

Advancing Health Disparities Research: Moving from Data and Statistics to Data-driven Solutions

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Background

Systematic and standardized data collection is an important step in documenting racial disparities in health.

In order to advance health disparities research and move to action, we must transition from data collection and statistical analysis to data driven solutions.

Goals

Discuss the importance of broadening our approach to collecting data on health disparities

Discuss the importance of engaging communities in the data collection process

Provide an example of a community-academic partnership and its approach to data collection and dissemination

Key points that will be discussed

Broaden the concept of race

Move beyond individual level data

Link quantitative with qualitative data

Engage community partners and stakeholders
in data collection and dissemination

Ensure a diverse public health workforce

Broadening the concept of race

A key construct in health disparities research is race.

Much of disparities research focuses on describing differences in disease prevalence, presentation, treatment, and outcomes and the stratification of data by race.

If race is the focus or unit of analysis for determining variations in health, then there should be a unifying definition of race.

When we measure race what do we mean?

Broadening the concept of race

Directive 15: Race and ethnicity standards for federal statistics and administrative reporting were issued by the Office of Management and Budget (OMB) for the classification of federal data on race and ethnicity.

They stemmed from the need to enforce civil rights law and to monitor equal access in housing, education, employment, and other areas of discrimination.

They represent a social-political construct and are not anthropologically or scientifically based.

Broadening the concept of race

Researchers have also defined race as a social rather than a biological construct.

When viewed solely as a biological construct, racial health disparities become immutable and non-modifiable through intervention.

As a social-political construct, race has implications for access to care, residential segregation, education, and access to healthy foods and recreational facilities...

thus differential exposures to unhealthy environments and differential opportunities for healthy behaviors.

Hypertension as an example

Blacks have the highest prevalence of hypertension compared to other racial groups and are almost twice as likely to suffer hypertension-related adverse events such as renal disease, heart failure, and stroke.

From a biological perspective, studies show that *in utero* maternal stress or nutritional deficiency can lead to genetic modifications in the embryonic kidney that increases susceptibility to hypertension.

While this view is compelling, it does not lend itself to public health intervention.

Hypertension

Socially and politically, blacks have higher risk of maternal stress and nutritional deficiency.

This may explain the observation of a greater prevalence for hypertension among adults.

Through a social and political lens, this may have implications for health disparities in hypertension, and points to solutions by intervening in social determinants of health such as poverty, stress, and access to healthy foods.

Broadening the concept of race

Other variables that are distinct yet interrelated to race should also be considered when collecting data:

Acculturation is a process in which members of one cultural group adopt the beliefs and behaviors of another group.

Acculturation is multidimensional and includes lifestyle, beliefs language, attitudes and norms.

Ethnicity refers to sharing of common culture or language.

Hypertension

The Multiethnic Study of Atherosclerosis found that birthplace outside the US and speaking a non-English language at home were each associated with a lower prevalence of hypertension.

For participants born outside the US, each 10-year increment of years in the US was associated with a higher prevalence of hypertension after adjustment for age, gender, and socioeconomic status.

Move beyond data collection at the individual level

Health disparities research must also take a social ecological perspective which views public health/ health promotion interventions as occurring at multiple levels and targeting individual, organizational and environmental-level factors.

However, current data collection identifies individual characteristics such as race, ethnicity, gender, and income.

Data collection should also look at community level variables such as perceptions of neighborhood cohesion, environmental exposures, neighborhood safety, and community support. These variable provide avenues for intervening at the community level.

Hypertension

A cross-sectional survey of approximately 2,000 older adults recruited from senior centers in NYC found that individuals who perceive higher social cohesion in their neighborhoods practice more comprehensive HTN management.

Neighborhood Social Cohesion Scale

People around here are willing to help their neighbors; This is a close-knit neighborhood; People in this neighborhood can be trusted; People in this neighborhood generally don't get along with each other; People in this neighborhood do not share the same values.

Link quantitative with qualitative data

Richard Kreuger defines a focus group as a “carefully planned discussion designed to obtain perceptions in a defined area of interest in a permissive, non-threatening environment.”

Link quantitative with qualitative data

- Gather information about a phenomenon of interest
- Generate a research hypothesis
- Identify potential for problem
- Understand perceptions and beliefs
- Generate impressions of an idea
- Understand barriers, challenges, facilitators to particular health behavior

Hypertension

In-depth individual patient interviews were conducted using a questionnaire format.

The following probe was used as an introduction:

“While doctors have special ways of understanding illness, you may have ideas which may be different from what doctors think. It will help us to help others with high blood pressure if we understand what high blood pressure means to you and how it has affected you.”

Hypertension

A major concept that emerged when patients described their experiences with hypertension was:

The etiology of hypertension:

“I believe high blood pressure is all emotional because I always had low blood pressure until a death in the family.”

“It is inherited, my mother was hypertensive and my dad is taking medication but so far no one has had a stroke.”

“Pork or salt on a regular raises blood pressure.”

Engage community stakeholder in data collection and dissemination process

In order to advance disparities research we must also address challenges:

- Recruitment
- Settings may not be conducive to recruitment
- Sustainability
- Trust

CBPR-Definition

NIH Definition:

The **process of scientific inquiry** is such that community members, persons affected by the health condition, disability or issue under study, or other key stakeholders in the community's health have the opportunity to be **full participants** in each phase of the work (conception - design - conduct - analysis - interpretation - conclusions - communication of results).

Community-based participatory research in data collection and dissemination

Enhancing the reliability and validity of
measurement instruments (particularly surveys)
through in-depth and honest feedback

Improving data collection through increased
response rates and decreased social desirability
response patterns

Increasing accurate and culturally sensitive
interpretation of findings

Ensure a diverse public health workforce

Health disparities research is an important process for identifying factors that underlie health disparities and inequities and for developing effective interventions.

A diverse public health workforce is needed in order to advance health disparities research and accelerate the development of effective and culturally responsive solutions.

There is a need for diverse researchers who can interact with and engage community members and understand the social and political climate in which they live.

Ensure a diverse public health workforce

Provide insight on non-traditional research settings

- Faith-based organizations

- Local vendors (barbershops)

Provide a more global perspective on the problem

- Global perspective on health

Deal with sensitive topics

- Sexual orientation

- Disability research

Key points

Broaden the concept of race

Move beyond individual level data

Link quantitative with qualitative data

Engage community partners and stakeholders in the data collection and dissemination

Ensure a diverse public health workforce