Communicating Effectively about Cancer Genetics with Patients of Low Health Literacy

National Cancer Policy Forum Workshop

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What do we mean by cancer genetics?

- Personalized Medicine
- Precision Medicine
- Genomics
- Computational Medicine

**Prevention**: Risk assessment using polygenic risk scores or PRS

**Prevention/Treatment**: Germline testing and genetic counseling for hereditary cancer

**Treatment**: Molecular tumor testing and targeted treatments
Challenges Integrating Genetics into Cancer Care

- Underrepresentation in genomic databases increases potential for inequities
  - E.g. lack of diversity in Genome Wide Association Studies (GWAS) → less accurate/potentially harmful use of polygenic risk scores; more uncertain results in hereditary cancer testing

- Diversity Imperative for Genomics Research
  - All of Us Research Program
  - Other NIH initiatives e.g. Clinical Sequencing Evidence-Generating Research Consortium (CSER2)

- Genomic Literacy is low
Genomic literacy is necessary to realize the promise of Genomic Medicine.
Relevance for the general population

“Communication is the most common procedure in medicine”

- Physicians commonly overestimate patients’ literacy (and numeracy) levels
- Health information and the healthcare system can be difficult even for highly skilled people to navigate
- A new diagnosis or a stressful medical situation can make it hard anyone to understand
Communication in Genetic Counseling for Hereditary Breast & Ovarian Cancer (HBOC)


- Research Questions:
  - How do these communication challenges play out in cancer genetic counseling in safety net settings?
  - What can we do to improve the communication?
Results: Information Mismatch

1. Too Much Information
2. Complex Terminology and Conceptually Difficult Presentation of Information
3. Information Perceived as not Relevant by the Patient
4. Counselors Unintentionally Inhibited Patient Engagement and Question-Asking
5. Vague Discussions of Screening and Prevention Recommendations

Principles of Effective Communication

- The clinician, not the patient, is responsible for effective communication.
- The ‘universal precaution principle’: all patients may benefit from plain language.
- Patient comprehension can and should be verified.
- Adapting for literacy/numeracy level requires commitment, flexibility, and practice.
Training on Effective Communication for Genetic Counselors

- Recognize Limited Literacy
- Use Plain Language
- Focus on Key Messages & Avoid TMI
- Use Risk Communication Best Practices (e.g. frequencies & absolute risks)
- Assess Comprehension
- Working with LEP patients & Interpreters

CHARM: Cancer Health Assessment Reaching Many

Purpose: to increase access to genetic testing for hereditary cancer in “underserved populations”
- Low income
- Low literacy
- Minority populations

Patients aged 18-49 years
- Kaiser Permanente Northwest
- Denver Health a federally-qualified healthcare center
- English or Spanish Speakers
Adults, 18-50 years

Risk Assessment

Join Study/Consent

Yes

Clinical Sequencing

50%

Randomization

Traditional Counseling

50%

Modified Counseling

No

Usual care group

Observation

Physician or Self-referral

Surveys @ Baseline, 2 weeks, and 6 months

Compare utilization between study ppts and usual care
Approach to Communication in CHARM

- All materials designed for accessibility for limited health & genomic literacy with stakeholder input
- All translated & culturally adapted to Spanish
- Web-based consent with illustrations and audio
- Training of medical interpreters on exome sequencing
Saliva sample for clinical exome sequencing

Categories of Results:
- Cancer Risk: 39 genes
- Medically Actionable: 79 genes
- Carrier: 14 genes

Genetic counselors return results by phone
Traditional: Usual Care

- Conceptually and linguistically complex
  - Analogies/hypotheticals
  - Jargon/technical language
  - Passive voice to convey uncertainty indirectly

- Emphasis on Education
  - Detailed genetic information
  - Unidirectional transfer of information from counselor to participant

Modified: Literacy Focus

Conceptually and linguistically simplified
- Direct & concrete
- Plain language
- Active voice to minimize uncertainty

Emphasis on Communication and Psychosocial Counseling
- More dialogue & participant engagement
- Focus on relationship building, rapport, empathy
Modified Counselor Training Overview

Session 1: Recognizing Limited Literacy
Session 2: Adapting your approach
Session 3: Assessing Comprehension
Session 4: Risk Communication
Session 5: Working with LEP patients and Interpreters
Session 6: Review/Practice/Discuss

• Observations of other counselors
• Ongoing case conferences to discuss cases, review methods, share ideas
Data and Outcome measures

**Baseline, 2 week, 6 month surveys**
(n= ~880)
- Demographics
- Communication
- Quantity of information
- Understanding of cancer risk and recommended f-u care
- Satisfaction
- Quality of interpretation

**Qualitative Interviews**
- 2-3 weeks after RD (n=50)
- Re-interviewed at 6 months (n=25)
- How and why the modified counseling works/doesn’t work
- Family communication
- Follow up care

**Audio Recordings of Results Disclosure calls**
- Coding for fidelity to Modified/Traditional
- Used to tailor Qualitative Interviews
Next Steps/Topics for Discussion

- Beyond supplemental training--integrate into graduate education
  - Emphasize relationship building vs information/education
- Changes in genetic counseling—quickly evolving field
  - Focus on test results vs pre-test counseling
  - Shortage of GCs
  - Larger and larger genomic tests
- Not just about genetic counselors—
  - Explosion of Direct-to Consumer testing
  - Managing risk and screening in primary care
CHARM study team

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