Institutional Humility & Engaging Diverse Communities in Cancer Research

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My background, training and experiences are diverse

BA ’91: Linguistics
MS ’93-96: Health Sciences
MD ’93-98
Resident ‘98-’05: Surgery
Colorectal Fellowship ’07
Health Policy Fellowship ‘08
MPH ’06
Minority health disparities
Assistant & Associate Professor ’08-’16

Board of Directors,
Bay Area Black Women’s Health Project (’93-’96)

Saturday School for Community Leaders (’95)

Community Based Participatory Research Training (‘12)
Jeannette Barnes (1935-1993)
Motivation for my work in health equity & disparities

- 58 years old
- Presented with a locally advanced breast mass (stage III B)
- Admitted for IV antibiotics; chemotherapy
- Died in the hospital (never having received palliative radiation therapy)
Disparities in Cancer are Longstanding

Traditional explanations for disparities in cancer survival focus on the individual.

**Patient Characteristics**
- Chronic disease/comorbid states
- Late stage at diagnosis

**Insurance Status**
- Lack of access to care contributes to poor outcomes

**Genetic explanations**
- Racial/ethnic minorities have more aggressive tumors
Health disparities are a population level problem.
No disparities in colon cancer survival within an integrated system

Kaplan-Meier Curves Comparing Survival by race/ethnicity in the integrated setting versus all other settings (Colon Cancer, stage I-III; California 2001-2006)

Rhoads KF & Patel MI. JCO 2015
Place Matters

WHERE YOU GO FOR CARE DETERMINES WHAT CARE YOU GET
Racial/Ethnic Diversity is Low in Cancer Clinical Trials, Nationally
‘Lack of Trust’ is an expected response to (historically) untrustworthy behavior
Magnitude of structural & physician and patient barriers to inclusion

Methods:
- N=13 trials
- N=8800 patients

Unger, et al. JNCI 2019
Magnitude of structural & physician and patient barriers to inclusion

Multi-level determinants of clinical trial inclusion

Unger, et al. JNCI 2019
Magnitude of structural & physician and patient barriers to inclusion

Figure 4. Magnitude of barriers for each condition for academic sites, community sites, and all sites combined. The P value was derived from a z score in a random effects model. A two-sided test was used.

Unger, et al. JNCI 2019
Population level problems require system level solutions
Create Patient centered trial portfolios

- **Assess the match between available trials & patients**
  - Be intentional about the development of trial portfolios
  - Cancer Centers need to increase the efficiency of opening trials

- **Consider partnerships with community based care settings**
  - These settings serve a higher proportion of racial/ethnic minorities
  - But have a higher proportion of mismatch (patients to trials)

- **Leverage institutional opportunities to make participation appealing & feasible**
  - Community Advisory Board—consultation on trial design/recruitment approaches, cultural tailoring of materials
  - Patient Family Advisory Council—improving patient experience; reducing financial barriers, increasing financial transparency
The System Won’t Change Unless We (Organize &) Demand It!

be the change you wish to see in the world...
-gandhi
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THANK YOU!