Life Course Indicator: Perceived Experiences of Racial Discrimination in Healthcare among Adults

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Perceived Experiences of Racial Discrimination in Health Care among Adults (LC-15)

Brief description: Percent of adults reporting racial discrimination in health care

Indicator category: Discrimination and Segregation

Indicator domain: Risk/Outcome

Numerator: Adults 18 and over reporting perceived racial discrimination in health care

Denominator: Total adults 18 and over

Potential modifiers: Race, ethnicity, age, SES, geographic location

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: Numerator: Include those who answered 1 (1=Worse than other races) and 4 (4=Worse than some races, better than others) to the question "Within the past 12 months, when seeking health care, do you feel your experiences were worse than, the same as, or better than for people of other races?"

Recommendation: if you want to construct a comparison group, we recommend grouping 2 (The same as other races) and 3 (Better than other races) together. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
As a life course indicator, the experience of racial discrimination in health care is critical to understanding the impact of racism across the lifespan and across generations, why disparities in health outcomes persist and what can be done to reverse these trends. For the purposes of this discussion, the phrases “perceived discrimination” and “experience of discrimination” will be treated as having the same meaning, which is to say that a person is reporting their lived experiences with discrimination; no self-report health survey is able to assess the intent of those inflicting the discrimination.

A key factor in exploring issues of discrimination is to use a clear definition of racism. Krieger defines racism as, "Institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict, by judgment and action, the lives of those against whom they discriminate" (Krieger 2003). This definition is useful because it calls out actions of the individual as well as the policies that contribute to system level institutionalized racism. A further examination of the levels of racism put forth by Jones describes three levels, which include the above-described institutionalized and personally mediated racism, and introduces a third level, internalized racism, which she defines as, “Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth” (Jones 2000). All three levels of racism contribute to poor health outcomes.

Hausmann et al used the 2004 BRFSS perceived discrimination data from seven states to study the impact on health outcomes for the three largest racial/ethnic groups in the United States (white, African American, and Hispanic); African Americans perceived discrimination three times more often than white Americans, and those who perceived discrimination were twice as likely to report poor health status compared with those who did not (Hausmann et al 2008).

Implications for equity
Racial disparities in health outcomes persist in many areas of health care in the United States and are well documented (Lewit et al 1995). Disparities remain even after controlling for access to health care, health insurance status, and socioeconomic status.

Experience of racism is negatively associated with mental well-being and physical health. The mental and physical effects of racism have been compared to responses similar to those seen resulting from trauma (Mendez et al 2012, Purnell et al 2012). Patients who perceive that they are receiving sub-standard care because of their race/ethnicity or other characteristics are less likely to continue seeking care at that facility or any other facility (Ertel et al 2012).

Racism in health care can occur at the physician-patient level and at the health care system level; components of system-level racism can be characterized as institutionalized racism. As outlined in the Institute of Medicine’s Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, racial and ethnic disparities are consistently present across a wide array of diseases, and the quality of health care services received varies by race and ethnicity, with African Americans and Hispanic/Latino Americans receiving poorer quality care than white Americans (Smedley 2009). Schulman et al found that the race and sex of the patient affected physician’s decisions about recommending cardiac catheterization even after adjusting for symptoms, clinical characteristics, and physician estimates of the probability of coronary disease; black females were least likely to be referred for cardiac catheterization compared with white males (Schulman et al 1999). This study, which used actors and controlled symptom scenarios, is supported by numerous epidemiologic studies of differences in treatment by race and sex (see list within references).

At least one factor that underlies the issue of discrimination in health care is what some call a legacy of racism in health care in the United States that has contributed to distrust in the health care system. The Tuskegee Syphilis Study, in which researchers from the government (the U.S. Public Health Service) withheld treatment from 400 black men with syphilis in Alabama, has been well described. Kennedy et al explore the historical context that contributes to distrust of the health care system, which includes experiences with slavery and segregation, feelings of being used as experimental guinea pigs, and belief of being treated differently from white patients (Kennedy et al 2007). Part of achieving equity is not just to provide equal access to health care, but to ensure that the access is equitable, meaning that it meets the needs of the person receiving it.
As proposed by Lu and Halfon (2003), if the persistent disparity in health outcomes is at least in part attributable to the impact of racism experienced by African Americans over generations, it is essential to monitor the experiences of discrimination when receiving health care for all adults, as well as women’s experiences of discrimination immediately before and during pregnancy and the experiences of racism reported by children. These three life course indicators provide the field of MCH and our partners with a powerful picture of the pervasive experience of racism, which is the first step in being able to design strategies to reverse racism and restore equity.

Public health impact
There is evidence to suggest that people who perceive more discrimination directed at themselves or other members of their racial/ethnic group are at greater risk for poor mental and physical health status (Ross et al. 2012, Hummer et al. 2010). Given the many studies that have documented the impact of differential treatment based on race that persists even when controlling for socioeconomic factors, a decrease in the experience of racism during health care interactions should lead to better health outcomes and a narrowing of health disparities on nearly every disease measure. Besides the long-term health outcome impacts, there are more immediate consequences of experiencing racism in health care, including dissatisfaction with the care received (Bird et al. 2004, Bankert et al. 2006), a decrease in the likelihood that a person will continue to seek care (Blanchard and Lurie 2004), and a decrease in receiving preventive health services (Trivedi and Ayanian 2006).

Leverage or realign resources
Many public health agencies have begun to implement principles of cultural competence. Betancourt et al defined a framework for cultural competence that addresses barriers to appropriate care at the organizational (leadership/workforce), structural (processes of care), and clinical (provider-patient encounter) levels (Betancourt et al. 2003). Experiences of racism occur at all levels of patient interaction, from receptionist to surgeon, and therefore work to assure culturally and linguistically appropriate care must extend beyond just the provider-patient relationship. All members of facility or practice staff should be included in training and implementation of cultural competence. Health care systems also can reach out to community services that work to eliminate racism and engage in new partnerships to develop programs for their institution.

Efforts to address the experiences of discrimination in health care and health research have utilized the concepts of “undoing racism” and community-based participatory research (CBPR) to begin the conversations around racism and begin to establish trust (PISAB 2013, Yonas et al. 2006). It should be noted that efforts to “un-do” racism and achieve equity require more than a short-term training and will include an authentic partnership between care providers, public health, and communities, including community leaders, to take strides toward improving experiences of care and equity in health care in the long-term.

Predict an individual’s health and wellness and/or that of their offspring
In their seminal paper on the life course perspective, Lu and Halfon posit that a portion of the racial and ethnic disparities in birth outcomes in the United States are attributable to the experience of discrimination on the basis of race (Lu and Halfon 2003). Further, there is evidence that race-based discrimination has impacts not only on a woman’s health and her birth outcomes, but also has impacts on birth outcomes across generations; studies focused primarily on birhweight have demonstrated that a mother who was born low birthweight is more likely to have a child born low birthweight, that the fetal environment (including the experience of stress by the mother during pregnancy) impacts the health of that adult, including coronary artery disease and hypertension risk, and that the impact of maternal weight on the weight of her offspring is independent of factors such as receipt of adequate prenatal care (Emmanuel 1986, Barker et al. 1993, Coutinho et al. 1997, Collins et al. 2003). Additionally, the concept of “weathering,” or early health deterioration among African American women, as introduced and explored by Geronimus (1992 and 1996), explicitly points to the cumulative nature of the impact of discrimination on the health of African American women; “This hypothesis suggests that maternal age be reexamined as being not only a developmental indicator but also a reflection of the ways in which social inequality, racial discrimination, or race bias in exposures to psychosocial or environmental hazards may, on a population level, affect differentially the health of black vs. white women who will become mothers, not only in absolute terms, but also interactively with each other and cumulatively as women age” (Geronimus 1996).
The experience of racism in health care is further compounded by experience of racism in other areas of life including residential segregation, which also is a life course indicator. According to Williams & Collins (2001), segregation is a main source of racial and ethnic differences in socioeconomic status (SES) by determining equitable access to education and employment opportunities, as well as environmental conditions that may impact health (e.g., health care access, healthy food or physical activity environments), all of which have great implications for racial and ethnic differences in health.

**Data Criteria**

**Data availability**
The Behavioral Risk Factor Surveillance System (BRFSS) is the world’s largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States annually since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. The Centers for Disease Control and Prevention (CDC) provides state and national level prevalence data on their website.

The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There also are CDC supported modules that address specific topics that states can use. States may develop additional questions to supplement the core questions. Modules used by states are noted on the CDC website.

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents. The 2012 data files were released in August 2013, indicating an approximate eight month delay in availability.

The proposed indicator comes from a BRFSS optional module (Reactions to Race) that is not asked by all states and is not included within the BRFSS on a routine basis. It is estimated that no more than a 1/3 of the states actually use this module in any given year, but the module is available for use by all states.

**Data quality**
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys, including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for more than 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.7 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that
weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

**Simplicity of indicator**

This indicator is relatively simple to calculate across geographic regions, once the data has been downloaded and made available. Because of the BRFSS sampling methods and it being a cross sectional telephone survey, the data must be weighted. Weights are included in the data sets. The indicator also is simple to explain to different audiences.

The question on BRFSS states “Within the past 12 months, when seeking health care, do you feel your experiences were worse than, the same as, or better than for people of other races?” For those who do not know about other people’s experiences when seeking health care, interviewers are to say: “This question is asking about your perceptions when seeking health care. It does not require specific knowledge about other people’s experiences.” Respondents who indicate 1 (1=Worse than other races) and 4 (4=Worse than some races, better than others will be included in the numerator of this indicator (Karlsen et al 2002).

**References**


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This publication was supported by a grant from the W.K. Kellogg Foundation. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the W.K. Kellogg Foundation.

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