Communicating About Genomics

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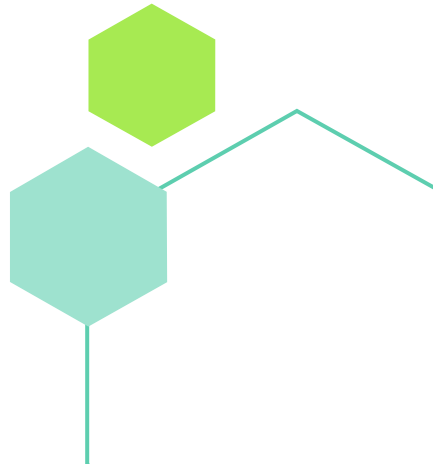
Learning Objectives

- Explain the role of CHWs in supporting patients with genetic diagnoses
- Demonstrate effective communication strategies for discussing genetic risk with patients and families.
- Identify challenges and solutions when helping patients share genetic information with relatives.
- Guide patients in finding and using social support networks for genetic conditions.
- Educate patients and families about genetic risks in a culturally appropriate manner.



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Helping Clients Identify Social Support

Social support - a network of family, friends, and peers

- Helps to cope with stress of cancer diagnosis, treatment, and recovery
- May provide physical, psychological, financial, mental, and emotional support

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Other Types of Social Support

specialized support groups

psychotherapy counseling

advocacy organizations

genetic counseling

online groups/platforms

specialty genetics management clinics

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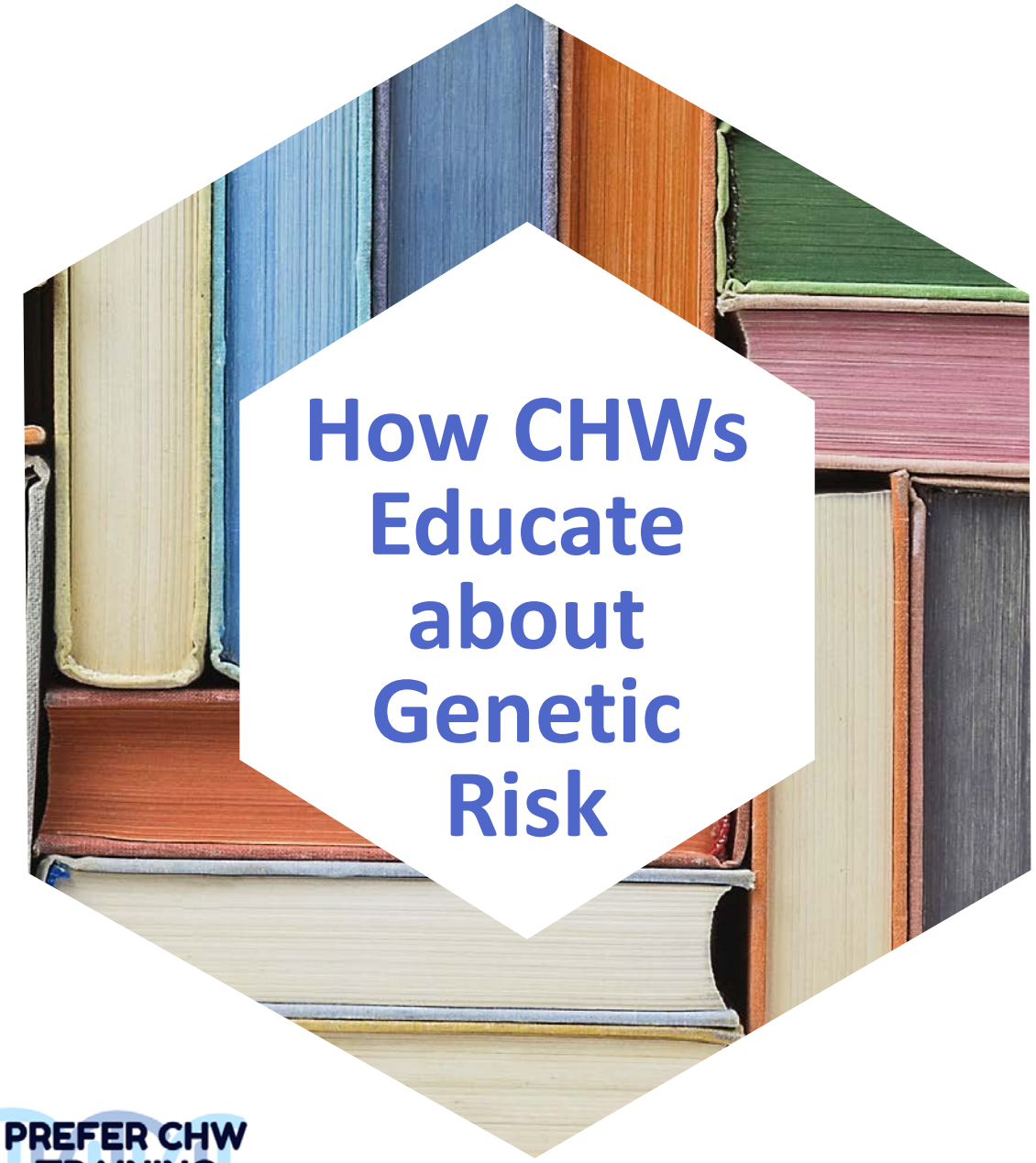

How CHWs Educate about Genetic Risk

- Explain genetic conditions
- Assist in collecting family history
- Encourage patients to talk to their doctors
- Provide examples of questions to ask
- Decide which conversations should be 1-on-1 or in a group
- Share patient education resources

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Why Communicate About Familial Risk?

- Benefits both the patient and their relatives.
- Family members can provide support
- Empowers family members to make informed decisions about their own health
- Family members may pursue cascade screening

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Cascade Testing

- Identifying at-risk family members when a genetic conditions is found in one person
- Begins by testing closest relatives who are most likely to have the same genetic change
- If a relative tests positive, their immediate family members are encouraged to get tested as well

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Why is Cascade Testing Important?

Early detection and prevention	• allows family members to take preventive actions or seek early treatment
Personalized risk management	• helps individuals make informed screening and lifestyle decisions
Cost-effectiveness	• can reduce long-term health care costs by preventing advanced disease
Empowerment of families	• provides knowledge to support and protect relatives from genetic conditions

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Helpful Questions to Ask

Understanding family dynamics	How do you feel about sharing genetic health information with your family?
	Are there any family members who might be particularly interested or concerned about genetics?
	Are there any family members you would prefer not to discuss genetics with?

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Helpful Questions to Ask

Sharing results and family risk	Would you like some help thinking through how to share genetic information with your family?
	Do you have any concerns about reaching out to family or friends regarding your genetic health information?
	Would it be helpful to develop a plan for how you can talk to your family about genetic risk over time?

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Helpful Questions to Ask

Seeking additional support and community resources	Do you have any close friends who are good at listening or helping you think through important health decisions?
	Would you be interested in finding community-based support groups for people with similar genetic risks or health concerns?
	How do you usually like to receive emotional support? Would you prefer in-person, phone calls, or online groups?

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Challenges Talking about Familial Risk

- Lack of genetic and/or health literacy
- Fear of causing distress to family members
- Inability to contact family members
- Under- or overestimating genetic risk
- Disclosure to selective family members
- Strained family relationships

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Navigating Communication Challenges

Lack of genetic and/or health literacy

Simplify complex concepts

Use real life examples

Provide written resources

Offer follow-up discussions

Fear of causing distress among family members

Normalize the conversation

Focus on the positive outcomes

Respect timing and readiness for disclosure

Inability to contact family members

Provide tools like scripts for difficult conversations

Use alternative channels (group chats, social media)

Encourage broader family engagement

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Navigating Communication Challenges

Under- or overestimating genetic risk

- **Provide accurate risk information**
- **Normalize uncertainty (genetics is only one factor of health)**
- **Encourage genetic counseling**

Strained family relationships

- Respect privacy and autonomy
- Affirm their right to decide who share information with
- Provide strategies for sharing sensitive information

Workbook Activity #10

1. Michelle is a 30-year-old female with a family history of breast cancer in her mother (diagnosed at 42) and maternal grandmother (diagnosed at 56). Her father is deceased, and she does not know much about her paternal side of the family. Michelle is interested in genetic testing for hereditary breast cancer but is unsure of how she would access this in her community and comes to you for help.
   - *How would you advise Michelle on next steps?*

2. After navigating Michelle to the appropriate resources, she decides to pursue germline genetic testing for HBOC. She is found to have a pathogenic variant in BRCA1. Michelle's family is small, but she does have a paternal half-sister who lives nearby. Michelle is unsure if she should contact her half-sister and comes to you for advice.
   - *How might you guide Michelle?*

3. David is a 45-year-old male with a family history of colorectal cancer. His father was diagnosed at age 50, and his paternal uncle was diagnosed at age 58. David has heard of Lynch syndrome but is unsure what it means for him or his family. He is also worried about his younger brother, who is 40 and has not yet had any colorectal cancer screenings. David is hesitant to bring up genetic testing with his family and comes to you for guidance.
   - *What steps would you take to help David understand Lynch syndrome and encourage him to talk to his family about his concerns?*