Talking to Children about Genetic Disorders

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Objectives

• To understand special considerations when children receive a genetic diagnosis

• To discuss communication of genetic information in families

• To discuss the role of doctors, genetic counselors, and other health care professionals in communicating genetic information
The “best” way for a parent to discuss information on genetic condition

- Concern with how information may impact child’s self-esteem, coping, and anxiety level
- Whether child should be present or absent from genetic counseling discussion
- Many feel the need to delay genetic test result disclosure as a way of protecting, prolonging child’s childhood
- May not know how, when, or what information to provide
- If child was diagnosed early in life, it may have been a long time since parent received education on the diagnosis
  - Parent may feel uncertain or insecure in their own understanding
When is genetic testing done for VHL?

• Generally, genetic testing in children is pursued only when the results can guide health management
  – For VHL, targeted examinations and imaging studies done throughout life, starting in childhood

• Diagnostic testing
  – Individual with features of VHL (ex: spinal hemangioblastomas or retinal angiomas) in whom VHL diagnosis is already suspected

• Pre-symptomatic testing
  – Healthy individual with no known signs of VHL is tested for mutation previously identified in the family (and often in one of the parents)
Genetic testing in minors - considerations

• Testing may be offered for a child who is too young to give their informed assent
  – Potential loss for autonomy

• Child may not be able to remember genetic counseling session
  – Will test result be discussed with them when they are older?

• Emotional reactions
  – Affected and unaffected parent
  – Those with experience caring for loved ones with the condition
  – Affected children may be treated differently than unaffected children; older children may be treated differently than younger children

• Surveillance fatigue and burnout
Parents attitudes towards presymptomatic genetic diagnosis in children

- French VHL study group of 14 VHL patients with children (11 women, 3 men)
- Majority wanted children tested as soon as possible
- Those with disease onset after age 20 did not know if they themselves would have wanted the information sooner
- Most said they would share news of a positive result with their children but could not specify at what age

How and when should children be informed of their genetic status?

- Past research on communication needs of children in families with VHL is limited
- Similarities/Differences between inherited VHL and VHL occurring de novo
- We can learn from other past studies done exploring communication needs in families affected with genetic conditions other than VHL
  - How families cope and understand the genetic condition affecting them
An analysis on communication between parent and child - Overall Themes

• Imparting genetic information to one’s children is daunting

• Guidance and support from health care providers on how to deliver information was deemed to be important but was often not available

• Parents decision to disclose results had profound effects on children’s ability of cope and adapt to their condition
  – The way children want this information discussed may be different than how the parents provided that information to them

Learning from families through research interviews: Parents’ perspective

- Parents reported the experience of discussing genetic risk information as being emotionally difficult.

- Many felt that health professionals could provide more assistance with how to discuss these issues throughout their child’s development.

Learning from families through research interviews- Children’s perspective

- Children preferred to learn about their condition gradually throughout childhood

- Informal conversations that occurred while doing other things alongside their parent
  - Preparing a meal, gardening, riding in the car
  - Was true for both affected and unaffected children in a family

Age of information disclosure

- Study of 17 adolescents with genetic conditions
- Majority stated that they would have preferred learning about their genetic condition between 6 and 10 years of age

- Genetic counseling in adolescence
  - Focus on their understanding and management of their health condition rather than reproductive risks

- Parents were primary source of genetic information
  - Followed by doctors or other health care professions
  - Many wanted to be seen by their provider with their parent(s) present

Szybowska et al., Assessing the informational needs of adolescents with a genetic condition: what do they want to know? J Genet Couns. 2007; 16(2):201-210
• Detailed in many studies, genetic information becomes part of the family narrative or culture

• Plays a role in the process of making meaning and adapting to life events

• Talking about who else in the family was a carrier or affected helped normalize the information

• Shared family identity
Benefits of child-centered open communication

• Children could come to terms with genetic risk in a natural and self-driven way when:
  – provided with developmentally appropriate information
  – could ask questions and understand at their own pace

• Children felt like they had always known about their condition and rarely remembered the single moment that they were told they were affected

When information was kept secret

- Children struggled to understand what was happening
- Children had misconceptions about their diagnosis and what it meant for them
- Later reported that this led to increased stress and negative emotional experiences for both the children and their parents — resentment, continued distrust and tense familial relationships
- When parents assumed their children would come to them with questions as a sign of readiness, this typically did not happen
- Not acknowledging the genetic condition in the family dissuaded the children from asking questions — They did not want to upset their parents
When communication became more open

• Greater understanding of shared reality emerged

• Allowed parents and children to better cope and understand each other

• No parents who engaged in open communication with their children expressed regret in their decision to do so

Health care providers

• Families vary in their abilities to discuss genetic information with their children

• Genetic counselors and health providers can facilitate communication by helping the family consider:
  – What is being said to the child
  – What the child is overhearing
  – How the parents plan on presenting information to the child going forward

• Should elicit perceived barriers to communication

• Provide a safe place for parents to practice these discussions
Health providers can provide increased emotional and informational support

• Provide resources with techniques, diagrams, and appropriate language to use while communicating with their children

• Support groups or professional psychosocial counseling can be encouraged
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Questions?
Comments?