COMMENTARY
DISPARITIES IN DATA FOR AMERICAN INDIANS AND ALASKA NATIVES

Dorothy A. Rhoades, M.D., M.P.H.

Accurate assessment of health disparities across populations requires methods that minimize biases in differences in health characteristics and outcomes. National summaries of disparities among racial and ethnic groups in the United States depend on large, representative, uniform data collection efforts. As emphasized by the Institute of Medicine, standardized data collection is critically important to understand and eliminate racial disparities (Institute of Medicine, 2003).

American Indians and Alaska Natives (AI/ANs) have significant and well-documented disparities in health status compared to the general United States population. Less well documented are disparities in health care for AI/ANs. Although much attention in recent years has focused on disparities in health care in the United States, AI/ANs are often not included in such studies. The National Healthcare Disparities Report is perhaps the most important source of information examining disparities in health care for the U.S. (Agency for Healthcare Research and Quality, 2005). However, Moy and others previously found that the data and measures of quality chosen for use in the National Healthcare Disparities Report, ironically, had limited ability to address racial disparities (Moy, Arispe, Holmes, & Andrews, 2005).

In this issue of *American Indian and Alaska Native Mental Health Research: The Journal of the National Center* Moy and others focus specifically on the gaps in data for assessing health care disparities for AI/ANs in the National Healthcare Disparities Report (Moy, Smith, Johansson, & Andrews, 2006). The authors quantify deficiencies in national health care data among AI/ANs, revealing that less than half the measures used in the report to assess disparities in health care quality or access can be used for AI/ANs populations. AI/ANs not only experience disparities in health, they also experience disparities in data.

Few reports exist on the disparities of national health data for AI/ANs. One found that older AI/ANs are markedly underrepresented in national datasets. Of 190 large or national health data sets for older age groups, only 13% contained 100 or more AI/ANs aged 65 or older

(Rhoades, 2006). National organizations have also recognized the underrepresentation of AI/ANs. The National Committee on Vital and Health Statistics, for example, concluded that data collection on AI/AN populations is "seriously inadequate" and has called for increased efforts to improve AI/AN information in national datasets (National Committee on Vital and Health Statistics, 2003). A report prepared for the Commonwealth Fund notes that data requirements and methods for collection and reporting vary across federal agencies, and also calls for improvements in racial data (Perot & Youdelman, 2001) as has the Institute of Medicine (Institute of Medicine, 2003).

The lack of measures that can currently be used to assess health care disparity for AI/ANs may be even worse than reported by Moy et al. In particular, racial misclassification should be included as a data collection issue affecting the reliability of estimates of health care disparities even for the adequate sources of data identified. The National Center for Health Statistics, which is responsible for the National Vital Statistics System, evaluated the quality of national vital event data and found that death rates for AI/ANs were underestimated by nearly 21% compared with 11% for Asians and 2% for Hispanics (Rosenberg et al., 1999). The Centers for Medicare and Medicaid (CMS) enrollment database has been compared with data from the U.S. Census and the Medicare Current Beneficiary Survey and found to be less than 60 percent accurate for all racial classifications other than Black or White (Arday, Arday, Monroe, & Zhang, 2000). Such data are obtained through Social Security Administration files, which are incomplete with respect to racial and ethnic data. Completion of forms such as used in the CMS Minimum Data Set, which was also used in the National Healthcare Disparities Report, may not require verification of racial or ethnic group. Similarly, misclassification has plagued Surveillance, Epidemiology, and End Results (SEER) databases in the past, leading to underestimation of the burden of cancer among some AI/ANs (Frost, Taylor, & Fries, 1992).

The Indian Health Service system, which provides health care services for nearly 1.5 million AI/ANs, is developing information systems to improve collection of quality measurements for its patient population (Sequist, Cullen, & Ayanian, 2005). Plans include creation of a Data Warehouse capable of integrating both administrative and clinical data within one repository. Use of measures comparable if not identical to those tracked by the National Healthcare Disparities Report would add greatly to our understanding of health care disparities. However, these efforts will still leave gaps in information for the entire AI/AN population and continued improvements in national data collection are required.

As Moy et al. (2006) point out, national data frequently fail to collect adequate information for generating reliable estimates for AI/ANs, which may lead to undetected health care problems and missed opportunities to reduce disparities. Indeed, an example of how such disparities in data collection led to underrecognition of a serious public health problem is the impact of cardiovascular disease among AI/ANs (Rhoades, 2005). National vital event data, such as used in the National Healthcare Disparities Report, consistently suggest that CVD mortality rates among AI/ANs compare favorably to the general population. However, these studies do not account for the effect of racial misclassification, which disproportionately affects AI/ANs. Adjustment for racial misclassification by the Indian Health Service (Indian Health Service, 1996, 2004) as well as the population-based epidemiologic Strong Heart Study (Howard, et al., 1999; Lee, et al., 1998) demonstrated that AI/ANs actually have higher, not lower, mortality from CVD and that this disparity is increasing. Dependence solely on vital event data for mortality outcomes would have resulted in a continued and serious underestimation of the extent of the problem of CVD, the leading cause of death for AI/ANs. One wonders what major problems in health care for AI/ANs have already been overlooked due to the poor quality of national comparative data.

Dorothy A. Rhoades, M.D., M.P.H.
Assistant Professor
American Indian and Alaska Native Programs
University of Colorado at Denver and Health Sciences Center
Mail Stop F800
PO Box 6508
Aurora, CO 80045-0508
Phone: (303) 724-1414
Fax: (303) 724-1474
E-mail: drhoades@myuw.net

References

Agency for Healthcare Research and Quality. (2005). *2005 National healthcare disparities report* (AHRQ Publication No. 06-0017). Rockville, MD: Author.

Arday, S. L., Arday, D. R., Monroe, S., & Zhang, J. (2000). HCFA's racial and ethnic data: Current accuracy and recent improvements. *Health Care Financing Review, 21*(4), 107-116.

Frost, F., Taylor, V., & Fries, E. (1992). Racial misclassification of Native Americans in a surveillance, epidemiology, and end results cancer registry. *Journal of the National Cancer Institute, 84*(12), 957-962.

Howard, B. V., Lee, E. T., Cowan, L. D., Devereux, R. B., Galloway, J. M., Go, O. T., et al. (1999). Rising tide of cardiovascular disease in American Indians. The Strong Heart Study. *Circulation, 99*(18), 2389-2395.

Indian Health Service. (1996). *Adjusting for miscoding of Indian race on state death certificates* (Final Report). Rockville, MD: Author.

Indian Health Service. (2004). *Trends in Indian health, 2000-2001*. Rockville, MD: Author.

Institute of Medicine. (2003). Data collection and monitoring. In B. D. Smedley, A. Y. Stith, & A. R. Nelson (Eds.), *Unequal treatment: Confronting racial and ethnic disparities in health care* (pp. 215-234). Washington, D.C.: National Academies Press.

Lee, E. T., Cowan, L. D., Welty, T. K., Sievers, M., Howard, W. J., Oopik, A., et al. (1998). All-cause mortality and cardiovascular disease mortality in three American Indian populations, aged 45-74 years, 1984-1988. The Strong Heart Study. *American Journal of Epidemiology, 147*(11), 995-1008.

Moy, E., Arispe, I. E., Holmes, J. S., & Andrews, R. M. (2005). Preparing the National Healthcare Disparities Report: Gaps in data for assessing racial, ethnic, and socioeconomic disparities in health care. *Medical Care, 43*(3 Suppl), I9-I16.

Moy, E., Smith, C. R., Johansson, P., & Andrews, R. (2006). Gaps in data for American Indians and Alaska Natives in the National Healthcare Disparities Report. *American Indian and Alaska Native Mental Health Research: The Journal of the National Center, 13*(1): 52-69.

National Committee on Vital and Health Statistics. (2003). *Letter to the Secretary on populations-based data for racial and ethnic minorities*. Retrieved March 10, 2006, from www.ncvhs.hhs.gov/030327lt.htm

Perot, R. T., & Youdelman, M. (2001). *Racial, ethnic, and primary language data collection in the health care system: An assessment of federal policies and practices* (Publication No. 492). New York: The Commonwealth Fund.

Rhoades, D. A. (2005). Racial misclassification and disparities in cardiovascular disease among American Indians and Alaska Natives. *Circulation, 111*, 1250-1256.

Rhoades, D. A. (2006). National health data and older American Indians and Alaska Natives. *Journal of Applied Gerontology, Supplement to 25*(1), 9S-26S.

Rosenberg, H. M., Maurer, J. D., Sorlie, P. D., Johnson, N. J., MacDorman, M. F., Hoyert, D. L., et al. (1999). Quality of death rates by race and Hispanic-origin: a summary of current research, 1999. *Vital and Health Statistics, 2*(128), 1-13.

Sequist, T. D., Cullen, T., & Ayanian, J. Z. (2005). Information technology as a tool to improve the quality of American Indian health care. *American Journal of Public Health, 95*(12), 2173-2179.