Is Current and Future Science Widening the Gap in Health Disparities?

Amelie G. Ramirez, DrPH

Director, Institute for Health Promotion Research
Associate Director for Cancer Prevention and Health Disparities, Cancer Therapy & Research Center
The UT Health Science Center at San Antonio
Trending up?

1971
Nixon’s “War on Cancer”

2015
Obama’s “Moonshot to Cure Cancer”

Cancer knowledge =
Targeted therapy =
Clinical trials =
Gene sequencing =

Advances in big data =
Immunotherapy =
National tumor genome database =

But where does this leave health disparities? = ↔
Why are minorities being left behind?

Minorities face barriers in accessing quality care:

- Insurance / immigrant status / work issues
- Co-morbidities
- System problems
- Transportation
- Lack of knowledge of healthcare system
- Cultural barriers (language, acculturation)

- Less likely to be screened for cancer
- More likely to be treated at lower-quality hospitals or hospitals with large minority and Medicare populations

Why are minorities being left behind?

Only 5% of clinical trial enrollees are minority (2.2% Latino)

- Most research data are extracted from uniform study populations of comprised largely of white men
- Most clinical trials are run by large medical centers, not the small community hospitals where many people, including minorities, receive treatment
- Precision medicine requires participation and inclusion of a diverse patient population—not just those who can afford and readily access care

Why are minorities being left behind?

Fewer minorities get genetic testing (only 4% of Latinas for BC)

- Genetic heterogeneity exists between/among population groups (Dean identified 6 genetic mutations among Latinas, only one had been reported in literature)
- Women with higher incomes = significantly more likely to get genetic profiling, even w/ same insurance coverage as those with lower incomes
- Even with genetic testing / profiling, targeted therapy may be too expensive
- ACA helps, but even reducing cost-sharing by 25% (closing of “doughnut hole” by 2020), those on Medicare w/o low-income subsidies may still spend $10K out of pocket, negatively affecting adherence to oral cancer drugs

Why are minorities being left behind?

Underinvestment in prevention

- Money spent on genetic or genome-focused research was 50% greater than that spent on research areas that included the word “prevention” in 2014.
- The gap in cancer health disparities will not be closed when so much more money and attention is invested in individual treatment rather than public health and disease prevention.

References: Bayer et al, 2015; Goozner, 2016; Lopes, 2015
Why are minorities being left behind?

BIG DATA can exclude minorities

- Jonas Lerman’s “data subordination”
- “Billions of people worldwide remain on Big Data’s periphery. Their information is not regularly collected or analyzed, because they do not routinely engage in activities that Big Data is designed to capture. Consequently, their preferences and needs risk being routinely ignored when governments and private industry use big data and advanced analytics to shape public policy and the marketplace”

References: Delaware Online, 2015 (delonline.us/1UGtePi)
What’s working right now?

Important strategies include:

- Patient navigation (culturally competent, can reduce screening/knowledge barriers)
- NCI community network programs
- Practice-based research networks to make clinical trial enrollment more accessible; one boosted enrollment from 5.4% to 10.2%
- Multilevel interventions/studies

Emerging solution: Drug parity laws

36 states have enacted drug parity laws (as of 8/2015) to relieve out-of-pocket expenses for oral chemotherapy agents

- However, extent of laws’ benefits is unclear; concern over increased insurance premiums and prior-authorization that creates additional barriers to access

Cancer Drug Coverage Parity Act →
Introduced into House and Senate in 2015

- Would require private insurance plans with IV chemotherapy benefits to provide parity for oral and self-injectable anticancer drugs

References: Kircher et al, 2016; ASCO, 2015
Emerging solution: Big Data as “Human-Centered”

“Big Data is created by or derived from human activities, communications, movements, and behaviors.”

– Dr. Ming-Hsiang Tsou, Center for Human Dynamics in the Mobile Age, SDSU

Big data should refer to big ideas, big impacts, and big changes for our society rather than only focusing on big volume

- Social life data, health data (EMR, cancer registries, outbreak tracking), scientific research data, business/commercial data, GPS transportation/traffic data
- Analysis requires multidisciplinary collaboration

References: Webinar, 2015 (bit.ly/1PSpaxl)
Emerging solution: Big Data as “Disparities-Focused”

“The next big step is using the acquired knowledge to build even more knowledge and applying what is learned… to find better treatments, better prevention and better ways of getting those better treatments and preventive interventions to people who need them.” – Dr. Otis Brawley, CMO, American Cancer Society

- NY acquiring data on LGBT community to provide better tailored public health services
- In Cincinnati, collecting “race, ethnicity, and language” (REL) data is helping healthcare providers identify disparities in care and create accountability
- Camden (NJ) group is creating Social Determinants of Health Database (SDD) to combine health + social data on vulnerable groups and care coordination

References: NY Times, 2016 (nyti.ms/1QEQ5tk); Huff Post, 2014 (huff.to/1u0OyoA); Healthcare Informatics, 2014 (bit.ly/1qUi5zO); Health Affairs, 2015 (bit.ly/1MTsxAl);
Emerging solution: Big Data as “Mobile Friendly”

Mobile technology is seen as the great equalizer

- 84% of low-income adults have access to a mobile phone
- Smartphones increasingly come equipped with sensors that monitor health-related data (i.e., heart rate, steps, routes traveled, and user activity levels)
- U-Mich gathering and analyzing large, diverse population health datasets by leveraging emerging Big Data sources (social media sites, GPS-based data from personal devices, and citizen-created maps)
- Fair Food Network’s app advances mobile payment technology by processing SNAP food assistance benefits more simply, affordably at farmers’ markets

References: Health Affairs Blog, 2015 (bit.ly/1MTsxAi); Michigan website, 2015 (bit.ly/1mazKSi)
Applying what we know: Big Data

Jonas Lerman, State Department Attorney, Visiting Scholar at George Washington University Law School

In designing new public-safety and job-training programs, forecasting future housing and transportation needs, and allocating funds for schools and medical research … public institutions could be required to consider, and perhaps work to mitigate, the disparate impact that their use of Big Data may have on persons who live outside or on the margins of government datasets.

References: Delaware Online, 2015 (delonline.us/1UGtePi)
The U.S. needs to develop a national consortium of cohorts that is truly representative of the diversity of the U.S. population. NIH plans to build a national consortium of at least one million Americans within the next five years that confronts this need.
Applying what we know: Training providers on disparities

Susan Skochelak, Vice President for Medical Education, American Medical Association (AMA)

Teaching physicians to think about disparities goes “hand in glove” with implementing technology that can help address them. (AMA medical students are analyzing big data sets to analyze health trends better understand vulnerable patient populations and address health disparities.)

References: Pittsburgh Post-Gazette, 2015 (bit.ly/1j3HGE0)
Applying what we know: Multifaceted approach

John Z. Ayanian, Director of the Institute for Healthcare Policy and Innovation, University of Michigan

1. Provide insurance coverage and access to high-quality care for all Americans.
2. Promote a diverse health care workforce.
3. Deliver patient-centered care.
4. Maintain accurate, complete race and ethnicity data to monitor disparities in care.
5. Set measurable goals for improving quality of care, and ensure that goals are achieved equitably for all racial and ethnic groups.

Call to action

Every scientific or technologic advance that you see, hear about, or that you create: **Ask yourself, how will this affect the disparate populations who are on the fringes?**

Incorporate health disparities into every single thing you do!
References

References

- Dusetzina SB, Keating NL. Mind the gap: why closing the doughnut hole is insufficient for increasing medicare beneficiary access to oral chemotherapy. *J Clin Oncol.* 2016;34(4):375-382.