Breaking News to Families-Genetic Counseling Perspective

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“Your X-rays are kind of depressing, so here’s Susan and me in front of the Eiffel Tower.”
There are no experts

- Breaking bad news is hard for all clinicians
- Training is limited across health professionals
- Training is particularly limited in the area of fetal diagnosis
- Even experienced fetal medicine providers find the uncertainty challenging
  - Are we playing “God”?  
  - How do we offer clear explanations while also being empathetic?
Common responses to bad news

- Denial
- Anger
- Fear
- Despair
- Guilt & shame
- Sadness
- Greif

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Unique to fetal diagnosis

- Findings are rarely 100% clear
  - Gray area leaves room for interpretation
  - Provider dependent explanations
- Imaging is our main tool (cannot do physical or developmental exam or review symptoms)
- High anxiety/vulnerable population
- Timing is an issue: patients may be considering abortion based on the findings and discussion
- Very few birth defects can be fixed before delivery
- Risk for increased maternal anxiety impacting the pregnancy
How do we avoid patients feeling like...

- Victims
- Of
- Modern
- Imaging
- Technology
The “ABCDE’s” of breaking bad news

- **A**dvance preparation
- **B**uild a therapeutic environment/relationship
- **C**ommunicate well
- **D**eal with patient and family reactions
- **E**ncourage and validate emotions
Advance preparation

• Review patient medical and pregnancy history
• Speak with referring physician/genetic counselor to obtain any additional information about patient
• If there will be multiple providers meeting with the patient have a clear and unified plan for results disclosure
• Anticipate patient questions and have resources available
• Allow enough time
Build a therapeutic environment

• Help patient plan for logistics of visit
• Arrange for a quiet space without interruptions
• Be mindful of pregnancy state
• Introduce all members of the medical team and clearly explain their roles
• Confirm the patient’s understanding of the reason for the referral
• Ask what they are looking for from the discussion
Communicate well

• Be direct and clear about what is known and what is not known
• Be kind, empathetic and patient
• Avoid medical terminology
• Allow time for silence
• Use pictures and diagrams when appropriate
• Ask patients to articulate their understanding of what they have been told
• Be willing to repeat what you have said and be open to using a different way to explain things if patient is not understanding
Deal with patient and family reactions

- Address questions in real time as they are asked
- Assess reactions and family dynamic
- Allow for all types of responses to information
- Explore feelings
- Bring in additional support if needed
- Express empathy
- Correct misconceptions
Encourage and validate emotions

- Acknowledge the difficulty of receiving a poor/uncertain diagnosis
- Ask about family environment
- Explore core values and beliefs
- Address needs—immediate and long term
- Support the patient/couple in decisions
- Make appropriate referrals for additional support
- Emphasize availability for follow up questions
Case Example

- Patient is 20 weeks gestation referred for ventriculomegaly and possible absent cavum septum pellucidum
- Fetal MRI/ultrasound reveals agenesis of the corpus callosum and concern for small head circumference
- Genetic counselor informs team that fetal karyotype and microarray results by amniocentesis are normal and that the couple is considering termination based on the imaging findings today
Key points- decision making patient

- Be honest about known and unknown with the diagnosis
- Describe the findings and then ask if the couple wants to see pictures (don’t assume)
- Assess the couple’s comfort with uncertainty
- Emphasize support for any decision they make
- Be sensitive to terminology “your baby”, gender disclosure etc.
- Allow time for follow up discussions after the couple has time to process the information
Case Example 2

- Patient is 20 weeks gestation
- Fetal ultrasound reveals multiple abnormalities in a fetus known to have trisomy 18 by CVS
- Patient has been informed of the diagnosis prior to the appointment
- Couple has made the decision to continue the pregnancy
Key points- Continuing pregnancy

• Ask the patient what they understand about the diagnosis and findings we might expect on imaging
• Describe findings and ask if they want to see pictures, confirm they know gender
• Involve neonatology/genetics/palliative care for delivery planning
• Ensure couple has access to support resources or refer as needed
• Address questions and offer contact information for follow up questions or concerns
References


