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Racially Segregated Health Data-- Its Validity, Implications, and Use By Health Care Providers

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Racially Segregated Health Data--
Its Validity, Implications, and Use By Health Care Providers
Dawn D. Shears
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Running Head: Racially Segregated Health Data

Table of Contents

Introduction	3
Review of the Literature	4
Methods	14
Findings	14
Table 1	15
Conclusion	17
List of Works Cited	20
Appendixes	23

Racially Segregated Health Data--

Its Validity, Implications, and Use By Health Care Providers

Introduction

The purpose of this paper is to gain a deeper understanding of the meaning of race as a variable related to health; I will do this chiefly by asking questions rather than answering them. My first exposure to this issue came in the form of an intake questionnaire at a family doctor's office. Among all of the demographic information I was asked to give was race; I was required to choose between the ever-present categories of "white, black, Hispanic, Asian pacific islander" and "other," in order to describe myself. I couldn't help but ponder the importance of this information and what role it played in my medical care. I was curious whether this method of categorization could render more potential harm than good by instantly labeling each patient with "race," which, for many, may be stigmatizing. As studies have concluded that racial stereotypes can affect health care providers' perceptions of patients and the quality of care given, I wonder: Why do we segregate our health data this way? What benefits are expected? What are the detriments? What are the origins behind this use of health related data? Could it be time to re-evaluate our thinking on this topic? These are but a few of the questions which prompted me to explore this issue in depth.

Review of the Literature

When exploring the issue of race-segregated health data, it is imperative that we consider the collection methods used by data sources such as the U.S. Census Bureau and the National Center for Health Statistics because these agencies provide the backbone of statistical data for many public health studies. There is, in fact, much controversy over the lack of consistency in the way these agencies have collected their racial data over the years. For example, "persons who were Black, American Indian, Chinese or Japanese were not included as separate groups until the various censuses of 1850 to 1870" (Lacey and Nandy, 1990, p. 25). Persons of mixed parentage, starting in 1980, were asked to use the race of their mother to identify themselves. This differed entirely from the method used in 1970 in which the race of the same person's father was used. Individuals who did not classify themselves as fitting one of the given race categories but who wrote in *other, Cuban, Puerto Rican, Mexican or Dominican* were counted as "white." The Asian and Pacific Islander category was synthesized in 1980 to include persons who were Chinese, Filipino, Japanese, Asian Indian or others from similar geographic areas. In the previous censuses, Asian Indians were classified as white.

A related issue, the census undercount of black males,

dates back to the 1870 census and is still a considerable problem. Currently, the undercount of African American men between the ages of 35 to 54 is estimated to be between 16 and 19 percent. As David R. Williams notes in "The Concept of Race and Health Status in America," "Mathematically, any rate that uses an undercounted denominator is increased in exact proportion to the undercount of the population in the denominator" (Williams, Mourey, & Warren, 1994, p. 28).

The National Notifiable Diseases Surveillance System (NNDSS) of the Centers for Disease Control is another data source for public health statistics in the United States. Like the U.S. Census Bureau, the methods the NNDSS uses for the collection of race-classified health data contain many inconsistencies and its data have been labeled "incomplete" with wide variances existing from state to state. Morbidity rates provided by the NNDSS are based upon data from only a few states and those states often use different methods and coding in their reports, which may affect comparisons of race data overall. The methods of reporting race used by the NNDSS may also differ from the methods used by the Census Bureau which creates problems with consistency when comparing data from these agencies (Buehler, Stroup, Klaucke, & Berkelman, 1989). Needless to say, it is understandable why one of the national health objectives earmarked for the year 2000 is to "develop and implement a

national process to identify important data needs for disease prevention and health promotion, *including data for racial/ethnic minorities* [italics added], and to establish mechanisms to meet these needs" (Office of Disease Prevention and Health Promotion, 1990, objective 22.4). On a state level, current statistics from the Illinois Department of Public Health do not always use extensive classifications for race. In some instances the divisions are "white" and "nonwhite" (Lacey). Other agencies tend to use "white," "black," and "other" (Wilson, 1993). This "other" category, used to designate persons of an unlisted race or persons of mixed parentage, is experiencing a huge increase in membership. The increase in interracial marriages and diversity is not only rendering older racial categories obsolete, this phenomenon is also bringing into question the practice of racial categorization itself (Sandor, 1994).

Another way in which inconsistencies are introduced into the process of collecting race-classified health data is from errors made during the reporting process itself. As illustrated earlier, changes in the way the categories for race are delineated over time can prove confusing, and this is no less true with regard to self-report as a method for determining race. This is especially relevant when classifying persons with distinctly different races in their

parentage. What happens when this information is being collected by an observer-reporter from the Census Bureau or other data collection agency? What are the criteria which are used to determine whether a person is white, black, or other? Too many times this decision is made without clear guidelines, as in the case of a physician or midwife designating race on a birth certificate (Davis, 1991). This can result not only in discrepancies between self-identified race and the race observed by the reporter but also in variations among the classifications different agencies use for the same person's race (Williams).

With the difficulties of obtaining consistency in making racial distinctions in health data set aside, why do we segregate health data according to race in the first place? Although this has been a time-honored tradition in medicine and public health, is it time to question the thinking behind treatment of racially classified health data as a standard? The roots of this tradition are lodged in the belief that vast genetic differences occur between different races. The theory for racial differences in health is based on a genetic model which was conceived in the late 18th century. This genetic model asserted that race was a "valid biological category, that the genes that determine race are linked to those that determine health, and that the health of a population is largely determined by

the biological constitution of the population" (Williams, 1994, p.3). We now know that although the concept of race may be socially meaningful, it has limited biological significance. There is "more genetic variation within races than between them" (Williams, p.3). We are unique in this country in the way that we define and describe race and assign to it different characteristics. In many ways, our methods of dividing our health statistics into categories of race, or white and nonwhite classifications, seem to be simply a reflection of this country's heritage of racial segregation. For some time, scholars have feared that in the process of segregating health statistics on the basis of race, we are also fueling false beliefs about behavior of those who are not white within both the health community and society in general (Terris, 1973). One example which seems to support these fears is what appears to be usage of a special rule which has been applied in the U.S. As F. James Davis points out in his book, Who is Black?: One Nation's Definition, "No other ethnic population in the nation, including those with visibly non-caucasoid features, is defined and counted according to a one-drop rule" (p. 12). The "American institution known informally as 'the one-drop-rule' . . . defines as black a person with as little as a single drop of black blood" (Wright, 1994, p.48). Behind the one-drop-rule was the belief that each race had a

separate blood type which was associated with a set of physical traits and social behaviors. One explanation for the existence of the one-drop-rule is that it was implemented primarily to create as many slaves as possible (Wright). A less formalized explanation can be derived from the possibility that the stigma of blackness was so powerful that any amount of it was sufficient to endow the entire stigma.

If we discontinued our segregation of medical data on the basis of race, what determinant of risk do we propose to use instead? Two determinants which have proven far more important epidemiologically than race are occupation and religion. In years past, Britain conducted a decennial analysis of occupational mortality which provided valuable information for identifying high-risk populations. "Most of our knowledge of differential mortality by occupation and social class has been obtained from this series of studies;" the U.S. has only undertaken a comparable set of studies once, in 1950 (Terris, p. 479). These studies provided valuable information for the identification of populations at high risk for certain diseases. Unfortunately, many epidemiologists are not familiar with the studies (Terris). "Religion has proved to be a valuable marker for epidemiological purposes. This is because certain religions are associated with specific practices with regard to

alcohol, tobacco and so forth. Considerable light has been cast on the epidemiology of cancer of the lung, esophagus and other sites as the result of studies comparing the incidence of these diseases in different religious groups. Yet no one would dare to demand that all mortality statistics be classified by religion in the interest of epidemiology and disease control . . . but if not by religion, why then by color (Terris, p. 479)?

Socioeconomic status (SES) has also been explored as a possible alternative to the classification of race. There are problems, though, in how we go about defining SES. Should we use geographic locale, which accounts for economic variation, income level, assets, occupation, or level of education to define SES? Further complicating the use of SES is the effect which racism has in determining a person's socioeconomic situation. Quality of education, amount of wages received and purchasing power are only a few of the related factors which are affected by race. More directly, racism can determine the quantity and quality of medical care which an individual receives. By and large, we have little awareness of all "the mechanisms and processes by which racial discrimination may affect health" (Williams, 1994, p. 7).

Given the complexities of classifying race for health data and the related discrepancies which have rendered the

resulting data all but useless, it is obvious that if we are to continue to use the classification of race, some improvements must be made to create consistency. One solution which has been suggested for this statistical dilemma is the use of a "multiracial" category in the year 2000 Census. Basically, the multiracial category is aimed, not at all persons of mixed ancestry, but specifically at persons who have parents who are recognized as being from different races (Wright). While it appears that the adoption of a multiracial category would solve some problems in classifying persons who identify with more than one race, there are those who submit that more problems could be created than will be solved. For example, the increase in the proposed multiracial category would create a resulting decrease in the race categories from which these persons would be withdrawn. This resulting decrease would affect funding of certain programs which benefit minorities. This is why some experts are concerned that the establishment of a multiracial category could undermine the advancement of "nonwhites" in our society (Wright). Furthermore, this idea seems to be, in its simplest form, only a modernization of the term mulatto.

One concern about the use of race-categorized health data is the role it may play in the perpetuation of racial stereotypes on the part of health care providers and the

resulting lapses in health care quality that could result. In a study of medical students and their stereotypes of patients, it was concluded "that factors such as social class, economic background, [and] ethnicity . . . do indeed affect clinical decision-making. The physician's reactions to these nonbiomedical variables often are not based on objective data but rather result from a life-long conditioning in which stereotypes have been unconsciously integrated into the physician's beliefs" (Johnson & Kurtz, 1989, p. 728). Specific examples of how racial stereotypes may affect physician's preventive treatment of patients was the subject of another study by Donald Gemson, M.D., who found that physicians whose patients included 50 percent or more blacks and Hispanics were significantly less likely to recommend mammography or influenza vaccine for patients 65 years or older (1988). These disparities in health care are further complicated by the fact that fewer African Americans and Hispanics have health insurance or a regular family practitioner (Williams).

Studies have been conducted to determine whether there are significant differences between medical treatment of white and minority patients. One of these, a study on revascularization procedures performed after coronary angiopathy, determined that "The adjusted odds of receiving a revascularization procedure after coronary angiography

were 78% higher for whites than blacks" (Ayanian, Udvarhelyi, Gatsonis, Pashos, & Epstein, 1993, p. 2642) and that "Physicians were less likely to recommend CABG surgery to blacks than whites . . . suggesting physicians were more aggressive in their therapeutic approach for white patients" (Ayanian, p. 2645). The same study concluded that the racial differences in administering this procedure were not a reflection of any impaired access to cardiologists or hospitals which perform the procedure but was potentially a result of "racial bias at the hospitals performing angiography" (Ayanian, p. 2642). Racial disparities in medical care have also been noted in patients receiving drug therapy for HIV infection and, perhaps more dramatically, for patients on waiting lists for renal transplants. In the case of the latter, one study published in the September 15, 1993 issue of The Journal of the American Medical Association concluded that "despite their constituting 31% of patients on waiting lists, blacks received only 22% of cadaveric kidney transplants in 1990, with a median waiting time of 13.9 months vs 7.6 months in whites" (Gaston, Ayres Dooley, & Diethelm, 1993, p. 1352). Other studies have shown that racial disparities exist in a broad spectrum of medical treatment including analgesia for long-bone fractures, treatment of alcoholism, and rehabilitation after a mastectomy (Moore, Stanton, Gopalan, & Chaisson, 1994).

After this exploration of the literature, I wanted to gain some actual data on the use of racially categorized health data and the attitudes of health professionals toward using this data. This data gathering took the form of an exploratory pilot study of a non-random sample of convenience in Jackson County, Illinois.

Methods

Using some principles of qualitative research (Wylde, 1994), I constructed an instrument which consisted of six open-ended questions regarding racially categorized health data [see appendix A for complete instrument]. After the instrument was reviewed by my advisor, I obtained approval for the research from the Carbondale Committee for R.I.H.S. The instrument was then mailed to fifteen health care providers in a range of disciplines from physical therapy to osteopathy. Nurses were included in the sample as well as physician's assistants, and physicians. By the end of a ten day period, I had received eight responses or slightly more than 50 percent.

Findings

Responses to the questions varied greatly although certain patterns of response were noted. Almost half the respondents stated that they *do not* utilize race-classified health data [see table 1, question 1], although one of these respondents stated that he/she sometimes uses this data to

diagnose/treat patients [see table 1, question 2]. All but one respondent reported that they ask patients to identify their race [table 1, question 5]. *More than half* of the sample felt that using racially categorized health data could cause problems, either directly or indirectly [table 1, question 4], but all except one respondent (who had no opinion on the question) felt that medical/health data should continue to be classified by race [table 1, question 6].

Quantitative Data From Items on Questionnaire

Instrument Item Number:	Question 1		Question 2		Question 3		Question 4		Question 5		Question 6	
	use	no	yes	no	are	none	yes	no	yes	no	yes	no
Positive or Negative:												
Responses:	4	4	5	3	6	2	5	3	7	1	7	0

Table 1

Since the questions used in the instrument were constructed in an open-ended format, the responses which were generated varied in both content and length. Some of the health care providers expressed concerns over the potential problems which the use of racially categorized health data could cause. One respondent stated that, "potentially [there could be problems] if [the] health care provider looks at the client's race and then makes the

diagnosis solely on race, rather than doing a full medical exam . . . " and that "OB/GYN literature state Afro American females of childbearing age who present with abdominal pain are at an increased incidence for PID" when in fact "Afro American females of child bearing age are at the same incidence for endometriosis/appendicitis and therefore should receive full evaluation." Another respondent was concerned because "some patients become suspect of the integrity of health care providers, wondering why the questions regarding race are asked . . . this cannot help the patient-provider relationship." In contrast to the last comment, there was another comment by a different respondent who uses racially classified health data to "identify . . . health problems like STD's and HIV." One respondent, who does not use this type of data, noted that if he/she used data classified by race he/she would "probably get criticized as racist." Among the respondents who stated that they do ask patients to identify their race, most noted that they did so because the government agencies that were funding their programs required the collection of this information.

Almost half of the respondents expressed at least some doubt over the usefulness of racially categorized health data. Comments ranged from concern that this information "may be stigmatizing to patients" to stronger opinions on

this matter: "After 21 years in this business, I am still trying to understand the necessity [of using this type of data]. If there is honest justification that proves statistics are used to educate those cultural groups at risk for disease and . . . the statistics are not used punitively, then continued gathering of these statistics is wise. But more explanation needs to be provided regarding why we ask these questions."

Conclusion

Even after my brief exploration of the use of race as a variable related to health, it is apparent that this is an extremely complex issue. Although I found answers to some of my questions, I have found that there are yet a multitude of other questions left unanswered: Is racially segregated health data beneficial? Could this method of categorization harm patients by perpetuating racial bias among health professionals? If we discontinue the use of racially segregated health data, what variable do we use instead?

After this investigation I am moved to make certain suggestions for the future. First, we need to explore possible alternatives to using race as a determinant of health risk. By focusing on race we may be overlooking other factors which could prove much more useful for epidemiological purposes. Second, if we continue to use race as a determinant, efforts need to be made to develop

consistent data collection methods. This would mean a more thorough explication of race and ethnicity and the specific health-related aspects of belonging to a racial or ethnic minority group. Third, strides need to be made in the education of health professionals. Students need to become more aware of their own ingrained stereotypes and how these views can affect their clinical assessment of patients.

Because the use of race categorized health data has been the standard for many years, there is much resistance to exploration of an alternate means of assessing health risk. It is important to remember that many great breakthroughs in science and medicine would not have been made if the status quo had not been questioned. There are times when we as health professionals need to perform a "reality check" by looking beyond the accepted standards to seek other, more effective methods of serving the public's health needs. David Williams states in "The Concept of Race and Health Status in America" that, "the Tuskegee Syphilis Study illustrates how the uncritical acceptance of normative beliefs about race can lead to the development of research hypotheses, and the initiation of research projects, that the researchers themselves would rule out under normal circumstances" (p. 3). Although this illustration is extreme, it drives home the point that we need to examine more critically the norms and standards that are used in

collecting health data. I personally agree that the time has come for "a courageous group of persons who are willing to exercise leadership and to chart a new agenda for research on racial or ethnic variations in health status" (Williams, p. 40).

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November 21, 1994

(Address)

Dear (Name):

My name is Dawn Shears, I am an undergraduate in Community Health Education at Southern Illinois University at Carbondale. As part of the criteria for graduating within the University's Honors Program, I am required to prepare a brief thesis paper. For one of the research components of my thesis entitled: Racially Segregated Health Data--Validity, Implications, and Use By Health Care Providers, I have selected you and 19 other health care providers in Jackson County and I am asking that all respond to a series of questions about their use of race-classified health data. You and the other health care providers were chosen non-randomly to represent what I personally feel is a wide spectrum of health disciplines.

Attached you will find a number of open-ended questions on this subject. Please respond to these questions in writing and return them in the enclosed self addressed, stamped envelope no later than Friday, December 2, 1994. Completing this brief questionnaire should take no more than 10 minutes of your time. Your response to these questions is strictly voluntary and your name will not be published or used in any way.

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, Southern Illinois University, Carbondale, IL 62901-4709. Phone: (618) 453-4543. If you have any questions about the questionnaire or the nature of my research project, please feel free to contact me at 457-7326 or 453-7789. You may also contact the professor who is advising me on this project, Dr. Ella P. Lacey, at Southern Illinois University, School of Medicine, Behavioral and Social Science, 1002 W. Whitney, Carbondale, IL 62901. Phone: (618) 453-1856.

Thank you for your time and cooperation!

Sincerely,

Dawn Shears

1. What types of medical/health data, classified according to race, do you utilize?
2. Is race-classified data useful for your diagnosis/treatment of patients?
3. What do you perceive are the benefits of using race-classified medical/health data?
4. Do you feel that there are any problems caused, directly or indirectly, from using data which are classified by race?
5. In your own practice, do you/does your office ask patients to identify their race?
If so, how is this information used?
6. Do you think that medical/health data should continue to be classified by race? Why or why not?

SIUC HSC FORM A

REQUEST FOR APPROVAL OF RESEARCH ACTIVITIES INVOLVING HUMAN SUBJECTS

This approval is valid for one (1) year from the approval date. Researchers must request a renewal to continue the research after that date. This approval form must be included in all Master's theses/research papers and Doctoral dissertations involving human subjects to be submitted to the Graduate School.

PROJECT TITLE: Racially Segregated Health Data--Its Validity, Implications, and Use By Health Care Providers

CERTIFICATION STATEMENT:

In making this application, I(we) certify that I(we) have read and understand the University's policies and procedures governing research activities involving human subjects, and that I(we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) accept responsibility for the research described, including work by students under my(our) direction, (2) obtain written approval from the Human Subjects Committee of any changes from the originally approved protocol BEFORE making those changes, (3) retain signed informed consent forms, in a secure location separate from the data, for at least three years after the completion of the research, and (4) report immediately all adverse effects of the study on the subjects to the Chairperson of the Human Subjects Committee, Carbondale, Illinois, (618) 453-4543, and to the Director of the Office of Research Development and Administration, Southern Illinois University at Carbondale, (618) 453-4531.

Dawn Dee Shears

Dawn Dee Shears

10-25-94

RESEARCHER(S) or PROJECT DIRECTORS

DATE

Please print or type out name below signature

Dr. Ella P. Lacey

Ella P. Lacey

10-25-94

RESEARCHER'S ADVISOR (required for all student projects)

DATE

Please print or type out name below signature

The request submitted by the above researcher(s) was approved by the SIUC Human Subjects Committee.

Robert C. Roache

11/16/94

CHAIRPERSON, SOUTHERN ILLINOIS UNIVERSITY HUMAN SUBJECTS COMMITTEE

DATE