Communicating Cancer Risk with Extended Family Members

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Disclosure

I have no relevant financial or nonfinancial relationships to disclose.

Family Communication of Genetic Information to Relatives

- Why its so important
- What are the barriers
- What to share
- Which tools to use when sharing
Why Sharing Genetic Information is Important: A Family perspective

- Allows other family members to understand their risk for cancer and provides them with the information to prevent or detect cancer at early stages
  - Tailored family screening recommendations
  - Chemoprevention (ex Tamoxifen and Aspirin)
  - Risk reducing surgeries
  - Detect cancers at treatable stages
  - Cancer Treatments and medication (ex PARP)
  - Clinical trials
  - Reproductive options

Why Sharing Information is Important: A health care model perspective

- Cascade Testing and Screening: The mechanism for identifying people at risk for a genetic condition by a process of systematic family tracing.

- Sharing genetic information with at risk relatives can lead to cascade testing and screening

Cascade Screening

1st degree

1st degree

2nd degree

2nd degree

3rd degree

proband
Testing relatives is key to making Lynch screening affordable

Figure 2: Sensitivity analysis of number of relatives tested per proband.

Family Dynamics

The Barriers of Communicating Genetic Information

- Cultural
- Lack of understanding
- Fear of discrimination
- Not knowing what to share or how it will impact other family members
- Family relationship dynamics
- Emotional Impact
- "Bad news" or feel uncomfortable about sharing
Who is Getting the Information in the Family?

TABLE V. Agreement in Power for an Agent Inferring Behaviors about the Genetic Test Result

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<th>x (1)</th>
<th>Agreement group</th>
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Communication of Genetic Information: The Impact on the Family's Decision-Making Process

Family Communication Following Genetic Testing

What Facilitates or Impedes Family Communication Following Genetic Testing for Cancer Risk? A Systematic Review and Meta-Synthesis of Primary Qualitative Research

What to Share

Evacuating the Situation of educational materials in communicating about Lynch syndrome to at-risk relatives.

Abstract

Understanding how family members communicate about Lynch syndrome in a public health setting can be a crucial strategy in developing effective communication practices. This study evaluated the effectiveness of family communication about Lynch syndrome in a public health setting, with a focus on the role of healthcare providers and family members in the communication process. Results indicate that healthcare providers play a significant role in promoting family communication about Lynch syndrome, and that family members benefit from the support of healthcare providers in making informed decisions about genetic testing.

Keywords: Lynch syndrome, family communication, genetic testing, public health.
Materials to Share

- Genetic test results
- Family tree
- Screening recommendations
- Family letter from your genetic counselor/provider

Methods for Sharing Genetic Information

- Verbally (face to face or phone)
- Mail
- Email
- Online tools
  - Social Media
  - Check Your Genes
  - Kintalk

Check Your Genes

- Family Notification Service
  - Customize template letters to send via email or postal mail
  - Can attach a copy test to email as well
- Information about genetic testing and HBOC
- Links to Resources

https://www.checkyourgenes.org
Kintalk

- Help families share genetic information.
- Increase cascade testing and screening.
- Educate members about HBOC and Lynch Syndrome (LS) through multiple media platforms.
- Connect people with HBOC and LS through moderated interactive discussions.

1st Layer of Kintalk

Connect with others who have HBOC or BRCAs mutations or Lynch syndrome in our Kintalk Groups.

Helping Families Now: We help families by providing free education, support and help finding early.

2nd Layer of Kintalk: Profile/Sharing Portal

Send invite

Who should be in my Kintalk member? Then you can invite them to your Kintalk member.

Your Name

Note:

Sharing member's login is not a feature supported by the current Kintalk.

Share

Template

Recipient

Send invitation

With invites and shares.
2nd Layer of Kintalk: Profile/Sharing Portal

3rd Layer: Kintalk communities
- LS, HBOC & Hereditary Cancer Syndrome Communities
- Podcasts by UCSF specialists
- Twitter: @KintalkUCSF
- YouTube Channel: Kintalk UCSF
- Moderated Q & A forum
- Resources including
  - Basics of genetics and heredity
  - How to find a genetic counselor
  - Information on other hereditary cancer syndromes
  - NCCN screening recommendations

Telegenetics: The Future of Kintalk
Telegenetics: The Future of Kintalk

Hereditary Cancer Clinic
UCSF Center for BRCA Research

- All new patients have a combined visit with a genetic counselor and nurse practitioner
- Using guidelines established by the steering committee, the NP and genetic counselors lay out prevention and surveillance plans for patients based on individual needs
- Patients are referred to specialists as necessary based on their care plan and/or results of screenings

Family Communication
“Every breast or ovarian cancer patient with a BRCA1 or BRCA2 mutation detected after diagnosis is a missed opportunity to prevent a cancer. No woman with a BRCA1 or BRCA2 mutation should die from breast or ovarian cancer”

- Mary Claire King, NSGC 2016