Current and Classic Resources, October-December 2010

Current Resources

Sharff DP, Matthews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. Journal of Health Care for the Poor and Underserved. 2010;21: 879–897.

Aims: "This exploratory, qualitative study was undertaken to attempt to understand the barriers to research participation particular to African American adults who reside in a mid-size urban area."
Sample: African America adults, focus groups were designed to be homogenous for participation in previous research, age categories and gender or socioeconomic status (education and income).
Methodology: Qualitative, focus groups
Results: "A number of *barrier* themes were identified in the study, including mistrust of researchers and the health care system, fear related to research participation, inadequate information about research and opportunities to participate, inconvenience, questionable reputation of the researcher or research institution, and logistical concerns."
Discussion: While knowledge, either accurate or not, regarding the Tuskegee experiments remain a common source of distrust of medical research. Mistrust is also generated by the continued experience of disrespect and discrimination in healthcare.

Stewart KA, Higgins PC, McLaughlin CG, Williams TV, Granger E, Croghan TW. Differences in prevalence, treatment, and outcomes of asthma among a diverse population of children with equal access to care. Arch Pediatr Adolesc Med. 2010;164(8):720-726.

Aims: "Our primary research question was whether similar access to medical care through the MHS among a diverse population minimized racial and ethnic differences in prevalence of diagnosed asthma, treatment, and outcomes observed in previous studies."
Sample: Children 2-17 who were continuously enrolled in TRICARE Prime, where military treatment facilities serve as the principle care providers. The cohort included 822,900 children, with exclusion criteria including not matched to parent, missing racial or ethnic data, not Hispanic, non-Hispanic black, or non-Hispanic white. It also excluded patients who had no inpatient or outpatient claims for that year.
Methodology: Retrospective cohort analysis
Results: Black or Hispanic children were significantly more likely that white children to have an asthma diagnosis, potentially avoidable asthma hospitalizations, and emergency department visits and less likely to visit a specialist after adjusting for demographics and socioeconomic status. (see article for specific Odds Ratios by age group and race/ethnicity).
Discussion: This was a retrospective analysis of a population that presumably had similar access to medical care by being enrolled in the same health care plan. While there are multiple confounding variables that can effect asthma diagnosis and severity, this study suggest the persistence of asthma diagnosis and outcome disparities despite universal access and adjusting for demographic and socioeconomic factors.

Classic Resources

Swartzberg JG, VanGeest JB, Wang CC, Eds. Understanding Health Literacy: Implications for Medicine and Public Health. Chicago, IL: AMA Press; 2005.

"An estimated 90 million adult—nearly half the adults in the United States—may have trouble understanding common health care communications, such as prescription instructions, test results and insurance forms." This book provide an overview and epidemiology of health literacy, implications for testing and health care, and challenges low health literacy creates in communication, shared decision making, informed consent and health care delivery. It also discusses the relationship between health literacy and health outcomes.

Hornblum AM. Acres of Skin: Human Experiments at Holmesburg Prison—A True Story of Abuse and Exploitation in the Name of Medical Science. New York, NY: Routledge Press; 1999.

This is a description of over 50 medical experiments that occurred between 1951 and 1974 at the Holmesburg Prison in Philadephia, Pennsylvania. The experiments involved over 1000 inmates and where principally conducted by Albert Kligman, MD, a professor of dermatology at the University of Pennsylvania Medical School. Most experiments consisted of dermal application of substances but also included oral administration and injection. Substances studied included dioxin, radioactive materials, LSD, infectious diseases and Retin-A. Co-sponsors included the U.S. Army, CIA, Dow Chemical and Johnson & Johnson. It is a classic example of coercive experimentation of vulnerable populations with substantial risk to the subjects.

If you would like to contribute an annotated reference contact: Timothy P. Hickman, MD, MEd, MPH or Fariha Shafi, MD