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Delivering Life Altering News

Developed by Geraldine Huynh and Dr. Debra Andrews for PedsCases.com.
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Hi, my name is Geraldine Huynh, and I am a fourth year medical student at the University of Alberta. This podcast was developed in collaboration with by Dr. Debra Andrews, a developmental pediatrician at the Glenrose Rehabilitation Hospital in Edmonton.

The objectives are to:

1. Compare and contrast “Delivering life-altering news” vs. “breaking bad news”
2. Apply Robert Buckman’s 6 step SPIKES protocol

Delivering life altering news is one of the most stressful, special and important moments a doctor shares with a patient and their family. The goal is not just to impart information, but to help reduce uncertainty, clarify goals of future care and strengthen the therapeutic relationship.

Telling a family about a child’s developmental diagnosis, for example, autism or intellectual disability, is challenging because it requires a competent understanding of the medical facts, an understanding of the individual patient and their family, and empathy for the multitude of emotions and uncertainty a developmental diagnosis engenders. Young children themselves will not be at a developmental level to understand the implications of a diagnosis and its subsequent management, and if they have significant delays, they may even be oblivious to the information and not remember this event. In contrast, however, the parents will remember in very great detail the way in which this news was delivered. For many parents they will remember those words forever. When news is shared with a child, the information should be delivered at the level of that child’s understanding.

In Western countries, studies found that the vast majority of patients and families want to know their diagnosis and prognosis. In non-western countries, fewer than half of patients are told their diagnosis, and patients are less likely to be told prognostic

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information. Defining news as “bad” heavily depends on each family’s beliefs and perceptions. Although commonly known as “breaking bad news”, as we explore this topic from a developmental pediatric perspective, “delivering life altering news” or delivering “unexpected news” frames the topic from the family’s lens.

Let’s start by discussing a case:

Henry is an 8 year old boy. The chief concerns from the family are severe expressive and receptive language delays, delayed learning in school, and difficulty developing friendships with his peers—he tends to play with the younger children. Henry has not received any previous diagnoses. He was born at 34weeks gestation with a birth weight of 5lbs 2 ounces but had a relatively uncomplicated medical course. He is currently on no medications. His vision and hearing have been formally assessed, and there are no concerns. There is a family history of Autism Spectrum Disorder and global developmental delay in a male cousin, and a brother who is deaf. After a comprehensive assessment involving psychology, speech language pathology, audiology, OT, and PT, as well as your own medical assessment, how do you convey to Henry and his parents that he has a moderate intellectual disability?

Intellectual disability, formerly called mental retardation, means that Henry’s overall cognitive ability is delayed compared to his peers, and he will require enhanced developmental and educational supports to meet his best potential. He will need lifelong support from his family to make important life decisions. Because of Henry’s new diagnosis and the family history of developmental delays, you will want to talk to them about a future genetic work-up of Henry’s intellectual disability.

Oncologist and ethicist Robert Buckman has a 6 step SPIKES protocol for delivering “life-altering news.” Although originally intended for delivering a serious medical diagnosis like cancer, we can apply it with modification to sharing the news of a disability with Henry’s parents.

The **SPIKES** protocol includes:

- **Setting**
- **Perception**
- **Invitation**
- **Knowledge**
- **Empathy**
- **Strategy**

Setting

Firstly, talk to Henry’s family as soon as possible and in person. When you as the doctor receive the diagnostic information from other health professionals, book an appointment to see the family to go over these results as soon as you can. Try to find a quiet private room. Book sufficient time, and make sure your staff know not to disturb you and the

family. Ask Henry's parents if they want any other family members or visitors to be present. Start by asking Henry's parents: "How are you feeling at the moment?"

It's important to know if the parents are ready to receive the results before launching into a sensitive conversation. This demonstrates that this is going to be a 2 way conversation and also shows that you are interested in their well-being.

Prepare a roadmap in your mind and outline the topics that you'll try to cover. During this emotionally laden conversation, Henry's parents may understand and retain relatively little information. However, they may recall the specific words you chose to use years later. Let them know that this is only the first of many discussions.

Decide on your objectives (E.g. diagnosis, treatment plan, prognosis, and available supports) depending on the patient's status and your own role in the health care team.

Perception

Next, check the family's understanding. Gain an impression of what they already know about Henry and how serious they understand the developmental diagnosis to be. What have they made of his challenges and all of the different assessments so far? How did they think all those tests went? What do they think that the results mean? Listen to the response in detail and compare the medical reality to their initial impression. Note their emotional state, educational level and vocabulary. What words might they be avoiding? Be aware of their nonverbal communication and body language. Take note of any discordance between verbal and nonverbal communication.

Invitation

Ask permission to deliver the news. Ensure Henry's parents have given a clear invitation to share information and ask them at what level do they want to know what's going on. Between 75%-97% of parents want to know the diagnosis and prognosis in full disclosure. But first ask, "Would you like me to tell you the full details of the diagnosis?"

Knowledge

Proceed with the next step by invitation. Talk about the diagnosis and pause often to give them time to digest. Begin from Henry's parents' own starting point. Ask what they know about the condition and their previous experiences. Try to speak accurately without too much medical jargon. Reinforcing parts of what they've said or what they've noticed will give them confidence that their view of the situation has been heard and been taken seriously, and this also increases their sense of competence as parents.

****Next, if you need to, align their perception of the situation closer to the medical facts as you know them. Give information in small chunks. Most patients and families fail to**

retain up to 50% of the information given, even it is about something simple. The more serious and more complex the condition, the less information may be retained. Reassure Henry's parents that they don't have to recall everything you have said, and that this is an ongoing conversation. Gradually introduce the more serious prognostic points and wait for the family to respond at each stage. Check reception frequently and convey that it matters to you if things don't make sense. E.g. "Am I making sense? This must be confusing, but do you follow most of what I'm saying?" Provide written information if you can so the family can refer back to it at home as they are processing this news.

In regards to prognosis, foreseeing the future course of a developmental condition is often challenging, but we still want to provide some meaningful anticipatory guidance if possible. Clinicians are accurate only 20% of the time and tend to be overly optimistic. There is a correlation that the longer the relationship with a family, the lower the likelihood that the shared prognosis will be correct. Some patients or families may interpret minimal information as withholding of frightening news. Patients or parents who receive more elements of prognostic disclosure are more likely to report communication-related hope, even when the likelihood of successful intervention or cure is low. It's important to tell parents the concrete ways their child's condition will change and be monitored over time. You can assure them that Henry will learn and grow at his own rate and in his own way. It will be important to compare him to himself and not to other children.

Throughout, allow Henry's parents to speak. In their shock, they may need encouragement to voice questions, but this will give them a sense of control. Reinforce and clarify the information by asking them to repeat the general ideas of what you have said.

Empathy (behavior, body language)

This step is applied throughout the conversation. Try to elicit the family's agenda, concerns and anxieties. They don't necessarily have to be fully addressed right away, but you can acknowledge what they are talking about and return to it. Don't ignore! Listen for the buried question. If short on time, recognize that an issue or concern is important to them and arrange another time to have a detailed talk about it. You cannot meet every demand or agree with everything that every parent says, but listen and identify what they may be saying. It may help to explicitly write the unaddressed issues in the chart so that parents feel their concerns have been acknowledged as important and will be addressed.

Strategy

Lastly, try to blend Henry's parents' agenda with yours by acknowledging their questions and concerns and trying to include them in the topics you cover. Assess their reactions and then respond to them. Parents are often looking to you to make sense of

any confusion and to offer plans for the future. Integrate what you know of their agenda, the medical scenario and the plan of management. Distinguish the fixable from the unfixable (with both medical and psychosocial problems). Don't be unrealistically overoptimistic or "overbid" about the future. It is hard to tell a family that their child will not learn as other children do, and easier to say "Wait and see" or "Perhaps he'll grow out of it," but that won't be true. Be honest, but still leave room for hope. Make a plan or strategy and explain it. Look at the people and psychological resources beyond yourself available to the family. Help Henry understand what he can do for himself, and encourage his independence**. Help the family identify their own coping strategies and supports. Ask if they have any questions. Summarize, make a contract and then follow-through.

Final Comments

It's important to understand our own feelings before attempting to communicate life altering news. We can go into these conversations with fears of being at fault and blamed, unleashing a disagreeable reaction, or not knowing all the answers. Those feelings may be magnified when the patient is a child, and when we know that the diagnosis will alter that child's life trajectory. We may have our own personal discomforts and biases about certain diagnoses, but attempts to shield people from the truth can have damaging effects. The failure to give accurate and honest information can prevent families from coming to terms with their child's diagnosis, and with making plans and decisions regarding their child's future. Identifying and acknowledging the family's emotions upon hearing life-altering news, while also maintaining the role of guiding expert is crucial. However, in most situations, there are opportunities for further clarification, and this first conversation is the beginning of a process, especially if you will be their primary care provider. Parents need to know that you will be there with them as they journey through their child's developmental diagnosis.

The objectives that were discussed:

1. Compare & contrast "Delivering life-altering news" vs. "breaking bad news"
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I remember watching Dr. Andrews share a story with a family who was wondering about the future of their daughter with Intellectual Disability. Dr. Andrews shared about another patient who loved flowers and learned to be skillful in making arrangements by watching her aunt who owned a flower shop. The young woman went on to work and thrive as a professional florist. The story reframed the parents' expectations and helped them think more broadly about possibilities for their child's future. It reminded me to not underestimate the power of storytelling, how all children face uncertainty in their future health and career, and to balance discussing "abilities" and "disabilities". Although daunting, these conversations also have the opportunity to convey hope and meaning within illness and reinforce the goals the family has for their child.

Thank you for listening.

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