Cancer Health Disparities Research

Are we racing along the biomedical super highway or....?

Rena J. Pasick, DrPH
Fred Hutchinson Health Disparities Research Center & The Center for Community Health Promotion
April 27, 2015
Topics

- Critical challenges in cancer health disparities - encountered along the super highway
- Evolving methodologies - to help us navigate
Part I
Critical Challenges
Apophenia

- Seeing patterns or connections where there is none
- A form of delusional psychosis
National Cancer Institute –designated comprehensive cancer centers

41 elite research institutions that meet rigorous criteria for world-class, state-of-the-art programs in multidisciplinary cancer research
Advances in biomedical science will *exacerbate* cancer disparities

...as those who are currently underserved fall further and further behind

- Lack of diversity in cancer clinical trials
- Lack of access to high quality care (e.g., academic health centers) where scientific discoveries most rapidly translate into practice

**Do you see it?**

..... or is it just me?
“A rising tide lifts all boats”
Clinical trials provide state of the art cancer therapies

Mounting evidence of genetic or physiologic distinctions among racial and ethnic groups that influence disease risk and severity, and response to treatment

Enrollment into cancer trials predicted lower overall and cancer specific mortality among common cancer sites*

The rising tide is leaving many behind

- <10% of clinical trial participants are “minorities”
- Less than 2% of the NCI’s clinical trials focus on any racial/minority population as their primary emphasis
Socio-Cultural Influences on Participation In Clinical Trial

- Marginalization/Discrimination
- Distrust
- Lack of participation
- Poor health outcomes
- Health Literacy
- Relational Culture
Relational culture – the paramount importance of that bond with someone who feels familiar and has the potential to understand you; the importance of feeling cared about

*I don’t know you.... so I can’t hear you*

Implications of relational culture for participation in research

It’s about comfort, familiarity, and TRUST

- Where does the initial recruitment information originate?
  - Good: someone from my community
  - Better: a close friend
  - Best: a respected recognized local leader/role model
  - Not so much: everything else

- Who leads and who implements the study?
  - People from my community who have entered the field of biomedicine and been successful (I’m proud and impressed; I support them)
  - People from the unfamiliar world of science, from an unfamiliar community, who I can’t relate to and who probably don’t care about me? (I’m not interested; whatever it is, it can’t be relevant for me; it might be bad for me)
In 2014, the U.S. Food and Drug Administration (FDA) approved 10 new drugs and several new tests for the diagnosis, treatment or management of cancer, and more than 771 promising therapies are in the pipeline.

Advances in treatment have produced improvements in the five-year survival rate for many cancer types, and there are now 14.5 million Americans who are cancer survivors today.

The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge

IOM 1999

The State of Cancer Care in America: 2015
American Society of Clinical Oncology
- **Persistent inequities.** The benefits of cancer screening and treatment advances have not been experienced evenly across racial and ethnic groups, as evidenced by differences in incidence and mortality rates.

- The Affordable Care Act has successfully *expanded access* to insurance and cancer care services, millions of Americans remain uninsured
  - while other individuals with public and private plans continue to lack sufficient coverage for high-quality cancer care.

The State of Cancer Care in America: 2015
American Society of Clinical Oncology
Quality

Progress in Cancer Care

Does access to health care = quality cancer treatment?
CANCER OUTCOMES

Medicaid recipients vs non-Medicaid insured adults (473,722 Cancer Patients*)

- Significantly more likely to present with distant disease
- Significantly less likely to receive surgery and/or radiation therapy
- Significantly more likely to die of their cancer
- Those with Medicaid seemed to have only marginally improved survival compared with those who were uninsured

*10 most deadly cancers/SEER

GV Walker, et al., JCO Oct 1, 2014:3118-3125
CANCER OUTCOMES

All other forms of coverage > Medicaid > Uninsured

GV Walker, et al., JCO Oct 1, 2014:3118-3125
Health Inequities

When disparities are due to systematic injustices, such as segregation and unequal treatment.

Inequities present not only as differential health status, but differential access to needed medical procedures and access to quality medical care.

Abnormal Mammogram Follow-Up Time > 60 days

Start Treatment Within 30 Days

% Abnormal mammogram follow-up time longer than 60 days

% Start treatment within 30 days

CDC, National Program of Cancer Registries
Time to follow-up of abnormal mammogram (n=16,109 abnormal mammograms)

SF Mammography Registry 1997-08

"Your appointment with the doctor is at eleven-fifteen, but his appointment with you is at twelve-fifteen."
Highest income patients receive latest/best care

Income inequality was associated with early adoption across clinical practices in two ways:

- similar to the diffusion of new and expensive technologies, residence in areas with high levels of income inequality was associated with higher use of the test.
- in areas with greater income inequality, the highest-income people may access a new technology first, even among insured women with the same coverage for gene expression profiling.

For this and other tests of established value, “uneven diffusion by place and by population groups could drive an increase in health care disparities.”

Ponce et al., Health Affairs 34,4(2015):609-615
Equal treatment yields equal outcomes

- Differences in cancer treatment by setting/patient mix are well documented
- Adherence to NCCN guidelines studied in 30,000 CCR records of patients with CRC
- Compared adherence & outcomes in Integrated Hlth Sys (VA) vs other systems and across race/ethnicity
- Higher NCCN adherence in IHS vs other
- Minorities received higher level of evidence-based tx in IHS vs other
- Black race associated with higher mortality in non-IHS

KF Rhoads et al., JCO 33, 2015
Part II
Evolving Methodologies
Behavior still matters

- Acknowledges and embraces the complex multi-level determinants of health and disease – and situates behavior as a critical influence
  - while also recognizing the “longtime overemphasis on behavioral determinants”

- An “inescapable variable” in the pathway between upstream etiologies and the incidence or prevalence of most disease

- The “shifting role” of behavior from simple discrete causes of infections and injuries to more complex interrelationships of behavior and environment (e.g., obesity)

- Behavior as a consequence of cognitions, environments, and genetics

Behavior still matters (con’t)

- The relevance of predisposing, enabling, and reinforcing factors in multi-level understandings of behavior and health
  - Predisposing factors (antecedents of behavior) reside in the individual as attitudes, values, beliefs, and perceptions….”but are shaped over time by cultural and social exposures”
  - Enabling factors are “underplayed in most psychological studies of health behavior, but are critical…conditions of the environment that facilitate (or impede) enactment of predispositions”
  - Reinforcing factors supports (or impedes) essential repetition/maintenance of behaviors through rewards or incentives

Behavior still matters (con’t)

- Interaction of SES, environments, and behavior
  - SES as predisposing determinant of behavior…shaping behavior from the outset
  - SES as enabling determinant…motivation alone can’t function without needed resources; education as fundamental enabling factor
  - SES as reinforcing determinant – policies and campaigns built on the principle of social responsibility

Addresses inattention to culture as critical context for behavior and health

Seeks to broaden understanding of what culture is – “consisting of dynamic and ecologically-based inter-related elements that function together as a living, adapting system,” and what culture does - its “tools and processes enable humans to interpret the world in which we live through social norms of beliefs, attitudes, spiritual and emotional explanations, and practices.”

Shows limitations of current practices: using nominal, dichotomous variables of race and/or ethnicity and/or ancestry to represent culture.
Paradigm Wars

- relentless focus on differences
- ‘superiority’
  - of qualitative: deep, rich observational data
  - of quantitative: hard, generalizable
- “cannot & should not be combined”
http://obssr.od.nih.gov/mixed_methods_research/

Best Practices for Mixed Methods Research in the Health Sciences

Commissioned by the
Office of Behavioral and Social Sciences Research (OBSSR)
Helen I. Meissner, Ph.D., Office of Behavioral and Social Sciences Research
By
John W. Creswell, Ph.D., University of Nebraska-Lincoln
Ann Carroll Klassen, Ph.D., Drexel University
Vicki L. Plano Clark, Ph.D., University of Nebraska-Lincoln
Katherine Clegg Smith, Ph.D., Johns Hopkins University

With the Assistance of a Specially Appointed Working Group
How do we get where we need to go?

- Raise awareness of the connection between the health gap and the income gap: funds for medical science cut two ways

- Advocate for greater investment in health disparities research – including clinical trials

- Acknowledge and embrace culture as it operates in the real world

- Mixed methods will point the way
Thank You!