



Review

Challenges of health measurement in studies of health disparities



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ABSTRACT

Health disparities are increasingly studied in and across a growing array of societies. While novel contexts and comparisons are a promising development, this commentary highlights four challenges to finding appropriate and adequate health measures when making comparisons across groups within a society or across distinctive societies. These challenges affect the accuracy with which we characterize the degree of inequality, limiting possibilities for effectively targeting resources to improve health and reduce disparities. First, comparisons may be challenged by different distributions of disease and second, by variation in the availability and quality of vital events and census data often used to measure health. Third, the comparability of self-reported information about specific health conditions may vary across social groups or societies because of diagnosis bias or diagnosis avoidance. Fourth, self-reported overall health measures or measures of specific symptoms may not be comparable across groups if they use different reference groups or interpret questions or concepts differently. We explain specific issues that make up each type of challenge and show how they may lead to underestimates or inflation of estimated health disparities. We also discuss approaches that have been used to address them in prior research, note where further innovation is needed to solve lingering problems, and make recommendations for improving future research. Many of our examples are drawn from South Africa or the United States, societies characterized by substantial socioeconomic inequality across ethnic groups and wide disparities in many health outcomes, but the issues explored throughout apply to a wide variety of contexts and inquiries.

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1. Introduction

Interest in understanding the nature, extent, and causes of health disparities has expanded dramatically. Historically, many studies focused on North America and Europe, but increasingly, health disparities are studied within and across a wider array of societies. The growing diversity of contexts studied highlights the difficulty of finding appropriate and adequate measures of health when comparing across groups or societies. These challenges affect the accuracy with which we characterize the degree of inequality, limiting possibilities for effectively targeting resources to improve health and reduce disparities. This commentary highlights four common challenges: different distributions of disease, variation in the availability and quality of vital events and census data, variation in the comparability of self-reported information about specific health conditions due to diagnosis bias or avoidance, and challenges to comparability of self-reported overall health or symptoms measures.

Other challenges of measurement and comparability have been noted in health research, such as difficulties measuring race/ethnicity or socioeconomic status, or the mechanisms underlying disparities, such as discrimination or acculturation (Murray and Frenk, 2008; Stewart and Nápoles-Springer, 2003). We focus instead on the potential pitfalls of using commonly-available measures of health when comparing diverse groups. Earlier studies pursuing a variety of research aims with different comparison populations have noted some aspects of the challenges we discuss (see for example Bardage et al., 2005; Bramley et al., 2005; Lima-Costa et al., 2012; Murray and Frenk, 2008). Our contribution is a more focused commentary on the measurement of health in studies of health disparities, with clear recommendations for improving future research. We explain specific issues that make up each type of challenge and show how they may lead to underestimates or inflation of estimated health disparities. We also discuss approaches that have been used to address them in prior research and note where further innovation is needed to solve lingering problems.

We do not attempt an exhaustive literature review, but highlight these common challenges with clarifying exemplars, many drawn from South Africa or the United States, nations with substantial

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socioeconomic inequality across ethnic groups and wide disparities on many health outcomes. These societies clearly exemplify challenges faced by researchers who want to consider within-nation health disparities generated by politicized and/or racialized material resource divides. South Africa in particular is a context where socioeconomic and epidemiologic characteristics of wealthy and low-income societies coexist, making it particularly illustrative of challenges to both within- and across-society comparisons. South Africa and the U.S. also are cases that challenge social scientists to be mindful of the potential limitations of available measures of health that have been strongly influenced by systems of power unique to each society. Historically- and socially-embedded systems of inequality have shaped health policy and institutionalized practices that underlie both the disparities in health outcomes under study and the availability and quality of information about the health of differently-situated groups (Krieger, 2011). While these societies are particularly apt for illustration, we also use examples from other societies and comparisons. We draw mainly from sociology, demography and social epidemiology to frame our commentary, but the issues and examples explored throughout apply to a wide variety of contexts, perspectives, and inquiries.

2. Challenge one: differences in disease distributions across groups

2.1. Description of the problem and implications

Differences in the distribution of disease across societies and across groups within societies can make it difficult to find a common health metric on which to compare the affluent and the poor. Traditionally, diseases associated with poverty have included communicable diseases such as tuberculosis, malaria, and infectious diseases of childhood (DFID, 2000), and morbidity related to maternal, perinatal and nutritional problems. By contrast, chronic diseases, poor mental health, and harmful health-related behaviors dominate the disease profile of wealthier, more industrialized societies, complicating cross-national comparisons of health. Profiles of disease are in transition for any society; with macroeconomic development and diffusion of better infrastructure and medical care, they experience “epidemiologic transition.” In the classic rendering, a profile of disease dominated by communicable diseases and conditions associated with malnutrition or lack of basic infrastructure transitions to a profile dominated by chronic disease (Omran, 1971). However, more recent studies show that the disease profiles of lower-income societies are much more complicated than Omran’s account of universal, linear epidemiologic transition would suggest. While infectious disease and other “diseases of poverty” continue to be a burden, chronic diseases increasingly are taking a toll on low-income populations (World Health Organization 2005).

Moreover, epidemiologic transition has not proceeded at the same rate across groups within some societies. The burden of communicable diseases, malnutrition and maternal and perinatal problems may linger for poor groups even while chronic diseases also begin to affect them (Schneider et al., 2009; Steyn and Schneider, 2001). Uneven epidemiologic transition has been labeled “protracted–polarized transition” (Frenk et al., 1989) and characterizes some contemporary middle- and lower-income societies. Some have argued that uneven transition within societies is not random or temporary, but rather may reflect underlying systems of power in a given society and may thus persist if it remains beneficial to more advantaged groups (Krieger, 2011). Complicating the picture further, some societies have experienced “counter transitions” when emergent communicable diseases like HIV/AIDS reverse recent mortality and morbidity gains (Kahn et al., 2007),

and potentially widen gaps between advantaged and disadvantaged groups.

Difficulties comparing the health of societies or social groups with different profiles of disease burden could lead to over- or under-estimates of health disparity, depending on the specific health outcome considered. While chronic diseases may affect all groups to some degree, focusing on chronic conditions underestimates the total burden of disease for the poor, who also still cope with diseases of poverty. Moreover, earlier mortality of poorer individuals means that they are less likely to survive long enough to be at risk for some chronic diseases that manifest later in life (Willson et al., 2007), so their burden of chronic disease could appear artificially low. Conversely, a focus on diseases of poverty, such as diarrheal disease deaths, would show stark disparity between advantaged and disadvantaged groups but likely be unrepresentative of the overall level of health inequality because disparities for other health problems are narrower.

2.2. Strategies for addressing the problem

At a minimum, researchers should consider the suitability of a particular health indicator for comparison across groups or societies characterized by very different distributions of disease. As one solution to this challenge of comparability, overall mortality rates have been used to gauge the relative survival across societies or groups within societies, but do not capture considerable nuance in health status among survivors. Alternatively, researchers have compared across multiple indicators of morbidity and mortality, as does a study of disparities in mortality rates, life expectancy, coronary heart disease and diabetes prevalence, self-rated health, activity limitation and sedentariness that shows “...pervasive—albeit not invariable—patterns suggesting incremental income or education gradients for a range of important health indicators among both children and adults” in the U.S. (Braveman et al., 2010: S189). However, in some contexts data may not be available on such a wide range of reliable outcomes and even where they are available, results from a variety of indicators may not neatly or conclusively show consistent disparities (Braveman et al., 2010).

An alternative measure that attempts to summarize the relative health standing of societies with very different profiles of disease is the disability adjusted life year (DALY) (World Health Organization, 2009). Health economists created the DALY measure to quantify the global burden of disease (Murray et al., 2002). DALYs integrate years lost from premature mortality and from living with a disability to arrive at a summary measure of the health status of a population or group (Mont, 2007). This makes it useful for calculating and comparing burdens of disease that arise from a broad array of factors contributing to poor health (e.g., malnutrition, chronic diseases, substance use), and thus addressing the challenges of comparing societies or groups within societies that are at different stages of epidemiologic transition. Nonetheless, the DALY measure has been critiqued for being “blind” to contextual and socioeconomic factors that modify how an individual may experience morbidity, making it unclear whether a given condition should count as “disabling” in every context (Mont, 2007). For example, a health condition limiting the ability to carry heavy objects or work long hours in a standing position may restrict employment and financial well-being in an agriculturally-based economy or for some jobs in industrialized economies, and thus may justifiably represent disability. However, the same condition may not affect employability and access to resources in a more service-based economy or occupation, or where mobility aids are widely available. Others have critiqued DALY measures for being driven mainly by mortality rates, leading to underestimates of the burden of many tropical diseases of poverty that do not have high mortality rates

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