do if it doesn't."
- ❑ WAIT and GIVE them TIME:

AVOID:

There is NO need to paint the illness or possible outcomes as worse than they already are in order to force the person to accept the diagnosis, the course of their illness or the fact that they are at the end of their life.

Such tactics only destroy any remaining hope, any ability to be hopeful when the person eventually accepts the situation even if hope is for a better quality of life while dying.

Displacement

- ❑ Displacement is used to divert emotions into actions and activities. It is an important way of coping however it can increase distress
- ❑ Displacement may result in a quest during which the patient attempts to fulfill a previous ambition. Quests may also be expressions of denial.
- ❑ Assess whether displacement is helping patient cope or not.

Fear and Anxiety

- ❑ Fear is common and is caused by specific triggers as opposed to anxiety which is more diffuse, more chronic, and which takes longer to resolve even after trigger is gone
- ❑ Physicians should acknowledge the emotion non-judgmentally and ask the patient and/or family what their fear, and /or anxiety is caused by
- ❑ Physicians must offer information and support but be careful not to over reassure and provide false hope

Anger

- ❑ Anger is a common response to unexpected or distressing news. It may also be a reaction whose goal is to disguise fear
- ❑ Anger may be directed at many targets such as*:
 1. against disease
 2. loss of control or powerlessness
 3. loss of potential
 4. laws of nature/ God/randomness
 5. self: if activities caused or contributed to illness, if they missed opportunities for earlier recognition and treatment of their illness or missed opportunities to fulfill their goals and dreams
 6. friends and families: envious of their better health, anger about old disagreements/fights, anger over receiving their continuous advice, “smothering” or abandonment
 7. medical team: who cannot cure illness or who are failing to alleviate their pain or other symptoms

* From Buckman R., *How to Break Bad News: A Guide for Health care Professionals*, Johns Hopkins University Press Baltimore 1992 p. 139

- ❑ Physicians should not reply to anger with anger: this response only escalates a bad situation. Instead, give permission to talk about their anger: “You appear angry about this, let’s talk about it.” “Let’s talk about your feelings, they are

important.” “ I can understand that you are angry.” and provide confines to the expression of this anger if needed: “You can say whatever you want, you can scream and yell but you cannot throw objects, destroy any property, or hit anyone in this room.”

Guilt

- ❑ Guilt is defined as self-blame, sorrow and regret
- ❑ Physicians need to be on alert – patients and families are often reluctant to share their feelings of guilt and yet may be deeply distressed by them
- ❑ Source is often self- blame for not seeking medical attention sooner. In many situations, they can be reassured that their time of presentation may not have changed the ultimate course of illness: “ Even if you had come to the hospital sooner and we had diagnosed your infection sooner, you may still have become this sick. I understand that you blame yourself but many people would have done the same”
- ❑ Can reinforce the importance of not dwelling on the past but the need to concentrate on issues here and now: “ It does not help you to keep dwelling on the past and blaming yourself for your illness. I can see how this is draining you emotionally. Together, we need to concentrate our energies in the present and see what we can do to alleviate your pain”
- ❑ May also be valuable to normalize their interpretations of their illness: “ I can understand why you would think you were just tired: you were very busy. A lot of people would have thought the same....”
- ❑ Physicians must be careful not to contribute to these feelings of guilt through messages conveyed verbally or non-verbally.
- ❑ Other sources of guilt may be due to things the person has left undone or, disputes they have not resolved. Physicians may be able to help them and support them as they attempt to heal these rifts or attain these goals (if realistic) in their remaining life

Despair/ Depression

- ❑ When a person confronts the end of life, it is not uncommon for them to alternate between hope and despair
- ❑ Clinical depression may occur in 20% or more and may require psychiatric consultation
- ❑ It is important to allow people to express these emotions and to express empathy, compassion and support but again physicians must avoid being over-reassuring and providing false hope. Instead need to reinforce that they will not be abandoned
- ❑ If the patient starts to cry, non-verbal communication can be a powerful way to convey support. Rather than attempting to change the subject, minimize the

importance of the news and provide false hope or filling the air with words, physicians should not be afraid of silence and, having a box of tissues handy, should move closer

- Physicians may consider touching the person on the forearm to convey support: this depends on their personality (whether they are comfortable with such a gesture – if not it will seem awkward) and the patient’s comfort with being touched
- If it is not clear what is making the person cry, ask: “Are you able to tell me what is making you cry at the moment?”
- Be prepared to stay in the room with the patient until they are calmer

Relief

- Physicians may be surprised when patients respond to bad or unexpected news with relief. This response does not mean person does not understand or has misinterpreted the information
- Relief is usually seen if the illness was difficult to diagnose, or if the patient was worried about the diagnosis
- Relief may also occur if the patient and family finally feel someone is telling them the truth
- Initial relief does not mean that the person will not experience a range of other emotions (guilt, disbelief, despair, anger etc.) in time. Physicians should not be complacent if met by relief but should ensure follow up appointment is made and be prepared to address these other emotions as they arise

Shielding or “Don’t Tell”

- When upset after receiving news, patients may seek to shield their family from the knowledge or families, anticipating new, may seek to shield the patient
- In response, physicians need to explore the feelings and motivations behind the shielding: “Tell me what you are worried about if they are told.” “Help me understand what you fear they will do or say.”
- In some cultures, informing the patient of bad news is seen as harmful. These views should be respected and physicians should be prepared to talk to the person designated by the patient (see above)
- **If a patient says “don’t tell”** after his/her reasoning has been explored and physician has offered to help tell family, physicians have ethical and legal obligation to obey even though this may diminish the ability of the patient to be supported by their family
- **If the family says don’t tell**, physicians should explore their reasoning and allow them to express these protective emotions. However, physicians must explain that as physicians they have ethical and legal duty to tell the patient unless the patient waives this right and substitutes another to receive information and make decisions in his/her place.

- Physicians should offer to ask the patient these questions in private (see section on what they want/need to know) and ensure the family is present when news is conveyed so they can support the patient

Discover the Patient's Goals, Hopes and Fears

- Any decision a person makes is made in the context of that person's life, his/her current circumstances and past experiences, his/her sense of self, things that make him/her happy and that he/she values and believes in, his/her ambitions, expectations, hopes and fears
- These goals, hopes, values, fears must be discovered and explored in order:
 1. To convey empathy and caring; shows you see the patient as a unique person
 2. To be able to provide effective emotional and psychological support
 3. To develop a treatment plan that will respect the dignity and intrinsic worth of the person
 4. To recognize and respect the person as different from the health care provider

Address their Needs

- These needs may depend on the purpose of the meeting.
- If the **purpose was to break bad news**  **Check and Respond to Immediate Needs**

“Is there anyone I could call to be with you?”

“Is there anyone you want me to call and share this information with?”

“How will you get home?”

“Is there anyone at home who will be able to support you as you adjust to this news?”

“We need to discuss what we will do if your pain is not controlled tonight.”

- If the **purpose was decision-making**  **Check Understanding / Remaining Questions/ Need for More Time/ Comfort with Decision***

* see [End-of-Life Decision-making Module](#)

- If the **purpose was to update or to convey support About Pain and Symptom Control and Coping Abilities**  **Ask Him/Her**

“Is your pain controlled? When is it bothering you?”

“How is your shortness of breath?”

“How has this illness affected your ability to do things you enjoy?”

“ How has this illness affected your day-to-day life?”

“How are you coping?”

“Are you receiving enough help to cope at home?”

Is there anyone that you would like to talk to?”

“Is there anyone you would like me to call to explain what is happening?”

Develop a Plan

- If the **purpose was to break bad news**: When will we have more information?
Who will need to be consulted?
When will we meet again to discuss the future?
- As discussed above, it may not be appropriate to discuss the future at the time bad, sad or unexpected news is broken. Physicians need to assess the appropriateness of discussing end-of-life decisions at the same time on an individual basis
- If the **purpose was to decide on the treatment plan**: see [End-of-Life Decision-Making Module](#)
- If the **purpose was to provide support**: What are we going to do?
How can we improve ability to cope?
How can we increase enjoyment of life?
How can we diminish fears?
- If palliative care is to be involved, physicians need to explain what palliative care can offer, explain their expertise in pain and symptom management,

emotional and psychological support and goal of improving remaining quality of life.

- Because of societal and medical community's misconceptions regarding palliative care (either cure OR palliation rather than a more appropriately integrated approach to care), the mention of palliative care may unfortunately cause patients to feel abandoned and that the only thing left is death.

Arrange for Follow-Up

- Invite them to share any un-addressed concerns:
“Do you have any questions that we have not discussed?”
“Many people, when they receive this type of news forget questions they want to ask. I usually encourage them to make a list of questions they have which we can go over during your next visit.”
“If any questions come up, any at all, please don't hesitate to call me.”
“There is no such thing as a trivial question, no such thing as a question that is not worth asking.”
- Normalize their experience and acknowledge that communication problems are common in emotionally charged circumstances
“We have shared a lot of information. It is not uncommon for people who have received this news (or in similar situations) to forget some of what we discussed or to mix things up. If, after you leave, you are unclear about something we talked about, please call and ask me to go over it again.”
“If anything I have said is not clear, please ask me to go over it again. I will explain it in a different way or as many times as is necessary.”
- Provide contact information and set a time for the next meeting

Communication Mistakes

- Circumstances such as fatigue, hunger, emotional depletion or patients and families we find “difficult” (for whatever personal reason) can also lead to a meeting we are less than satisfied with
- Mistakes can be retrieved:
 1. by sharing your emotions: “I am feeling really frustrated right now. You appear to be frustrated too. Let's discuss what is happening here” or ‘Let's start over.’
“I can see you appear to be angry. Can you tell me what I have said that has made you angry?” “I understand that you are angry, I would be angry too.”

2. by apologizing and saying, “I am sorry, I did not mean that the way it sounded.” “ I am tired and that did not come out the right.”
3. by backing up and explaining medical jargon

Additional and Special Points

Communicating with the Family if the Patient is Capable

- While the physician’s relationship with the patient is of primary importance, the physician should not ignore the family since autonomy is often only an illusion; once someone is ill, he/she usually will rely on friends and family for support, advice. More than in any other situation, serious illness turns the patient and family into a unit of care
- It is important to ask patients before any planned meeting whether they want their family and, if so, who they want from their family to be there
- It is important to support the family so they can support their ill loved one
- Families will experience sadness, fear and/or guilt and will be struggling to reorganize their roles within the family community while confronting their impending loss. They frequently need to be reassured that anticipatory grief is normal reaction
- Physicians may need to help families find the words to express their love and caring
- Be prepared to recommend that families seek additional support either from you – set up their own meetings with you separate from those of the patient – or arrange for them to see their family MD if you are specialist. This is not an excuse for specialists to abandon family but recognition that they may not have the time to provide as much support as family needs. It is also an opportunity to recognize the relationship that may already exist between the family doctor, patient and family. Specialists should however be prepared to set aside some time, if the family is present during the patient’s visit, to ask the family members how they are coping, if they are eating and sleeping.
- Give the family members time to express emotions. This can be done either with the patient present or privately since the family member(s) may not want to discuss their experiences in front of the patient since the family may see it as adding to his/her burden

- Ask them if they would they like additional support from social work or chaplain

Estranged Family Members/Family From Away

- Families are often scattered across the country. Relatives often appear after having received news over the phone from a variety of other family members and/or friends.
- Misunderstandings and misinformation are a frequent problem.
- These family members may therefore be more anxious especially if arrangements to travel to see sick relatives were difficult to make and they rushed in from across the country to see their loved one. They may feel guilty for not having been closer or for not arriving sooner.
- They may also feel guilty if there had been pre-existing rifts within the family especially if these rifts contributed to the delay in them being notified of the illness.
- The distance between them and their sick loved one may cause them to disbelieve or deny the severity of the illness. They may not have seen the changes, the signs of illness that have already occurred, for example the weight loss or decrease in energy. They may be overprotective and attempt to shield their sick relative in an attempt to make up for being so far away.
- They may also be angry with their sick relative (who may be perceived as having caused their own illness, or they may be angry at him/her for not telling them of illness, or may still be angry over old feuds). They may be angry with themselves (for being far away, etc.), or angry with God or fate.
- These family members may have traveled alone and may be isolated from the rest of the family. Distanced from their friends, spouses and children, these family members may be particularly vulnerable to a lack of support.
- For all these reasons, when these family members first meet with physician there is likely to be a sense of urgency and family member is likely to be seen as very demanding.
- If the patient consents to the physician informing these family members, physicians need to be prepared to begin at the start of the illness with their explanations and to be flexible: it is not uncommon to have to tell these family members the bottom line first and offer explanations later. It is crucial to ask them what they know before beginning explanations. Physicians should acknowledge the difficulties in family members experience when they live so far away

and ask them how they arrived, where are they staying, have they eaten, slept.

- Be prepared to recognize their emotions and deal with them.

Communication Over the Phone

- Physicians are often taught to avoid giving bad, sad or unexpected news over the phone since they are more able to give support in person. However, in today's world giving news over the phone may be a necessity. When called, most people want to know why you are calling. In event of an emergency or unexpected call, most people will want to know what is happening immediately and will not want to wait until they come into hospital
- Physicians need to make sure they know who they are talking to i.e. whether a friend or a young child has answered the phone

Introduce yourself, ask who you are speaking to

Keep it simple and clear and invite them down to the hospital where can give more information, explanations in detail

Listen for response: clear emotions and the tone of his/her voice are all you have

Be prepared for silences but realize it's even harder to know what they mean: has the person you are talking to gone into shock, did they understand, are they fighting to regain composure or have they fallen asleep

Be empathetic

Attend to immediate practical concerns: encourage them not to drive. Who else can you call? Is there anyone there to support them?

When Language is a Barrier

- Use the same approach but ideally arrange for a professional translator who is comfortable translating bad news.
- Tell the translator that their role is only to translate, not to expand on what you have said or to offer their own explanations or interpretations. .

- Emphasize the importance of confidentiality to the translator: he/she is not to discuss the imparted information with anyone but the patient.
- Warn the translator about the nature of the news to be communicated before the interview so that it does not come as a shock to him/her.
- Avoid using family members as translators if possible since acting as a translator confuses their role within the family and may raise confidentiality issues. Family members may be more inclined to modify news to shield their loved one. However, family members still need to play a supportive role.
- Sit in a triangle with translator and patient to make it easier to turn to the translator. Give information in short chunks, verify understanding and support emotionally.

Professional as Patient or Family Member

- Medical professionals have increased needs for information. They are therefore often perceived to be difficult or demanding as patients or family members
- On the other hand, illness may compromise their ability to think rationally and problems can arise when their physicians treat them as colleagues rather than patients. Seen as a colleague, the professional may not receive the empathy or emotional, psychological support they need as people – since colleagues are not often supported in these ways
- Physicians, when treating other physicians, need to acknowledge their expertise (don't be condescending!) and be prepared to support them through all of the emotions we discussed above
- It is important not to treat them automatically as a physician or nurse instead of a patient. They may have worked in a field unrelated to their current illness and assuming they have an in-depth knowledge of their current illness and treatments may be a mistake

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See

www.utoronto.ca/jcb

www.cme.utoronto.ca/endof/life

www.bayerinstitute.org

(Bayer Institute for Health Care Communication – Courses)

Detailed Case Scenario

David Hawk is a 30-year-old man who presents with fatigue and weight loss. He is very active and has played competitive basketball for the last 7 years, the last four of which he has been on the national team. He began to notice that he was more tired and seemed to have problems keeping up with his teammates about 6 months ago. He also noticed that he was losing weight – maybe 10 pounds in the last two months – and recently developed night sweats. However, he was in the midst of preparing for his PhD thesis defense and ascribed his symptoms to studying hard and to anxiety.

He came to see you because he noticed some lumps in his neck when he was shaving. Initially he thought these were because he had a slight sore throat but they did not go away.

You have followed him since he was a child. Outside of a few sports related ligamentous injuries, he has always been healthy. He does not admit to any HIV risk factors. He has just successfully defended his PhD thesis in Biochemistry and has just been hired by a well-known pharmaceutical company. He is very excited and has told you that after all his years of studying “life seems to be just beginning.”

He has two brothers, John aged 32 and Bill aged 28, with whom he is very close. His parents are also your patients: his father has class II angina and his mother has mild asthma.

Initial Physical Exam:

He is thinner than you remember. When you weigh him it is clear that he has lost 20 pounds, not 10. He has enlarged cervical nodes, roughly 2-3 cm which are hard and but not fixed. Similarly he has enlarged axillary and inguinal nodes. Rest of his exam is not remarkable. There is no evidence of infection.

Lab: CBC is Normal, Monospot and HIV tests are negative

Lymph node biopsy reveals Hodgkins Disease.

David: “I can’t believe this is happening. I thought you said it would not be anything serious!” They have clearly made a mistake and mixed my tests results up with someone else’s”.....

“Did you think it was something serious? Why didn’t you tell me??”

Teaching Instructions for Opinion Leaders

- Communication is best taught on one to one or small group basis.
 - Of all skills, people tend to view their communication abilities as defining who they are. Teaching communication skills requires a real sensitivity to the learner's sense of self and a real effort to create an environment in which they do not feel criticized or threatened as a person.
1. Distribute the case scenario. Allow participants a couple of minutes to read the information or have one of the participants read the scenario the case scenario
 2. Ask the learner what their objectives are in participating in an end-of-life communication skills course:

Teaching Tip: Helpful Questions to Develop a Learner Centered Approach

- What aspects of communication around end-of-life issues are most difficult for them?
- What topics or emotions have arisen in their past conversations with patients and families that they found difficult to respond to, or that they did not know what to respond to?
- What situations are uncomfortable for them? What is it about these situations that make them uncomfortable? How have past experiences, personal and professional, contributed to their discomfort when faced with these situations?
- What skills in discussions around end of life issues do they want to improve?

TIP: Sharing personal experiences with learners can be invaluable and can allow learners to gain insight as to why they find certain situations difficult and may enhance their abilities to improve their skills in the future.

3. Have the participants role-play the breaking bad news scenario and structure "David's" responses to fit the needs of the learner, i.e., participant playing the

- role of David can go on to display guilt, anger, denial etc... based on learner's identified needs
4. Alternatively, the facilitator can assume the role of David and ask participants to develop responses to his comments and emotions
 5. Alternatively, ask participants to respond to David's initial comments. Should identify the problem generated by providing false reassurance, identify and explore the emotions he demonstrates in his opening lines (disbelief, denial, anger, guilt)
 6. Discuss how feedback will be given and how learner will indicate he/she needs help or time out
 7. Participants to self-reflect on their experiences while in their respective roles, e.g.: What would he have said/felt, if I had said...? What were you thinking when you asked... ?
 8. Encourage them to explore different ways of conveying the same message and impact of these different ways to convey message on "David"

Teaching Tip – Feedback and Star Performance Model:

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- Ensure private, without interruptions.
- **Let them tell you how they felt it went.** What they were happy with? Did they feel they had accomplished their goals? What did they do to accomplish them in this interview that they could use in the next interview? What did they think they could improve on? OR What happened that they did not achieve their goal?

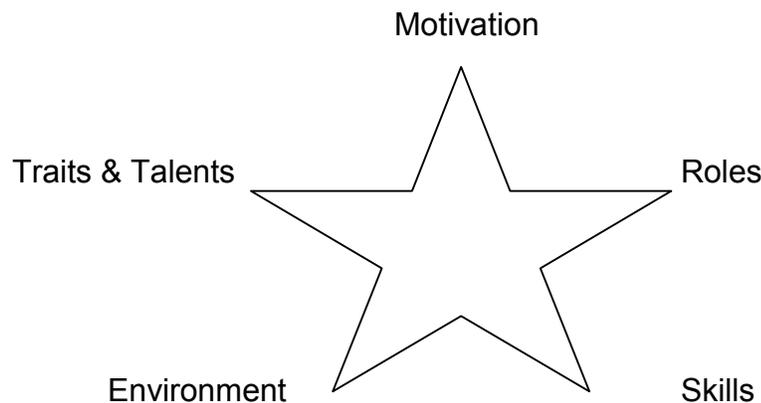
□ **Dr. V. Keller's Model of Feedback:**

Less threatening, more constructive than other models such as Positive-Negative-Positive feedback

4 Categories:

1. Things to continue to do
2. Things to start or do more of
3. Things to consider doing (Stretch)
4. Things to stop doing

- **STAR PERFORMANCE MODEL:** use to diagnose factors that may prevent a learner from achieving his/her goals:



**For more on how to teach communication skills and improve your own communication skills, please refer to and attend the excellent Bayer Institute of Communication Skills courses

9. Review the learning issues that have not been dealt with and assign tasks.