Breaking Bad News

Learning Objectives

- Students will be able to
 - Define bad news
 - Describe Buckman's 6 step protocol for breaking bad news
 - List potential client responses to bad news
 - Apply these concepts to genetic counseling demonstrated through role plays and clinical practice

What is Bad News?

Give an example from clinical or personal experience

Defining Bad News

- "Information likely to drastically alter a patient's view of his or her future." (Buckman, 1992)
- "...situations where there is either a feeling of no hope, a threat to one's mental or physical well-being, a risk of upsetting an established lifestyle, or where the message given conveys fewer choices in his or her life..."

What is Bad News?

- Results in a cognitive, behavioral or emotional impact that persists for some time after the news is received
- May be perceived as bad from the perspective of the giver, the receiver, or both
 - perception of severity varies for each person
 - one cannot estimate the impact of bad news until the recipient's expectations and understanding is determined

Why is Breaking Bad News Difficult?

What are your thoughts?

Why is Breaking Bad News Difficult?

- Concern for how the news will affect client
- Client's fears of social stigma and impact of disability and illness
- Fear of client's reaction to the news
- Uncertainty in dealing with intense emotional response
- Fear of being blamed
- Fear of how this affects you/expressing emotion
- Challenge of delivering the news appropriately and sensitively for this client
- Not wanting to take away hope

The way bad news is given is important, according to Buckman

- "...some unhappiness is caused by what the client is hearing, but dissatisfaction with the way they hear it is most commonly caused by:
 - The doctor not listening or not appearing to listen
 - The doctor using jargon
 - The doctor talking down to the patient"

Words of Wisdom: Buckman

"An expert in breaking bad news is not someone who gets it right every time—he or she is merely someone who gets it wrong less often, and who is less flustered when things do not go smoothly."

HOW TO BREAK BAD NEWS: A GUIDE FOR HEALTH CARE PROFESSIONALS

Robert Buckman, M.D. The Six-Step Protocol

Advance Preparation

- Review all relevant clinical information
- Be prepared to share pertinent lab reports
- Mentally rehearse how you will deliver the bad news. Think about specific words or phrases to use and to avoid.
- Arrange for adequate time, space, with no interruptions
- Think about how the client will react and how you can respond

Advance Preparation

Use

- "I'm sorry to have to tell you this"
- "I know this is not good news for you"
- "I was hoping for a better result"

Avoid

- "You knew....We talked about...this was a possibility"
- "I see this all of the time"
- "There's always next time"

Get the physical context right:

- Where and to whom are you speaking?
- Arrange for important family members to be present
- In person; not over the telephone
- In a separate, private room
- Take control of the situation to help you and the family to be more relaxed

- Maintain control of the immediate environment, to the extent that you can.
- "I know it's a bit of a walk, but it'll be much easier to talk if we can sit down." You'll find it easier to ask questions if we find somewhere quiet and private."
 - draw curtains
 - close the door
 - sit down (and not behind a big desk)

- If you must stand, lean against the wall; it gives the illusion that you are there for them and not about to exit until both you and they are finished
- Be sure you know to whom you are speaking-ASK!
- Obtain permission--with whom can you discuss the diagnosis

- Be respectful:
 - patient covered up
 - use appropriate names
 - keep a comfortable distance
 - pay attention to your own body language
 - make eye contact

- Start the conversation with a question to assess the client's state before launching into a sensitive conversation
 - "How are you feeling right now?"
 - "How are things today?"
 - "Do you feel well enough to talk for a bit?"

If the need for the conversation is pressing:

"I know you are not feeling well, but perhaps we could talk for a few minutes now, then I could come back tomorrow"

- Find out what the patient knows about the impact of the illness on his or her future
- "Before you tell, ask"
 - "What have you made of the diagnosis so far?"
 - "Have you been very worried about the pregnancy?"
 - "Have you been thinking that this might be something serious when the test was repeated?"
 - "Can you tell me what you remember about why the amniocentesis test was recommended?"

- Utilize your full concentration and listening skills
- Listen to the patient's responses for:
 - What is the patient's understanding of the situation?
 - How much has she understood and how close to reality are her impressions?
 - Assess the style of the patient's statementswhat words/vocabulary is she using/avoiding?

- Take no notice of the patient's profession:
 - "I know you are a nurse/doctor, but I hope you won't mind if I start at the beginning and if I'm covering old ground you'll tell me."

The emotional content of the patient's statements, verbal and nonverbal

- At this point, you have minimized discomfort of both yourself and the patient
- The patient knows you are trying to listen and that you are interested in what she thinks is going on

Step 3: Finding out how much the patient wants to know

- How much information is desired; at what level does the family want to know what's going on?
 - Several studies indicate that more distress is caused by not discussing information than by discussion
 - Asking patients what they want allows them to exercise their preferences

Step 3: Finding out how much the patient wants to know

Phrasing the question:

- "I have the results of your genetic testing, but I just want to make sure that this is still information you want to know."
- "Are you the kind of person who likes the full details of the diagnosis, or would you prefer just to hear about the options available to you?"

Step 3: Finding out how much the patient wants to know

- You want to get a clear invitation from the patient to share information.
- If the patient expresses a preference not to discuss the information, leave the option open for later discussion.
 - "That's fine. If you change your mind or you want any questions answered, just call me."
 - "I'll be sure to check back with you in a few days."

- The informing interview has two parts, aligning and educating:
 - Aligning
 - start from the patient's starting point
 - line up the information you wish to impart on the patient's knowledge baseline
 - You have already heard how much the patient knows about the situation, and the vocabulary she uses to discuss it
 - Gives the patient confidence that her view of the situation has been heard and is being taken seriously

- Educating: the process by which the professional brings the patient's understanding of the medical situation closer to the facts
 - Give a warning shot
 - □ Give information in small chunks
 - Avoid using jargon
 - Check reception frequently
 - Reinforce and clarify
 - Monitor your own communication level
 - Listen for the patient's concerns
 - Engage in "therapeutic dialogue"

- Give a warning shot
- Providing some warning that bad news is coming may lessen the shock that can follow the disclosure of bad news
- "Unfortunately, I have some (unexpected) (bad) news to tell you."
- "I'm sorry, but the test results are not what you were hoping for..."
- "I'm sorry to tell you..."

- If there is apparently a large gap between the patient's expectations and the reality of the situation, you can facilitate the patient's understanding by giving a warning that things are more serious than they appear to the patient.
- "Well, the test results that I received indicate that the situation does appear to be more serious than Dr. Smith implied."

- Preceding the warning shot, a narrative of events can be an extremely useful technique, as it is easy to follow and helps the patient to frame her questions as the story continues
 - "When you visited Dr. M at the beginning of the pregnancy, blood was taken and Dr. M ordered a lot of tests on it. One of the tests that was done showed... Then the nurse scheduled you for an amniocentesis that you had in January. I have the results of the baby's chromosome results from the amniocentesis test, and I am sorry to tell you that the results are not what we were hoping for...."
 - Gives the client time to focus and prepare for the news
 - "The test showed that there is an extra chromosome 21 in every cell...which means the baby has Down syndrome."

- Give most of the critical information in 2-3 sentences
- Use limited genetic/medical terminology
- Allow time for silence-often means that the client is thinking or feeling something important
- Allow time for tears; offer tissue to convey the message that crying is allowed
- Touch the client's shoulder/arm or move closer to her to imply that it is OK to show emotion
- Avoid the urge to talk to overcome your own discomfort

- Identify and acknowledge the client's reaction
- Common reactions to bad news: despair, grief, depression, denial, anger
- "I know this isn't what you wanted to hear. I wish the news (results; information) could have been better."

- Decide on your agenda: diagnosis, treatment plan, prognosis or support
- You should have some form of an agenda in mind. It is easiest to state the rough outline of the interview before beginning this part:
 - "I'll start off by telling you about the condition and the health effects for the baby, then we can discuss all of that and the future and anything else you wish. We don't have to talk about everything today, though. Lets see how it goes; we can always meet again tomorrow, or next week."
 - Be aware that the client will not retain most of what is said after the initial bad news

- Use English, not Medspeak
 - triple screen, lethal, neurofibroma
- Check your communication level
 - If the patient replies using a different vocabulary, try to adapt your language to the patient's

- Check reception frequently
 - "Tell me, what you are thinking about all of this now?"
 - "Am I making sense?"
 - "Do you follow what I am saying?"
 - "What questions do you have?"

- Reinforce and clarify the information frequently
 - Clarification: Make sure you both mean the same thing
- Get the patient to repeat the general drift of what you have been saying
 - "Why don't we talk about what you think about caring for a child with Down syndrome and what you think that means for you and your family."

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Repeat important points yourself

■ "I know we talked about a lot of facts, so why don't I summarize the pros and cons of both amniocentesis and CVS. I'll write out a chart and you can have this paper and go over it at home if you want to. Don't be afraid to call me tomorrow if you'd like me to review any part of it for you."

- Use diagrams and written messages
 - Simple scribbles on the back of an envelope or scrap of paper
 - Diagrams about the form of inheritance, how the translocation can result in unbalanced offspring, triplet repeat expansion ranges

- Use any written or recorded material available
 - brochures, resources: Be aware of their content
 - "I've told you about all the important and common effects that occur in adults with tuberous sclerosis, but I want you to know that there can be other effects. They're very rare, and you can read about them in this brochure, if you want to. Some people like to have the complete list of things that have been reported to occur and that's why they have the full details in the pamphlet. I've told you about the common features of tuberous sclerosis, so if you don't feel like you need more information about the rarer things right now, you can always look at the brochure at another time."

Listen for the patient's concerns

In counseling a couple about Down syndrome newly diagnosed in their baby, the woman's biggest concern may be the fear of her husband leaving her and the kids.

It is counterproductive to proceed according to your own agenda, ignoring the patient's

As you transmit information to the patient, you are also listening for the patient's reaction and trying to elicit her agenda

- Try to elicit the patient's "shopping list" of concerns and anxieties
 - hair loss from chemotherapy
 - sexual implications of colostomy
- Listen for the buried question
 - sexuality issues in Down syndrome
- Be prepared to be led
 - You may draw a session to a close, and then find that the patient wants to start part of it again

- Try to blend your agenda with the patient's
 - You are changing or accommodating to adapt to the patient's point of view, and that sense of compromise will make the patient feel that you are interested in supporting her
- Therapeutic dialogue
 - the professional listens to, hears, and responds to the patient's reactions to the information

- As you obtain the list of concerns from the patient, acknowledge the items on it and try to include them in the topics that you cover
 - "Alzheimer's occurs in older adults with Down syndrome, and because your father has Alzheimer's, I know you are very worried about the possibility that the baby will develop Alzheimer's when she is older. I will tell you everything I know about this, but can we first talk about the health effects of Down syndrome that need some attention in the first few weeks and months of her life?"

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Step 5. Responding to the patient's feelings

- Identify and acknowledge the patient's reaction, distinguishing adaptive from maladaptive reactions
 - humor/guilt
 - crying/collapse
 - realistic hope/unrealistic hope
 - disbelief, shock, denial, displacement, fear and anxiety, anger and blame, guilt, hope, despair, depression, over dependency, relief, bargaining

Step 5. Responding to the patient's feelings

- Identify and acknowledge the clients reaction
- Inquire about the patient's emotional and spiritual needs, and support systems
- Identify patient's coping strategies and reinforce them
- Offer realistic hope
- Avoid trying to be overly reassuring

"The success or failure of the breaking bad news interview ultimately depends on how the patient reacts and how you respond to those reactions and feelings."

Step 6. Planning and follow-through

Planning for the future

- Demonstrate an understanding of the patient's problem list
- Indicate you can distinguish the fixable from the unfixable. It is not useful to be unrealistically overoptimistic about the future
- Ask what the client will do after leaving the session

Step 6. Planning and follow-through

- Make a plan or strategy and explain it
- The management of the medical condition forms part of the support of the patient
 - "When Joey is 6 weeks old, the plan for early intervention can begin. You will need to call the program this week in order to get him scheduled. Here is the phone #. If you have any problems, give me a call and I can help you with this."
 - "We'll deal with each problem as it arises."
 - "Preparing for the worst doesn't stop us from hoping for the best."
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Step 6. Planning and follow-through Make a contract

- "What questions would you like to ask me now?"
- It is useful to tell patients that this is not the last chance to discuss any major issues, and to encourage them to jot down any other questions that occur on a piece of paper and to bring this with them to the next visit, or to call you.
- "Here is the phone # for Cardiology so you can get the echo done this week. You should hear from a mom from the Down Syndrome Association in a few days. I'll also plan to touch base when you come to see Dr. xyz in two weeks. I'll call you on Friday to see how you're doing. If you want to talk anytime, just give me a call."

Breaking Bad News on the Telephone

- Balance the need to provide basic information about the situation while avoiding extended counseling during the initial moments of shock
- Some patients may accept a brief phone conversation with the initial statement of bad news, a statement of sympathy, and a f-up plan
- Some patients may attempt to take control of the situation (and their grief/pain) by trying to ask too many ??'s
- Acknowledge the difficulty of waiting for a followup appt for extended discussion
- Gently, but firmly, limit the extent of the conversation

The Counselor's Needs

- Attend to your own needs during and after the delivery of bad news
- These experiences trigger powerful feelings
- With whom can you discuss the experience? (peer supervision)