Exploring Innovative Solutions & Models of Success
Disparities & Access to Genomic Medicine

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Access & Communication are the bridge connecting genetic discoveries with patients who will benefit.

Currently, those with the greatest need have the least opportunity to receive the best care.

Barriers on this pathway will INCREASE cancer disparities.
Research Focus

In low resource settings

Using inductive & deductive paradigms

Qualitative & quantitative methods

With multi-ethnic & multi-lingual populations

- Identify those at high risk for HBOC
  - among affected/unaffected
  - in clinic/community settings

- Innovate to improve access to/use of genetic counseling
  - via multiple channels

- Maximize effective communication
  - low health literacy
  - limited English proficiency
RCT to ascertain whether low-income phone service callers would agree to family history screening, and if high risk, would obtain free genetic counseling. Interventions: immediate offer of GC app’t vs receipt of brochure with instructions on how to obtain GC

709 (58%) of eligible callers completed brief FH screener (“6-Point Scale”); 99 (14%) were high risk

Results: In all, 58% of high risk women were counseled; significantly more among the immediate appointment (38%) vs. brochure (5%) (p=0.0001). These callers are “low-hanging fruit” GC by phone was required for 54% of those counseled

Statewide Communication to Reach High-Risk Low-SES Women

Pasick/NCI R01 2007-12

- Joseph et al, Pub Hlth Gen 2012
- Pasick et al, AJPH 2016
Translating Cancer Genetics for the Safety Net Setting

Joseph/Susan G. Komen 2012-16

- Ethnography of communication between genetic counselors and low-income English-, Spanish- and Cantonese-speaking patients in safety net settings to assess communication effectiveness from the patient’s perspective.

- Observations/audio recording of 170 HBOC genetic counseling sessions/65 stimulated recall patient interviews; pilot test GC training in effective communication.

- Results: Serious mismatch between information provided and what patients wanted and could comprehend; more so using interpreters. GCs knew they were not getting through and highly valued the training. Some strategies have proved challenging to put into practice.

- Joseph et al., J Gen Couns 2017
- Cheng et al., J Comm Gen 2017
- Kamara et al., J Gen Couns 2017
Study 3.

Identification & Education of Low-Income Women at Risk for Hereditary Breast Cancer

Pasick/Susan G. Komen 2010-16

- Feasibility study of culturally tailored HBOC education in African American churches; main outcome: ID of high-risk women and their receipt of genetic counseling

- Participatory development of workshop curriculum & training of health ministry leaders; 41 workshops over 4 years generated 745 pre/post surveys and 729 family hx screeners

- Results: Successful refinement of key messages significantly raised post-workshop knowledge; overall, 84 high-risk women were identified and 50% obtained counseling.

Surprisingly, women who only filled out the family hx screener at Sunday Service were counseled at a higher rate than those who attended a 2-hour workshop

Stewart et al., Pub Hlth Gen 2016
Comparison of 3 Modes of Genetic Counseling in High-Risk Public Hospital Patients (GC3)

Pasick/NCI R01 2016-21

- Genetic counseling is concentrated in academic centers; remote counseling is needed to reach low-income women - but little is known about the quality and effectiveness of remote counseling, particularly in the context of low health literacy and LEP

- Mixed methods RCT to compare in-person, phone, and video GC in 3 public hospitals; English-, Chinese- and Spanish-speaking patients. Target sample size: 540

- Process outcomes to date: a simple family hx form can be completed by patients in a variety of clinics
  - ~10,000 completed in 10 months
  - 634 (6.6%) potentially high-risk
  - 242 (38%) enrolled
  - 167 (69%) counseled
  - 144 (86%) completed follow-up survey
Progress

- Understanding the problems of reach, trust, communication

- Efficiencies in reach are achievable - but building trust and communicating effectively is very time-, money- and labor-intensive

- Imperatives
  - Provide information and services to people where they are, with words they understand, and messages that are meaningful to them
  - All people and materials must meet these criterion
  - Train and retrain clinicians to avoid TMI, to use plain talk, and to check for comprehension
Remaining Challenges

- To achieve an educated public with participation from all sectors requires investment in innovative approaches and a much more diverse public health workforce

- Shortage of genetic counselors – and lack of diversity

- Policies to foster training of counselors and clinicians in effective communication

- Establish communication channels and partnerships between academic medical centers and safety net providers
Thank You!