

AMCHIP 2009

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Public Health Data to Address Disparities: Meeting the Challenge.

Handout on presentation by
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Legislation, Acts, Executive orders, regulations and other activities that provide a requirement/ obligation/precedence to collect data on ethnicity and race

- Office of Management and Budget (OMB) revised standards (1997)
- Health Insurance Portability and Accountability Act of 1996
- Initiative to Eliminate Racial and Ethnic Disparities in Health (1998)
- Consumer Bill of Rights and Responsibilities (1997)
- Benefits Improvement and Protection Act (2000)
- Report of U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equity* (1999)
- Executive Orders 13166 "Improving Access to Services for Persons with Limited English Proficiency" and 13125 "Improving the Quality of Life of Asian Americans and Pacific Islanders" (2000)
- Minority and Health Disparities Research and Education Act of 2000
- Department of Health and Human Services Title VI Regulations (1964)
- Department of Health and Human Services Inclusion Policy (1997)
- Healthy People 2010 (2000)
- Culturally and Linguistically Appropriate Services (2000)
- HHS Data Council Activities (ongoing)
- National Committee on Vital Health Statistics (ongoing)

When implementing Standardization for data collection the following need to be looked at Who provides the information

Information should always be provided by patients or their caretakers. It should never be done by observation alone.

When to collect

This depends on context of collection. For care providers it should take place upon admission or patient registration to ensure appropriate fields are completed when the patient begins treatment.

What racial and ethnic categories should be used

Start with the U.S. Census or the Office of Management and Budget (OMB) categories. More granular categories (to use for internal purposes) can be used, but these granular categories should have the capacity to be aggregated to the broader OMB categories for reporting purposes.

Where should data be stored

Data should be stored in a standard electronic format for easy data linking to other sources.

Patient Concerns

Concerns should be addressed up front and clearly, prior to obtaining information. Issues of power, culture, language, confidentiality and collection context needs to be clearly understood by the client.

Staff training

Employers need to provide ongoing training and evaluation to staff.

Methodology of data collection

The methods used in data collection needs to include the issues above but also the purpose of the data that is being collected. To be a meaningful unit of analysis the definition of the categories needs to be well understood. The categories need to reflect the target population of the geographical area as well as the need for data collection. The usefulness of the data for future needs and data linking will also play an important role as to how it will be standardized.

The specificity of race/ethnicity in data collection.

When looking at race/ethnicity we need to first look at what those categories mean. The terms race and ethnicity have been used interchangeably and may cause some confusion as to their context and use. The use of “race” was exclusively used as a category by the USA government up until the 1960’s when the civil rights movement created a catalyst for change. Until that time people were categorized as White or not (Allen, 1990). As a result of the OMB Directive 15, there are now 4 categories of race and one of ethnicity. There is still ambiguity in the meaning of these categories both by researchers and participants in research.

Race/ethnicity as a social construct is constantly evolving and how the term is used in research requires a defined process and should not be used as a proxy for a catchall of unmeasured or undefined variables (Winker, 2004). Differences of race/ethnicity based on a range of context, such as rural vs. urban, intra and inter race/ethnicity as well as the degree of enculturation and acculturation are some of the factors that need to be taken into account when looking at race/ethnicity (J. Escarce, Morales, & Rumbaut, 2006).

When collecting data on race/ethnicity there are three challenges that researchers come across when incorporating data into reports about race/ethnicity (Kaplan & Bennett, 2003; Winker, 2004). First, is to account for the limitations of race/ethnicity classifications. The use of the words race and ethnicity and their meaning has become complex and confusing and validity and reliability of race/ethnic classification is not to be assumed as many classifications are not self-disclosed but assigned by others and are open to bias of the classifier. Self-classification also has its problems as well and the context of data collection needs to be incorporated in both method and analysis. Labels of race/ethnicity do not have uniform definitions and a definition that reflects the context of the research needs to be applied when findings are disseminated (Winker, 2004).

Second there is a need to distinguish between race/ethnicity as a risk factor or as a risk marker. Being categorized as a race/ethnic group may be used as a risk marker of the prevalence of a health outcome because it is higher in your race/ethnic group. This is not the same as a risk factor as there may well be a diverse range of the condition within any categorized race/ethnic group.

Third, to avoid contributing to the racialism of society, writing about race/ethnicity requires that you do not perpetuate stigmatization and stereotyping by making assumptions about between group differences or portraying a message that implies or provides an unintentional message that stigmatizes or stereotypes that group (Bonham, Warshauer-Baker, & Collins, 2005). To be able to do this first there needs to be data collected that will provide knowledge about inter and intra race/ethnicity differences. When using ethnicity it needs to be defined and the reason given for its use. There also should be comparisons if using more than one data source. To avoid stigmatization or stereotypes, SES and social class need to be collected in data sets and then reported as being adjusted for or not.

When literature was reviewed by others as to the nature of “race” and ethnicity as a determinant of health almost all used “race” and or ethnicity as a determinate (a search of articles from 1921 to 2000) (Dressler, Oths, & Gravlee, 2005). There were however rarely any explicit definitions of race or ethnicity found. In one study of 121 health services articles none defined “race” and in another of 165 studies five defined “race” and ethnic categories but from the definitions failed to make clear the differences between the categories (Dressler et al., 2005). There was also a lack of why ethnicity was used as a variable in the studies or how individuals were assigned to what race/ethnic group.

Ethnicity, homogeneity, generalization and data collection

In a study to analyze ethnic disparities, demographics and health status within sub groups of ethnic minorities, it was found that almost all studies usually focused on Black vs. White or Black and Hispanic vs. White disparities (Flores, Bauchner, Feinstein, & Nguyen, 1999; Wu & Schimmele, 2005). The other race/ethnic groups are relegated to “insufficient sample size” to be able to reach any statistically reliable conclusions; this is an area that requires urgent attention in future data collection methodology. There is a real danger that the findings based on limited race/ethnic categories are then generalized to be representative of all race/ethnic minorities, which in turn may be used as an evidence base to generate policy or interventions.

Race/ethnicity is not homogeneous and there are differences between ethnic groups. This basic well known assumption appears to be forgotten when looking at data on race/ethnicity. Cancer within the Asian category is reported to have a lower incidence for American Asian than in others groups. When Asian intra-race differences were investigated the results reported were very different (McCracken et al., 2007). For example Vietnamese men have liver cancer and die from it at a rate seven times higher than that of White men. McCracken *et al* (2007) provided evidence that there are vast differences in cancer between the five ethnic Asian groups looked at and looking at all Asian ethnic groups together as a homogeneous group provides an inaccurate picture of the issues of cancer for this group.

The time for making cursory empirical observations between ethnic minorities viewed as a homogeneous group should be at an end. This will not be an easy task given the nature of how ethnicity is collected as a data point within national and state data collection methods. Other methods of data collection may need to be found to address this gap in data collection so that ethnicity can be a meaningful unit of analysis.

Bicultural and Multicultural world views in data collection

The US can be viewed from two culturally environments, Bicultural and Multicultural. There are First Nations Peoples with tribal identities, when dealing with data collection that involves First Nations Peoples as with all other things in relation to these peoples it needs to be from a bicultural perspective. All other peoples of the US are from a world view of a multicultural perspective. The bases of this world view is that the First Nations People are just that, first

nations and the remainder of the people are immigrants and make up a multicultural mix of people that interact with the first nations people. These two world views need to be reflected in data collection methods so that colonization is not perpetuated through data collection. This adds a dimension to data collection that may have in the past gone unnoticed but still needs to be explored.

Issues that may help in data collection

- State agencies respond to different federal requirements of race/ethnic data, this makes state data collection problematic a state standardization will help the health of the people of the State.
- Hospital records, birth and death records may not match so who provides the accurate data?
- Factors other than vital statistics need to be collected to provide factors that can be disaggregated such as; Emigration and generational issues of time in country as well as enculturation of dominant culture and the role of cultural diffusion, language and other SES factors.
- People that self disclose may refuse or are reluctant to provide this information. It may be asked in the wrong way or not asked at all. The respondent may not feel comfortable or are skeptical on the motive for asking the question.
- Multiracial responses although reported as being small (1-2%) the impact is significant.
- Small population data sets such as American Indian, Asian, and Pacific Island (small populations) need to be considered when looking at method design.
- Causal links between health and SES can be circular, poor health can lead to diminished availability to education and employment opportunities and lower incomes – lower incomes can lead to restricted access to health care and poor health. Race/ethnic populations are over represented in both these environment. To understand causality we need to disaggregate these factors from the data. To be able to accomplish this desegregation we need to have good data to start with. As this is being accomplished the appropriate use of race/ ethnic data is not to perpetuate health disparities but to discover the determinants that are inhibiting equity of health. At the same time if data on race/ethnicity is not helping health equality it is then hindering it – race/ethnicity data is not neutral.
- The cost of changing IT systems as well as modifying forms and procedures is expensive and there is motivation to only do it once - standardization will assist in this process in this era of increased motivation for e-health.
- Privacy and confidentiality requirements need to be incorporated in data collection and storage methodologies and based on existing systems this may be problematic.
- Legality of data collection – only CA,MD,NH,NJ have specific regulations or statutes to prohibit data collection in specific instance no state has blanket prohibitions (as at 2001) (National Health Law Program, 2001).
- Barriers to data linking are confidentiality and acquiring the data links across agencies each with their own data protection regulations
- There is three ways to collect data
 - Get new data
 - Live with limitations of existing data
 - Re code based on Surname or geocoding (this is only a best guess, and has limitations on usefulness)

An annotated bibliographic list is provided for further investigation

Annotated Bibliography: Data collection to eliminate health disparities.

The Lalonde report 1974 (Canadian minister of health) highlighted that factors other than medical contributed to reducing mortality, such as biology, environment, lifestyle – social determinants of health

Reason to look at inter and intra ethnic differences

(Kimbrow, Bzostek, Goldman, & Rodriguez, 2007)

When looking at education as a determinant there are differences between different ethnic groups as well as those with time in country. Those that are foreign born educational differences are more modest than those born in USA. Immigrants are more likely to be healthier than those that remain. Health practices based on social class may differ to groups of immigrants i.e. South American poor do not smoke or drink that is the domain of the wealthy

Important for society as a whole

(Syme, 2008)

Provides three reasons there is a need for a new approach to reduce racial and class inequalities.

1) Requirement for a focus on social determinants of health that are “up-stream”. 2) If we look at these fundamental societal factors we may not care enough to take action. 3) A conceptual model is required and funding is needed as well as a need to understand how important this impacts on society as a whole.

(Berk, Schur, & Feldman, 2007)

Development and trends in data collection at the federal level and interaction of private survey along with issues of funding for method development are discussed. The move to telephone survey, longer questions and lower response rate due to lack in confidence of government and confidentiality. There is duplication of collection of data. Foundations are seen as the catalysts of methodological development.

(Bilheimer & Sisk, 2008)

Data limitations continue to restrict efforts to identify ethnic health disparities and identify underlying causes. Collaboration between private and public stakeholders is the most promising practice given budget constraints by state and federal agencies. **PROBLEMS.** Problems of self identification and limits of the OMB categorization are present. Under sampling in national surveys so that no statistical analysis of “other”. Missing data from medical, administrative and insurance records. Insufficient state and local data. Lack of information on contributing factors. **Strategies to address data problems** Increase self reported ethnicity. Improve reliability of estimates by over sampling. Another process is data linking to create a more robust data set. Indirect estimation and modeling. The most cost effective way to obtain good data is to piggy back on existing survey.

(Herbert, Sisk, & Howell, 2008)

Definition of race and ethnic disparities lay on a continuum with little or no connection to overt discrimination but when a difference becomes a disparity is still a subjective call. Issues of power and inequality are factors of disparity. Definition of race and ethnicity are given. Factors and the rationale as to be included or not into measurement of health disparities are given. Good paper for arguing for a standardized definition of health disparity.

(Weinick, Caglia, Friedman, & Flaherty, 2007)

Mandated regulation to collect ethnic and racial information to provide data on health care and eliminate disparities of care in Massachusetts. They implemented three policies 1 the data is self identified, 2. Categories should reflect the Massachusetts ethnic population (there was 31 ethnic categories), 3. The categories should be able to roll up to meet OMB 15 directive. The question of Latino is an issue that needs addressing at each state level through pre test period (single vs. pre question order).

(Bierman, Lurie, Collins, & Eisenberg, 2002)

Health plans that have viable data collecting strategies can play a vital role in eliminating health disparities by using the data collected. Use of data within managed care programs can 1. Inform program development, planning and priority setting, 2. Target quality improvement, 3. Understand differences in improvement, 4. understand health needs of populations, 5. Resource cultural and linguistic appropriate interventions, 6. Evaluate and monitor effectiveness of interventions. Ethnicity data is collected in different ways and at differing times depending on the system. Data linking to other organizations makes it possible to obtain more robust data. Reliability is an issue due to the multiple methods of data collection. Geocoding is a possibility but centers more on socioeconomic factors based on geographical smaller areas and homogeneity of ethnicity. Multi source data sets can provide high confidence for white/black but low confidence for other ethnicity. BARRIERS to data collection, business will and the benefits perceived are still developing. Non- standardized data collection methods. Interpretation of ethnic data within context of SES, language, acculturation, health literacy, neighborhood characteristics. Perceived legal barriers. Privacy and confidentiality issues. Misuse of data. Timing of data collection. Public reporting and accountability. Cost. Needs are quality improvements are dependent on good data quality. Data collection requires categories that mirror state population and ability to collapse to OMB categories. Collection based on self identification and systems of confidentiality. Data that collects SES, language, acculturation, health literacy, neighborhood characteristics and other factors are required to investigate lower levels of analysis. Pilot projects to test systems including representatives of diverse target populations. Education of the public and other stakeholders.

(Kreuter & McClure, 2004)

Culture as a factor in enhancing the effectiveness of health communication programs. The variance of culture as it is used is explored. This document relates to systems of effective communication of health so to be inclusive of cultural factors.

(Derose, Schuster, Fielding, & Asch, 2002)

Theory concepts of public health framework, assessment, policy and assurance and how this is dealt with in local health districts.

(Braveman, 2006)

Looks at health disparities/inequality vs. health equity. Great article that goes deep into this argument. See p 180. Health disparities are about differences in health between groups of people that are advantaged socially and those that are not and are systematic, potentially avoidable differences in health. It is often assumed that elimination of health disparities is achieved in the

elimination of disparities in health care but the influences on health are found in the nonmedical determinants based on unequal opportunities in housing education employment. There is a provision for a system of measurement based on three indicators 1. A health determinant such as health care, living condition or policy 2. A social position such as ethnicity, gender, income and 3. Method of comparing the stratified groups such as a ratio. There is also a systematic approach to informing efforts to reduce the disparity gap. 1 chose a health indicator and categorize group into a social strata. 2. Calculate rates of health indicators in each social stratum. 3. Calculate rate ratio with a priori most advantaged group for each indicator. 4. Examine changes over time. 6. Conduct multivariate analysis in overall sample of those in stratum that are at most elevated risk and compare that with those that are at most advantaged to identify areas that require more investigation.

(Chen, Petitti, & Enger, 2004)

This study looked at geocoding of blocks based on 2000 census and compared to hospitalization records and birth certificates the geocoding by ethnicity did not match concluding that for a large sample of geocoding it was unable to predict ethnicity. Conflicting findings with 2 other studies but variances are discussed.

(Holup et al., 2007)

The practical application of OMB directive modified. There was confusion in its use and this was the case for Asian Hawaii pacific. Categories used to describe race/ethnicity need to be understood by the target population if it is not wrong generalization and analysis interpretation can be obtained. This paper tests this for Asian category and some particularly Pilipino may not identify as Asian (pacific Island, Spanish, white). As a method providing definitions when using minimum categories.

(Bennett, 2000)

The look at the descriptor “race” has been categorized over time and utilized in the collection of census data from 1790 – 2000. Although stated in the beginning of the document that race is socially constructed and is not a reference to biology, anthropology or genetics it is repeatedly reinforced as such by collecting census data base of blood quantum that is based on biological or genetics as in the one drop rule. This categorization was based largely on observation of the enumerator until 1960 when forms were posted out and self identification was used, those of mixed blood were categorized as the minority of that categorization. For the 1970 the self identification rule was used and all of the house hold was of the same race as the head of house unless the enumerator found out otherwise. In 1980 the OMB categorization was used and the inclusion of Hispanic most other were included as white and when multiple race were identified the mothers race was used or if mothers race not identified then the first category identified was used the term race was not used but was reintroduced in the 1990 census. In 1990 there were 14 separate response categories. 2000 census allowed for multiple categorizations and the OMB calcification of PI to be separated with Hawaiian from Asian. The censuses now has 15 categories that can fold back to the OMB 5 categories. In the 2000 census the issue of Hispanic as being self identified as a race and not an ethnicity has led to the ethnic question being asked first and race second.

(Baumeister, Marchi, Pearl, Williams, & Braveman, 2000)

The sensitivity of recorded birth race entry on birth certificates by hospital nurses and corresponding self identification of mothers in a follow interview for the state of California. The findings of Native American Alaskan Native were only 54% with the balance mainly recorded as white. This may be due to observational subjectivity of the hospital recording staff as opposed to requesting self identification from the hospital recording staff. All other ethnicities were high in sensitivity.

(Kwok & Yankaskas, 2001)

A study of validity of census data to determine race and education as SES indicators. Geocoding was conducted and were compared with self identification of ethnicity and education and were assessed against mammography registry for 39546 women in North Carolina. It was found that census data on race and education for SES were accurate predictors of white populations but not for ethnic minorities.

(James, 2001)

The argument for how not to and how to use the term race is put forward. The historical use of the term race in census collections. The use of race as independent, dependant and natural factor in statistical analysis is the best I have seen.

(Aspinall, 2001)

In response to the burgeoning interest in ethnic health issues and related published research, a number of recent contributors have attempted to clarify or systematize the usage of overarching terminology like 'ethnicity', 'race', 'culture', and 'racism', including the development of guidelines. However, the operational problems of how to collect ethnicity data in studies of the sociology of health and illness have not been satisfactorily addressed. This paper explores conceptual issues, notably, the meanings of ethnic identity and ethnic origin/ancestry; methodological approaches, including which dimensions to collect, multidimensional versus global measures, and exclusive groups versus optional ethnicity; and also practical issues such as method of assignment. The approach calls for a stronger development of the theoretical understandings of ethnicity and work on how best ethnicity should be conceptualized and measured in the different approaches to explaining ethnic inequalities in health.

(Hunt & Megyesi, 2007)

Many researchers are currently studying the distribution of genetic variations among diverse groups, with particular interest in explaining racial/ethnic health disparities. However, the use of racial/ethnic categories as variables in biological research is controversial. Just how racial/ethnic categories are conceptualized, operationalized, and interpreted is a key consideration in determining the legitimacy of their use, but has received little attention. We conducted semi-structured, open-ended interviews with 30 human genetics scientists from the US and Canada who use racial/ethnic variables in their research. They discussed the types of classifications they use, the criteria upon which they are based, and their methods for classifying individual samples and subjects. We found definitions of racial/ethnic variables were often lacking or unclear, the specific categories they used were inconsistent and context specific, and classification practices were often implicit and unexamined. We conclude that such conceptual and practical problems are inherent to routinely used racial/ethnic categories themselves, and that they lack sufficient rigor to be used as key variables in biological research. It is our position that it is unacceptable to persist in the constructing of scientific arguments based on these highly ambiguous variables.

(Mays, Ponce, Washington, & Cochran, 2003) DATA ISSUES

Emerging methods in the measurement of race and ethnicity have important implications for the field of public health. Traditionally, information on race and/or ethnicity has been integral to our understanding of the health issues affecting the U.S. population. We review some of the complexities created by new classification approaches made possible by the inclusion of multiple-race assessment in the U.S. Census and large health surveys. We discuss the importance of these classification decisions in understanding racial/ethnic health and health care access disparities. The trend toward increasing racial and ethnic diversity in the United States will put further pressure on the public health industry to develop consistent and useful approaches to racial/ethnic classifications. The need for distinct and clear definitions of race and ethnicity are needed for health. Examples are given in all areas and recommendations for solutions.

(Laws & Heckscher, 2002)

OBJECTIVE: Efforts are underway to standardize "racial" and "ethnic" identification in public health data systems under the Revised Minimum Standards for the Classification of Federal Data on Race and Ethnicity issued in 1997. This study analyzed the racial and ethnic constructs and labels used in public health data systems maintained by the six New England states in light of these standards. **METHODS:** The authors surveyed public health officials responsible for ongoing individual-level data systems and reviewed relevant documents. **RESULTS:** Information was obtained on 169 of 170 identified data systems. Ninety-one systems (54%) conformed to the federal standard in having separate "race" and "ethnicity" fields, yet many of these did not conform to the standard in other respects. Fifty-five systems had only a race field; of these, 20 included no identifiers corresponding to Hispanic and/or Latino ethnicity. Three systems used only an ethnicity field. The systems used various lists of racial and/or ethnic categories, and overlapping but not fully comparable labels. Few systems allowed for identification of ancestry groups not included in the revised federal guidelines but with large populations in New England, such as Brazilians. Some definitions and coding instructions seemed inconsistent with social and geographic reality. **CONCLUSIONS:** These public health data systems used inconsistent methods for classifying people by race and ethnicity. Standardization according to federal standards would improve comparability, but would limit options for defining and including some ethnic groups while forcing other groups to be aggregated in single race categories, perhaps inappropriately. Fundamental reconsideration of racial and ethnic categorization is called for. In short race and ethnicity data is collected as if they were the same in some systems and not in others with most data rolled back to meet OMB or NCHS directions.

(Kressin, Chang, Hendricks, & Kazis, 2003)

Data collected by VA is inconsistent with self disclosure of race/ethnicity worse for PI AS and worst of all for AIAN. The more contact between VA and client (visits to VA for medical action) the more accurate the records.

(Gomez, Kelsey, Glaser, Lee, & Sidney, 2004)

Variance of self reported and data collected in hospital in patient records. Sencitivity and predicitability high for black, white, slightly lower for Asian and verl low for Hispanic and AIAN.

(Griffith, Moy, Reischl, & Dayton, 2006)

The elimination of racial and ethnic health inequities has become a central focus of health education and the national health agenda. The documentation of an increasing gap in life expectancy and other health outcomes suggests the need for more effective strategies to eliminate health inequities, which can be informed by better monitoring and evaluation data. Although the sophistication and volume of health data available have increased dramatically in recent years, this article examines the quality of the current data collected to achieve the goal of eliminating racial and ethnic health inequities. This article explores several key aspects of data to inform addressing inequities including terminology, the role of data, and explanations of the problem. The authors conclude with recommendations for refining data collection to facilitate the elimination of racial and ethnic health inequities and suggest how the Society for Public Health Education can become a more central figure in our national efforts.

(D. Williams, Lavizzo-Mourey, & Warren, 1994)

Race is an unscientific, societally constructed taxonomy that is based on an ideology that views some human population groups as inherently superior to others on the basis of external physical characteristics or geographic origin. The concept of race is socially meaningful but of limited biological significance. Racial or ethnic variations in health status result primarily from variations among races in exposure or vulnerability to behavioral, psychosocial, material, and environmental risk factors and resources. Additional data that capture the specific factors that contribute to group differences in disease must be collected. However, reductions in racial disparities in health will ultimately require change in the larger societal institutions and structures that determine exposure to pathogenic conditions. More attention needs to be given to the ways that racism, in its multiple forms, affects health status. Socio-economic status is a central determinant of health status, overlaps the concept of race, but is not equivalent to race. Inadequate attention has been given to the range of variation in social, cultural, and health characteristics within and between racial or ethnic minority populations. There is a growing emphasis, both within and without the Federal Government, on the collection of racial or ethnic identifiers in health data systems, but noncoverage of the Asian and Pacific Islander population, Native Americans, and subgroups of the Hispanic population is still a major problem. However, for all racial or ethnic groups, we need not only more data but better data. We must be more active in directly measuring the health-related aspects of belonging to these social categories

(Nazroo, 2003)

Differences in health across ethnic groups have been documented in the United States and the United Kingdom. The extent to which socioeconomic inequalities underlie such differences remains contested, with many instead focusing on cultural or genetic explanations. In both the United States and the United Kingdom, data limitations have greatly hampered investigations of ethnic inequalities in health. Perhaps foremost of these is the inadequate measurement of ethnicity, but also important is the lack of good data on socioeconomic position, particularly data that address life-course issues. Other elements of social disadvantage, particularly experiences of racism, are also neglected. The author reviews existing evidence and presents new evidence to suggest that social and economic inequalities, underpinned by racism, are fundamental causes of ethnic inequalities in health.

(Probst, Moore, Glover, & Samuels, 2004)

Rural racial/ethnic minorities constitute a forgotten population. The limited research addressing rural Black, Hispanic, and American Indian/ Alaska Native populations suggests that disparities in health and in health care access found among rural racial/ ethnic minority populations are generally more severe than those among urban racial/ethnic minorities. We suggest that disparities must be understood as both collective and contextual phenomena. Rural racial/ ethnic minority disparities in part stem from the aggregation of disadvantaged individuals in rural areas. Disparities also emerge from a context of limited educational and economic opportunity. Linking public health planning to the education and economic development sectors will reduce racial/ ethnic minority disparities while increasing overall wellbeing in rural communities

(Ford & Kelly, 2005)

Objectives

Veterans Affairs (VA) patient populations are becoming increasingly diverse in race and ethnicity. The purpose of this paper is to (1) document the importance of using consistent standards of conceptualizing and categorizing race and ethnicity in health services research, (2) provide an overview of different methods currently used to assess race and ethnicity in health services research, and (3) suggest assessment methods that could be incorporated into health services research to ensure accurate assessment of disease prevalence and incidence, as well as accounts of appropriate health services use, in patients with different racial and ethnic backgrounds.

Design

A critical review of published literature was used.

Principal Findings

Race is a complex, multidimensional construct. For some individuals, institutionalized racism and internalized racism are intertwined in the effects of race on health outcomes and health services use. Ethnicity is most commonly used as a social-political construct and includes shared origin, shared language, and shared cultural traditions. Acculturation appears to affect the strength of the relationships among ethnicity, health outcomes, and health services use.

Conclusions

Improved and consistent methods of data collection need to be developed for use by VA researchers across the country. VA research sites with patients representing specific population groups could use a core set of demographic items in addition to expanded modules designed to assess the ethnic diversity within these population groups. Improved and consistent methods of data collection could result in the collection of higher-quality data, which could lead to the identification of race- and ethnic-specific health services needs. These investigations could in turn lead to the development of interventions designed to reduce or eliminate these disparities.

(Kawachi, Daniels, & Robinson, 2005)

In this essay we examine three competing causal interpretations of racial disparities in health. The first approach views race as a biologically meaningful category and racial disparities in health as reflecting inherited susceptibility to disease. The second approach treats race as a proxy for class and views socioeconomic stratification as the real culprit behind racial disparities. The third approach treats race as neither a biological category nor a proxy for class, but as a distinct construct, akin to caste. We point to historical, political, and ideological obstacles that have hindered the analysis of race and class as codeterminants of disparities in health. [ABSTRACT FROM AUTHOR]

(Nerenz, 2005)

Health care organizations-health plans, hospitals, community health centers, clinics, and group practices-can play an important role in the elimination of racial/ethnic disparities in health care. There are now a number of examples of organizations that have been successful in reducing or eliminating disparities, and a number of published examples of how quality improvement initiatives can improve care for members of targeted minority groups, thereby contributing to the elimination of disparities. [ABSTRACT FROM AUTHOR]

(Sheldon & Parker, 1992)

'Race' and 'ethnicity' are increasingly being used as variables in health research. However, studies have been mainly descriptive and have not been used to develop and evaluate strategies to improve health care. In part this reflects the poor analytical standards. The statuses of the concepts of 'race' and 'ethnicity' as research tools are rarely considered and there is poor consistency in terminology. This paper gives an overview of the research literature and raises questions about the validity of 'race' and 'ethnicity' as epidemiological variables. The tendency to collect routine ethnic data and include ethnic variables in an ad hoc and uncritical way in the United Kingdom and other countries may help transform minorities into mere statistical categories and produce data and findings which reinforce stereotypes. Multiculturalists ethnic health explanations also tend to displace more material explanations of health outcomes. It is concluded that more thought and care is needed before data are routinely categorized by ethnicity, or race or ethnicity are included as variables in research.

(D. Williams, 1996)

Looks at relationship of SES and race/ethnicity. Also methodological issues of assessing race. They include self-identification and observer identification discrepancies, changing racial classifications and identification, categorization of mixed race, census under count. Looks at how SES does not account completely for race and the need to include factors of racism, migration, acculturation and a more comprehensive assessment of SES.

(Bhopal & Donaldson, 1998)

Looks at the term white and that it is not a homogenous terms and provides a table showing the various terms used with recommendations of the use of each term.

(Sudano & Baker, 2006)

Pervasive health disparities continue to exist among racial/ethnic minority groups, but the factors related to these disparities have not been fully elucidated. We undertook this prospective cohort study to determine the independent contributions of socioeconomic status (SES), health behaviors, and health insurance in explaining racial/ethnic disparities in mortality and health declines. Our study period was 1992-1998, and our study population consists of a US nationally representative sample of 6286 non-Hispanic whites (W), 1391 non-Hispanic blacks (B), 405 Hispanics interviewed in English (H/E), and 318 Hispanics interviewed in Spanish (H/S), ages 51-61 in 1992 in the Health and Retirement Study. The main outcome measures were death; major decline in self-reported overall health (SROH); and combined outcome of death or major decline in SROH. Crude mortality rates over the 6-year study period for W, B, H/E and H/S were 5.8%, 10.6%, 5.8%, and 4.4%, respectively. Rates of major decline in SROH were 14.6%, 23.2%, 22.1% and 39.4%, for W, B, H/E and H/S, respectively. Higher mortality rates for B versus W were mostly explained by worse baseline health. For major decline in SROH, education, income, and net worth independently explained more of the disparities for all three

minority groups as compared to health behaviors and insurance, reducing the effect for B and H/E to non-significance, while leaving a significant elevated odds ratio for H/S. Without addressing the as-yet undetermined and pernicious effects of lower SES, public health initiatives that promote changing individual health behaviors and increasing rates of insurance coverage among blacks and Hispanics will not eliminate racial/ethnic health disparities.

(Cooper, 2002)

This paper examines inequalities in the self-reported health of men and women from white and minority ethnic groups in the UK using representative data from the Health Survey for England, 1993-1996. The results show substantially poorer health among all minority ethnic groups compared to whites of working-age. The absence of gender inequality in health among white adults contrasts with higher morbidity for many minority ethnic women compared to men in the same ethnic group. The analysis addresses whether socio-economic inequality is a potential explanation for this pattern of health inequality using measures of educational level, employment status, occupational social class and material deprivation. There are marked socio-economic differences according to gender and ethnic group: high morbidity is concentrated among adults who are most socio-economically disadvantaged, notably Pakistanis and Bangladeshis. Logistic regression analyses show that socio-economic inequality can account for a sizeable proportion of the health disadvantage experienced by minority ethnic men and women, but gender inequality in minority ethnic health remains after adjusting for socio-economic characteristics.

(Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2005)

Objectives. We describe a method to facilitate routine monitoring of socioeconomic health disparities in the United States. Methods. We analyzed geocoded public health surveillance data including events from birth to death (c. 1990) linked to 1990 census tract (CT) poverty data for Massachusetts and Rhode Island. Results. For virtually all outcomes, risk increased with CT poverty, and when we adjusted for CT poverty racial/ethnic disparities were substantially reduced. For half the outcomes, more than 50% of cases would not have occurred if population rates equaled those of persons in the least impoverished CTs. In the early 1990s, persons in the least impoverished CT were the only group meeting Healthy People 2000 objectives a decade ahead. Conclusions. Geocoding and use of the CT poverty measure permit routine monitoring of US socioeconomic inequalities in health, using a common and accessible metric. (Am J Public Health. 2005;95:312-323.). [ABSTRACT FROM AUTHOR]

(Aspinall, 2001)

In response to the burgeoning interest in ethnic health issues and related published research, a number of recent contributors have attempted to clarify or systematise the usage of overarching terminology like 'ethnicity', 'race', 'culture', and 'racism', including the development of guidelines. However, the operational problems of how to collect ethnicity data in studies of the sociology of health and illness have not been satisfactorily addressed. This paper explores conceptual issues, notably, the meanings of ethnic identity and ethnic origin/ancestry; methodological approaches, including which dimensions to collect, multidimensional versus global measures, and exclusive groups versus optional ethnicity; and also practical issues such as method of assignment. The approach calls for a stronger development of the theoretical understandings of ethnicity and work on how best ethnicity should be conceptualised and measured in the different approaches to explaining ethnic inequalities in health. [ABSTRACT FROM AUTHOR]

(Stehr-Green, Bettles, & Robertson, 2002)

Objectives. This study examined effects of racial/ethnic misclassification of American Indians and Alaskan natives on Washington State death certificates. Methods. Probabilistic record linkage were used to match the 1989-1997 state death files to the Northwest Tribal Registry. Results. We identified matches for 2819 decedents, including 414 (14.7%) who had been misclassified as non-American Indians and Alaskan natives on the death certificates. The likelihood of being correctly classified increased 3-fold for each higher level of American Indian and Alaskan native ancestry (odds ratio = 2.88; 95% confidence interval [CI] = 2.51, 3.30) and decreased by 6.9% per calendar year (95% CI = 2.0, 11.5). Conclusions. Systematic biases on death certificates in Washington State persist, Methods to reduce misclassification can improve data quality and enhance efforts to measure and reduce racial/ethnic health disparities. (Am J Public Health. 2002;92:443-444) [ABSTRACT FROM AUTHOR]

(Landrine & Klonoff, 2004)

Data on acculturation and ethnic-minority health indicate that acculturation has opposite effects on the same health behavior among different ethnic groups; opposite effects on different health behaviors within an ethnic group; opposite effects on the same health behavior for the women vs. the men of most ethnic groups; and no effect whatsoever on some health behaviors for some ethnic groups. This evidence is so incoherent that it is unintelligible, and hence it continues to be largely useless to health psychology and behavioral medicine. This paper presents a new theory of acculturation that renders these confusing data coherent by predicting such changes in minority health behavior a priori. By so doing, the operant model of acculturation has the potential to improve health promotion and disease prevention and thereby reduce ethnic health disparities. [ABSTRACT FROM AUTHOR]

(Massachusetts Health Policy Forum, 2001)

Identifications of challenges and solutions.

(Marshall, Walters, Scott, & Huang, 2007)

Review of 6 papers to form an intervention framework. Uses cultural leverage.

(Mechanic, 2005)

Socioeconomic status fundamentally affects most health and disease outcomes, but black Americans are doubly disadvantaged by low status, discrimination, and residential segregation. Improving health and removing disparities are essential goals, but some efforts that improve the health of blacks in important ways also increase black-white disparity ratios. People with more information, influence, resources, and social networks may be better able to take advantage of new technologies and scientific developments, initially increasing disparities. Better health and reduced mortality should be the key policy criteria, but these criteria should be linked with consideration of careful targeting to level the playing field and close disparities. [ABSTRACT FROM AUTHOR]

(Alexander, Lin, Sayla, & Wynia, 2008)

Objective. To develop a measure of physician engagement in addressing health care disparities. Data Sources/Study Design. Cross-sectional survey of a national sample of physicians assessing each hypothesized component of engagement (Awareness, Reflection/Empowerment, and Action [AREA]). Data Collection/Extraction Methods. Results examined using factorial analysis; predictive validity of final scale examined among highly engaged physicians. Principal Findings.

A nine-item scale derived from the AREA model has face validity, content validity, and applicability to a diverse group of physicians in measuring engagement. Partial correlations confirmed the mediating role of Reflection and/or Empowerment between Awareness and Action. Use of the scale among expert physicians suggests it reliably detects highly engaged physicians. Conclusions. A nine-item survey can measure physician engagement in addressing health care disparities.

(Cegala & Post, 2006)

Several factors affect observed racial/ethnic health disparities in the United States. Among them are features of provider-patient communication. In Study 1, the literature in patient communication skills training is reviewed to determine the extent to which researchers have reported comparative effects of interventions designed to enhance patients' communication skills and participation in medical interviews. Of the 27 studies reported, only 1 conducted a comparative analysis. In Study 2, a post hoc analysis of available communication skills training data sets is conducted to explore comparative intervention effectiveness. Similar to the results of the single report found in Study 1, the communication intervention was more effective with White than with non-White patients. These results are discussed with respect to implications for addressing racial/ethnic health disparities. [ABSTRACT FROM AUTHOR

(Waidmann & Rajan, 2000)

Health disparities among racial and ethnic groups have a long history and continue to exist in the United States. The U.S. government has established as a goal for the year 2010 the elimination of racial/ethnic health differences in six areas. This article examines disparities in one of those areas: access to high-quality health care. Several measures of access to and use of health care services are studied both nationally and in 13 diverse states. The authors find that both the magnitude of racial and ethnic disparity and the reasons behind it depend significantly on the state, the ethnic group, and the type of outcome measure being studied. Such information can be valuable for state and national policy makers in targeting resources and in designing effective strategies for the elimination of racial and ethnic disparities.

(Gibbs, Nsiah-Jefferson, McHugh, Trivedi, & Prothrow-Stith, 2006)

Eliminating racial and ethnic disparities in health status and health care, a major focus of Healthy People 2010, remains on the national agenda and among the priorities for the administration of President George W. Bush. Even though the elimination of racial and ethnic health disparities challenges the whole nation, individual states are on the front line of many initiatives and are often the focus of important policy efforts. In addition, it is important to focus on states because they are already responsible for much of the health and public health infrastructure, and several states have developed initiatives dating back to the release of Margaret Heckler's report on the gaps in health outcomes by race in 1985. This article makes the case for an outcome-oriented approach and provides a summary of lessons learned based upon preliminary investigations into constructing and applying two indices, the disparity reduction profile to measure effort and the disparity index to measure outcomes.

(Mays, Cochran, & Barnes, 2007)

Persistent and vexing health disadvantages accrue to African Americans despite decades of work to erase the effects of race discrimination in this country. Participating in these efforts, psychologists and other social scientists have hypothesized that African Americans' continuing experiences with racism and discrimination may lie at the root of the many well-documented

race-based physical health disparities that affect this population. With newly emerging methodologies in both measurement of contextual factors and functional neuroscience, an opportunity now exists to cleave together a comprehensive understanding of the ways in which discrimination has harmful effects on health. In this article, we review emerging work that locates the cause of race-based health disparities in the external effects of the contextual social space on the internal world of brain functioning and physiologic response. These approaches reflect the growing interdisciplinary nature of psychology in general, and the field of race relations in particular.

(D. R. Williams & Jackson, 2005)

Racial disparities in mortality over time reflect divergent pathways to the current large racial disparities in health. The residential concentration of African Americans is high and distinctive, and the related inequities in neighborhood environments, socio-economic circumstances, and medical care are important factors in initiating and maintaining racial disparities in health. Efforts are needed to identify and maximize health-enhancing resources that may reduce some of the negative effects of psychosocial factors on health. Health and health disparities are embedded in larger historical, geographic, sociocultural, economic, and political contexts. Changes in a broad range of public policies are likely to be central to effectively addressing racial disparities. [ABSTRACT FROM AUTHOR]

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