The Journal of Healthcare, Science and the Humanities

General Information

The Journal of Healthcare, Science and the Humanities is published by the National Center for Bioethics in Research and Health Care at Tuskegee University. The Journal is published in friendship with the Smithsonian Institution Office of Sponsored Projects. The Journal was first published in 2009 by the former Navy Medicine Institute for the Healthcare Humanities and Research Leadership. The Journal was transferred to the new publisher in 2012 as a private publication. The publisher today continues the mission of the Journal to benefit international academic and professional development regarding health, healthcare, the humanities, the sciences and social justice. ISSN (print): 2159-8880. ISSN (online): 2159-8819.

Correspondence

Manuscripts are to be submitted to the Senior Associate Editor. Submission of a manuscript is considered to be a representation that is not copyrighted, previously published, or concurrently under consideration for publishing by any other entity in print or electronic form. Contact JHSH for specific information for author, templates, and new material. The preferred communication is through email at jharrell@mytu.tuskegee.edu or via voice at +1 (334) 724-4554.

Subscriptions

Beginning in calendar year 2018, the Journal will be available through a standard subscription service. Until that time, the Journal can be electronically accessed at www.tuskegeebioethics.org. More information will be made available for the purchase of a yearly subscription in calendar year 2016. For more information at: Tuskegee University National Bioethics Center in Research and Health Care dial +1 (334) 724-4554.

Copyright Information

As a private sector publication, authors retain copyright for their articles; but grant to the Journal an irrevocable, paid-up, worldwide license to sue for any purpose, reproduce, distribute, or modify their articles in their entirety or portions thereof. Articles prepared by employees of the U.S. Government as part of their official duties are not copyrighted and are in the public domain. The Journal retains the right to grant permission to third party non-usage to others. Etc. Third party usage must give credit to the Journal and to the author(s). Opinions expressed in the Journal represent the opinions of the authors and do not reflect official policy of the institutions they may serve. Opinions in the Journal also do not reflect the opinions of the publishers or the institutions served by members of the Journal Editorial Board.
# Table of Contents

**Journal Editorial Board** ................................................................................................................................. 3

**Contributing Authors** ........................................................................................................................................ 7


**From the Editor’s Desk** ..................................................................................................................................... 17

   *Rueben C. Warren*

**Articles**

Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework Data Collection ................................................................. 23

   *Jane Delgado, Rueben C. Warren*

Commentary: What Does It All Mean? And, So What? Three Main Points To Discuss When Looking at Hispanic Data ........................................ 37

   *Norma A. Pérez*

Getting the Data Right for Latinos: Appropriate Language and Subgroup Data are Critical for Public Health and Social Justice .................................... 43

   *Glenn Flores*

Getting Data Right — and Righteous to Improve Hispanic or Latino Health ........................................................................................................ 60

   *Alfonso Rodríguez-Lainz, Mariana McDonald, Ana Penman-Aguilar, Drue H. Barrett*

Exploring the Associations Between Obesity and Infertility in United States Among African American and Latina Women: Findings from the National Survey for Family Growth (NSFG) ........................................ 84

   *Celene Craig, Reinetta Waldrop, Ernest Alema-Mensah*

Response to the 2015 PHEI Keynote Address, “Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee’? A Case Study in Passing Ethics Research from ‘Generation to Generation’” .................................................... 96

   *Kimberly N. Whitley*

Secondhand Smoke in the Workplace .................................................................................................................... 109

   *Suvak Patnaik, Mitali Nanda, Francisco Tejeda, Muktar Aliyu, Heather O’Hara*

**Book Review**

   *White Rage: The Unspoken Truth of Our Racial Divide* ................................................................. 125

   *Rueben C. Warren*

**Author Requirements** ........................................................................................................................................ 133
Journal Editorial Board

Executive Director
Rueben C. Warren, DDS, MPH, DrPH, MDiv

The Board of Governors
Tuskegee University Council of Deans

Interim Editor
Rueben C. Warren, DDS, MPH, DrPH, MDiv

Senior Associate Editor
Joan R. Harrell, DMIN, MDiv, MS

Assistant Senior Associate Editor
Wylin Wilson, PhD, MDiv, MS

Associate Editors
Henry Findlay, ED
Education, Cognition Science Distance Learning
Tuskegee University

Lisa Hill, MA, PhD
American History
Tuskegee University

Moni McIntyre, PhD
Moral Theology
Duquesne University

Brendan Ozawa-de Silva, PhD, MPhil, MTS
Modern History, Philosophy, Theological Studies
Emory University

Theirmo Thiam, PhD, MA
Political Science, International Relations, Comparative Politics, Culture
Tuskegee University

Roberta Troy, MS, PhD
Biochemistry, Molecular Biology, Health Disparities
Tuskegee University

Academic Review Committee Chair
Daryl Seriven, PhD, MS
Philosophy
Florida A&M University

Frank Franklin, PhD, JD, MPH
Director, Division of Treatment & Prevention Services, Epidemiology Division, OHSU-PSU Public Health, Volunteers of America Oregon Portland, Oregon

Sylvester Johnson, PhD
Associate Professor of African American Studies & Religious Studies
Department of Religion & African American Studies Northwestern University

Torhonda Lee, PhD, MCHES
Associate Professor of Public Health
Institute of Public Health
Florida A&M University

Adrienne R. Lotson, JD, MDiv
Cultural Anthropologist
Frederick Luthardt, MA, MA

Academic Review Committee Members
David Anderson, DDS, MDS, MA
Oral Health, Ethics & Health Policy Pennsylvania Dental Association

David Baines, MD
Family Medicine, American Indian and Alaska Native Health, Spirituality and Culture Anchorage Neighborhood Health Center University of Washington

Mill Etienne, MD
Neurology
Bon Secours Charity Health System New York Medical College

(cont.)
Journal Editorial Board

Academic Review Committee Members (cont.)

Bioethics Research Ethics, Human Research Ethics, Human Research Protections
John Hopkins University

George Nasinyama, BVM, MS, PhD
Epidemiology, Food Safety, Ecosystem Health
Makere University

Michael Owen, PhD
History, Education, Human Research Ethics, Research Integrity
University of Ontario Institute of Technology

Paulette Reneau, PhD
Assistant Professor of Genomics & Molecular Phylogenetics
Department of Biology
Florida A&M University

Edward L. Robinson Jr, PhD, MA
Instructor
Fullerton College

Tracy A. Thomas, PT, PhD

Associate Professor
Department of Physical Therapy
Florida A&M University

Ronald Thorpe, PhD
Associate Professor of Health, Behavior, & Society
Bloomberg School of Public Health & School of Medicine
Johns Hopkins University

Tanganyika Wilder, PhD
Assistant Professor of Cardiovascular Physiology
Department of Biology
Florida A&M University

Richard Wilkerson, PhD
Entomology
Smithsonian Institution
Preface

Contributing Authors

Muktar Aliya, MD, DrPH is an Associate Professor of Family and Community Medicine and Associate Director of the Occupational Medicine Residency Program at Meharry Medical College.

Ernest Alema-Mensah, Ph.D., M.S., D. Min., MDV, is a Principle Investigator in the department of Community Health and Preventive Medicine at Morehouse School of Medicine and Research Assistant Professor, Database Administrator, and Project Director for the National Black Leadership Initiative on Cancer II. He earned Bachelor of Science in Mathematics and Chemistry from University of Ghana in Accra, Ghana, his Master of Divinity from the Interdenominational Theological Center in Atlanta, GA, a Master of Science in Computer Science from Clark Atlanta University, his Doctor of Ministry from Columbia Theological Seminary in Decatur, GA, and his Ph. D. in International Public Health from Clark Atlanta University in Atlanta, GA. Dr. Mensah has over 16 publications, and multiple awards including the 2013 Morehouse School of Medicine Faculty Service Award, the 2014 Morehouse School of Medicine Award for 25 years of Outstanding Service, and the 2011 Morehouse School of Medicine Teaching Excellence Award.

Drue H. Barrett, Ph.D. and CAPT, U.S., Public Health Service is the Lead of the Public Health Ethics Unit and the Chair of the CDC Public Health Ethics Committee (PHEC). The Public Health Ethics Unit has been working to strengthen infrastructure in public health ethics at CDC by sponsoring training and offering a public health ethics consultation service. Under her leadership, the Public Health Ethics Unit has also developed training in public health ethics for local health officials, including a public health ethics casebook (published as an open access book by Springer Press in April 2016). Prior to assuming the role as the Public Health Ethics Lead, Dr. Barrett served for many years on CDC’s Institutional Review Boards (IRB), and chaired one of the IRBs. Other positions she has held at CDC include Acting Associate Director for Science in the National Center for Environmental Health/Agency for Toxic Substances and Disease Registry and Director of the Veterans Health Activity in the National Center for Environmental Health. Dr. Barrett received her Ph.D. in clinical psychology in 1990 from Georgia State University. She also completed two years postdoctoral training in epidemiology and public health through CDC’s Epidemic Intelligence Service program in the Cardiovascular Health Studies Branch of the National Center for Chronic Disease Prevention and Health Promotion.

Celene Craig, MPH is recent graduate of the Master of Public Health program at Morehouse School of Medicine (MSM). She earned her Bachelor of Science degree in Biology/Pre-Medicine from Spelman College in Atlanta, GA. While at MSM, Ms. Craig gained an interest for sexual and reproductive health focusing on African American and Latina women and global health. She completed internships as Behavioral Health Intern with the Southeast Addiction Technology Transfer Center Network, SAMSHA funded, as well as Health Advocate at Feminist Women’s Health Center both in Atlanta, GA. She also worked as a Natural Science Instructor for Ivy Preparatory Academy at Kirkwood for Girls Science Summer Program teaching various basic natural sciences to students in grades 6th-8th. Ms. Craig is currently a
graduate student in a Post Baccalaureate program at Rush University Medical Center in the
department of Biotechnology in Chicago, Illinois.

**Alex Crosby, MD,** is the Branch Chief of the Surveillance Branch of the Division of Violence
Prevention (DVP) in the National Center for Injury Prevention and Control (NCIPC). His work
involves descriptive and analytic research and community technical assistance in the prevention
of self-directed violence, interpersonal violence among adolescents, firearm-related injuries, and
assault among minorities. Dr. Crosby began his career at CDC in the Epidemic Intelligence
Service working on the epidemiology of violent injuries. In DVP, he has served in a variety of
capacities, including Team Leader for the Youth Violence and Suicide Prevention Team, Mortality
Surveillance Team leader of the Surveillance Branch, and Branch Chief of the Surveillance
Branch. Dr. Crosby received his BA in chemistry from Fisk University in Nashville, his MD from
Howard University College of Medicine in Washington, D.C. and his MPH in health policy and
management from Emory University School of Public Health in Atlanta, Georgia. He completed
two residencies, the first in family practice at Howard University Hospital, the second in general
preventive medicine and public health with the Morehouse School of Medicine and Georgia
Division of Public Health. In addition to his work at CDC, he is an adjunct faculty member in
the Department of Community Health and Preventive Medicine at the Morehouse School of
Medicine and lectures at Emory University’s Rollins School of Public Health.

**Jane L. Delgado, PhD, M.S.** leads the National Alliance for Hispanic Health (the Alliance)—
a science based and community driven organization with a mission of the best health outcomes
for all. Dr. Delgado serves on the Board of Health Care Services for The National Academies
of Sciences, Engineering, and Medicine and the Board of Governors for Argonne National
Labs. She also serves on the Board of the Lovelace Respiratory Research Institute; Keystone
Policy Center; and, the U.S. Soccer Foundation. Dr. Delgado has written numerous articles as
to Health: Consejos and Caring Answers (2010),” and “The Buena Salud Guide for a Healthy
Heart (2011),” were chosen by the Library Journal as one of the best health books for the year
they were published. In 2016 Latino Leaders named her to the 101 Most Influential Latinos
in the U.S. and in 2015 she received the FDA’s Dr. Harvey Wiley Award (highest award to
a civilian). Dr. Delgado served in the Immediate Office of then Secretary Margaret Heckler
of the U.S. Department of Health and Human Services (DHHS) and was a key force in the
development of the landmark “Report of the Secretary’s Task Force on Black and Minority
Health.” Prior to DHHS she held a variety of positions including Children’s Talent Coordinator
for Sesame Street. Her degrees include Ph.D. Clinical Psychology, SUNY Stony Brook and M.S.

**Glenn Flores, MD, FAAP** is Distinguished Chair of Health Policy Research at the Medica
Research Institute, Affiliate Professor of Public Health at the University of Minnesota, and
a Mayo Clinic Research Affiliate. He is a member of the Council of the American Pediatric
Society, the editorial board of *Journal of Health Care for the Poor and Underserved,* and the
National Advisory Committees of the RWJF Amos Medical Faculty Development Program
and RWJF Health Opportunity and Equity (HOPE) Measures. He is Director of the NIDDK/
APA Research in Academic Pediatrics Initiative on Diversity (RAPID). He received the 2010 APHA Helen Rodríguez-Triás Social Justice Award. He has been a consultant/NAC member for the US Surgeon General, IOM, CDC, NICHD, AMA, NHMA, First Focus, DHHS Office of Civil Rights, and Sesame Workshop. His 217 publications address a wide variety of research and policy issues.

**Mariana McDonald, DrPH, MPH, MA** is Associate Director of Health Disparities and Director of the Office of Health Disparities in CDC’s National Center for Emerging and Zoonotic Diseases. She co-founded the CDC/ATSDR Latino/Hispanic Health Work Group (LHHWG) in 2012, and currently serves as its co-chair. McDonald has worked in women’s and racial/ethnic minority health as a scientist, educator, and advocate for three decades. She received her DrPH and MPH from the UC Berkeley School of Public Health, and Masters in Women's Studies from Goddard College. Formerly a professor of public health at Tulane University, her expertise includes social determinants of health, neglected infections, cultural and linguistic competence, Latino/a health, and women’s health promotion. A poet, McDonald also developed trailblazing work on using the arts in health promotion. McDonald has provided leadership to numerous efforts to advance the health of women, people of color, and vulnerable populations since coming to CDC in 2002. She co-chaired the 2014 CDC seminar *Immigrant, Migrant, and Foreign-born Health: Addressing Health Disparities*, and envisioned and chaired the *International Conference on Women and Infectious Diseases* in 2004 and 2006. She was an invited speaker at the Institute of Medicine’s 2010 Workshop on Neglected Tropical Diseases (NTDS), presenting on NTDs’ global impact on women’s and children’s health. Bicultural/bilingual, she is a longtime member of the APHA’s Latino Caucus. Her awards include CDC/ATSDR’s Health Equity Mentor/Champion Award and Award for Distinguished Service to the Greater New Orleans Latino Community. She is a member of Delta Omega, the National Public Health Honor Society.

**Mitali Nanda, MD** is a Pediatrician at Capstone Pediatrics in Murfreesboro, TN after completing her Residency in New York in 2015.

**Heather O’Hara, MD, MSPH** originally from St. Louis, MO, attained her B.S. in Chemistry from Tuskegee University, M.S. in Organic Chemistry from Georgia Institute Technology and, M.D. and M.S.P.H degrees from Meharry Medical College. She is a board-certified physician in Occupational Medicine and General Preventive Medicine and Public Health. As Assistant Professor in the Department of Family and Community Medicine at Meharry Medical College in Nashville, TN, Dr. O’Hara serves as the Program Director for the Occupational and Preventive Medicine Residency programs. Her interests have primarily been focused on helping others to achieve and maintain a healthy lifestyle related to healthy eating, exercising, and the harms of tobacco and alcohol use to promote overall wellness in the public, as well as the workplace. She is involved with the various inter-related topics of obesity, breast cancer, integrative medicine and workplace safety. She has published in peer-reviewed publications on studies related to migrant farmworker work safety perceptions, perinatal factors and breast cancer risk, complementary and alternative therapies, musculoskeletal diseases, and sports nutrition needs before, during and after exercise.
Preface

Suvag Patnaik MD, MPH is a Resident in the Occupational Medicine Residency Program at Meharry Medical College.

Ana Penman-Aguilar, PhD, MPH serves as Associate Director for Science in CDC’s Office of Minority Health and Health Equity (OMHHE) where she provides leadership and consultation across a broad range of science, research, evaluation, and practice issues that advance the elimination of health disparities and achievement of health equity. Together with other OMHHE leaders, she jointly leads CDC’s efforts to decrease health disparities, address social determinants of health, and promote access to high quality preventive health care. She leads OMHHE’s Science Team, which is responsible for advancing science and practice across CDC surrounding the elimination of health disparities and the achievement of health equity. She recently co-led an effort to develop a major CDC report on the health of Hispanics and Latinos in the United States. The report, which followed sound practices regarding data disaggregation for advancement of health equity, and the team overseen by Dr. Penman-Aguilar were honored with the 2015 CDC and ATSDR Health Equity Award. She provides technical assistance to several national groups including the National Collaborative for Health Equity, on whose advisory board she serves. Dr. Penman-Aguilar has 20 years of experience working in public health research domestically and abroad and has authored scientific manuscripts exploring issues related to health equity and the health of vulnerable populations in the US and sub-Saharan Africa. Dr. Penman-Aguilar holds an MPH in International Health and Development from Tulane University School of Public Health and Tropical Medicine and a PhD in Epidemiology from the University of Alabama at Birmingham.

Norma Alicia Pérez, MD, DrPH, a Houston native, earned her MD from the Universidad de Monterrey, Monterrey, Mexico, and completed her residency training in Physical Medicine and Rehabilitation at the Universidad Nacional Autónoma de Mexico, Mexico City, Mexico. She was a practicing physiatrist in Mexico before returning to Houston where she completed her doctorate in Public Health in International and Family Health at the University of Texas – Houston, Health Science Center School of Public Health. She serves as Director of the Hispanic Center of Excellence School of Medicine at the University of Texas Medical Branch where she has faculty appointments with Internal Medicine-Geriatrics, and Preventive Medicine and Community Health. She is a member of the University of Texas System Women’s Senior Leaders Network and is Vice President for the Hispanic Serving Health Professions Schools.

Alfonso Rodríguez-Lainz, PhD, DVM, MPVM is an epidemiologist with the U.S.-Mexico Unit, CDC’s Division of Global Migration and Quarantine, based in San Diego, California. Dr. Rodriguez-Lainz main responsibilities include acting as a liaison, coordinator, planner and project lead for surveillance and health communication activities with Latin American migrants living in the United States. Prior to joining the CDC, Dr. Rodriguez-Lainz worked for the Public Health Institute (California) as the lead evaluator for a multinational project in Latin America. Other positions he has held include epidemiologist for Imperial County Health Department (California) and for the California Office of Binational Border Health, California Department of Public Health. Dr. Rodriguez-Lainz has a PhD in Epidemiology and Masters in Preventive Veterinary Medicine from the University of
Francisco Tejeda, MD attained his Bachelor’s in Science from the University of California, Los Angeles in Biology and his medical doctorate from the University of Iowa Carver College of Medicine. He is currently working on his M.S.P.H. and General Preventive Medicine residency at Meharry Medical College. Dr. Tejeda’s plan is acceptance into an addiction medicine fellowship.

Reinetta T. Waldrop, DrPH is an Assistant Professor of Health Administration, Management and Policy (HAMP) in the Department of Community Health and Preventive Medicine at Morehouse School of Medicine (MSM). She earned her Bachelor of Science in Zoology from Howard University in Washington, D.C., her Masters in Health Systems Management Engineering from The Georgia Institute of Technology in Atlanta, GA, and her Doctorate in Public Health from the University of Georgia, Athens, GA. At MSM Dr. Waldrop serves as core faculty for HAMP in the Master of Public Health Program. Prior to joining MSM, Dr. Waldrop was the Deputy Director for Administration for the Fulton County Department of Health and Wellness. She has also served as the CEO of a federally qualified health center, and the first administrator of Hughes Spalding Children’s Hospital, a care delivery unit of the Grady Health System. Dr. Waldrop currently holds Fellow status in the American College of Healthcare Executives.

Reuben C. Warren DDS, MPH, DrPH, MDiv is professor of bioethics and director, Tuskegee National Bioethics Center in Research and Healthcare. His adjunct full professor appointments include: The Interdenominational Theological Center, Morehouse School of Medicine; Emory’s Rollins School of Public Health, Schools of Dentistry and Graduate Studies, Meharry Medical College (MMC). He is the former Associate Director for Minority Health, Centers for Disease Control and Prevention and directed Infrastructure Development at the National Institute for Minority Health and Health Disparities, NIH. He is Dean Emeritus, School of Dentistry, MMC.

Kimberly N. Whitley, MPH is a third-year Integrative Biosciences Doctor of Philosophy student in the Integrative Biosciences PhD Program at Tuskegee University. Ms. Whitley is a third-generation descendant of John Goode, one of the male participants in the United States Public Health Service Syphilis Study at Tuskegee. She respectively earned her Bachelor of Science in Biology from Albany State University in Albany, Georgia; Master of Public Health degree from the Morehouse School of Medicine in Atlanta, Georgia; is a Tuskegee Alliance to Forge Pathways to Academic Careers (T-PAC) Scholar; National Science Foundation- Alliances for Graduate Education and the Professoriate (NSF-AGEP) Scholar; and member of the Golden Key International Honor Society. As a PhD student, her doctoral research foci include food insecurity in the Alabama Black Belt Counties, optimal health and well-being within the context of nutrition, food, environmental, and social justice coupled with community advocacy, policy and research.
2016 Public Health Ethics Forum


The Tom Harkin Global Communications Center, CDC – Atlanta, GA
April 22, 2016
Building 19, Auditorium B

Program Agenda*

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>07:30 a.m. – 08:30 a.m.</td>
<td>REGISTRATION</td>
</tr>
<tr>
<td></td>
<td>STUDENT POSTER EXHIBITS OPEN</td>
</tr>
<tr>
<td></td>
<td>(Conference Lobby Area)</td>
</tr>
<tr>
<td>08:30 a.m. – 08:45 a.m.</td>
<td>CULTURAL EXPRESSION</td>
</tr>
<tr>
<td></td>
<td>The Connection Between Culture, the Creative Arts, Healing, and Public Health</td>
</tr>
<tr>
<td></td>
<td>Moderator Dr. Mariana McDonald</td>
</tr>
<tr>
<td>08:45 a.m. – 09:15 a.m.</td>
<td>OPENING SESSION</td>
</tr>
<tr>
<td></td>
<td>Meeting Welcome &amp; Opening Remarks</td>
</tr>
<tr>
<td></td>
<td>Leandris C. Liburd, PhD, MPH</td>
</tr>
<tr>
<td></td>
<td>Associate Director for Minority Health and Health Equity</td>
</tr>
<tr>
<td></td>
<td>Office of Minority Health and Health Equity, CDC/ATSDR</td>
</tr>
<tr>
<td></td>
<td>Tuskegee University &amp; Purpose of the Public Health Ethics Forum</td>
</tr>
<tr>
<td></td>
<td>Rueben C. Warren, DDS, MPH, DrPH, MDiv</td>
</tr>
<tr>
<td></td>
<td>Professor of Bioethics and Director of the National Center for Bioethics in Research and Health Care</td>
</tr>
<tr>
<td></td>
<td>Tuskegee University</td>
</tr>
<tr>
<td></td>
<td>Cesar D. Fermin, PhD</td>
</tr>
<tr>
<td></td>
<td>Provost &amp; VP for Academic Affairs</td>
</tr>
<tr>
<td></td>
<td>Tuskegee University</td>
</tr>
<tr>
<td></td>
<td>CDC Opening Remarks</td>
</tr>
<tr>
<td></td>
<td>Carmen Villar, MSW</td>
</tr>
<tr>
<td></td>
<td>Chief of Staff, CDC/ATSDR</td>
</tr>
<tr>
<td>09:15 a.m. – 10:30 a.m.</td>
<td>KEYNOTE SPEAKER</td>
</tr>
<tr>
<td></td>
<td>Ethical Issues Related to Data Collection and Research in Hispanic Populations</td>
</tr>
<tr>
<td></td>
<td>Eliseo J. Pérez-Stable, MD</td>
</tr>
<tr>
<td></td>
<td>Director of the National Institute on Minority Health and Health Disparities , National Institutes of Health</td>
</tr>
<tr>
<td></td>
<td>Moderator Dr. Leandris Liburd</td>
</tr>
<tr>
<td></td>
<td>BREAK</td>
</tr>
<tr>
<td></td>
<td>VISIT STUDENT POSTER EXHIBITS</td>
</tr>
<tr>
<td></td>
<td>(Conference Lobby Area)</td>
</tr>
</tbody>
</table>

“Preservation of one’s own culture does not require contempt or disrespect for other cultures.”
- César Estrada Chávez
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Organizer/Presenter</th>
</tr>
</thead>
</table>
| 10:45 a.m. – 11:45 a.m.| PANEL 1: What is Public Health Ethics and What Does It Have To Do With Data? | Carla Saenz, PhD  
Ken Dominguez, MD, MPH, CAPT USPH  
Rafael Sánchez-Cárdenas, MD | Panel Organizer  
Dr. Mariana McDonald |
|                       | Establishing a Public Health Ethics Framework on Data                   | Regional Bioethics Advisor, Pan American Health Organization  
Medical Epidemiologist, Bioethics Advisor |
| 11:45 a.m. – 12:45 p.m.| LUNCH (Please Visit Poster Presentations)                              |                                                                                     |
| 12:45 p.m. – 01:45 p.m.| PANEL 2: Getting the Data Right!                                       | Glenda Flores, MD, FAAP  
Alfonso Rodríguez-Lainz, PhD, DVM, MPVM  
Guesnerth Josué Perea, MA  
Norma Perez, MD, DrPH  
Rafael Sánchez-Cárdenas, MD | Panel Organizer  
Dr. Rueben Warren |
|                       | Conference Capstone: What Does it all Mean? And, So What?              | Guesnerth Josué Perea, MA  
Norma Perez, MD, DrPH  
Rafael Sánchez-Cárdenas, MD | Panel Organizer  
Dr. Maureen Lichtveld |
| 01:45 p.m. – 02:45 p.m.| BREAK (Participants’ Activity)                                         |                                                                                     |
|                       | ‘GREEN LIGHT, YELLOW LIGHT & BLUE! WHAT ARE THREE (3) KEY PROGRAM PRIORITIES FOR YOU?’ |                                                                                     |
|                       | Naming and Prioritizing Your Program Needs                              |                                                                                     |
| 02:45 p.m. – 03:00 p.m.| 2016 Partners’ Final Thoughts: A Call To Action!                        | Dr. Leandris Liburd  
Ms. Marcela Gaitan  
Mr. Kem Williams  
Ms. Marcela Gaitan |
| 03:00 p.m. – 03:15 p.m.| Student Poster Awards Ceremony                                          | Dr. Gemechu B. Gerbi                                                             |
| 03:15 p.m. – 03:30 p.m.| ADJOURN                                                                 |                                                                                     |

*Agenda subject to change

“Preservation of one’s own culture does not require contempt or disrespect for other cultures.”  
- César Estrada Chávez
National Center for Bioethics in Research and Health Care

Looking Back to Move Forward
Preface

Message from the Interim Editor

Rueben C. Warren DDS, MPH, Dr. P.H., MDiv
Professor and Director of the National Center for Bioethics in Research and Health Care at Tuskegee University
Tell: (334) 724-4554
Email: warrenr@mytu.tusekgee.edu

This edition of the *Journal for Healthcare, Science and the Humanities*, features the 2016 Public Health Ethics Forum entitled, “Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice.” The symposium held April 22, 2016 was on the main campus of the Centers for Disease Control and Prevention. The collaborators for this event, for the second time, were: the National Center for Bioethics in Research and Health Care at Tuskegee University, Centers for Disease Control and Prevention, the CDC Office of Minority Health and Health Equity, and the Morehouse School of Medicine. Sponsoring partners included: the Hispanic Serving Health Professions Schools, the National Alliance for Hispanic Health, and the National Hispanic Medical Association. Symposium presenters included a broad array of persons directly involved in and/or committed to Hispanic/Latinx health. The symposium is the second forum to address salient issues impacting on the health of people of color. The first symposium was held in April 2015, honoring 100 years marking the death of Booker T. Washington, Founding President of Tuskegee University. In 1915, Booker T. Washington started Negro Health Week to address the health needs of the Black population. Over 100 years later, the National Center for Bioethics in Research and Health Care at Tuskegee University, Centers for Disease Control and Prevention, the CDC Office of Minority Health and Health Equity, and the Morehouse School of Medicine agreed to host a symposium to discern the progress made in improving the health of the African Americans. While the health of all people in the U.S. has improved, the health of African Americans had not proportionately improved compared to other populations. In fact, in 2005, 83,000 excess deaths were reported in the African American population. Excess deaths are the number of preventable deaths that occur in the African American population compared to what would be expected if the age and sex adjusted death rate was the same as their non-Hispanic white counterparts. While seldom reported, excess deaths also occur in the Hispanic/Latinx population.

To better understand the international scope of Hispanic/Latinx health, Rafael Sanchez-Cardenas MD, Vice Minister of International Relations, Ministry of Higher Education, Science and Technology, Dominican Republic, presented on health and technology in the Dominican Republic. Caesar Fermin PhD, Provost and Vice President for Academic Affairs at Tuskegee University, who is originally from the Dominican Republic, also provided opening comments on opportunities to engage Dominican Republic faculty and students in scholarly activities with U.S. universities. As a follow up to the symposium, Dr. Fermin headed a delegation of Tuskegee University senior administrators and faculty to visit the Dominican Republic. As a result of the visit, several Dominican students were admitted into PhD and MPH Programs at Tuskegee University in the Fall 2016 class. Dr. Fermin also translated into Spanish the abstracts from...
Preface


The topic areas covered in the 2016 Public Health Ethics Forum focused specifically on data issues associated to public health and public health ethics that impact directly on Hispanic/Latinx health (see the original Forum agenda included in this edition). Several of the presentations were prepared, submitted for peer review and are published in this edition. Concern about the appropriate collection and use of data was the major focus of this symposium. Eliseo J. Pérez- Stable MD, Director of the National Institute on Minority Health and Health Disparities, National Institutes of Health, gave the keynote address for the Opening Session. His comments provided an excellent framework for addressing the current challenges and opportunities in research, education and community engagement related to the health of an increasingly diverse U.S. population. Carla Saenz PhD, Regional Bioethics Advisor for the Pan American Health Organization, focused her comments on the ethics challenges that present when subsets of the Hispanic/Latinx populations are not included in the data collection process. She, along with Ken Dominguez MD, MPH, provided a thought-provoking framework for improving the process. In his presentation, Glen Flores MD, FAAP made clear that Hispanics/Latinx are the largest US racial/ethnic minority group, and they represent two-thirds of the people in the US with limited English proficiency (LEP). Failure to address this LEP issue is clearly a public health ethics violation with broad public health implications. He concluded that LEP and Hispanic/Latinx subgroups data should be collected on all national surveys and research projects (see complete article in this edition). Norma Pérez MD, DrPH challenged the interpretation and relevance of data by answering the questions, “What Does it all Mean? And, So What?” Read her excellent commentary in this edition to get the answers. Alfonzo Rodriguez-Lainz, PhD, DVM, MPVM, Mariana McDonald, DrPH, MPH, MA, Ana Penman-Aguilar, PhD, MPH, and Drue H. Barrett, PhD provided important information in his presentation by describing the U.S. Hispanic/Latinx population: 65% U.S-born, 35% Foreign-born, 76% are U.S citizens; 24% non-citizens, 75% Speak Spanish at home, 35% Limited English Proficient. He and his co-authors’ publication, in this edition, is drawn from his presentation, which details the public health challenges with “getting data right” to improve Hispanic/Latinx health.

Celene Craig, MPH, Reinetta Waldrop Dr. P.H., MPH and Ernest Alema-Mensah MS, MDiv, DMin, PhD from the Morehouse School of Medicine, co-authored an informative article in this edition which focuses on obesity and infertility among Latina and African American women. Suvag Patnaik, MD, MPH, Mitali Nanda, MD, Francisco Tejeda, MD, Muktar Aliyu, MD, DrPH and Heather O’Hara, MD, MSPH, FACOEM co-authored an article entitled, “Secondhand Smoke in the Workplace.” Both of these articles were presented as poster presentations during the 2016 Public Health Ethics Forum. The winners of that competitive poster presentation session were provided the opportunity to transform their posters into manuscripts and submit them for peer review and publication.
Kimberly N. Whitley, MPH presents a paper in response to the keynote address by Ralph Katz DDS. MPH., PhD on mistrust in research presented at the 2015 Public Health Ethics Intensive Course during the Annual Commemoration Events associated with the 1997 Apology of the U.S. Public Health Service Syphilis Study at Tuskegee. Ms. Whitley is the great great granddaughter of John, Goode, one of the men who was in the Syphilis Study. Whitley is a PhD Integrative Bioscience student at Tuskegee University.

Jane Delgado PhD, MA, President and CEO of the National Alliance for Hispanic Health, synthesized selected articles in this edition in Spanish and English. Dr. Delgado, a psychologist, contextualizes Hispanic/Latinx health in the U.S. population, largely due to the growth in the Hispanic/Latinx population. Enjoy this historic edition of the Journal for Healthcare, Science and the Humanities. Celebrate Hispanic/Latinx health!
Que la salud latina/hispana cuente: Promoción de un marco ético para la recopilación de datos en la salud pública

Jane L Delgado, PhD, MS
Presidenta y directora ejecutiva
Alianza Nacional para la Salud de los Hispanos (National Alliance for Hispanic Health)
Teléf: 202-797-4321
Email: jdelgado@healthyamericas.org

Rueben C. Warren, DDS, MPH, DrPH, MDIV
Profesor y director
Centro Nacional para la Bioética en la Investigación y Atención Médica (National Center for Bioethics in Research and Health Care) de la Universidad Tuskegee
Teléf: 334-724-4554
Email: warrenr@mytu.tuskegee.edu

Ya que 1 de cada 6 personas en Estados Unidos es hispana, --esto es, más de 60 millones de personas--, la necesidad de mejores sistemas de datos de salud que reflejen la experiencia hispana en salud es crucial para que este grupo reciba mejores servicios médicos y goce de mejor salud. Sin embargo, los esfuerzos por mejorar la recopilación de datos deben funcionar en un entorno que recoja Asociación Médica Hispana la experiencia de las comunidades hispanas que históricamente no han sido incluidas. En consecuencia, el diseño de sistemas de recopilación de datos ha resultado, en el mejor de los casos, en investigación basada en información incorrecta y, en el peor de ellos, en resultados derivados de prácticas poco éticas de investigación. El entendimiento de las dimensiones éticas de la recopilación de datos de salud es crucial en un nuevo enfoque sobre la salud y bienestar de los hispanos y la comunidad. A fin de promover la disciplina de ética en la salud pública, el 22 de abril de 2016, el Centro Nacional para la Bioética en la Investigación y Atención Médica de la Universidad Tuskegee, en colaboración con el Centro de Control y Prevención de Enfermedades (Centers for Disease Control and Prevention o CDC), la Facultad Morehouse de Medicina, la Asociación Médica Hispana Nacional (National Hispanic Medical Association), la Alianza Nacional para la Salud de los Hispanos y las Facultades de Profesiones Médicas que Prestan Servicios de Salud a los Hispanos (Hispanic-Health Serving Health Professions Schools) convocaron el “Foro de Ética en Salud Pública de 2016: Que la salud latina cuente: Promoción de un marco ético para la recopilación de datos en materia de salud pública” (“2016 Public Health Ethics Forum: Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection”).

En base a los comentarios de un grupo extenso de fuentes, el objetivo de esta importante reunión fue comprender el marco ético para la recopilación de datos en la comunidad hispana/latina, eliminar brechas de conocimientos y ofrecer recursos que puedan usar investigadores en el futuro. Entre los factores que impulsaron la conversación entre destacados expertos y las presentaciones que se produjeron estuvieron: (1) el número de hispanos en Estados Unidos, (2) la necesidad de contar con mejores datos y (3) la urgencia de tomar decisiones de salud pública dentro de un marco ético. En este resumen, destacamos: información básica sobre la comunidad hispana/latina, perspectivas importantes derivadas de presentaciones excepcionales y recomendaciones para el futuro.
En julio de 2015 la Oficina del Censo (Census Bureau) informó que la población total de Estados Unidos (los 50 estados y el Distrito de Columbia) era de 321,418,820 (US Census Bureau, julio de 2015). Entre ellos, había 197,993,993 personas de solamente raza blanca (no hispanos o latinos); 56,569,712 hispanos o latinos; 42,748,703 de solamente raza negra o afroamericanos; 17,999,454 de origen asiático solamente; 8,356,889 de dos o más razas, y 3,857,026 indígenas americanos o de Alaska. Por otra parte, a pesar de que la Oficina del Censo de Estados Unidos ha recopilado datos de Puerto Rico desde 1910, no se incluyó a sus 3,411,307 residentes en estas cifras. Cuando se agregan los datos de la población de Puerto Rico, el resultado es que hay más de 60 millones de hispanos en Estados Unidos. El mayor propulsor de crecimiento de la población hispana/latina han sido los nacimientos en Estados Unidos (Stepler y Brown, 2016).

Sin embargo, los sistemas existentes de recopilación de datos, especialmente en salud y salud pública, no han incluido a los hispanos adecuadamente. Por ejemplo, los hispanos solo representan aproximadamente 1% de los participantes en pruebas clínicas, lo que significa que la mayoría de los tratamientos y medicamentos que los hispanos toman hoy en día no cuentan con datos adecuados de investigación para entender las diferencias que puedan haber en su impacto (Norman, 2011). Es más, a pesar de que el Instituto Nacional de Salud (National Institutes of Health o NIH) declaró públicamente que una fuerza laboral más diversa en la investigación es una prioridad y afirmó además que la investigación con la participación de la comunidad es la óptima referencia, solo 3.4 por ciento de los principales investigadores que reciben fondos del NIH son hispanos, y de ellos, menos de la mitad tienen títulos de doctor en biomedicina (Oh, Galanter, Thakur, et al, 2015). Cerrar esta brecha entre la urgencia declarada de una base científica más robusta y diversa, y la inclusión representativa de los hispanos/latinos en el entorno de investigación fue un tema importante durante toda la reunión, y la mayoría de las presentaciones se centraron en maneras de resolver esta evidente omisión.

**Presentar el desafío ético.** El Dr. Eliseo Pérez-Stable dio la pauta en el discurso principal, que dejó en claro que la inclusión de todas las comunidades en pruebas clínicas es crucial para una óptima investigación científica. Tal inclusión resultaría en mejores conclusiones, ya que casi 40% de la población es hispana, afroamericana, asiática o indígena americana. Además habló sobre los valiosos aportes hechos por el Estudio de Latinos (Study of Latinos o SOL) realizado por el Instituto Nacional del Corazón, Pulmones y Sangre (National Heart, Lung, and Blood Institute o NHBLI). SOL no solo produjo un mejor entendimiento de la salud cardiovascular y los hispanos, sino que demostró la forma de realizar buenos estudios en un marco impulsado por la comunidad. La participación de más de 16,000 hispanos en el estudio SOL, de hecho, refuta la noción equivocada de que las comunidades hispanas no están dispuestas a participar en esfuerzos de investigación sobre la salud. El Dr. Eliseo Pérez-Stable enfatizó que es clara la necesidad de más y mejor investigación, e instó a los participantes a hacer avances en este campo.

**Marco histórico: un desafío ético.** Si bien la investigación es esencial, se debe realizar dentro de un marco ético, particularmente en vista del contexto histórico de investigación médica y de salud en comunidades subatendidas. La clave para la ética es generar confianza en las comunidades que se incluyen en la investigación. El consentimiento informado es fundamental para la investigación ética. Sin embargo, la evidencia revela que ha habido grandes brechas en consentimiento informado y, como resultado, las comunidades incluidas en la investigación se han visto afectadas. Kimberly N. Whitley, descendiente de uno de los participantes en el Estudio
de Sífilis del Departamento de Salud Pública de los Estados Unidos (United States Public Health Syphilis Study o USPHS) en Tuskegee dejó en claro en su presentación que “El legado y la verdad del Estudio de Sífilis USPHS en Tuskegee siguen afectando a sus descendientes en vida. Hasta que se revele toda la verdad, el legado del Estudio de Sífilis USPHS en Tuskegee continuará en debate”. El asunto de confianza y desconfianza va más allá de los descendientes del Estudio de Sífilis en Tuskegee, pues repercuten en los esfuerzos de investigación y las comunidades estudiadas.

Sin embargo, el Estudio de Sífilis USPHS en Tuskegee no fue un caso aislado. En 2005 la profesora Susan Mokotoff Reverby (Wellesley College) descubrió experimentos sobre sífilis realizados por Estados Unidos en Guatemala. Encontró pruebas de esta historia inédita mientras examinaba documentos históricos sobre el Estudio de Sífilis USPHS en Tuskegee. En el estudio de Guatemala, los médicos infectaron a soldados, prostitutas, presos y pacientes de salud mental con sífilis y otras enfermedades de transmisión sexual. Muchos de estos médicos fueron los mismos que realizaron el Estudio de Sífilis en Tuskegee. Otro ejemplo de cómo se promovió la desconfianza se produjo en Puerto Rico. En 1955, una gran prueba clínica sobre pastillas anticonceptivas se sometió a prueba con puertorriqueñas. Muchas de las mujeres no dominaban el inglés ni podían leer. Los investigadores pensaron que el estudio ayudaría a documentar si la píldora se podía usar en cualquier parte del mundo (Contraceptive trials, 2016).

**El desafío ético actual: obtener datos correctos.** Las trasgresiones éticas no son solo un problema histórico. En 1996, se reportó que “Un estudio auspiciado por el gobierno de dos vacunas contra el sarampión, iniciado en 1989 durante una gran epidemia en Estados Unidos y realizado en casi 1,500 bebés de grupos minoritarios en Los Ángeles no divulgó a los padres que una de las vacunas era experimental (Cimons, 1996)”. La mayoría de los niños que fueron parte del estudio eran hispanos o afroamericanos. La necesidad de ética en la salud pública era esencial entonces e incluso más ahora. Tanto el Dr. Rodriguez-Lainz y el Dr. Flores propiciaron en la conferencia una interesante conversación sobre estrategias y tácticas que se pueden usar en la investigación que son éticas y pueden producir resultados significativos.

En la presentación de Rodríguez-Lainz, McDonald, Pennman-Aguilar y Barrett, el Dr. Rodríguez-Lainz dijo, “La ética en la salud pública es una disciplina emergente que se ha expandido a los campos relacionados de ética clínica, ética de investigación y bioética”. El Dr. Rodríguez-Lainz et ál van más allá y dan más detalles sobre las consecuencias de los cuatro principios de Belmont (justicia, beneficencia, no maleficencia y respeto por las personas) en la ética de salud pública. Habló sobre la lógica y metodología para mejorar los elementos de datos y acceso lingüístico para comprender la salud latina/hispana a fin de ofrecer una evaluación significativa del crecimiento demográfico y tendencias de salud en Estados Unidos. Deja en claro que los elementos clave que se deben incluir en un sistema de datos robusto en la salud y atención de salud son información detallada sobre el subgrupo de origen de hispanos, idioma principal y factores relacionados a la migración.

Para los hispanos, esto con frecuencia significa diseñar un protocolo de investigación que pueda incorporar a personas con diversos niveles de dominio del idioma. Según el Censo de Estados Unidos (2013), hay 16.4 millones de hispanos o aproximadamente 1 de cada 4 hispanos que dicen que su capacidad de hablar inglés es menor a "muy buena". Sin embargo, la investigación presentada por el Dr. Glenn Flores indica que un análisis de importantes estudios publicados en revistas profesionales médicas descubrió que 74% de ellos excluían a personas con dominio
limitado del inglés. Presentó además los fundamentos científicos y éticos para usar el idioma adecuado y documentó la importancia de que profesionales capacitados realicen las traducciones.

El Dr. Flores enfatizó la importancia de traductores profesionales en servicios e investigación, y ofreció una lista obtenida de estudios de casos de lo dicho por un profesional de salud y lo que interpretó una persona no profesional. Al examinar las comparaciones, se nota el daño potencial de usar a un familiar u otro intérprete no capacitado en pacientes de cáncer con dominio limitado del inglés (Butow, et al 2013; Gany, et al 2010). El Dr. Flores enfatizó la importancia de datos de subgrupos al afirmar, “A fin de asegurar una calidad óptima en la atención de salud y resultados, atención ética e igualitaria, siempre se deben recopilar datos sobre idioma, dominio limitado del inglés y subgrupo latino de todos los pacientes, en encuestas nacionales e investigaciones”. Una vez que se recogen los datos, el desafío es analizarlos de manera que se obtengan resultados que presenten una visión más completa.

**El impacto de la investigación guiada por un marco ético.** El trabajo de Craig, Waldrop, Alema-Mensah y Crosby es un buen ejemplo de que analizar datos por subgrupo ayuda a reconfigurar asuntos. En este estudio, se analizaron datos de la Encuesta Nacional de Crecimiento Familiar (National Survey of Family Growth o NSFG) de 2006-2010 para determinar la relación entre la obesidad e infertilidad en afroamericanas y latinas en Estados Unidos. Si bien se ha estudiado la relación entre peso e infertilidad (Sharma, et al, 2013), estos resultados indicaron que no existía una relación significativa entre la obesidad e infertilidad cuando se comparaba a mujeres con peso insuficiente, normal y excesivo. Parte del espectro del peso corporal incluye a las personas identificadas como obesas o con sobrepeso. Las conclusiones revelaron que entre el 20 por ciento con infertilidad, las que tenían estudios universitarios o de posgrado eran más propensas a tener dificultad para salir embarazadas que quienes no se habían graduado de la secundaria.

Dado el impacto del tabaquismo en las comunidades hispanas, la investigación por Suvak Patnaik, Mitali Nanda, Francisco Tejeda, Muktar Alivu y Heather O’Hara ofrece soluciones. Este análisis incluyó las consecuencias para la política y defensoría, lo que incluye tendencias actuales en Estados Unidos de leyes que prohíben fumar en los centros laborales y el impacto diferencial para comunidades hispanas. Se ofrecieron recomendaciones para compañías en un estado o ciudad que no tiene una política que prohíbe fumar.

**El crucial papel de entender el contexto.** La Dra. Norma Pérez nos advirtió que incluso hay un límite en lo que pensamos que sabemos debido a las fallas en nuestros actuales sistemas. Affirmó, “El Sistema Estadístico de Datos Administrativos (Statistical Administrative Records System) es nuestra más extensa base de datos a nivel nacional que incluye información sobre el Censo. Sin embargo, no puede recopilar información sobre personas sin un número de Seguro Social y pasará por alto cierta información si la información personal de un hispano no se encuentra en el sistema principal”.

Al presentar datos, lo que claramente hace falta entender es el contexto en que los hispanos viven su vida. La reseña por el Dr. Rueben Warren de White Rage: The Unspoken Truth of Our Racial Divide deja en claro que la Dra. Carol Anderson ofreció un recuento académico de la verdad respecto a la lucha por libertad y justicia de los afroamericanos en Estados Unidos desde el periodo de la esclavitud hasta la actualidad. El libro ofrece una bibliografía para una
plétera de información histórica sobre los desafíos y éxitos en asegurar la justicia para las personas de raza negra en Estados Unidos.

Para los hispanos no existe un documento similar. Por lo tanto, no se llega a apreciar la historia de los hispanos/latinos en este continente y en Estados Unidos. Esta falta de contexto va desde no reconocer que los primeros asentamientos en este continente fueron en Puerto Rico, el oeste y sudoeste del país, (ver el recuadro de abajo) hasta las consecuencias de la mentalidad de un “Destino Manifiesto” en todo el continente americano.

- 1493 Colón llega a Puerto Rico en su segundo viaje.
- 1494 Colonos españoles llegan a México, trayendo la cultura y el idioma español y el catolicismo.
- 1565 Los españoles fundan St. Augustine (FL).
- 1598 Don Juan de Oñate empieza poblados en Nuevo México.
- 1607 Los colonos de London Company fundan Jamestown.
- 1620 Los peregrinos llegan a Plymouth Rock.
- 1803 Con la compra de Luisiana, Estados Unidos adquiere tierras que conforman todo o parte de: AR, CO, IA, KS, LA, MN, MO, NE, NM, ND, OK, SD y WY.
- 1821 España cede Florida formalmente a Estados Unidos.
- 1848 Después de la guerra entre Estados Unidos y México, el Tratado de Guadalupe Hidalgo cede tierras a Estados Unidos que conforman todo o parte de: AZ, CA, CO, NV, NM, TX, UT y WY. El tratado reconoce derechos lingüísticos, culturales y la propiedad de tierras.
- 1863 El presidente Lincoln proclama la emancipación de los esclavos.
- 1898 Termina la guerra entre España y Estados Unidos, Estados Unidos anexa Cuba y Puerto Rico.

Un llamado a la acción. Dadas las conversaciones del simposio, los documentos incluidos en este suplemento de la revista profesional y las presentaciones de la reunión, queda claro que es necesario dar tres importantes pasos:

1. Necesitamos mejores y más datos sobre los hispanos/latinos. Si bien existen más datos de los que había en décadas pasadas, el incremento de estudios y nivel de inclusión de las comunidades hispanas no ha mantenido el ritmo del aumento en grupos hispanos. Sin embargo, más no significa mejor automáticamente. La inclusión de hispanos como apenas 1% de los participantes en pruebas clínicas y 3.4% de los investigadores principales financiados por el NIH no refleja el crecimiento de las comunidades hispanas en Estados Unidos. Es necesario generar confianza y crear oportunidades de investigación que alienten a las personas a participar. Esto significa comprender por qué las personas quizás no deseen ser parte de un estudio y luego formular un plan que promueva su participación en un esfuerzo conjunto.

2. Necesitamos información y análisis más detallado a nivel individual. Los algoritmos que se basan en grupos que no son los atendidos no producen mejores resultados. La tendencia actual es atención y soluciones personalizadas, y los sistemas
de datos deben contar con la mayor información posible sobre cada persona. Cuando solo 4% de los estudios de asociación del genoma completo se han realizado en personas que no tienen ascendencia europea (Bustamante, Burchard, y De La Vega, 2011), no solo se trata de mala investigación científica, sino también poco ética.

3. **Es necesario tomar medidas pronto.** Desde el simposio de abril de 2016, nos hemos enterado de que hay una manera de explicar la longevidad en las comunidades hispanas y otras. La Paradoja Hispana parece tener un componente genético. Específicamente, “el índice de envejecimiento epigenético tiene una relación significativa con género, raza/origen étnico y, en menor medida, con factores de riesgo de enfermedades coronarias pero no los resultados de incidentes de enfermedades coronarias. Estos resultados pueden ayudar a explicar el índice de mortalidad más bajo que se observa en hispanos, afroamericanos mayores y mujeres (Horvath *et al.*, 2016)”. Es más, el esfuerzo de SOL nos ha demostrado que la investigación impulsada por la comunidad es eficaz y puede movilizar rápidamente a las comunidades hispanas para participar de manera significativa en estudios que mejorarán la base científica para todos.

Debemos tomar medidas ahora, pues la salud pública se encuentra ante un precipicio, y lo que hagamos ahora definirá el futuro. Debemos avanzar juntos, de manera ética, con el objetivo principal de mejorar la salud pública en la vanguardia. Todos los participantes en las deliberaciones del Foro de Ética en Salud Pública de 2016 y quienes leyeron los estudios recopilados en esta edición especial del *Journal of Healthcare, Science and the Humanities* tienen la esperanza de que avancemos hacia una base científica que refleje lo mejor de la ciencia. Se espera que al usar la perspectiva de ética en la salud pública, que incluye la participación de la comunidad, beneficencia y justicia social, este foro haya proporcionado recursos adicionales para que los científicos de salud pública, investigadores y profesionales en el campo, defensores de la comunidad y las propias comunidades comiencen a diseñar, realizar, implementar, evaluar e interpretar datos para mejorar la salud hispana/latina.

**Fuentes**


Cimons, M. CDC Says It Erred in Measles Study: Health agency failed to tell parents that one of two vaccines used on infants in L.A. during epidemic was experimental, officials say. *Los Angeles Times*. 17 de junio de 1996


Norman, K. Hispanics Remain Minority in Clinical Trials. Applied Clinical Trials, 1 de febrero de 2011.


Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection

Jane L Delgado, PhD, MS
President and CEO
National Alliance for Hispanic Health
Tel: 202-797-4321
Email: jdelgado@healthyamericas.org

Rueben Warren, DDS, Dr. P.H., MDiv
Professor and Director
National Center for Bioethics in Research and Health Care at Tuskegee University
Tel: 334-724-4554
Email: warrenr@mytu.tuskegee.edu

With one in six persons in the United States being Hispanic, over 60 million people, the need for improved health data systems that reflect the Hispanic health experience are critical to improved health and health services. Yet efforts to improve data collection must function in an environment burdened by the historical experience of Hispanic communities not being included. Consequently, the design of data collection systems has resulted, at best, with misinformed research and, at worst, with outcomes resulting from unethical research practices. Understanding the ethical dimensions of health data collection is critical to a renewed focus on Hispanic and community health and well-being. To advance the field of public health ethics, on April 22, 2016 the National Center for Bioethics in Research and Health Care of Tuskegee University, in collaboration with the Centers for Disease Control and Prevention (CDC), Morehouse School of Medicine, National Hispanic Medical Association, National Alliance for Hispanic Health and Hispanic-Health Serving Health Professions Schools, convened the “2016 Public Health Ethics Forum: Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection.”

Based on the input of a broad group of informants, the goal of this pivotal meeting was to understand the ethical framework of data collection in Hispanic/Latino communities and to fill the knowledge gaps and offer tools for use by future investigators. The drivers for the discussion among the leading experts and the papers that were produced included: (1) the number of Hispanics in the United States, (2) the necessity to have better data, and (3) the urgency to make public health decisions in an ethical framework. In this synthesis, we highlight: basic information about the Hispanic/ Latino population, major insights from the exceptional presentations, and recommendations for the future.

In July 2015 the Census Bureau reported that the total population of the U.S. (50 states and the District of Columbia) was 321,418,820 (US Census Bureau, July 2015). Of these 197,993,993 were White alone (not Hispanic or Latino); 56,569,712 were Hispanic or Latino; 42,748,703 were Black or African American alone; 17,999,454 were Asian alone; 8,356,889 were two or more races; and, 3,857,026 were American Indian and Alaska Native. Moreover, although the US Census has collected data from Puerto Rico since 1910, the 3,411,307 residents are not included in these numbers. When you add the population data for Puerto Rico,
the result is that there are over 60 million Hispanics in the U.S. The major driver of growth in the Hispanic/Latino population has been births in the U.S. (Stepler and Brown, 2016).

Nevertheless, existing systems for collecting data, especially in health and public health have not adequately included Hispanics. For example, Hispanics only account for about 1% of clinical trial participants, meaning that most treatments and medicines Hispanics take today did not have adequate research data to understand any differential impacts (Norman, 2011). Furthermore, despite the National Institutes of Health (NIH) publicly stating that a more diverse research workforce is a priority and also stating that community-based participatory research is the gold standard, only 3.4% of NIH-funded principal investigators are Hispanic; less than half their representation among those with biomedical doctoral degrees (Oh, Galanter, Thakur, et al, 2015). Bridging this gap between the stated urgency for a more robust and diverse science base and representative inclusion of Hispanics/Latinos in the research enterprise, was a major theme throughout the meeting with a majority of the presentations focusing on how to solve this glaring omission.

**Setting the Ethics Challenge.** Dr. Eliseo Pérez-Stable set the tone by his keynote, in which he made clear inclusion of all communities in clinical trials was critical to good science. Such inclusion would lead to better conclusions as nearly 40% of the population is Hispanic, African American, Asian, or Native American. He went on to discuss the valuable contributions made by the Study of Latinos (SOL) conducted by the National Heart, Lung, and Blood Institute (NHBLI). The SOL, not only enhanced a fuller understanding of cardiovascular health and Hispanics, it demonstrated how research can be done well, in a community-led framework. The participation of over 16,000 Hispanics in the SOL study stands as a living challenge to the misguided notion that Hispanic communities will not participate in health research efforts. Dr. Eliseo Pérez-Stable emphasized that the need for more and better research was clear and challenged participants to move the field forward.

**The Historical Framework – An Ethical Challenge.** While research is essential, it must be done in a framework that is ethical; particularly in light of the historical context of health and medical research in underserved communities. Key to ethics is establishing trust with the communities that are included in the research. Informed consent is fundamental to ethical research. Yet, the evidence reveals that there have been major gaps in informed consent and as a result, violated the communities included in the research. Kimberly N. Whitley, a descendant of one of the participants in the United States Public Health Syphilis Study (USPHS) at Tuskegee makes it clear in her paper that, “The legacy and truth of the USPHS Syphilis Study at Tuskegee are still held by living, descendant family members. Until that truth is fully revealed, the legacy of the USPHS Syphilis Study at Tuskegee will remain in question.” The issue of trust and the lack of trust go beyond the Syphilis Study at Tuskegee family descendants, as the repercussions are felt throughout the research enterprise and in targeted communities.

The USPHS Syphilis Study at Tuskegee, however, was not an isolated event. In 2005 Professor Susan Mokotoff Reverby of Wellesley College uncovered U.S. led syphilis experiments in Guatemala. She found the evidence of this untold story while looking at historical documents about the Syphilis Study at Tuskegee. In the Guatemala study doctors infected soldiers, prostitutes, prisoners, and mental health patients with syphilis and other sexually transmitted infections. Many of these doctors were the same ones who conducted the Syphilis Study at
Tuskegee. Another example of how lack of trust was promoted occurred in Puerto Rico. In 1955, a large clinical trial of birth control pills was tested on women in Puerto Rico. Many of the women were not fluent in English and could not read. The researchers thought the latter would help document whether the pills could be used anywhere in the world (contraceptive trials, 2016).

Today’s Ethical Challenge – Getting the Data Right. Ethical violations are not just a historical issue. In 1996, it was reported that, “A government-sponsored study of two measles vaccines, begun in 1989 during a major U.S. epidemic and conducted on nearly 1,500 minority infants in Los Angeles, failed to disclose to parents that one of the vaccines was experimental (Cimons,1996).” Most of the children who were in the study were Hispanic or African American. The need for public health ethics was essential then, and even more so now. Both D. Rodriguez-Lainz and Dr. Flores provided the conference with a rich discussion of the strategies and tactics research can employ that are ethical and produce meaningful results.

In the paper coauthored by Rodriguez-Lainz, McDonald, Pennman-Aguilar and Barrett, Dr. Rodriguez-Lainz states, “Public health ethics is an emerging discipline that has expanded upon the related fields of clinical ethics, research ethics, and bioethics.” Dr. Rodriguez-Lainz et al go even further and elaborate on the implications of the four Belmont principles (justice, beneficence, non-maleficence, and respect for persons) to public health ethics. He discussed the rationale and methodology for enhanced data elements and language access for understanding Latino/Hispanic health to provide a meaningful assessment of demographic growth and health trends for the United States. He makes clear that key elements to include in a robust health and health care data system are detailed Hispanic origin subgroup, primary language, and migration-related factors.

For Hispanics, this often means designing a research protocol that will be able to incorporate persons with varying degrees of language proficiency. According to the US Census (2013), there are 16.4 million Hispanics or about 1 in every 4 Hispanics who rate their English speaking ability less than “very well.” Yet research presented by Dr. Glenn Flores shows that a review of major medical journal studies found that 74% excluded persons of limited English proficiency. He goes on to present the scientific and ethical basis for using the appropriate language and documents the importance of having translations by a trained professional.

Dr. Flores’ research emphasizes the importance of trained professional translators in services and research and provides a list drawn from case studies of what was said by a health professional, and how it was translated by a lay person. Looking at the comparisons reveals the harm that may be done when using family members or other non-trained interpreters for LEP cancer patients (Butow, et al 2013; Gany, et al 2010). Dr. Flores makes the case for the importance of subgroup data by stating, “To ensure optimal healthcare quality and outcomes, ethical care, and equity, language, LEP, and Latino subgroup data should always be collected for all patients, national surveys, and research.” Once the data are collected, the challenge is to analyze these data in a way to get results that provide a more complete picture.

The Impact of Research Guided by an Ethics Framework. The work of Craig, Waldrop, Alema-Mensah, and Crosby is a good example of how analyzing data by subgroup helps to reframe issues. In the study presented, data were analyzed from the 2006-2010 National
Survey of Family Growth (NSFG) to determine the association between obesity and infertility in African American and Latina women in the United States. While body weight has been studied for its association with infertility (Sharma, et al, 2013), these results indicated that there was not a significant relationship between obesity and infertility when compared to underweight/normal/overweight women. Part of the spectrum of body weight includes those persons identified as overweight or obese. Findings revealed that of the 20% who experienced infertility, those with a college or graduate school education were more likely to experience difficulties getting pregnant than those with less than a high school diploma.

Given the impact of smoking on Hispanic communities, the paper by Suvak Patnaik, Mitali Nanda, Francisco Tejeda, Muktar Alivu, and Heather O’Hara, offers solutions. This review included the implications for policy and advocacy including current U.S. trends for laws mandating smoke free workplaces and the differential impact for Hispanic communities. Recommendations were offered for companies in a state or city that did not have a smoke free policy.

The Critical Role of Understanding Context. Dr. Norma Pérez warns us that there are limitations to even what we think we know because of flaws in our existing systems. She states, “The Statistical Administrative Records System is our largest national data base that includes Census information. However, it cannot gather information on persons found without a Social Security Number and it will miss information if a Hispanic’s personal information is not found in the mainstream system.”

While presenting facts, what is clearly missing is the context in which Hispanic lives are lived. Dr. Rueben Warren’s review of White Rage: The Unspoken Truth of Our Racial Divide makes clear that Dr. Carol Anderson provided a scholarly account of the Truth regarding the African American struggle for freedom and justice in the United States from the period of enslavement until today. The book provides a ready reference for a plethora of historical information about the challenges and successes in assuring justice for Black people in the United States.

For Hispanics, no similar document exists. Thus, there is a lack of appreciation about the history of Hispanics/Latino on this continent and in the U.S. This lack of context ranges from not recognizing that the first settlements on this continent were in Puerto Rico, the West, and Southwest, (see chart below) to the implications of a “Manifest Destiny” mindset, and its consequences throughout the Americas.

- 1493  Columbus in his second voyage lands in Puerto Rico.
- 1494  Spanish colonizers arrive in Mexico, bringing Spanish culture, language, and Catholicism.
- 1565  St. Augustine (FL) is founded by the Spanish.
- 1598  Don Juan de Oñate begins settlements in New Mexico.
- 1607  Jamestown is founded by London Company colonists.
- 1620  Pilgrims land at Plymouth Rock.
- 1803  Under Louisiana Purchase, US buys lands that form all or part of: AR, CO, IA, KS, LA, MN, MO, NE, NM, ND, OK, SD, and WY.
- 1821  Spain formally cedes Florida to the US.
A Call to Action. Given the symposium discussions, the papers that are included in this journal supplement, and the presentations at the meeting, three key steps are clear.

1. **We need more and better Hispanic/Latino data.** While there are more data than there were in past decades, the growth of studies and level of inclusion of Hispanic communities and researchers have not kept up with the growth of Hispanic populations. The inclusion of Hispanics as only 1% of clinical trial participants and 3.4% of NIH funded principal investigators is not keeping pace with the growth of Hispanic communities in the U.S. We need to build trust by creating opportunities for research that encourage people to participate. This means understanding the reasons people may not want to be part of a study and then drawing up a plan that engages them in a joint effort.

2. **We need more detailed information and analysis at the individual level.** Algorithms that are based on populations other than the ones being served do not result in better outcomes. When the trends are towards personalized care and solutions, data systems need to have as much information as possible on each person. When only 4% of genome-wide association studies have been conducted with persons of non-European descent (Bustamente, Burchard, and De La Vega, 2011), it is not only bad science, but unethical science.

3. **We need to move quickly.** Since the April 2016 symposium, we have learned that there is a way to explain the longevity in Hispanic communities and other communities. The Hispanic Paradox seems to have a genetic component. Specifically, “epigenetic aging rates are significantly associated with sex, race/ethnicity, and to a lesser extent with CHD risk factors, but not with incident CHD outcomes. These results may help elucidate lower than expected mortality rates observed in Hispanics, older African-Americans, and women (Horvath et al, 2016).” Furthermore, the SOL effort has shown us that community-led research is effective and can quickly mobilize Hispanic communities to participate in meaningful health research that will improve the science base for all.

We need to take these steps now as we are at a precipice in public health where the actions we take will define the future. We need to move forward together, ethically, and with the goal of improving public health at the forefront. It is the hope of all who participated in the 2016 Public Health Ethics Forum deliberations and who read the papers gathered in this special edition of the Journal of Healthcare, Science and the Humanities that we will move forward to a science base that reflects the best in science. Using the lens of public health ethics (which includes community engagement, beneficence and social justice), hopefully this forum has provided additional tools for public health scientists, researchers and practitioners and community advocates and communities themselves to design, conduct, implement, evaluate and translate data to improve Hispanic/Latino health.
References


Cimons, M. CDC Says It Erred in Measles Study: Health agency failed to tell parents that one of two vaccines used on infants in L.A. during epidemic was experimental, officials say. Los Angeles Times. June 17, 1996


Norman, K. Hispanics Remain Minority in Clinical Trials. Applied Clinical Trials, Feb 1, 2011.


Articles


Commentary: What Does It All Mean? And, So What? Three Main Points to Discuss When Looking at Hispanic Data

Norma A. Pérez, MD, DrPH
Director, Hispanic Center of Excellence
Assistant Professor of Internal Medicine-Geriatrics and Preventive Medicine and Community Health
Vice President, Hispanic Serving Health Professions Schools
University of Texas Medical Branch
Email: noaperez@utmb.edu

Abstract

Since the beginning of time, people have walked through known and unknown territories. Through fields with permission and without permission. Although we ourselves have placed blocks to that travel, broken bridges to cross, and drawn imaginary borders to identify ownership, these actions will not stop the eternal incandescent traveler seeking new land for opportunities, spiritual or physical growth, security, and survival. Because of the borders that we have placed on the land that all humans share, we must also keep track of the number of individuals who come and go for economics sake. The US/Mexico history tells us that the number of individuals living in a particular place will vary and obtaining an accurate count can be a continual struggle. Currently, the US can account for two underlying issues when addressing Hispanics. These two issues are: 1) the undocumented populations ranging from Mexico to the most recent years’ outburst due to the war with drugs from Central and South America and 2) the uninsured populations. These populations go hand-in-hand with those that are undocumented and those that hold a job without health benefits. Unlike other inconsistencies found in large data sets, which may be easily recoded, deleted, or marked as
incomplete, the data that we are referring to here is not gathered therefore not identifiable. This may confound the issues or contribute to skewed representation of the Hispanic populations.

Introduction

Not much has changed from the time of the early centuries, where people walked to get to their new destination. History tells us when harvesting season came, the northerners from Asia would travel to the south to Latin America to grow crops for their long journey back to the north and for a half of a year’s supply of food until the next harvesting season would come. Of those traveling, some survived and others would die due to the long travels, dehydration, or illness, or would simply settle along the way. We don’t experience those type of travels anymore, because we have modern transportation, but individuals who live in neighboring countries, such as Mexico, travel by foot to get to the land of the opportunity, not to harvest, but with very similar circumstances, to work and stock up for another season of labor. This simple everyday practice makes it difficult to keep track of those who come in and out of the country. Unlike Mexicans, Central and South Americans travel by train, plane, or boat; thus, their entry into the country is most likely accounted for.

According to the Economic Commission for Latin America and the Caribbean (2016), in 2014, 12 million Mexicans lived outside of their country and Colombia was the second most common South American country to have the most migrants. Indeed, 70% of all Latin American immigrants live in the US and approximately 4% of all Latin Americans migrate (“Emigrantes colombianos, los segundos en América Latina: México, el país con más nacionales que residen fuera de sus fronteras,” 2014). These numbers do not match up with the US Census for Hispanics.

According to the US Census, Hispanics constitute almost 18% of the nation’s total population. Of these, 64% are of Mexican descent with an approximate annual increase of 2% (US Census, 2015). These increases may be due to the current job and life insecurity present in Latin America due to the war in drugs, but it is important to note that the US shares history with Mexico dating back as far as the 1600’s. In 1691, Texas was named the first Spanish province and Mexico in 1852 sold almost 80% of its remaining land to the US. In 1917, Mexican workers were permitted to enter the US to work while in the 1930s Mexicans were deported back to Mexico. Though in 1940 the largest ethnic group to serve in World War II would be the Hispanics and, as a result of the labor shortage, the US agreed to permit Mexicans re-entry into the country to fill that gap. In 1954-1964, the Bracero Program was enacted, which brought more than 350,000 Mexican workers into the US. In Operation Wetback, 1954-1958, the US deported millions of undocumented Mexican workers.

Under the Reagan administration, millions of undocumented Mexicans received amnesty. With the launch of NAFTA in the early 1990’s, Californians passed Proposition 187, which allowed undocumented immigrants to receive public education and benefits from welfare and health care. Two years later, this legislation became unconstitutional. As you may observe, the fluctuation, coming, and going of Hispanics into and out of the US has been there all along. Therefore, the Census data shouldn’t sound alarming. On the contrary, it would behoove us to learn from history to better understand the dynamics and maybe properly know how to gather data from this large and ongoing population that we know today as the majority minority group (Public Broadcasting Service, 2013).
As a first generation college graduate, Mexican American, and with a strong interest in health care for all, I know it can be a daunting task, but doable if all those who share the same passion come together. When asked to speak at the 2016 CDC Forum on Hispanic Health Data, I was eager to share three points I have come to observe as a researcher in Hispanic health and as a Hispanic who lives and breathes what general lay Hispanics live and breathe. Our goal should be focused on improving Hispanic health and increasing Hispanic research participation, raising awareness of the health issues and ethics involved.

With that being said, I believe we are in need of a framework to provide a more accurate picture of the complexity of the Hispanic communities. One can consider the next three studies as the fathers of the recent era of Hispanic research. One of the largest and most successful research studies in the US on Hispanics is The Study of Latinos (SOL). Since 2006, 16,415 community residents from Bronx, Chicago, Miami, and San Diego have been surveyed and received a clinical examination. The main goal of this study was to identify risk factors that may have a protective or harmful role in the development of cardiovascular disease. This study was unique in the sampling because it targeted areas with a large concentration of Hispanics and intra-ethnic Hispanic groups. The Bronx represented Puerto Ricans; Chicago and San Diego represented Mexicans; and Miami represented Hispanics of Cuban descent (US Department of Health and Human Services, 2013).

The professor who coined the term Hispanic Paradox, Dr. Kyriakos Markides at the University of Texas Medical Branch, directs the largest and longest epidemiologic study on Hispanic elderly residing in five southwestern states (Arizona, California, Colorado, Texas, and New Mexico), The Hispanic Established Populations for Epidemiologic Studies of the Elderly (EPESE) dates back to the early 1990’s. This study was modeled after the design of the EPESE, 1981-1993. The sole purpose of the Hispanic EPESE was to provide estimates of the prevalence of key physical health conditions, mental health conditions, and functional impairments in older Mexican Americans and to compare these estimates with those for other populations. The Hispanic EPESE attempted to determine whether certain risk factors for mortality and morbidity operate differently in Mexican Americans than in non-Hispanic White Americans, African-Americans, and other major ethnic groups (Markides, 2009).

And finally, Dr. David E. Hayes-Bautista, Professor of Medicine and Director of the Center for the Study of Latino Health and Culture at the School of Medicine, UCLA, has brought light to Americans about the Mexican celebration, Cinco de Mayo. As Dr. Hayes-Bautista explains, the holiday is not Mexican at all, but rather an American one, created by Latinos in California during the mid-nineteenth century. Hayes-Bautista shows how the meaning of Cinco de Mayo has shifted over time: it embodied immigrant nostalgia in the 1930s, US patriotism during World War II, Chicano Power in the 1960s and 1970s, and commercial intentions in the 1980s and 1990s. For the past four years, Dr. Hayes-Bautista has been chosen one of the 101 Top Leaders of the Latino Community in the U.S. by Latino Leaders Magazine (Hayes-Bautista, 2012).

These fundamental studies provide us a place to begin in identifying the framework or frameworks that ultimately will help us identify the heterogeneity of Hispanics. The following are three points of discussion for the acquisition, retention, dissemination, and utilization of health data of undocumented and uninsured Hispanics.
Disparate Relationship

What does this mean? When we are looking at large data systems, we must be aware of the potential for misrepresentation that could lead to a Disparate Relationship.

The Statistical Administrative Records System is our largest national data base that includes Census information. However, it cannot gather information on persons found without a Social Security Number and it will miss information if a Hispanic’s personal information is not found in the mainstream system. The data base may include some of the uninsured, but it may not include the undocumented. Dr. Hayes Bautista notes, “The problems inherent in modern-day U.S. Census data – the chronic undercount of Latinos; difficulties in defining exactly who is a Latino; respondents’ confusion over not just race vs national origin but also self-identification as Hispanic – already were evident in censuses from 1850 to 1910.” (Introduction) These are issues that prevail in large data sets and as researchers we have not been able to compensate for the lack of data. As I prepared for the 2016 Public Health Forum, Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice, I thought of interviewing Karl Eschbach, PhD, Texas State Demographer for 2008-2010, as he has experienced, first-hand the issues of the data gathering and incorporation of data into the large data sets. Dr. Eschbach noted, “Working with the Texas Office of Rural and Community Affairs, we found that modelled data like the Census Bureau’s small area income and poverty estimates that are based on administrative records or general population surveys under-represent need for communities with large immigrant populations—a group that is missing from both types of data systems” (personal communication, April 3, 2016). This speaks of the lack of data from the marginalized immigrant population, thus a gap in representation for health care needs.

Numerator/Denominator Mis-Match

In the first U.S. Census in 1790, Hispanics were not identified separately. For the most part, Hispanics were fit into the White category, leaving the identification of Latinos/Hispanics vague. It wasn’t until 1930 that a category of Mexican was added to the Census. It was dropped from the list for four censuses and Hispanic origin was introduced in the 1970 census as a sample item. Since 1980, Hispanic has been a complete count census item (Pratt, Hixson, & Jones, 2015). This alone speaks of our reality when interpreting and utilizing data. The Hispanic ethnicity is a true and an all-American construct based on our reality that the U.S. is a melting pot. As scientists, we find reasons to form groups to identify patterns and as people we form groups for self-identity. Because of the inherent flaws of data gathering, we can find it difficult to merge large data sets, what I would call a mis-match of merging of data sets; the lack of sensitivity and accuracy of where Hispanics are and where they are not is important to any researcher; and finally, the increase of sharing data that authorities are not paying attention to. If not corrected, we will continue to miss populations, and we may overlook local or regional data that could be shared.
Privacy

My third point is the enactment of the Affordable Care Act. It has been noted in the literature that more have access to health care, but there is a greater distinction of those who are not legal, thus increasing lack of privacy and health disparity for disenfranchised populations. With the Affordable Care Act and the requirement for health insurance, the distinction between the insured and uninsured is much more obvious (Wallace, Torres, Sadegh-Nobari, Pourat, & Brown, 2012).

Discussion

We know that there is a rich history of Hispanics in the US and we can conclude that Hispanics are different from other populations in embracing their social relations, social structures, and family nucleus. Because of such complexity, they are difficult to identify as they engage differently from the mainstream American population. As scientists, we have not been able to define the heterogeneity of the Hispanic population from the socioeconomic status, occupational status, sexual orientation, sociocultural environments, Limited English Proficiency status, and health literacy to name a few. In 2012, the New York Times published the article, “For many Latinos, racial Identity is more cultural than color” (Navarro 2012). The main point of this article was the broad spectrum of people who identified themselves as Latino or Hispanics. Most based their identity on cultural concepts and did not identify with any of the race categories that the Census provided. Dr. Mary C. Waters, a Sociology Professor at Harvard, expounds, “Whenever you have people who can’t find themselves in the question, it’s a bad question.” (Navarro 2012). Hispanics identify themselves culturally, not racially and that is why it was so important for me to participate in the 2016 Public Health Ethics Forum at the CDC. We want to be respectful of people’s beliefs and values and we want to accurately see our populations and the health issues they are dealing with.

I interviewed Dr. Markides for this Forum and he said, “We have not yet understood the implications of rapidly growing numbers of older disabled Mexican Americans with respect to their dependence on their families. There is a need to systematically investigate how high rates of comorbidity, disability and cognitive impairment/dementia are influencing the quality of life of older Mexican American and other Hispanics and what the consequences of these trends are for the quality of life of their families” (personal email communication, April 3, 2016).

We are facing health crises that have significant social impact. In order to respond to these challenges effectively, we need to be able to identify them.
References


Getting the Data Right for Latinos: Appropriate Language and Subgroup Data are Critical for Public Health and Social Justice

Glenn Flores, MD, FAAP
Distinguished Chair of Health Policy Research
Medica Research Institute
Affiliate Professor of Public Health
Division of Health Policy and Management, University of Minnesota School of Public Health
Research Affiliate
Department of Health Sciences Research, Mayo Clinic
Mail Code CW105, P.O. Box 9310
Minneapolis, MN 55440-9310
Tel: (952) 992-3367
Fax: (952) 992-3367
E-mail: Glenn.Flores@Medica.com

Author Note

Abstracto
Latinos forman el mayor grupo minoritario racial, compuesto por dos terceras partes de Americanos con capacidad y entendimiento limitada de la lengua Inglesa (PLE). Este artículo demuestra la importancia de datos demográficos en subgrupos latinos para poder implementar medidas apropiadas de salud y justicia social. Los objetivos de este trabajo son evaluar: 1) prevalencia de PLE en latinos de los EEU, 2) como PLE impacta la salud social de este subgrupo, 3) Por que LEP es la mejor medida para entender impacto que deficiencia del Ingles tiene sobre datos, 4) colección de información acerca de PLE y salud social de este subgrupo por medio a investigación clínica, y 5) la importancia de colección de datos en subgrupos latinos demostrando el impacto que PLE tiene en la interacción de médicos con pacientes, calidad y certeza de información intercambiada en consultas, satisfacción de pacientes de los servicios proveídos, y su seguridad. Y, aunque PLE es la mejor medida de tal impacto, pocos centros de salud colectan información correlacionando variables que pueden mejorar el servicio ofrecido, peor no existen métodos de colección nacional tampoco. De hecho los datos disponibles muestran que 74% de encuestas excluyen PLE. Disparidad igual o mas alta que esa reportada acerca de otros grupos minoritarios existe en grupos Latinos. Por tanto optima salud social, eficiente, de equidad, y flexible debe tomar en cuenta si los participantes entienden las preguntas (Ingles o Español). De no ser así datos colectados no representan la realidad de los subgrupos Latinos.
Abstract

Latinos are the largest US racial/ethnic minority group, and they comprise two-thirds of Americans with limited English proficiency (LEP). This article addresses why accurate, appropriate language and subgroup data for Latinos are critical for public health and social justice. The objectives are to examine: 1) LEP prevalence among US Latinos; 2) how language barriers impact healthcare; 3) why LEP is the best measure for assessing language barriers; 4) collection of language and LEP data in clinical settings and research; and 5) the importance of collecting data on Latino subgroups. Language problems impact multiple aspects of healthcare, including access, health, service use, patient-clinician communication, satisfaction with care quality, and patient safety. LEP is the best measure of the impact of language on healthcare, but most hospitals and medical practices do not collect any language data and rarely collect LEP data, and no national surveys collect LEP data. A systematic review documents that 74% of studies exclude LEP subjects. Substantial healthcare disparities exist by Latino subgroup, which can equal or exceed those among major racial/ethnic groups. To ensure optimal healthcare quality and outcomes, ethical care, and equity, language, LEP, and Latino subgroup data should always be collected for all patients, national surveys, and research.

Keywords: Language, Hispanic Americans, Latinos, healthcare disparities, data collection, clinical research protocols, minority health, subgroups

Introduction

Latinos are the largest racial/ethnic minority group in America, numbering 56.6 million people and comprising 18% of the US population (US Census Bureau, 2016a). Latinos also account for almost two-thirds of Americans with limited English proficiency (LEP) (US Census Bureau, 2016b). This article addresses why accurate and appropriate language and subgroup data for Latinos are critical for public health and social justice. The five objectives are to: 1) examine LEP prevalence among US Latinos; 2) review how language barriers impact health and healthcare; 3) establish why LEP is the best measure for assessing language barriers in healthcare; 4) address the collection of language and LEP data in clinical settings, national surveys, and research; and 5) demonstrate the importance of collecting data on Latino subgroups.

LEP Prevalence in US Latinos

The world’s population of 7.3 billion people inhabits 195 countries and speaks 7,097 languages (US Census Bureau, 2016c; US Department of State, 2016; Ethnologue, 2016). LEP is defined by the US Census Bureau as a self-rated English speaking ability of less than “very well,” when given the following four choices to describe English proficiency: very well, well, not well, and not at all (US Census Bureau, 2013). Between 1990 and 2015, the number of people in the US speaking a language other than English at home rose from 31.8 million to 64.7 million, and the number of LEP Americans grew from 14 million to 25.9 million (US Census Bureau, 1995; US Census Bureau, 2016b). Over 11.9 million school-age children (22%) speak a language other than English at home, a number which has tripled since 1979, and 2.4 million school-age children (5%) are LEP (US Census Bureau, 2016d; Federal Interagency Forum on Child and Family Statistics, 2015).
Latinos who speak Spanish comprise the vast majority of both Americans who speak a language other than English at home and those who are LEP. Of the 64.7 million American who speak a language other than English at home, over 40 million (62%) are Latinos who speak Spanish (US Census Bureau, 2016b). Among the 25.9 million LEP Americans, Latinos comprise 16.4 million, equivalent to 64% (US Census Bureau, 2016b). By comparison, 19% of LEP Americans speak Asian and Pacific Islander languages, 14% speak other Indo-European languages, and 4% speak one of the remaining other languages (US Census Bureau, 2016b).

**How Language Barriers Impact Health and Healthcare**

Title VI of the Civil Rights Act of 1964 states that denial or delay of medical care for LEP patients due to language barriers constitutes a form of discrimination, and requires that all healthcare providers and institutions caring for Medicaid- or Medicare-covered patients to provide adequate language assistance to LEP patients (US Department of Health & Human Services, 2016). Nevertheless, decades of research documents that language problems continue to impact multiple aspects of health and healthcare, including access to healthcare, health status, use of health services, patient-healthcare provider communication, satisfaction with care, quality of care, and patient safety (Flores, 2005). For example, in psychiatric settings, compared with English-proficient patients, LEP patients have a greater likelihood of a diagnosis of more severe psychopathology, are more likely to leave the hospital against medical advice, are less likely to establish a good rapport with the physician or other healthcare provider, are less likely to receive an adequate explanation of their therapeutic regimen, and are less likely to give feedback to their physician or other healthcare providers (Flores, 2005).

**Communication**

Language barriers can have a profoundly adverse impact on communication between healthcare providers and LEP patients and families. In particular, ad hoc interpreters—which include family members, friends, untrained medical staff, and strangers from the waiting room or street—can result in especially deleterious consequences for LEP patients and families. For example, recent studies document the exceptionally egregious hazards of using ad hoc interpreters for LEP cancer patients (Table 1).

A study of a major pediatric residency program (Burbano O’Leary et al., 2003) found that 68% of the pediatric residents spoke little or no Spanish, and 53% of non-Spanish-proficient residents used inadequate language skills in patient care often or daily. Many of the pediatric residents reported that LEP families under their care never or only “sometimes” understood their child’s diagnosis (noted by 53% of residents), medications (28%), discharge instructions (43%), and follow-up plan (40%). Eighty percent of residents avoided all communication with LEP families. Although all of the pediatric residents agreed that hospital interpreters were effective, 75% reported never/only sometimes using hospital interpreters. A study of 128 pharmacies in a major US city (Bradshaw et al., 2007) found that 47% of pharmacies can never or only sometimes provide non-English-language (NEL) prescription labels; over half of pharmacies (54%) never or only sometimes can provide NEL information packets, including 15% who can never provide NEL packets; and about 2/3 of pharmacies (64%) never or only sometimes can orally communicate in NELs, including 1 in 6 who never can orally communicate in NELs.
**What Physician Stated in English** | **How Physician’s Statement Was Interpreted by Ad Hoc Interpreter**
--- | ---
“We think there is a 40% chance that the treatment will prolong your life.” | “The treatment will prolong your life”
“The doxyb could hurt your heart.” | “The doxy can give you pain.”
“The results of these tests lead me to conclude that you do have breast cancer.” | “This test will tell me if you have cancer.”
“One important thing that you have going for you is the fact that the cancer has probably been caught early.” | “One important thing is the fact that the cancer is working quickly in your body.”

---

**Table 1.** The hazards of using ad hoc interpreters for LEP cancer patients.a

<table>
<thead>
<tr>
<th>What Physician Stated in English</th>
<th>How Physician’s Statement Was Interpreted by Ad Hoc Interpreter</th>
</tr>
</thead>
<tbody>
<tr>
<td>“We think there is a 40% chance that the treatment will prolong your life.”</td>
<td>“The treatment will prolong your life”</td>
</tr>
<tr>
<td>“The doxyb could hurt your heart.”</td>
<td>“The doxy can give you pain.”</td>
</tr>
<tr>
<td>“The results of these tests lead me to conclude that you do have breast cancer.”</td>
<td>“This test will tell me if you have cancer.”</td>
</tr>
<tr>
<td>“One important thing that you have going for you is the fact that the cancer has probably been caught early.”</td>
<td>“One important thing is the fact that the cancer is working quickly in your body.”</td>
</tr>
</tbody>
</table>

---

a Data sources: Butow et al. (2013) and Gany et al. (2010).
b Refers to doxycycline, a chemotherapeutic agent.

---

**Health Processes, Outcomes, and Use of Services**

Interpreter services have been shown to positively impact health outcomes. In a study of children presenting to the emergency department, LEP patients with professional interpreters did not differ from English-proficient (EP) patients in test costs or use of IV hydration, and had a lower likelihood of testing (Hampers & McNulty, 2002). LEP patients with Type 2 diabetes mellitus who have trained professional interpreters are two times more likely than EP patients to receive care meeting American Diabetes Association guidelines, three times more likely than EP patients to have dietary consults, and do not differ from EP patients in 18 other processes/outcomes (Tocher & Larson, 1998). In patients with hypertension and diabetes, health status, physical functioning, psychological well-being, health perceptions, and pain scores are higher (i.e., better) in those with language-concordant vs. language-discordant physicians (Pérez-Stable et al., 1997).

---

**Quality and Patient Safety**

A study of a large children’s hospital in the Pacific Northwest revealed a twofold increased risk (odds ratio, 2.3; 95% confidence interval, 1.1–4.8) of serious medical events in Spanish-speaking patients requesting an interpreter vs. those not requesting interpreter (Cohen et al., 2005). Serious medical events included 10-fold medication errors, missed or delayed diagnoses, failure to monitor patients, diagnostic procedures performed on the wrong patient, incorrect diagnostic procedure performed, and administration of breast milk to the wrong patient. A published case describes a two-year-old child who fractured her clavicle after falling off her tricycle; a resident physician misinterpreted two Spanish words, diagnosed child abuse, and contacted Department of Social Services, who, without an interpreter, had the mother sign over custody of both of her children (Flores et al., 2000). In another case, a 10-month-old girl with iron-deficiency anemia was given a 13-fold overdose of iron and hospitalized for iron
intoxication after her LEP parents were given medication instructions and a prescription only in English (Flores, 2006a). The parents gave 15 ml. of iron elixir based on prescription label that read: “15 mg per 0.6 ml, 1.2 ml daily.” Misinterpretation of single Spanish word (“intoxicado”) in a Florida case resulted in an 18-year-old’s quadriplegia after being misdiagnosed with drug overdose; the patient’s hematomas, brain-stem compression, and paralysis were due to a ruptured aneurysm, and the hospital paid $71 million in a malpractice settlement (Harsham, 1984).

In a recently published case which occurred at a major children’s hospital (Flores, 2014), a six-month-old, previously healthy infant boy presented to an emergency department (ED) with vomiting and diarrhea. The triage history given by the mother was interpreted by the boy’s 12-year-old sister (and no medical interpreter was requested). The sister stated that the patient had four dirty diapers and three episodes of vomiting that day. The boy was triaged to a non-urgent level of care, in which documentation stated he had vomited seven times that day with no diarrhea. He was discharged shortly thereafter with a diagnosis of vomiting, and with instructions only in English for rehydration solution by mouth. Three days later, the boy returned to the ED in severe distress, with new onset of bloody stools. The boy was admitted to the hospital, and died six hours later of septic shock.

**Errors in Medical Interpretation and Their Clinical Consequences**

A recent study of interpreter errors and their potential consequences in LEP patient encounters in the emergency department compared professional medical interpreters vs. ad

<table>
<thead>
<tr>
<th>Statement</th>
<th>Translation of Spanish</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother: <em>La semana pasada, a él le dio mucho mareo, y no tenía fiebre ni nada, y la familia por parte de papá todos padecen de diabetes.</em></td>
<td>Last week, he had a lot of dizziness, and he did not have fever or anything, and his dad’s family all suffer from diabetes.</td>
</tr>
<tr>
<td>Doctor: Uh-hum</td>
<td></td>
</tr>
<tr>
<td>Mother: <em>A mí me da miedo porque él lo que estaba mareado, mareado, mareado y no tenía fiebre ni nada.</em></td>
<td>I’m scared because he’s dizzy, dizzy, dizzy and he didn’t have fever or anything.</td>
</tr>
<tr>
<td>Doctor: Ok. So she’s saying you look kind of yellow, is that what she’s saying?</td>
<td></td>
</tr>
<tr>
<td>Patient: ¿Es que si me vi amarillo?</td>
<td>Is it that I looked yellow?</td>
</tr>
<tr>
<td>Mother: Estaba como mareado, como pálido.</td>
<td>You were like dizzy, like pale.</td>
</tr>
<tr>
<td>Patient: Like I was like paralyzed, something like that.</td>
<td></td>
</tr>
</tbody>
</table>

* Data sources: Flores (2006b) and Flores et al. (2012).

*Figure 1.* Multiple omissions and false-fluency errors committed during an encounter in which a 12-year-old male presented to the emergency department with dizziness, and no interpreter was provided.*
hoc interpreters (family members, friend, untrained medical staff, and people pulled from the waiting room or street) vs. no interpreters (Flores et al., 2012). A total of 1,884 interpreter errors were noted; 18% had potential clinical consequences. The proportion of errors of potential consequence was significantly ($P < 0.001$) lower for professional (12%) vs. ad hoc (22%) vs. no interpreters (20%). Among professional interpreters, prior hours of interpreter training, but not years of experience, were significantly associated with error numbers, types, and potential consequences. The median errors by professional interpreters with $\geq 100$ hours of training was 12, vs. 33 for those with $< 100$ hours of training ($P < 0.01$). Those with $\geq 100$ hours of training committed lower proportions of errors of potential consequence overall (2% vs. 12%; $P = 0.03$) and in every error category. An example of multiple omissions and false-fluency errors committed when a 12-year-old male presented with dizziness and had no interpreter is summarized in Fig. 1.

The authors concluded that, compared with ad hoc interpreters and having no interpreter, professional hospital interpreters result in significantly lower proportions of omissions, false-fluency errors, and errors of potential clinical consequence, and that ad hoc interpreters and having no interpreter can cause miscommunication, a lower quality of care, and interpreter errors that have the potential to cause medical errors (Flores et al., 2012).

**LEP is the Best Measure for Assessing Language Barriers, But Collection of Language Data in Healthcare and Research is Inadequate**

*The Substantial Variability in Methods for Collecting Language Data*

There is a bewildering array of methods for collecting language data in healthcare. Such substantial variation can lead to inconsistencies, misclassifications, failure to identify LEP patients, and inability to provide language services to those who need them. Methods for collecting language data on patients and families include a positive response or nod of the head to the question, “do you speak English?”; the “quick take” of an untrained registration clerk or researcher using no formal screening question; the language of interview for forms or surveys; asking what is the “preferred language”; whether or not a patient or family requests an interpreter; the primary language spoken at home; and US Census questions on a language other than English spoken at home and LEP.

**LEP is the Best Measure for Assessing Language Barriers**

In spite of the tremendous variation in how language data are collected, the evidence clearly documents that LEP is the best measure of language barriers in healthcare. A study of 1,100 children and caregivers (Flores et al., 2005) compared the primary language spoken at home versus parental LEP and their associations with health status, access to care, and use of health services in children. In multivariable analyses adjusting for 11 covariates, parental LEP was shown to be associated with triple the odds of a child having fair or poor health status, double the odds of a child spending at least one day in bed for illness in the past year, and significantly greater odds of children not being brought in for needed medical care for six of nine access barriers to care (couldn’t afford medical care, being uninsured, the staff doesn’t
understand my culture, transportation difficulties, appointment difficulties, and the clinic is too far away). In contrast, the primary language spoken at home was not associated with any health-status or access outcome in the multivariable analyses.

**The Collection of Language Data in Clinical Settings and National Surveys is Unacceptably Low**

Although decades of research documents that language barriers impact health and healthcare, the collection of language data in clinical settings is unacceptably low. A national survey of 272 hospitals revealed that only 39% collect data on patients’ primary language, and no statistics are available on what proportions of hospitals or health plans collect LEP data, if any (Hasnain-Wynia et al., 2004). A national survey of internists showed that 65% have active LEP patients, but few practices have a formal mechanism for obtaining data on patients’ primary language, only 28% record patients’ primary language in the medical record, and there is no mention of whether any LEP data are collected (American College of Physicians, 2007).

Despite clear evidence that LEP is the best measure of language barriers in healthcare, no national surveys (to my knowledge) currently collect LEP data, and some national surveys collect no language data. A review of current practices in seven major national surveys reveals that three surveys collect no language data of any kind, two collect data on the language usually spoken at home, one records both the primary language spoken at home and the language of interview, and none assesses LEP (Table 2).

**Table 2.** The collection of language data in seven major national surveys.

<table>
<thead>
<tr>
<th>Survey Name</th>
<th>Language Measure Use in Survey</th>
<th>LEP Assessed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Health Interview Survey (NHIS)</td>
<td>Interview language</td>
<td>No</td>
</tr>
<tr>
<td>National Health and Nutrition Examination Survey (NHANES)</td>
<td>Language usually spoken at home&lt;sup&gt;b&lt;/sup&gt;</td>
<td>No</td>
</tr>
<tr>
<td>National Survey of Family Growth (NSFG)</td>
<td>Language(s) usually spoken at home&lt;sup&gt;c&lt;/sup&gt;</td>
<td>No</td>
</tr>
<tr>
<td>State and Local Area Integrated Telephone Survey (SLAIITS)</td>
<td>Primary language spoken in the home and interview language&lt;sup&gt;d&lt;/sup&gt;</td>
<td>No</td>
</tr>
<tr>
<td>National Vital Statistics System</td>
<td>None&lt;sup&gt;e&lt;/sup&gt;</td>
<td>No</td>
</tr>
<tr>
<td>National Death Index</td>
<td>None&lt;sup&gt;f&lt;/sup&gt;</td>
<td>No</td>
</tr>
<tr>
<td>National Ambulatory Medical Care Survey (NAMCS)</td>
<td>None&lt;sup&gt;g&lt;/sup&gt;</td>
<td>No</td>
</tr>
</tbody>
</table>

Three decades of research documents that the exclusion of LEP subjects from clinical research is rampant. A 1996 analysis of 172 studies published in major medical journals revealed that 74% excluded LEP subjects (Frayne et al., 1996). The most common reason for excluding LEP subjects was not having thought of issue, at 51%. Barriers to enrolling LEP subjects cited included lack of preexisting instruments in the target language (58%), the need to translate responses into English (55%), the expense of instrument translation (45%), and recruitment of bilingual staff (45%). Of those researchers who enrolled LEP subjects, however, 95% spent < 1/5 of the study budget to include LEP participants, 36% needed no additional funds to include LEP subjects, and 32% believed that the study results would have been different if LEP subjects were excluded (Frayne et al., 1996).

But a 2015 study showed that English-proficiency requirements for study participants have actually increased over time (Egleston et al., 2015). This analysis of 10,311 ClinicalTrials.gov protocols from before 1995 through 2013 documented that 7% of studies overall required patients to be EP, and English-proficiency requirements in clinical trials have increased steadily from a low of 1.5% of studies in 1995-1999 to 9% in 2010 or later. The study showed that the US Federal Government (13.2%) and NIH (6.1%) have significantly higher English-proficiency requirement rates vs. industry (2%). English-proficiency requirements were found to vary by intervention category, with the highest proportion in behavioral trials, at 28%, followed by trials of procedures (8%), devices (5%), and biologicals (0.4%).

Perhaps the persistence of unacceptably high rates of exclusion of LEP participants from clinical research should come as no surprise, given that there is insufficient federal and international guidance on inclusion and enrollment of LEP research subjects. A review of policies and procedures on 30 US Institutional Review Board (IRB) websites, including 23 top-ranked medical schools in research, revealed that although 97% addressed translating the complete consent document, only 53% discussed language barriers in research, 40% provided guidance on using interpreters, and 20% addressed ethical or legal problems in enrolling subjects when there are language barriers (Resnik & Jones, 2006). Indeed, only 17% of the IRB websites addressed problems with excluding LEP subjects from research, and a mere 7% provided guidance for translating other research materials, such as questionnaires, surveys, and brochures. One key conclusion by the study authors was: “Intentionally excluding LEP people would be unfair to potential LEP subjects. Principles of justice, discussed in The Belmont Report, requires fair procedures and outcomes in subject selection. It is unfair to exclude research subjects from a study without a valid scientific or ethical reason” (Resnik & Jones, 2006). The authors also cogently point out that “Intentionally excluding LEP persons may violate federal research regulations, which state: ‘Selection of subjects should be equitable. In making this assessment, the IRB should take into account the purposes of the research and the setting in which the research will be conducted and should be particularly cognizant of the special problems of research involving vulnerable populations (45 C.F.R. 46.111(a)(3) and 21 C.F.R. 56.111(a)(s))’” (Resnik & Jones, 2006).

The Ease of Assessing LEP in Clinical Settings and Research

It is easy to assess patient and family LEP in clinical practice and research, and it requires very little time. Three simple questions US Census Bureau questions determine
whether the person speaks a language other than English, what that language is, and the self-rated ability to speak English (Fig. 2).

<table>
<thead>
<tr>
<th>14a. Does this person speak a language other than English at home?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes</td>
</tr>
</tbody>
</table>

b. What is this language?
(For example: Korean, Italian, Spanish, Vietnamese)

c. How well does this person speak English?

- □ Very well
- □ Well
- □ Not well
- □ Not at all

Any response to 14c other than “very well” (i.e., well, not well, or not at all) is classified as limited English proficiency (LEP).

Data sources: US Census Bureau (2013)

**Figure 2.** Determining whether a person has limited English proficiency using US Census Bureau questions from the American Community Survey.

Any person who confirms that a language other than English is spoken at home and reports a self-rated ability to speak English of anything other than “very well” is classified as LEP.

**The Importance of Collecting Data on Latino Subgroups**

Substantial health and healthcare disparities exist in the US by Latino subgroup. These subgroup disparities may equal or exceed those among the major racial/ethnic groups in America. But Latino subgroup data are not consistently collected in clinical practice, national surveys, or healthcare systems.

For example, a nationally representative analysis of US children in the late 1990s (Fig. 3) revealed that Cuban children had the lowest poverty rate of the Latino subgroups, a rate which was lower than Asian/Pacific Islander children and approached that of white children, whereas Mexican-American children had a poverty rate which was approximately equivalent to that of African-American and American Indian/Alaska Native Children, and Puerto Rican children had a poverty rate which exceeded that of all of the major racial/ethnic groups and all other Latino subgroups (Flores et al., 1999). For going more than a year since the last physician visit, however, Mexican-American children had the highest rate and Puerto Rican children the lowest rate when compared with all other racial/ethnic groups and Cuban children.

The authors concluded that Latino subgroup differences in demographics, health, and use of services equal or surpass differences among major ethnic groups. In multivariable analyses (adjusting for family income, parental education, and other relevant covariates), almost all Latino subgroup disparities persisted in suboptimal health status, an excessive time interval since the last physician visit, and the numbers of bed days for illness and physician visits in the past year.
A recent analysis of the prevalence of cardiovascular-disease risk factor among six Latino subgroups in the US revealed marked and significant differences which included percentage-point differences of up to 13 for hypertension in males, 10 for diabetes mellitus in females, 21 in female obesity, and 23 in female smoking rates (Daviglus et al, 2012). Data from nine years of the National Health Interview Survey (Borrell et al., 2009) show that the prevalence of diabetes mellitus is highest among African-Americans, at 10%, and differs little between Latinos (7.4%) and whites (7%). Examination of diabetes prevalence among six Latino subgroups, however, reveals that Puerto Ricans have the highest prevalence (11%), exceeding that of African-Americans, and South and Central Americans have the lowest prevalence (4%), well below that of whites (Fig. 4).

Many of these subgroup disparities in diabetes persisted after multivariable adjustment for relevant confounders, underscoring that failure to examine Latino subgroups would mask subgroup disparities of importance for public and population health.

Similarly, a study of cancer mortality in Florida (Martinez-Tyson et al., 2009) found that Latinos had lower overall male and female mortality, compared with whites, but analyses of four Latino subgroups revealed particularly high rates among Cubans (approaching those of whites among females), whereas Mexican Americans had approximately half the mortality rate of Cubans (Fig. 5).

Figure 5. Age-adjusted cancer mortality rates in the state of Florida for whites, Latinos, and Latino subgroups.

Data sources:
- Borell et al. (2009)
- Martinez-Tyson et al. (2009)
A recent study revealed that Latino subgroup differences in HIV mortality almost span the spectrum of HIV disparities among the major racial/ethnic groups (Clark et al., 2015). US HIV mortality rates among African-Americans (122.2 deaths per 100,000) and Latinos (28.3/100,000) are considerably higher than among whites (11.2/100,000). Among Latino subgroups, HIV mortality rates range from as low as 16.9/100,000 among Mexican-Americans to high as 100.9/100,000 (Fig. 6).

Figure 6. Age-adjusted HIV mortality rates in the US for whites, African-Americans, Latinos, and Latino subgroups.a

Conclusions

In conclusion, 16.4 million Americans (1 in 18) are LEP and speak Spanish. Language problems impact multiple aspects of healthcare, including access to healthcare, health status, use of health services, patient-clinician communication, satisfaction with care, quality of care, and patient safety. LEP is the most helpful data source in assessing the impact of language on health and health care, but most hospitals and medical practices do not collect any kind of language data and rarely collect LEP data, and no national surveys in the US collect LEP data. A review of major medical journals documents that 74% of studies exclude LEP subjects, with the most common reason being not having thought of issue.

Substantial health and healthcare disparities exist by Latino subgroup. These subgroup disparities may equal or exceed those among major racial/ethnic groups. Failure to collect Latino subgroup data can result in adverse consequences which can include over-testing of low-risk subgroups and under-diagnosis and inadequate treatment of high-risk subgroups.
To ensure optimal healthcare quality and outcomes, ethical care, and equity, data on the languages spoken at home, LEP, and Latino subgroups should always be collected for all patients and primary caregivers of children, on national surveys of health and healthcare, and in health and healthcare studies.

References


Getting Data Right — and Righteous to Improve Hispanic or Latino Health

Alfonso Rodríguez-Lainz, PhD, DVM, MPVM¹, Mariana McDonald, DrPH, MPH, MA², Ana Penman-Aguilar, PhD, MPH³ and Drue H. Barrett, PhD⁴
¹ Division of Global Migration and Quarantine, NCEZID, CDC; ² Office of Health Disparities, NCEZID, CDC; ³ Office of Minority Health and Health Equity, CDC; ⁴ Public Health Ethics Unit, Office of Scientific Integrity, Office of the Associate Director for Science, CDC

Corresponding author: Alfonso Rodríguez-Lainz, PhD, DVM, MPVM
Epidemiologist, U.S.-Mexico Unit, Division of Global Migration and Quarantine
Centers for Disease Control and Prevention
3851 Rosecrans St., Suite 715
San Diego, CA 92110
Tel: (619) 692-8406
Fax: (619) 692-8821
Email: jqi3@cdc.gov

Mariana McDonald, DrPH, MPH, MA
Associate Director of Health Disparities
Director, Office of Health Disparities
National Center for Emerging and Zoonotic Infectious Diseases
Centers for Disease Control and Prevention
1600 Clifton Road NE, Mailstop D-62
Atlanta, Georgia 30333
Tel: (404) 639-7921
Fax: (404) 639-7562
Email: mmcdonald@cdc.gov

Ana Penman-Aguilar, PhD, MPH
Associate Director for Science
Office of Minority Health & Health Equity (OMHHE)
Centers for Disease Control & Prevention (CDC)
4770 Buford Highway NE – Mailstop K77
Atlanta, GA 30333
Tel: (770) 488-8194
Email: bpv4@cdc.gov
Author Note

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Abstract

Hispanics or Latinos constitute the largest racial/ethnic minority in the United States. They are also a very diverse population. Latino/Hispanic’s health varies significantly for subgroups defined by national origin, race, primary language, and migration-related factors (place of birth, immigration status, years of residence in the United States). Most Hispanics speak Spanish at home, and one-third have limited English proficiency (LEP). There is growing awareness on the
importance for population health monitoring programs to collect those data elements (Hispanic subgroup, primary language, and migration-related factors) that better capture Hispanics’ diversity, and to provide language assistance (translation of data collection forms, interpreters) to ensure meaningful inclusion of all Latinos/Hispanics in national health monitoring. There are strong ethical and scientific reasons for such expansion of data collection by public health entities. First, expand data elements can help identify otherwise hidden Hispanic subpopulations’ health disparities. This may promote a more just and equitable distribution of health resources to underserved populations. Second, language access is needed to ensure fair and legal treatment of LEP individuals in federally supported data collection activities. Finally, these strategies are likely to improve the quality and representativeness of data needed to monitor and address the health of all Latino/Hispanic populations in the United States.

Keywords: Hispanic health, Latino health, health equity, health disparities, public health ethics, data collection, language access, limited English proficiency

Introduction

The 55.2 million Hispanics or Latinos (the terms “Hispanic,” “Latino,” and “Latino/Hispanic” are used interchangeably in this report) constitute the largest racial/ethnic minority group in the United States (Stepler & Baron, 2016). The U.S Office of Management and Budget (OMB) currently defines “Hispanic or Latino” as U.S. residents of Cuban, Mexican, Puerto Rican, South or Central America, or “other” Spanish culture or origin. Hispanic origin is based on self-identification, and can be viewed as the heritage, nationality group, lineage, or country of birth of the person or the person’s parents or ancestors before arrival in the United States. People who identify their origin as Hispanic or Latino may be any race (Office of Management and Budget [OMB], 1997).

Latinos/Hispanics are among the most culturally, linguistically, and racially diverse populations in the United States. They trace their roots to many ancestral origins, mostly from Latin American and Caribbean countries. The majority are of Mexican origin, followed by Puerto Ricans, Salvadorans, and Cubans. Many consider themselves to be “Afro-descendent” or of “indigenous background” (Krogstad & Lopez, 2016; Lopez & Gonzalez-Barrera, 2016). Nearly three out of four Hispanics speak Spanish at home, while others are monolingual English speakers or speak one of the many indigenous languages from Latin America (Stepler & Baron, 2016).

For decades, adverse economic conditions, political unrest, wars, insecurity, and environmental disasters in Latin American countries have propelled millions to seek a more secure and prosperous life for themselves and their families in the United States. The arrival of immigrants and their U.S.-born children has been a major driver behind Latino population growth and diversity (Pew Research Center, 2015).

There is strong evidence that determinants of health and health outcomes of Latinos/Hispanics in the United States vary significantly for subgroups defined by national origin, race, primary language, place of birth, and migration-related factors such as years of residence in the United States and immigration status (DHFS, 2014; Dominguez et al., 2015; Singh, Rodríguez-Lainz, & Kogan, 2013; Singh & Lin, 2013). For example, the age-adjusted percentage of adult Hispanics in the United States with multiple chronic conditions
(including hypertension, coronary heart disease, diabetes, cancer, or asthma) was lower than among non-Hispanics (20.8% vs. 24.6%); however, the percentage for Hispanics of Puerto Rican origin (27.3%) was higher than for non-Hispanics (Lucas, Freeman, & Adams, 2016). As illustrated in Figure 1, adult Hispanics have overall lower health insurance coverage compared to non-Hispanic Whites, while Mexican foreign-born individuals experience the greatest health insurance disparity (Singh & Lin, 2013). Language and migration-related characteristics of foreign-born parents affect the health and access to healthcare of their children born in the United States (Singh & Lin, 2013; Pastor, Reuben & Duran, 2015).

The following examples illustrate the importance of collecting expanded detailed (“granular”) racial and ethnic data, language, and migration-related data in order to identify health needs and disparities among Latino/Hispanic subpopulations. That conclusion is supported by multiple reports by federal agencies, advisory groups, non-governmental organizations, and health researchers that have recommended collecting those data elements in a way that properly represents the increasing racial, cultural and linguistic diversity of the U.S. population in general and Latinos in particular, and can assist with identifying underserved subpopulations.


*Born in Puerto Rico

Note: Adjusted for age, gender, marital status, education, poverty, and employment

Figure 1. Lack of health insurance coverage (%) for adult Non-Hispanic (NH) Whites and selected Hispanic-origin subgroups by place of birth (NHIS 2008-2010)
Such information is considered important for monitoring and eliminating health disparities in the United States (Department of Health and Human Services [DHHS], 2005, 2014; Dominguez et al, 2015; Dorsey et al., 2014; Institute of Medicine [IOM], 2009; National Research Council [NRC], 2004; Richardson, 2016). Title VI of the Civil Rights Act of 1964 (Title VI), which prohibits intentional discrimination of the basis of race, color or national origin in the provision of any services supported by federal funds, provides the legal foundation for the collection of race, ethnicity and primary language (as a proxy for national origin) data (Perot & Youdelman, 2001). Thus the collection of these data elements is also important for monitoring nondiscrimination in the provision of health services (Dorsey et al., 2014; NRC, 2004).

In addition to gathering these expanded data elements, there is another data collection issue especially relevant to Hispanics: language access. Because the majority (73%) of Hispanics speak Spanish at home, and nearly one-third have LEP (Stepler & Baron, 2016), it is important to implement strategies that facilitate Latino participation in data collection activities (DHHS, 2013a). Important ethical and scientific questions include the following: If data collection methods are designed exclusively for English-fluent Hispanics, who is being excluded? Is it ethical to exclude those populations? How does this exclusion affect the representativeness and quality of data collected? In 2000, Presidential Executive Order 13166 directed each federal agency to develop a plan to ensure that the programs and activities they normally provide in English are accessible to LEP persons and thus avoid discrimination on the basis of national origin in violation of title VI of the Civil Rights Act of 1964” (U.S. Department of Justice, 2000). The National Standards for Culturally and Linguistic Appropriate Services (CLAS), which also apply to public health programs, recommend offering language services to individuals with LEP (DHHS, 2013a).

Gathering the needed expanded data elements in a linguistically and culturally appropriate way is critical to: a) ensure fair representation of Latinos/Hispanics’ subpopulations in federal data collection systems; b) monitor health status and identify priority community health problems, including health disparities; c) design and implement linguistically and culturally appropriate public health interventions; d) ensure fair and effective policies and distribution of public health resources and actions; and d) evaluate effectiveness, accessibility, and quality of health services (Dorsey et al., 2014; NRC, 2004; Public Health Functions Steering Committee, 1994).

In this paper the authors provide additional background on the growth and diversity of the Latino/Hispanic population in the United States. The authors then discuss gaps in the availability and quality of national Latino health data. Next the authors propose strategies for consideration by public health programs to expand and enhance Latino health data, based on guidance and recommendations from the U.S. Department of Health and Human Services (DHHS), other organizations and researchers. Both the suggested expanded data elements and provision of language access in data collection are discussed. Finally, the authors provide both scientific and ethical rationales for implementation of the proposed strategies. While this paper focuses on Latinos/Hispanics, this discussion is relevant to all population health data collection implemented or supported by federal agencies, including national population-based surveys, research, public health surveillance, disease registries, and other activities used to assess and monitor the health of the U.S. population.
Latinos/Hispanics in the United States: Growth and Diversity

To better illustrate why and how enhanced data elements and language access are important for Latino/Hispanic health, we provide a review of demographic growth and trends for this population in the United States. The percentage of Latino/Hispanics in the United States has surged over the past decades, from 3.5% to 17.3% of the total U.S. population between 1960 and 2014. In some states, including some non-traditional destinations for Hispanics (i.e., places to which Hispanics have not historically emigrated in large numbers, such as Georgia and Colorado), the Hispanic population growth has been even more accelerated (Turner, Wildsmith, Guzman & Alvira-Hammond, 2016).

Latinos/Hispanics are the youngest major racial or ethnic group in the United States, with a median age of 28 years (19 years for U.S.-born Hispanics), compared to 33 years of age for African-American, 36 years of age for Asians, and 43 years of age for Whites (Stepler & Baron, 2016). Mexicans are by far the largest Hispanic origin group (35.4 million or 64.0% of all Latinos/Hispanics), followed by Puerto Ricans (5.3 million or 9.6%) and Salvadorans (2.1 million or 3.8%). For Latinos/Hispanics, the concepts of race and ethnicity are complex and varied. According to surveys by the Pew Research Center, 26% of adult Latinos/Hispanics in the United States self-identify as Afro-Latino, Afro-Caribbean, or of African descent with roots in Latin America, while only 18% of those report their race as black or African-American. Similarly, 25% say they are of indigenous background, while only 0.9% report their race as American-Indian or Alaska Native, as defined by the U.S. Census Bureau (Krogstad & Lopez, 2016; Lopez G & Gonzalez-Barrera, 2016; Stepler & Baron, 2016).

Most Latinos/Hispanics living in the United States (65%) are U.S.-born. This includes 8.5 million Puerto Ricans, both on the island of Puerto Rico and in the U.S. Puerto Rican diaspora, who are U.S. citizens by birth. Among the 35% of Hispanics who are foreign-born, the majority are from Mexico (60.2%). The percentage of foreign-born varies widely across Hispanic origin groups. For example, 65% of Hondurans and Colombians and 32.9% of Mexicans living in the United States are foreign-born. In terms of immigration status, 76.8% of Hispanics are U.S. citizens (either U.S.-born or naturalized). More than three-quarters of foreign-born Latinos have been living in the United States for more than 10 years (Stepler & Baron, 2016).

Most (73.0%) Hispanics speak Spanish at home, and 25.8% speak only English (Stepler & Baron, 2016). English proficiency varies by Hispanic origin, nativity, education, gender, age, and years residing in the United States, among other factors. For example, 50% or more of Salvadorans, Guatemalans, and Hondurans, respectively, have LEP, compared to 32% of Mexicans and 17% of Puerto Ricans. By nativity, 65.6% of foreign-born Hispanics have LEP vs. 10.6% of U.S.-born Hispanics. A higher percentage of Hispanic adults have LEP compared to children 5 to 17 years old (38.2% vs. 12.4%, respectively). As would be expected, longer residence in the United States is associated with increasing English proficiency among the foreign-born (Stepler & Baron, 2016).

Latinos/Hispanics have the lowest healthcare insurance coverage of any racial/ethnic group in the United States (Smith and Medalla, 2015). The magnitude of this disparity varies by Latino/Hispanic origin, and is primarily driven by very low coverage among the foreign-born (Smith and Medalla, 2015). Latinos/Hispanics also have lower educational attainment and higher rates of living in poverty compared to other racial/ethnic groups (Stepler & Baron,
A high proportion of Latinos report experiencing discrimination because of their race, ethnicity, or assumed immigration status (Ayón, 2015; Krogstad & Lopez, 2016).

Are Latino/Hispanic Health Data Needs Being Met?

This snapshot of Latino/Hispanic demographics demonstrates Latinos’ growing significance as a share of the total U.S.-population, as well as a major driver in the United States’ sociodemographic diversity. As a consequence, Latino/Hispanic health is highly relevant to the overall future health of the nation. Thus it is important to ensure that data collected and reported by national data systems is of quality and representative of diverse Hispanic subpopulations.

Limitations in the inclusiveness, specificity, availability, and quality of Latino/Hispanic health data, has been widely noted in various landmark reports and studies (DHHS 2005, 2014; Dominguez et al., 2015; Dorsey et al., 2014; IOM, 2009; NRC, 2004). Reported data gaps for Latino/Hispanic health include:

a. Lack of collection, analysis, and/or reporting of ethnicity, primary language, place of birth, length of time in the United States and immigration status in public health information systems (Beltran et al., 2011; DHHS, 2005; Dominguez et al., 2015; Dorsey et al., 2014; IOM, 2009; Johnson, Blewett, & Davern, 2010; NRC, 2004).

b. Lack of collection detailed Hispanic subgroup information. By grouping diverse Latino/Hispanic subpopulations together for statistical and programmatic purposes into a broad and single “Hispanic” ethnic category, important differences in risk factors and health disparities affecting those subpopulations are likely to be missed, and thus remain unaddressed (DHHS, 2005, 2014; Singh, Rodriguez-Lainz, & Kogan, 2013).

c. Even when data elements are included in data collection instruments, the elements may not actually be collected. This problem can be widespread, such as in the National Notifiable Disease Surveillance System, in which more than half of reported cases lack ethnicity information (Adekoya, Truman, & Ajani, 2015).

d. Questionable validity of information due to limited translation and lack of cultural validation of data collection instruments and/or availability of qualified Spanish-English interpreters to facilitate communication with people with LEP (Landrine & Corral, 2014; Li et al., 2001).

e. Lack of representation due to non-inclusion or small/inadequate sample sizes of Latino/Hispanic subpopulations. Many national Latino/Hispanic health statistics are likely driven by the health of Mexicans, given their overrepresentation among Hispanics (Logan & Turner, 2013).

Given these gaps, it is no surprise that for many health issues, the United States currently has an incomplete picture of the health of Latino/Hispanic subpopulations, their burden of disease, and their risk factors. The reasons for these limitations and gaps in Latino/Hispanic health data can be multiple. One challenge is the complexity of the concepts of race and ethnicity and the categories used to collect them, which may be confusing or even considered inappropriate by respondents (OMB, 2016). Federal initiatives are underway to improve the collection and acceptability of racial and ethnic information by federal programs, including the U.S. Census Bureau (OMB, 2016).
In addition, multiple regulation, statutes, policies and practices influence what data are collected; these vary across federal agencies and over time (Perot & Youdelman, 2016). For many federal programs there is no requirement to collect race, ethnicity, language or migration-related data (Perot & Youdelman, 2016). Missing information may be due to questions not being asked or responders refusing to provide personal information (Perot & Youdelman, 2001).

Uniformity and comparability of federal statistics depends on the existence of standards for collection and on those being properly implemented. The Office of Management and Budget (OMB) has developed standards for collecting and presenting data on race and ethnicity (OMB, 1997). Currently there are no federal standards for language or migration-related data (Perot & Youdelman, 2016). The current (1997) OMB data standards require federal agencies to use a minimum of two ethnic categories when collecting and reporting population information: “Hispanic or Latino” and “Not Hispanic or Latino” (OMB, 1997). The OMB directive permits, and encourages, the collection of more detailed racial and ethnic categories, provided they can be aggregated to the minimum standard categories (OMB, 1997). However, according to OMB, the minimum reporting categories have often been misinterpreted as the only permissible ones (OMB 2016). That might partly explain the limited availability of detailed racial and ethnic data in federal statistics. In 2011, DHHS published new data standards that included more detailed racial and ethnic categories (beyond OMB 1997 minimum standards) and also (for the first time), the requirement to collect primary language. However, DHHS data standards apply only to federally-supported population-based surveys and have not been fully implemented (DHHS, 2011).

**Data Needed to Capture Hispanic or Latino Population’s Diversity**

As indicated earlier, there has been growing awareness among federal agencies, advisory groups and health researchers, about the importance of collecting standardized data elements that would allow better assessment of health disparities within racial and ethnic minority subgroups and other underserved communities, and evaluate efforts addressing them (DHHS, 2005, 2014; Dominguez et al., 2015; Dorsey et al., 2014; IOM, 2009; NRC, 2004; Wildsmith, Ansari & Guzman, 2015; Richardson, 2016)

The two data elements for which there is greater consensus in terms of their priority for data collection are more "granular" (that is, detailed) racial and ethnic origin subcategories and primary language (Beltran et al., 2011; Blendon et al., 2007; Dean et al., 2016; DHHS, 2005, 2014; Dominguez et al., 2015; Dorsey & Graham, 2011; Islam et al., 2010; Institute of Medicine, 2009; National Committee on Vital and Health Statistics [NCVHS], 1968; NRC, 2004; Penman-Aguilar et al., 2016; Holland & Palaniappan, 2012).

These two data elements are also included in the DHHS’s 2011 Data Standards (DHHS, 2011). Although HHS data standards reportedly only apply to federally supported population-based surveys (DHHS, 2011), the Affordable Care Act (ACA) legislation on which the standards are based actually relates to “any federally conducted or supported healthcare or public health program, activity, or survey” “to the extent practicable” (Patient Protection and Affordable Care Act, 2010; Dorsey & Graham, 2011). The rationale for including expanded data elements in population surveys has relevance for many other public health data sources used to monitor the health of the U.S. population, such as surveillance systems, disease registries, and vital statistics.
Detailed Hispanic subgroup information is important to document disparities in health determinants and outcomes between and among Latino/Hispanic subpopulations (Dominguez et al., 2015; Islam et al., 2010; Logan & Turner, 2013; Lucas et al., 2016; Singh & Lin, 2013). Primary language data is needed, first and foremost, to prioritize languages for which translation and interpretation are needed for rigorous data collection and provision of public health services, activities that are highly dependent on effective communication (DHHS, 2005; IOM, 2009; NRC, 2004). Primary language also serves as a proxy for acculturation, which has been shown to affect health status and which many view as essential for identifying appropriate approaches to providing health services (NRC, 2004).

The importance of collecting migration-related data by public health data systems has been recognized for decades (NCVHS, 1968). In a globalized world, migration is a social determinant of health, which affects access to care and disease risk of migrants and their families (Gushulak, Weekers & MacPherson, 2009). In more recent years, the body of scientific evidence has grown about the diverse effects of migration-related factors (e.g., place of birth, years of U.S. residence, and citizenship) on the health of Latinos/Hispanics and other racial/ethnic minorities (Beltran et al., 2011; Blendon et al., 2007; DHHS, 2005, 2014; Dominguez et al., 2015; IOM, 2009; Islam et al., 2010; Koch-Weser et al., 2004; NRC, 2004; Singh, Rodriguez-Lainz, & Kogan, 2013). For example, compared to U.S.-born Hispanics, Hispanics born in Puerto Rico and Latin America experience greater inequities in access to care, and are at higher risk of some conditions and diseases, including neglected infections (Colson et al., 2014; Hotez, 2008; Kimbro, Gorman, & Schachter, 2012; Lu et al., 2014; Steege et al., 2014); while at lower risk for other conditions, such as breast and lung cancer (Singh, Rodriguez-Lainz & Kogan, 2013).

For Hispanics, the above-noted expanded data element recommendations point to the importance for federally-supported programs of collecting the following information in a standardized manner (DHHS, 2005, 2014; Dominguez et al., 2015; IOM, 2009; NRC, 2004; Richardson, 2016; NCVHS, 1968; Wildsmith, Ansari & Guzman, 2015):

a. **Detailed Hispanic origin subgroup.** The HHS data standards include the following subgroups: Mexican, Puerto Rican, Cuban and Other Hispanic (DHHS, 2011). Collection of additional Latino subgroups has been recommended (Wildsmith, Ansari & Guzman, 2015). Noting self-identification as Afro-Latino (increasingly referred to as Afro-descendent) or indigenous is also important.

b. **Primary language.** The 2011 HHS data standards include questions on English-speaking proficiency and language spoken at home (DHHS, 2011).

c. **Migration-related factors.** This includes Place of birth (to include the U.S. Island Territories and the specific country of birth for those born outside the United States). Other important migration-related data elements are the length of time a person has been living in the United States and immigration status (e.g., citizenship). The U.S. Census Bureau has validated questions to collect that information (U.S. Census Bureau, 2016)

(Note: For child-related data collection, all the above variables should be collected about parents (Wildsmith, Ansari & Guzman, 2015).

In addition to the collection of expanded standard data elements and provision of language access, it is also important that culturally and scientifically appropriate data collection
methodologies be used with Hispanic populations. Sampling and recruitment methods and modes of interviewing need to be appropriate to specific Latino/Hispanic subpopulations. For example, oversampling geographic areas of concentration for specific subpopulations and engaging community-based organizations or leaders to gain trust of community members (Brown, 2015). In addition, appropriate sample sizes in surveys would ensure statistical reliability of estimates for Latino/Hispanic subpopulations. Finally, targeted studies of smaller or harder-to-reach Latino/Hispanic sub-populations (e.g., farmworkers, recent immigrants, non-Spanish speaking indigenous population) could increase the likelihood of these groups being properly represented in national data sets (DHHS, 2005; NRC, 2004).

“No entiendo” (“I don’t understand”):
Provision of Language Access for Data Collection

The question of language access in data collection also looms large among data challenges impacting Latino/Hispanics’ health. If data collection instruments (printed or electronic forms) are not available in Spanish and/or Spanish-speaking interpreters are not available during data collection, a high proportion of Hispanics could be essentially excluded from the data collection activity. This issue not only affects many Latinos, but also others among the 25.3 million (9%) of the U.S. population who are LEP. (Of note, this statistic reflects an 81% increase between 1990 and 2011 (Whatley & Batalova, 2013). Populations with LEP frequently include disproportionately high numbers of vulnerable individuals, such as those living in poverty, the less educated, and the elderly (Li et al., 2001).

Ongoing federal efforts have been carried out to improve the cultural and linguistic appropriateness of healthcare services and public health programs, including the publication of national standards and DHHS’s Language Access Plan (DHHS, 2013a, 2013b). According to DHHS’s 2011 Language Access Plan, language access is achieved when individuals with limited English proficiency (LEP) (i.e., speak English less than “very well”) can communicate effectively with HHS employees and contractors and participate in HHS programs and activities (DHHS, 2013b). The DHHS Plan includes two “essential elements” of language access: a) providing oral language assistance services, such as qualified interpreters; and b) translating and making accessible “vital documents” in languages other than English (DHHS, 2013b). DHHS’s Language Access Plan states DHHS agencies must provide oral and written language services needed to assist individuals with LEP to communicate effectively with DHHS staff and contractors and gain meaningful access and an equal opportunity to participate in the services, activities, programs, or other benefits administered by DHHS. (DHHS, 2013b). In addition, HHS has strongly recommended that, among other recommendations related to cultural and linguistic appropriate services, all members of the health and healthcare community, including public health personnel, use cultural and linguistically competent personnel to collect health information from individuals (DHHS, 2013a).

Information about provision of language access by public health data systems is incomplete. It has been reported that a number of national population health surveys translate their questionnaires into Spanish and provide access to bilingual English-Spanish interviewers (Waksberg, Levine & Marker, 2000). In spite of existing federal and state language access laws specific to healthcare settings, gaps in availability and quality of language services have been reported due to lack of comprehensive implementation and enforcement (Youdelman, 2008).
Provision of language access by federal data collection systems is particularly relevant in three instances: 1) for racial/ethnic minorities with a high proportion of individuals with LEP (for example, 50% or more of Salvadorans, Guatemalans, and Hondurans are LEP); 2) geographic areas where individuals with LEP are a high proportion of the population (e.g., 19% of California’s population are LEP); and 3) for health issues and conditions for which people with LEP experience disparities (e.g., occupational health, infectious and parasitic diseases, access to health services) and/or have different risk factors compared to English-speaking individuals (Holland & Palaniappan, 2012; Hunt & Bhopal, 2004; Koch-Weser et al., 2004; Lee, Nguyen, Jawad & Kurata, 2008; Link, Mokdad, Stackhouse & Flowers, 2006).

A number of strategies have been recommended to enhance provision of language access for data collection. These include:

a. Translation of data collection instruments into the main languages spoken by individuals with LEP in the target population. Translation and back translation are the minimum recommended strategies; it is also important to ensure equivalence of meaning across languages by approaches such as cognitive testing, focus groups, and/or piloting with the target monolingual Spanish-speaking population (DHHS, 2005; Fukijishiro et al., 2010; Hunt & Bhopal, 2004; Landrine & Corral, 2014; Li et al., 2001).

b. Cross-cultural validation of data collection instruments. Questions included on data collection forms need to be conceptually and functionally equivalent for all participants, independent of their culture, preferred language, and English-speaking ability. Even when instruments are translated, measurement errors may still occur because of differences in the use and interpretation of specific terms, culturally based attitudes and beliefs about health issues (such as mental or physical well-being), inappropriate or unclear response categories, the order and context in which the items are presented, and/or differences in perceived social desirability of certain answers (DHHS 2013a; Hunt & Bhopal, 2004; Li et al., 2001; Westat 2007).

c. Use of trained interviewers and/or third-party (e.g., by phone) interpreters who are fluent in the most frequently used languages spoken by individuals with LEP in the target population. The use of community or agency staff that speak a variety of languages but are not trained interpreters should be considered with caution because of the difficulty in ensuring the quality of the interpretation. Although the use of English-speaking household members or community members as interpreters may improve participation by individuals with LEP; their use may also be a barrier to data collection because participants may be reluctant to share information about confidential or culturally sensitive topics with someone from their community (Hu, Link, & Mokdad, 2010; Hunt & Bhopal, 2004; Li et al., 2001; Link et al., 2006).

Although cost is frequently mentioned as the most significant barrier to including individuals with LEP in data collection activities, an increasing number of innovative approaches and technologies exist that can decrease such cost. For example, the rapidly expanding realm of machine translation technology can allow professional translators to focus on refining a translation, thus reducing the time required to complete a translation. Another approach worth exploring is the use or adaptation of relevant questionnaires validated by other organizations (Li et al., 2001).
Ethical and Scientific Implications of Public Health Data Collection Practices

Alongside poor language access practices, the potential negative results of current data element identification and collection practices have a number of ethical and scientific and technical implications.

A. Ethical implications: Doing “what is right”

Public health ethics is an emerging discipline that has expanded upon the related fields of clinical ethics, research ethics, and bioethics (Beauchamp & Childress, 2012; Coughlin, 2009; Ortmann et al., 2016). The discipline is also informed by public health professionals’ codes of conduct (e.g., American Public Health Association and American College of Epidemiology) and by public health core values and beliefs regarding the role of health, science, and community (American College of Epidemiology, 2000; Lee, Heilig, & White, 2012; Public Health Leadership Society, 2002).

Because of the population focus of public health, ethical considerations for public health practice include broader social and political considerations than those raised in traditional clinical or biomedical ethical questions. Thus, the field of public health ethics brings a fundamental consideration of social justice and a focus on achieving health equity. The “dream of social justice” requires that ethics be applied to all aspects of public health practice and services, including data collection. Consideration of the ethical aspects of public data collection have mainly focused on protecting privacy and confidentiality and on data use issues (Coughlin, 2006; Lee, Heilig, & White, 2012). Broader issues of data element identification and data collection have also become part of the current discourse on health equity (Beltran et al., 2011; Blendon et al., 2007; Braveman et al., 2006; Dean et al., 2016; Penman-Aguilar et al., 2016).

When exploring ethical considerations for the expansion of data elements to better meet Hispanic or Latino health needs, it is useful to consider the four basic bioethical principles (also referred to as the Belmont Principles) (Beauchamp & Childress, 2012): justice, beneficence, non-maleficence, and respect for persons, while also applying the lens of what is unique about public health ethics, (i.e., a focus on prevention and addressing the root causes of disease, achieving community or population benefit, the interdependence of people, and striving for social justice and solidarity (Ortmann et al., 2016).

a. Justice: this principle is about ensuring that social burdens and benefits are distributed fairly across populations (Heilig & Sweeney, 2010). In public health, it implies ensuring that conditions for health are available to all, especially those who are vulnerable and disenfranchised (Lee, Heilig, & White, 2012). It also means that public health actions and services should not discriminate against individuals on the basis of their race, ethnicity, nationality, religious beliefs, sex, sexual orientation, or disability (Heilig & Sweeney, 2010).

For public health data collection, first and foremost, the principle of justice supports and echoes the importance of making all Latinos/Hispanics — and subpopulations — count in all public health data collection efforts. This is related to the concept of “equity in data capture across populations” (Heilig & Sweeney, 2010). In other words,
no population (Hispanic or other population group) should be systematically and unfairly excluded from participating in a federally supported data collection activity. If there is a valid exception in which populations are knowingly excluded, we suggest that, from ethical and scientific perspectives, the onus is on the data collector to provide a valid rationale for why their data collection effort is an exception. Ensuring equity in data capture would also help fulfill the requirement for federal agencies to ensure non-discrimination on the basis of race, color, or national origin (Dorsey et al., 2014). Given that primary language is a proxy for national origin, it implies that federal data systems need effective strategies to allow individuals with LEP opportunities equal to English speakers to participate and benefit from data collection activities. Li et al (2001) have argued that equal access to federally sponsored programs (which would include national public health monitoring data systems) is a “basic civil right regardless of whether or not an individual is a fluent English speaker”.

The application of the justice principle has led to the collection and analysis of information on social determinants of health (including structural factors) and calls to identify and eliminate health disparities by addressing those determinants (Heilig & Sweeney, 2010). In public health, it is also critical to collect data to support just and equitable distribution of care and prevention resources (Lee, Heilig, & White, 2012). Failure to properly reflect Latino/Hispanic subpopulations experiencing disparities in data collection efforts is counter to, and even fails, this principle.

An ethical and social justice based approach to data collection takes pains to create and maintain community trust, ensures informed and empowered community participation, and ensures that all information collected is used to benefit affected communities (Helig & Sweeney, 2010). Timely engagement of the target communities is important prior to acquiring or disseminating data, especially when the data are sensitive or populations are particularly vulnerable (Lee, Heilig, & White, 2012). This, in turn, might help to improve the actual data collection system and increase the likelihood of the community acting on the findings (Helig & Sweeney, 2010).

b. **Beneficence** (doing good) and **non-maleficence** (doing no harm): These two complementary principles direct us to strive to maximize possible benefits and minimize possible harms of any action (Heilig & Sweeney, 2010; Beauchamp & Childress, 2012). Beneficence implies the duty to promote health by collecting, analyzing, and using data to inform and prioritize public health interventions (Heilig & Sweeney, 2010). There is also an obligation by those collecting public health information from a community to share their findings in a timely fashion, utilizing culturally and linguistically appropriate methods so that community will benefit from their participation (Heilig & Sweeney, 2010).

In particular, the collection and reporting of granular race, ethnicity, and primary language “on all public health data sets” is considered an essential component to achieving health equity (Richardson, 2016). If Latino/Hispanic subpopulations are not identified by the data system, their particular health issues are more likely to be unrecognized and, thus, ignored. Another aspect of beneficence in data collection is making language access a standard rather than an exception. Doing so will increase
the inclusion of Hispanics and make it possible for health needs and perspectives to be reflected in programs, research, and surveillance. The opposite — exclusion — is a denial of the principle of non-maleficence, or doing no harm.

Both lack of collection of data elements needed to identify Latino/Hispanic subgroups experiencing disparities and language exclusion practices can produce biased information which may cause harm, including implementation of ineffective public health interventions and misallocation of funds to the most “visible” (not necessarily most underserved) subgroups, and, ultimately, failure to prevent/control disease and reduce health disparities (Lee, Heilig, & White, 2012). Even if the appropriate data collection procedures are implemented, if data are not analyzed and reported disaggregated by Latino/Hispanic subgroups, those populations essentially remain invisible. Latino/Hispanics in the United States include many vulnerable groups, with limited social capital, including individuals with LEP, victims of human trafficking, asylum seekers, indigenous persons, migrant workers, and unauthorized immigrants (Truman et al., 2009). Because of the ethical obligation to use (i.e., act on) information collected to benefit overburdened and underserved communities and to reduce health inequities (Lee, Heilig, & White, 2012), collecting data on Latino/Hispanic subgroups will contribute to public health efforts to protect and improve the health of the most vulnerable.

Some potential harms for participants in public health data collection activities include the time burden of completing interviews and, in some circumstances, the anxiety or grief caused by sharing painful or sensitive personal information (Coughlin, 2009). Another potential harm is the stigmatization of communities by disseminating health findings that may reinforce negative social and cultural stereotypes. As a consequence, community members may experience discrimination in employment or housing, may have their access to healthcare and other public benefits limited, or have their immigration status jeopardized. Similar harms can result from breaches in confidentiality (Coughlin, 2009). The risk of community stigmatization can be reduced by emphasizing relevant structural and social determinants for the identified health disparity and highlighting strategies to address the disparity and improve the health of the community and general population. The risk of stigmatization must always be weighed against the communities’ need for information, regardless of whether the findings are troubling, so that they can mobilize to protect their own health, as well as the potential benefit of additional targeted resources to address health disparities (Heilig & Sweeney, 2010; Lee, Heilig, & White, 2012). To mitigate potential harms, the affected community should be consulted about the best communication messages and ways to disseminate the information (vs. traditional mass media messages) (Lee, Heilig, & White, 2012). Other potential harms of data collection can also be reduced by collecting individual identifiers only when absolutely necessary for public health purposes, by acquiring the minimal amount of information needed, and by developing policies and procedures that ensure appropriate access to and use of the data and protection of participants from the risk of disclosure of information (Heilig and Sweeney, 2010).
c. **Respect for persons** is the obligation to treat individuals as autonomous agents who have the ability to make their own decisions and to act on these decisions free from interference or coercion (Beauchamp & Childress, 2012). The principle of respect for persons is the underlying concept for obtaining informed consent, and it accords special protections for persons with diminished autonomy (Beauchamp & Childress, 2012; Heilig & Sweeney, 2010). In public health practice, this principle often must be weighed against the need to protect the common good (e.g., use of interventions which may limit personal autonomy, such as quarantine and isolation, when needed to control the spread of infectious diseases). For data collection, a core application of this ethical principle is the requirement to seek free and informed consent by prospective subjects for public health research (Heilig & Sweeney, 2010). Other public health data collection activities (e.g., public health surveillance) by necessity sometimes involve the collection of individual-level, identifiable data without explicit patient consent; this is justified by the obligation of public health to protect population health and prevent harm (Heilig & Sweeney, 2010; Lee, Heilig, & White, 2012). Still, those data elements must represent the minimal necessary information needed to achieve effective public health actions, and the data must be maintained securely and confidentially (Lee, Heilig, & White, 2012).

**B. Scientific and technical implications: collecting valid and representative data**

Besides these ethical considerations, failure to collect the data elements needed to properly monitor and investigate Latino/Hispanic subpopulations’ health, and to provide language access have a range of scientific and technical implications that may negatively impact the quality and usefulness of the data collected. As described earlier, lack of collection of granular ethnic and language data may hide emerging health issues and health disparities affecting Latino/Hispanic subpopulations. This may result in less-effective public health interventions and use of resources.

Failure to provide language access can potentially exclude a high percentage of the target population for a data system. Such practices can effectively make whole populations invisible and distort evidence. For example, English-only data systems could exclude the more than 32% of Hispanics that have LEP and half of all Salvadorans, Guatemalans, and Hondurans. The percentage excluded could be even larger if the target populations are adults and include a high proportion of foreign-born individuals (Landrine & Corral, 2014). Participants in English-only systems are also more likely to be U.S.-born, more acculturated, better educated, with a higher income, and better access to healthcare. This can potentially result in the introduction of additional biases in the findings (Hunt & Bhopal, 2004; Koch-Weser et al., 2004; Landrine & Corral, 2014; Lee et al., 2008; Li et al., 2001). Unbiased data collection that is complete enough to answer the public health questions of the day is a hallmark of good stewardship of public health resources.

If language access is not provided, the data system and related public health program may be less acceptable for a community with a high number of individuals with LEP if they feel excluded from participating (CDC, 2001). That may result in lower response rates, which, in turn, can cast great doubt on the representativeness of the data (Koch-Weser et al., 2004; Ladrine & Corral, 2014; Li et al., 2001).
Quality of the data can also be influenced by lack of translation of data collection forms and unavailability of qualified interpreters. If a respondent with LEP does not understand the questions being asked, and/or the person collecting the data misinterprets the participants’ responses, the validity and completeness of the information are likely to suffer (Li et al., 2001; Pastor, Reuben, & Duran, 2015; Pearson, Garvin, Ford, & Balluz, 2010). Thus, language access in data systems and programs will likely result in better data down the road.

**Conclusion - Moving Forward**

Data collection practices that have not adapted to the increased ethnic, cultural, and linguistic diversity of the United States, and objectively exclude language minorities from data collection activities, currently contribute to the near invisibility of tens of millions of persons residing in the United States, particularly many Hispanic or Latino persons. This invisibility, and the concomitant potential exclusion from public health priorities, amounts to injustice that highlights the importance of ensuring equity in data collection. The above-described challenges to the quality and representativeness of data collected by national public health monitoring systems can be expected to increase in the future as the size and share of Hispanic origin subgroups and language minority populations increase in the United States (Li et al., 2001).

A consensus on the need for collection of additional standardized data elements on Hispanic or Latino health needs, as well as improved practices to ensure language access in data collection is growing. A number of valuable tools exist to promote sound and inclusive Latino/Hispanic health-related data practices. Some of these include established national guidelines and recommendations discussed earlier. These recommendations are often feasible and achievable, as demonstrated by the data systems that have implemented most or some of those practices. For example, the National Notifiable Disease Surveillance System (NNDSS) in 2014 and Arbonet in 2016 (for Zika case reporting) added country of birth to their report forms (CDC, 2016a). In 2016, the CDC Listeria Initiative added detailed race and ethnicity, country of birth, and language, and their questionnaire is available in Spanish (CDC, 2016b). The National Immunization Survey (Child)’s questionnaire is available in Spanish and the program provides bilingual staff interviewers and use of Language Line Services for interpretation in multiple languages (U.S. National Center for Health Statistics, 2007). The 2016 questionnaire collects granular race and ethnicity information for the child and parent and the child’s country of birth (U.S. National Center for Health Statistics, 2016).

In the authors’ view, and based on the literature discussed in this paper, expansion of data element selection and collection could improve the quality and representativeness of data needed to monitor and address the health of all Latino/Hispanic subpopulations. Expanding and strengthening data collection for Latino/Hispanic health is firmly based on ethical and social justice principles. This paper has provided both ethical and scientific arguments to support those contentions. Data collection improvements are a prerequisite for identifying and addressing racial/ethnic health disparities, promoting health equity, and improving the health of an increasingly diverse nation. In this article, the authors have focused on Latino/Hispanic health, but the same arguments apply to other racial and ethnic populations which have to date been typically characterized as monolithic, such as Asian Americans.
Although implementation of these recommendations may imply the need for additional personnel and/or financial resources, the authors believe that cost alone never justifies inaction. Implementing, as resources allow, the appropriate expanded data collection practices required by the reality of 21st century U.S. population diversity is sound public health practice. The authors hope this paper will contribute to the dialogue regarding how to confront data collection challenges and address health inequities and inspire action, bringing closer the time when no Hispanic or Latino community in the United States will be “invisible” and instead all will be routinely and robustly counted and included in the nation’s public health data and intervention initiatives.

References


Exploring the Associations Between Obesity and Infertility in United States Among African American and Latina Women: Findings from the National Survey for Family Growth (NSFG)

Celene Craig, MPH
Graduate Student, Master of Public Health Program
Morehouse School of Medicine
720 Westview Drive, SW
NCPC 346
Atlanta, GA 30310-1495
Tel: (404) 285-0085
Email: ccraig@msm.edu

Reinetta Waldrop, DrPH, MSHS, FACHE
Assistant Professor, Department of Community Health and Preventive Medicine
Master of Public Health Program
Morehouse School of Medicine
720 Westview Drive, SW
NCPC 344-A
Atlanta, GA 30310-1495
Tel: 404-752-1904
Fax: 404-752-1051
Email: rwaldrop@msm.edu

Ernest Alema-Mensah, MDiv, DMin, MS, PhD
Department of Community Health and Preventative Medicine
Research Assistant Professor, Clinical Research Center
Morehouse School of Medicine
720 Westview Drive, SW
Atlanta, GA 30310-1495
Tel: 404-752-1623
Email: eamensah@msm.edu

Alex E. Crosby, MD, MPH
Branch Chief, Surveillance Branch, Division of Violence Prevention
National Center for Injury Prevention and Control
Centers for Disease Control and Prevention
1600 Clifton Rd
Atlanta, GA 30333
Tel: 770-488-4410
Email: aec1@cdc.gov
Author Note

This study was approved by the Institutional Review Board at Morehouse School of Medicine. The authors have no financial conflicts of interest to report. This article does not contain any studies with human participants or animals performed by any of the authors. The findings and conclusions in this report are those of the authors. This study was part of a preliminary Master of Public Health research study conducted at the Morehouse School of Medicine. All authors were needed to add to the current body of literature on women’s reproductive health and racial disparities that exist.

Abstract

Infertility is a major public health issue that affects over six million women in the United States (U.S.). Physical lifestyle factors like body weight may have a significant impact on a woman’s fertility status. The objective of this study was to examine the associations between obesity and infertility in African American and Latina women in the U.S. The data for this study were obtained from the 2006-2010 National Survey for Family Growth. After the exclusion criterion was applied, a total of 409 women was included in this study. Univariate analyses (descriptive frequencies), bivariate analyses (fisher’s exact tests and chi-square tests), and multivariate analyses (multivariable logistic regression) were performed on Body Mass Index (BMI), race/ethnicity, and infertility variables. Analyses were conducted using Statistical Analysis System (SAS) version 9.3. Findings revealed that twenty percent (n=81) of the 409 women experienced infertility. Of those who experienced infertility, those with a college education (OR: 5.03; 95% CI: 2.03-12.45) and those with a graduate school education (OR: 6.73; 95% CI: 2.35-19.24) were more likely to experience difficulty getting pregnant than those with less than a high school diploma. There was no significant association between BMI (underweight, normal weight, overweight, and obese) and infertility.

Keywords: women’s health, reproductive health, infertility, obesity, NSFG
Introduction

According to the Centers for Disease Control and Prevention (CDC) 2014, the World Health Organization (WHO) and the American Society for Reproductive Medicine define infertility as an actual disease. Infertility is a major public health issue affecting over six million women in the United States (Abma, Chandra, Mosher, Peterson, & Piccinino, 1997; Jain, T., 2006). A top priority for the nationally known health initiative, Healthy People 2020, is to decrease the number of people affected by infertility (Office of Disease Prevention and Health Promotion, 2016; Sharma, Biedenharn, Fedor, & Agarwal, 2013).

There are varying scientific definitions for infertility in the literature. For example, the CDC defines infertility as “the inability of couples (married or cohabitating partners) to conceive a clinical pregnancy after a year or more of unprotected intercourse” (Centers for Disease Control and Prevention [CDC], 2014). Other organizations such as the WHO define infertility as the inability to maintain or carry a pregnancy to a live birth, without regard to marital or cohabitating status (World Health Organization [WHO], 2015). For the purpose of this study, infertility was constructed to be defined as the inability of a woman to become pregnant after trying to conceive with continuous sexual intercourse for 12 months or more. This includes women who are not sterile and those who have not used contraception in the last 12 months. Also included in the definition are women who cannot maintain a pregnancy or those who cannot carry a pregnancy to term regardless of marital status or cohabitation status.

In contrast, fecundability is a term used to categorize a woman's probability of becoming pregnant in a single menstrual cycle. The term suggest that the women did not become pregnant in their previous menstrual cycle (CDC, 2014). However, impaired fecundity is a type of infertility defined by women of any marital or cohabiting status who are non-surgically sterile, who report having problems conceiving or carrying a pregnancy full-term, and women who are unable to conceive after three years of unprotected intercourse (Bitler & Schmidt, 2006). While over 7.3 million people (men and women) in general suffer from infertility in the United States, African American women are almost two times more likely to experience infertility than Caucasian women at 12% compared to 7% (Baptiste, 2014).

Involuntary infertility can present itself in different forms namely primary, secondary, and resolved infertility. According to the CDC, primary infertility is defined as a woman never being pregnant, secondary infertility as the failure to conceive after having previously delivered an infant without the use of infertility treatment, and resolved infertility as pregnancies that occur after one year of trying without medical intervention (CDC, 2014).

Certain lifestyle habits are also believed to decrease female fertility due to their effects on the female biological processes. These lifestyle habits include smoking, excessive alcohol use, physical or emotional stress, and extreme weight gain or loss (CDC, 2015).

Over the last decade, studies have shown a significant increase in the percentage of individuals who are identified as overweight and obese (Ogden, Yanovski, Carroll, & Flegal, 2007; Baskin, Ard, Franklin, & Allison, 2005; Flegal, Carroll, Kit, & Ogden, 2012). Obesity has become a public health problem that has reached epidemic proportions in the United States (Nohr et al., 2009). The increases in those who are overweight and obese include women of childbearing age. During the same period, studies have noted increased risks in
adverse fertility-related health outcomes such as increased infertility, sub-infertility (increased-to-pregnancy), and miscarriage (Luke et al., 2010). From 2006-2008, overall 25.6% of African Americans, Caucasians, and Latinos within the United States were obese. However, minority populations are particularly affected by obesity with African-Americans and Latinos having a greater prevalence when compared to Caucasians (23.7%) at 35.7% and 28.7%, respectively (Pan et al., 2009).

The term “Latino” and “Latina” was used in this study replacing “Hispanic”. The term Latino was formally adopted by the U.S. to denote a broader more inclusive population of Spanish speaking individuals (Yankauer, 1987). It is often used interchangeably with the term Hispanic. For this study the term Latina women is used to refer to all women of a Latino and Hispanic background.

There are several risk factors known to influence infertility including social, economic, psychological, and physical factors (CDC, 2014). Physical lifestyle factors, such as body weight, are being studied for their association with infertility (Sharma, Biedenharn, Fedor, & Agarwal, 2013). Part of the spectrum of body weight includes those persons identified as overweight or obese. The World Health Organization (WHO) defines obesity as having a body mass index (BMI) greater than or equal to 30 kg/M² (WHO, 1997; Ogden, Yanovski, Carroll, & Flegal, 2007).

**Methods**

The data utilized in this study were collected from the 2006-2010 National Survey of Family Growth (NSFG) to determine the association between obesity and infertility in African American and Latina women in the United States. The NSFG is a nationally representative multistage area probability sample and it has been conducted eight times from 1973-2013 (Chandra, Copen, & Harvey, 2013). The NSFG was originally designed as a national fertility survey of the United States, with a focus on factors such as contraception, infertility, sexual activity, and marriage that explain trends and ethnic/race differences in birth rates (CDC, 2015). The NSFG currently also gives detailed information on factors effecting childbearing, marriage, and parenthood. The 2006-2010 NSFG interviewed a sample of 10,416 men and 12,279 women ages 15-45 in the United States. The original data collection was conducted as face-to-face, multi-question interviews with women in the initial interview.

**Sample**

The female study population for the NSFG was childbearing age women of all races between ages 15-45. The target population for this research was African American and Latina women of child bearing ages, between 18-45 years of age, within the United States. The unit of measurement was individual women, and included women for any marital status 20-45. Even though infertility can affect women 19 years or younger, this age group was not included in this study because data for the BMI variable for the age group was not measured. In addition, men were excluded from this research. NSFG collects data nationally from households in all 50 states and the District of Columbia in 110 major areas or primary sampling units (PSUs). PSUs are counties or adjacent counties divided nationally into four parts. All 12,279 participants were initially used and the sample population became more defined as the
inclusion and exclusion criteria were further defined. The final target population included 409 women that were eligible for this study.

**Study Measures and Variables**

The responses of the 2006-2010 NSFG interviews were analyzed to explore if there was an association between infertility status and BMI in African American and Latina women between 20-45 years of age in the United States. All measures in this study were based on when the original data was obtained from the 2006-2010 NSFG interviewers.

**Dependent Variables**

The outcome and dependent variable of interest in this study was fertility status. Infertility status among women in NSFG was constructed based on answers to the following questions on fecundity, contraceptive use, sexual activity, and marital status:

1. What is your fecundity status?
2. Have you used contraceptives within the past 12 months?
3. How many months of non-intercourse in the past 12 months?
4. What is your informal marital status?

The constructed variable was defined by the clinical definition of infertility by the WHO. A female was defined as infertile at the time of interview if she was sexually active each month for at least 12 months, not sterile, had not used contraceptives 12 months prior, and did not become pregnant.

**Independent Variables**

The independent variables of interest in this study were race/ethnicity and BMI. Other independent variables that were assessed were age, marital status, and education. Self-reported by recall were the women’s height and weight and computed a Body-Mass Index was derived from the formula “ROUND [(RWEIGHT) / (INCHES)**2] * 703]” in the NSFG. BMI was categorized into the following: Obese (BMI ≥30), Overweight (BMI 25.0 - 29.9), and Underweight (BMI <18.5)/Normal or Healthy Weight (BMI 18.5 – 24.9). In the NSFG, race/ethnicity was categorized by four categories: Non-Hispanic White, Non-Hispanic Black, Hispanic, and Non-Hispanic Other.

**Data Analysis**

A statistical analysis was conducted using version 9.3 of Statistical Analysis System (SAS). In univariate analyses, descriptive frequencies were used to describe select characteristics of the study population and independent variables. Bivariate analyses were conducted by cross tabulation and chi-square test to assess the association between infertility status and race, BMI, age, education, and marital status. A multivariable logistic regression model was used to estimate adjusted odds ratios (ORs) and 95% confidence intervals (95% CIs) for factors associated with infertility status. A p-value of less than or equal to 0.05 was used to establish statistical significance. If a variable in the bivariate analyses had a p-value ≤0.05, it was entered into the multivariable logistic model.
Results

Respondent Characteristics

A total of 409 women ages 20-45 years were included in this study (Table 1). The majority of participants were Caucasian (44.5%). There were 5% more African American (26.4%) respondents than Latina (21.76%). Over 38% (n=156) of the women had a college education and 64.5% of the women were currently married. Women were equally represented in terms of age (Table 1).

Table 1. Frequency Distribution of Study Respondents by Select Characteristics: 2006-2010 National Survey for Family Growth, United States

<table>
<thead>
<tr>
<th>Sample Socio-demographic Characteristics (n=409)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>409</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>32.76</td>
</tr>
<tr>
<td>30-36</td>
<td>34.72</td>
</tr>
<tr>
<td>37-45</td>
<td>32.52</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Latina</td>
<td>21.76</td>
</tr>
<tr>
<td>Non-Latina Caucasian</td>
<td>44.50</td>
</tr>
<tr>
<td>Non-Latina African American</td>
<td>26.41</td>
</tr>
<tr>
<td>Non-Latina Other</td>
<td>7.33</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Currently Married</td>
<td>64.55</td>
</tr>
<tr>
<td>Not Married but Living with Opposite Sex Partner</td>
<td>16.38</td>
</tr>
<tr>
<td>Divorced/Separated for Reasons of Marital Discord</td>
<td>3.67</td>
</tr>
<tr>
<td>Never Been Married</td>
<td>15.40</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Less Than a High School Diploma</td>
<td>24.21</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>25.67</td>
</tr>
<tr>
<td>College Education</td>
<td>38.14</td>
</tr>
<tr>
<td>Graduate School of Higher</td>
<td>11.98</td>
</tr>
</tbody>
</table>

Effects of Obesity on Infertility

The bivariate analysis of cross tabulation and chi-square test (Table 2) identified the associations with socio-demographic characteristics, infertility, and BMI. Results indicate that 19.80% (n=81) of women meeting study criteria (no contraceptive usage, zero months of non-intercourse, neither surgically or non-surgically sterile, and never became pregnant)
Articles

Table 2. Frequency Distribution of Study Respondents by Select Characteristics: 2006-2010 National Survey for Family Growth, United States

<table>
<thead>
<tr>
<th>Select Characteristics</th>
<th>Have you ever been pregnant? (N=409)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes n (%)</td>
<td>No n (%)</td>
</tr>
<tr>
<td>Overall</td>
<td>328 (80.20%)</td>
<td>81 (19.80%)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>76 (23.17)</td>
<td>13 (16.05)</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>136 (41.49)</td>
<td>46 (36.79)</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>92 (28.05)</td>
<td>16 (19.75)</td>
</tr>
<tr>
<td>Non-Hispanic Other</td>
<td>24 (7.32)</td>
<td>6 (7.41)</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29 years</td>
<td>111 (33.84)</td>
<td>23 (28.40)</td>
</tr>
<tr>
<td>30-36 years</td>
<td>111 (33.84)</td>
<td>31 (38.27)</td>
</tr>
<tr>
<td>37-44 years</td>
<td>106 (32.32)</td>
<td>27 (33.33)</td>
</tr>
<tr>
<td>Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school diploma</td>
<td>92 (28.05)</td>
<td>7 (8.64)</td>
</tr>
<tr>
<td>High school diploma</td>
<td>90 (27.44)</td>
<td>15 (18.52)</td>
</tr>
<tr>
<td>College Education</td>
<td>113 (34.45)</td>
<td>43 (53.09)</td>
</tr>
<tr>
<td>Graduate Education</td>
<td>33 (10.06)</td>
<td>16 (19.75)</td>
</tr>
<tr>
<td>Body Mass Index</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Underweight</td>
<td>7 (2.13)</td>
<td>3 (3.70)</td>
</tr>
<tr>
<td>Normal/Health Weight</td>
<td>100 (30.49)</td>
<td>32 (39.51)</td>
</tr>
<tr>
<td>Overweight</td>
<td>88 (26.83)</td>
<td>18 (22.22)</td>
</tr>
<tr>
<td>Obese</td>
<td>133 (40.55)</td>
<td>28 (34.57)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Currently Married</td>
<td>207 (63.11)</td>
<td>57 (70.37)</td>
</tr>
<tr>
<td>Not Married but living with opposite sex partner</td>
<td>54 (16.46)</td>
<td>13 (16.05)</td>
</tr>
<tr>
<td>Divorce</td>
<td>14 (4.27)</td>
<td>1 (1.23)</td>
</tr>
<tr>
<td>Never been married</td>
<td>53 (16.16)</td>
<td>10 (12.35)</td>
</tr>
</tbody>
</table>

were considered infertile. There were significant differences between age (p=0.0078), marital status (p=0.0015), BMI (p=0.0028), and education (p<.0001). All variables were included in the multivariable logistic regression model. Also, race/ethnicity (p=0.09), was included in the multivariable logistic regression model since it was an outcome of interest (Table 2).

The multivariable analysis, revealed that factors associated with a higher odds of infertility included having a college level education (OR= 5.036, 95% CI= 2.03-12.45) and graduate school level (OR=6.735, 95% CI= 2.357-19.246; Table 3). Results of the logistic regression show that the relationship between obesity and infertility is not significant (OR =
Table 3. Multivariate Associations between Respondents Who Have Never Been Pregnant by Select Characteristics and Body Mass Index: 2006-2010 National Survey for Family Growth, United States

<table>
<thead>
<tr>
<th>Select Characteristics</th>
<th>Have you ever been pregnant?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (N=81)</td>
</tr>
<tr>
<td></td>
<td>AOR</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>REF</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.831</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>0.690</td>
</tr>
<tr>
<td>Non-Hispanic Other</td>
<td>0.594</td>
</tr>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
</tr>
<tr>
<td>20-29 years</td>
<td>REF</td>
</tr>
<tr>
<td>30-36 years</td>
<td>1.153</td>
</tr>
<tr>
<td>37-44 years</td>
<td>0.962</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school diploma</td>
<td>REF</td>
</tr>
<tr>
<td>High school diploma</td>
<td>2.045</td>
</tr>
<tr>
<td>College Education</td>
<td>5.036</td>
</tr>
<tr>
<td>Graduate Education</td>
<td>6.735</td>
</tr>
<tr>
<td><strong>Body Mass Index</strong></td>
<td></td>
</tr>
<tr>
<td>Underweight/Normal Weight</td>
<td>REF</td>
</tr>
<tr>
<td>Overweight</td>
<td>0.680</td>
</tr>
<tr>
<td>Obese</td>
<td>0.728</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Currently Married</td>
<td>REF</td>
</tr>
<tr>
<td>Not Married but living with opposite sex partner</td>
<td>1.265</td>
</tr>
<tr>
<td>Divorce</td>
<td>0.404</td>
</tr>
<tr>
<td>Never been married</td>
<td>0.921</td>
</tr>
</tbody>
</table>

Discussion

While some studies did show an association between obesity and infertility (Mola, 2009; Norman, 2010; Jungheim, Travieso, & Hopeman, 2013), the results of this study did not support the hypothesis that there is an association between obesity and infertility in African American and Latino women in the United States. However, this study did demonstrate a
significant association between African American and Latino women that were infertile and their education at the college and graduate levels. In contrast, Bitler, M., & Schmidt, L. (2006), demonstrated an association between infertility and lower levels of education namely high school dropouts.

Although race was a main variable of focus for the study, it was not seen to be associated with obesity and infertility in both race/ethnic groups. However, descriptive statistics results showed that more African American women (n=16) were infertile and were not able to get pregnant compared to Latino women (n=13). This, however, may be due to the small sample size of Latino women (89 out of 409) that were included in the infertility definition constructed for this study.

All variables in the logistic regression model were determined by the literature to be associated with infertility. Infertility services were not controlled for in the logistic regression model because it is not a predictor of infertility. However, 37% of women who were infertile and never became pregnant after 12 continuous months decided to use infertility services.

Results of this study showed that when women with college and graduate level education were compared to women with less than a high school diploma, they were more likely to be infertile, thus not becoming pregnant.

**Study Limitations and Strengths**

This study uses a national representative sample of non-institutionalized women between the ages of 20-45 in the United States. However, it was not without limitations. There are some limitations with the variables used. The non-significant relationship between obesity and infertility in this study may be a result of infertility being defined by four constructs derived from previous literature in comparison to the single variable for infertility provided by the NSFG. Attempting to broaden the strength of the infertility definition could threaten internal validity of the measures.

Also, unique to this study and potentially a strength, the marital status variable was not exclusive to only married women, all informal marital statuses used in the NSFG were included in order to better capture the general population. Additionally, other strengths of this study included the use of a representative sample that was randomized across the United States in PSUs. This method of sampling minimizes threats to external validity.

Women who were excluded from the sample population were women with < 1 month of non-intercourse, women who used any form of contraception in a year, and women who were surgically and non-surgically sterile. These exclusions may have skewed results due to limitations associated with recall bias when the women were initially interviewed. BMI was also not measured at the time of interview but self-reported. Therefore, clinically measured BMI or excess body fat/weight was not available.

The available sample population decreased due to exclusion criteria for the clinical definition of infertility. A full representative sample of additional women who met the infertility criteria would be needed for the exploration of a larger sample size. Sample size threats
to external validity may possibly exist. In addition, the association between educational level and infertility are difficult to interpret due to all data being collected at one point in time; only an association, not causation, can be determined.

**Conclusion**

This study analyzed the associations between obesity and infertility in African American and Latino women with in the United States. The results showed that there is no relationship between infertility and BMI based on the data analyzed. However, education was a participant characteristic that was shown to be significant in this study. Results revealed that women with college and graduate school levels of education were more likely to be infertile and not become pregnant. Post-graduate educated women were almost seven times more likely to be infertile than women with less than a high school education. This study could possibly disprove the assumption that women of lower educational levels are at a higher risk for adverse reproductive health outcomes.

Literature shows that the body of evidence relating to obesity and reproductive health outcomes such as infertility has been contradictory. Like several previous studies on obesity and infertility where obesity was seen not to be associated with infertility, this study did not show an association between obesity and infertility among African American and Latino women in the NSFG population. In addition, this study could possibly disprove the assumption that obese women's reproductive health is compromised due to lifestyle and health behavior risk factors.

As noted in the literature, there are many different definitions of infertility and different measurements of obesity that have resulted in a range of various findings related to the topic. This investigation demonstrated the importance of identifying universal definitions for BMI measurements as well as for infertility with respect to marital status, sexual activity, and contraceptive use. A universal clinical and public health definition should be created for both obesity (excess body fat/or weight) and infertility to concisely explore the association of prevalence.

There are several questions raised by this study that could be explored through future research, including recommending further research on the impact of varying levels of education on a woman’s overall reproductive health, specifically as it relates to infertility. Although, level of education was not an independent variable of interest during the study, it was found to be very significant in findings and therefore warrants discussion. Possible reasons as to why higher levels of education have a significant correlation to fertility shown through this study potentially are due to the peak of fertility which normally occurs in a woman’s 20’s and declines in a woman’s 30’s particularly after 35. Each cycle as a woman gets older shows a depletion in her eggs. Therefore, the reproductive clock is a very critical aspect of determining the ideal time to start a family. In comparison to this proven concept of the reproductive clock, women who are obtaining higher levels of education have shorter fertility windows due to time devoted to education. Thus, explaining the findings, that higher education levels impact fertility negatively and posits the reason why a myriad of risk factors including social, economic, psychological, and physical factors influence infertility. As a result, increasing a level of education is a social and economic risk factor directly affecting infertility through a truncated optimal fertility window.
References


Centers for Disease Control and Prevention (2014). National Public Health Action Plan for the Detection, Prevention, and Management of Infertility, Atlanta, Georgia: Centers for Disease Control and Prevention, 1-4


Response to the 2015 PHEI Keynote Address, “Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee’? A Case Study in Passing Ethics Research from ‘Generation to Generation’

Kimberly N. Whitley, MPH
3rd Year Integrative Biosciences PhD Student
Tuskegee University
1200 West Montgomery Road
Tuskegee, AL 36088
Email: kwhitley8201@mytu.tuskegee.edu

Author Note
The views and opinions expressed here are those of the author alone. The content of this article is documented through the author’s experience. There are no financial conflicts of interest. This subject material is a reflection and projection of ideas evolved from the author’s response to the keynote address at the 2015 Tuskegee Public Health Ethics Intensive (PHEI) Course.

Abstract
The infamous United States Public Health Service (USPHS) Study of Untreated Syphilis in the Negro Male was an egregious act involving the participation of over 600 victimized Black men in Macon County, Alabama during a 40-year period. Because of the 1972 media exposure that marked the end of the infamous study; several implications arose which included identifying,
searching, and elucidating its legacy. At the 2015 Public Health Ethics Intensive (PHEI) Course, Dr. Ralph Katz, Professor of Epidemiology and Health at New York University, delivered the keynote address, “Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee’? A Case Study in Passing Ethics Research from ‘Generation to Generation’”. This article is in response to the 2015 PHEI keynote address leading to the synthesis of new information. The purpose of this article is to describe new research perspectives and knowledge that could be generated from incorporating descendant family members’ participation, especially millennial descendant family members, in the search of the legacy of the United States Public Health Service Syphilis Study at Tuskegee. An ethical framework is proposed utilizing a community based participatory approach to serve as a basis for narrative ethics.

**Keywords:** United States Public Health Service Syphilis Study, legacy, narrative ethics, descendant family members, ethical framework

**Introduction**

Since 2012, the three-day Public Health Ethics Intensive Course (PHEIC) has been a part of the Commemoration of the Presidential Apology for the United States Public Health Service Syphilis Study (USPHS) at Tuskegee. The PHEIC is structured for the engagement of an integrative group of scholars, professionals, researchers, policy officials, community advocates and students to enlighten participants on ethical and political aspects of public health policy and public health ethics. The 2015 theme was “Assuring Ethics from Generation to Generation”. A significant keynote address, “Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee- A Case Study in Passing Ethics Research from ‘Generation to Generation’” was delivered by Dr. Ralph V. Katz.

The purpose of this article is to describe new research perspectives and knowledge that could be generated from incorporating descendant family members’ participation in search of the “legacy” of the USPHS Syphilis Study at Tuskegee. To the author’s knowledge, this is the first peer-reviewed journal article to be written by a third-generation descendant family member of the USPHS Syphilis Study who is investigating its legacy and is a current student at Tuskegee University. It is with this moral authority and moral obligation that the legacy of the USPHS Syphilis Study is assured from generation to generation and that the voices of the descendants’ fathers, great-grandfathers, and great-great grandfathers are always heard.

The origins of the infamous and heinous USPHS Syphilis Study has been chronicled and examined by James H. Jones and extensively by Susan Mokotoff Reverby (Jones 1981; Reverby, 2000). The inception of the USPHS Syphilis Study was in November 1929 under a $50,000, 12-month grant from the Julius Rosenwald Fund (Jones, 1981). Julius Rosenwald, a Jewish philanthropist and part-owner of Sears Roebuck and Company, believed in the welfare of African Americans in the rural South highlighting education and healthcare as one of its initiatives (Gray, 1998). An alliance was formed between the Rosenwald Fund and the United States Public Health Service as an effort to expand access to the medically underserved and “poorest” Black rural communities in the South (Gray, 1998). At the time, there was a higher incidence of syphilis found in African Americans. Under this grant, the USPHS conducted studies to determine the prevalence of syphilis among Blacks and explore the possibilities of
mass treatment in the rural South (Reverby, 2000). During their surveillance and monitoring of syphilis-control programs, the USPHS recommended six locations for the program: Macon County, Alabama; Scott County, Mississippi; Tipton County, Tennessee; Glynn County, Georgia; Pitt County, North Carolina; Albemarle County, Virginia. Of the six locations, Macon County had the highest prevalence (36%) of syphilis (Jones, 1981). After a year, the Rosenwald Study ended and it concluded that mass syphilitic treatments could be successfully implemented in rural African-American areas (Jones, 1981).

In a nefarious turn of events, a decision made by the Chief USPHS Venereal Disease Division and author of the Rosenwald Study report, Dr. Taliaferro Clark, caused for the inception of the “Tuskegee Syphilis Study” with the aid of Tuskegee Institute and the local health department in October 1932 (Jones, 1981; Reverby, 2000). Dr. Clark infamously regarded the Tuskegee Syphilis Study as a classic “study in nature” rather than “experiment” (Reverby, 2000). So then, the Study’s participants were preyed on and selected solely-based upon their social conditions: education, income, race, gender and social status. Even though the finite numbers of the men victimized by USPHS Syphilis Study are unknown, a consensus is that 399 syphilitic men (assigned to the experiment group) and 201 non-syphilitic men (assigned to the control arm) participated in the Study. No therapeutic treatments were given to the men even when penicillin became available for syphilis in 1947 (Jones, 1981). The Study lasted for four decades until an Associate Press news reporter, Jean Heller, disclosed the study to the general population on July 26, 1972 (Jones, 1981). The Study officially ended October 1972 (Jones, 1981). Shortly after, Attorney Fred Gray filed a $1.8 billion class-action lawsuit against the United States’ Health, Education and Welfare (HEW), Public Health Service (PHS), Centers for Disease Control and Prevention (CDC), the State of Alabama, the State of Board of Health of Alabama, the Milbank Fund and some individuals connected with the study on behalf of the men in the study, their wives, children and family (Reverby, 2000). A settlement of $10 million was reached. The United States government offered medical treatment and insurance to the men's wives and children who contracted syphilis.

Since the media disclosure marking the end of the Study, there are and have been common misconceptions detailing the USPHS Syphilis Study at Tuskegee. For the purposes of this article, The USPHS Syphilis Study at Tuskegee, will be interchangeably referred to as “the Study”. A major misconception involving the men of the Study is their socioeconomic status. Not all men that participated in the Study were poor, uneducated or illiterate, sharecroppers or tenant farmers. While some of the men were characterized and labeled as poor and illiterate, there were some men who were not. This misconception is perpetuated due to the lack of written protocols accurately describing the population. Another major misconception is the viewing of the movie, Miss Evers’ Boys, in which many equate the motion picture’s romanticized drama as fact. Miss Evers’ Boys provides a fictitious account of the USPHS Syphilis Study at Tuskegee. The erroneous conception that the syphilitic men were given treatment in the form of penicillin and the reversal and reduction of power between “Nurse Evers” and governmental and medical officials is profoundly wrong (Konwiser, Konwiser, Stelzer, Kavanagh, and Sargent, 1997). In addition to common misconceptions, there are often misnomers associated with the Study’s name such as “The Tuskegee Syphils Experiment”, “The Tuskegee Study of Untreated Syphilis”, and “The Tuskegee Experiment”. The correct name and association is the “Tuskegee Study of Untreated Syphilis in the Male Negro” or the most current title, “The USPHS Syphilis Study at Tuskegee”. Highlighting the emphasis of “Male Negro” provides humanizing characteristics rather than “subjects” (Mays, 2011). Accentuating and asserting the role of the USPHS in the study demonstrates the proper ownership by whom the study was conducted.
Another misconception is that the USPHS Syphilis Study at Tuskegee was a biomedical study. The USPHS researchers were not interested in treating the men, remarking that the chief of the USPHS Venereal Disease Division called the Study a classic “study in nature” and an “unusual opportunity for observation” (Reverby, 2000). It was, however, a quasi-experimental, epidemiological study (longitudinal study) observing the natural progression of syphilis pathology. The “so-called” study was, in fact, focused in public health (Warren, Williams, and Wilson, 2012). Lastly, the men were not injected with syphilis. Some of the men were in late-stage or had latent syphilis prior to the study. It is possible that initially the unaffected men could have developed syphilis throughout the course of the study. There is no tangible data to verify the accurate accounts. No research protocol was written (Williams and Williams, 2011).

Public health at its nucleus is charged with protecting the population's health. Health as being described as “a dynamic relationship focused on the physical, social, psychological and spiritual well-being of the individuals and/or group and their interaction with the physical and social environment” (Warren, 1998). Public Health Service (PHS) officials committed several public health ethics violations when implementing and continuing the Study for 40 years. On the contrary, in 1966, the United States Surgeon General proposed a directive which called for a prior review of the research protocol (outlining human research and investigations) before implementing the research. Public health ethics as a practice concerns itself with applying principles and values established on an ethical framework (code of ethics) to aid in public health decision making (Centers for Disease Control and Prevention Office of the Associate Director of Science [CDC-OADS], 2015; Public Health Leadership Society [PHLS], 2002). Some of these principles include: protection and promotion of health, achievement of community health with respect of individuals’ rights, and to provide communities with information needed for informed consent (decision-making) (PHLS, 2002). Some of the lack of ethical procedures include an absent, written research protocol outlining the potential risks and harms, lack of informed consent by participants, withholding of treatment, and coercion. These issues posed the ethical dilemma of “doing good in the name of science”.

Because of the “doing good in the name of science” ethical dilemma, implications of the study have made a profound impact on research. Arthur Caplan stated that institutional review boards (IRB) were established because of the Study (R. Warren, personal communication, September 21, 2016). An institutional review board is a committee consisting of researchers who review and approve research concerning human subjects. Another result was the 1979 Belmont Report that outlined ethical principles and guidelines for the protection of human subjects of research (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1972). In 1993, under the National Institutes of Health (NIH) Revitalization Act, women and minorities were to be included in clinical research (Pinn, 2011). Additionally, all researchers must be certified in conducting research by participating in an on-line NIH Training on Human Subjects.

On May 16, 1997, 42nd United States President William “Bill” Clinton issued a Presidential Apology to the men, survivors (eight living at the time), their wives, and children of the USPHS Syphilis Study at Tuskegee. To note, the Presidential Apology was not only an address to admit the egregious acts and wrongdoing of the United States government but also, a step towards a healing movement for the survivors’ and their families and families who were descendants of the deceased men. As an implication of the Presidential Apology, the first and only presidentially mandated bioethics center, The National Center for Bioethics in Research
and Health Care, was established in January 1999 on Tuskegee University’s campus. The National Center for Bioethics in Research and Health Care serves as a reminder of transforming the negative legacy of the USPHS Syphilis Study to a legacy that can be positively transformed through research, education and advocacy.

**Comprehending Logic: A Quantitative Perspective**

Katz et al. (2016) presented a keynote address, “Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee’? A Case Study in Passing Ethics Research from ‘Generation to Generation’” at the 2015 Public Health Ethics Intensive Course. The purpose of the study was to explore whether the USPHS Syphilis Study may have been the “trigger event” that led to the Mistrust-In-Research as a research-based field of study. To investigate this matter, two hypotheses were used. Initially, Katz et al. (2016) hypothesized that the 1972 media exposure from the USPHS Syphilis Study and the resulting immediate public reaction of shock and anger was the likely “trigger event” for generation of the Mistrust-In-Research as an original research field. Upon “serendipitous” events, these authors formulated a second hypothesis after the rejection of the first which was supported their findings fitting the observed data. The second hypothesis suggested that the generation of the MIR research field of study was due to the publication of *Bad Blood* by James H. Jones in 1981. The authors found that the second hypothesis was supported by the observed data inferring that teeming academic research was a result of the conscious reading of *Bad Blood*. Katz et al. (2016) concluded that perhaps the data collected may have discovered or uncovered another legacy of the USPHS Syphilis Study at Tuskegee.

The authors conducted a systematic literary search (databases: PubMed, Embase, and Embase Classic) from 1900-2011. Key terms used in their search included: mistrust, trust, conspiracy, fear, biomedical, medical, studies, research, Biomedical Research, Research, African Americans, African, American, minority groups, minority, groups, minorities, minority. Boolean operators were used in various combinations with the key terms to generate results. From their literary search, 1,016 abstracts were found with only 710 being identified as relevant to the present study. To distinguish which articles were to be used for their study, an extensive seven-step review process was employed over a two-year period (2012-2014). Additionally, the authors created “MIR” forms to categorize only MIR published papers. These forms included the MIR Abstract Categorization (MAC) and Relevant Article Abstraction Categorization (RAAC) form. The MAC form is a 5-item screening tool to aid in categorizing originally identified published abstracts. Then, a 5-item (of a16-item) RAAC form was used to verify that the abstracts (279) that screened as ‘likely original research articles’ from the MAC form was the confirmed original research article when reviewed by the abstractors. After completion of the RAAC form, a total of 189 MIR original research article was used for analysis. Data were input and analyzed in Microsoft Excel and SPSS Version 21.

The first formulated hypothesis was rejected because the data did not meet two criteria: 1) Earliest MIR Research article would have to occur at the 1972 (year of media disclosure, 2) Histogram should demonstrate an 8-10 year (mid-1980s) expected lag time for the occurrence of MIR original research articles. Katz et al. (2016) speculated that the 8-10-year lag period was due to grant writing, securing funding, conducting and analyzing the research data, and finally manuscript preparation for publication. The second hypothesis, however, supported the two criteria demonstrating that *Bad Blood* was the genesis or “trigger event” of the MIR original field of study.
Katz et al. (2016) provided an exhaustive study in the search for the legacy of the USPHS Syphilis Study at Tuskegee. Upon reading the study, the idea to initiate the search for the truth in the Mistrust-In-Research field of study evolved. The following questions arose: 1) Can researchers truly quantify and accurately interpret such a legacy or synthesize a research model to search for a truth, such as that of USPHS Syphilis Study? 2) Are researchers searching for the “truth” of the legacy? 3) Or are researchers trying to elucidate and find an answer as to why Blacks (or African Americans) have a high prevalence or reluctance to participation in biomedical or clinical research, using the legacy of the Study as a default answer? 4) Is it permissible for researchers to not have an absolute answer? 5) Who truly benefits from this knowledge: researchers, the community, descendant family members?

Interestingly, was how Katz et al. (2016) drew their conclusions. These authors concluded that the data the histogram produced in Figure 3, demonstrate that the 1981 Bad Blood publication was seemingly the trigger event for the geneses of the MIR field of research not the media disclosure and immediate public shock. In 1972, Jean Heller broke the story in the New York Times, “Syphilis Victims in U.S. Study went Untreated for 40 years”. However, in the book Bad Blood, James H. Jones stated:

“I have incurred many debts in writing Bad Blood, I first came across materials on the Tuskegee Study in 1969, while investigating another topic in the National Archives. I did not know that the experiment was still going on then. When Jean Heller broke the story in 1972, I was as shocked as everyone else, but I knew exactly where to go to initiate research on the topic (Jones, 1981, p. xi).”

The media exposure, immediate shock and power of resources led to the trigger event for the MIR field of study to inspire James Jones to write the book hence the academic researchers producing articles.

Previously, the following question was posed: Can researchers truly quantify and accurately interpret such a legacy or synthesize a research model to search for a truth, such as that of USPHS Syphilis Study? Research can attempt to quantify the USPHS Syphilis Study’s legacy but how can that be when the truth has not been fully revealed. In this attempt, a brief literature search was conducted for the “quantified legacy” of the USPHS Syphilis Study at Tuskegee.

A primary computerized literature search was conducted from September 2016 to October 2016 to identify and collect relevant research articles using databases PubMed, EBSCO and ERIC (Education Resources Information Center). Published manuscripts that appeared in peer-reviewed journals were collected as primary sources of data. Key terms included Tuskegee, legacy, syphilis which were searched as “Tuskegee AND legacy AND syphilis”. The brief literature search is intended to provide evidence that the quantitative analyses, while insightful and beneficial for building culturally competent interventions, only speculates the legacy of the USPHS Syphilis Study not reveal its truthfulness. From the search results, PubMed, EBSCO, and ERIC produced twenty-seven, seven and two results, respectively. The following inclusion criteria were used to determine the appropriateness for the literature search: 1) Removal of duplicate studies 2) Removal of research articles authored or co-authored by Ralph V. Katz 3) Removal of qualitative studies 4) Removal of basic science studies 5) Mention of the Study but not investigating the legacy. The results totaled to three. For the literature review, three journal articles were reviewed. This review is not
an attempt to provide descriptive statistics or other statistical tests, but to provide how the articles for review were selected.

The common theme of these quantitative analyses was to determine which predictors (race, knowledge, awareness, perceptions, conspiracy beliefs etc.) affected African American decisions in participating (versus other ethnicities) in biomedical or clinical research. Seemingly these studies, used the “legacy” of the Study as a safety net for trying to explain the lack of participation of African Americans in different research environments or distrust in the healthcare system, rather than understanding and identifying other legacies of the USPHS Syphilis Study at Tuskegee. The negative legacy that these authors continue to perpetuate without understanding the narrative truth of the legacy is harmful. None of the articles reviewed discussed that the legacy of the USPHS has not been elucidated and that there is still an ongoing search for the legacy. These studies highlight the redundancy of the “safety net legacy” theme. Brandon, Isaac, and LaVeist (2005) conducted a cross-sectional study to determine the Black-White racial differences in the relationship between knowledge of the Tuskegee Syphilis and medical mistrust of the healthcare system. Methods included using a telephone survey of random sample of residents (n=401) in Baltimore City, MD (Brandon et al., 2005). To note, this study was a part of larger longitudinal study to explore distrust of the healthcare system among minorities (Brandon et al., 2005). The knowledge of Tuskegee was evaluated by six items and mistrust was measured using the seven-item Medical Mistrust Index (MMI). Demographic variables were also measured. These authors found that there are not racial differences in the knowledge of African Americans comparative to Whites (Brandon et al., 2005). Similarly, another study investigated a different population (prison offenders) about their awareness of the Study and its impact on their decision to decline research participation (Poythress, Epstein, Stiles & Edens, 2011). Poythress et al. (2011) found the knowledge of the “Tuskegee Study” had a small impact on the offenders’ decision in participating in research. Contrarily, Mays, Coles and Cochran (2012) addresses if the Study’s legacy is found in current HIV/AIDS concerns and misbeliefs among heterosexual African-Americans and Latinos. Results suggested that there are other factors responsible for low enrollment in biomedical and behavioral studies even though knowledge of the Study serves as a strong predictor for beliefs in conspiracies about HIV/AIDS (Mays et al. 2012). These studies highlight the need for the continued search of the legacy of the Study. Neither studies mentioned how the legacy of the Study could be defined or re-defined even though some studies briefly discussed moving away from the legacy as an answer for low or no participation by Blacks or African Americans.

Defying and Re-Defining Logic: A Qualitative Perspective

The nucleus for the true legacy of the USPHS Syphilis Study at Tuskegee comes from and is still held by the living, descendant family members of the 600 (and counting) victimized men of the Study. The legacy of the Study does not originate from archival records or in databases such as PubMed or Embase. Until the truth is fully revealed by descendant family members, the legacy of the study and its truth are still in question. The generation of new qualitative research perspectives for the legacy of the Study involving descendant family members will require a community-based participatory research (CBPR) approach serving as a basis for narrative ethics. The goal of these combined research approaches (CBPR and narrative ethics) is not to exploit the experiences of descendant family members for research gain to further a research agenda. It is to provide an understanding and closure for the identity of the legacy of the USPHS Syphilis
Study through cultural transmission of intergenerational experiences delivered by sharing of stories. This paradigm shift should be purposively driven by descendant family members who represent a “small-connected community” (Damianakis and Woodford, 2012).

CBPR, also known as participatory action research, is a dynamic, collaborative research approach that requires the equitable participation of researchers and the community in all phases of research (Israel, Schulz Parker, and Becker, 1998; Turnbull, Freisen, and Ramirez, 1998; Blumenthal, 2011). There are several fundamental principles guiding CBPR cited by many researchers referencing the work of Israel and colleagues. Israel et al. (1998) proposed eight principles to guide this collaborative partnership: 1) Recognizes community as a unit of identity, 2) Builds on strengths and resources within the community, 3) Facilitates collaborative partnerships in all phases of the research, 4) Integrates knowledge and action for mutual benefit of all partners, 5) Promotes a co-learning and empowering process that attends to inequalities, 6) Involves a cyclical and iterative process, 7) Addresses health from both positive and ecological perspectives and, 8) Disseminates findings and knowledge gained to all partners. These principles are founded-on ethics and community empowerment (Blumenthal, 2011). All elements of CBPR do not have to be met and should be discussed between the researcher and community (Bogart and Uyeda, 2009).

Naturally, narrative ethics evolves from the synthesis of CBPR. Narrative ethics involves story-telling, giving the narrator control of how the story is told and shaped (Geisler, 2006). The ethical dilemma is placed in their story (Geisler, 2006). Also, narrative ethics provide moral insight on an individual’s value of principles and rules for moral reasoning, moral education, and closure in one form or another usually by making choices (Geisler, 2006).

Prior to implementing CBPR and narrative ethics, descendant family members must first identify the notion of family (e.g. who is family? what constitutes a family? etc.) and the meaning of being a descendant (e.g. what does the term ‘descendant’ mean to the family member? how does being labeled a descendant impact or influence decisions on revealing the truth of the Study? who identifies as a descendant? etc.). Wimberly (2012) identified concerns of descendant family members in, “Ethical Responsibility in Healing and Protecting the Families of the U.S. Public Health Service Syphilis Study in African American Men at Tuskegee: An Intergenerational Storytelling Approach,” by convening with family leaders at the National Center for Bioethics in Research and Health Care. The concerns that Wimberly (2012) identified remain prevalent today, even though some concerns are in resolution. Additionally, relaying that the notion and identity of family should be primary (Wimberly, 2012). After this identification, the elucidation process for the legacy of the Study as well as understanding the label of “descendant” can begin.

Out of the revelation of comprehending the notion of family and being a descendant, cultural transmission (passing of cultural information such as attitudes, norms, values and beliefs to each other) of the legacy between older and younger descendant family members should be the next step (Carl, 2011). A key generation of descendant family members that are missing from the descendant family meetings with the National Bioethics Center is the millennial generation. Presently, the legacy of the USPHS Syphilis Study at Tuskegee is sitting with and inside the experiences of the elder, descendant family members. With all respect given to their human experiences, these experiences and their legacy as elder, descendant family members will be lost, silenced or faded when they are no longer able to provide their narratives.
The role of descendant family members in CBPR and narrative ethics will require an adaptation of CBPR principles that can be implemented to help guide narratives with the inclusion of younger generations (18 years of age and above). Descendant family members represent a “small-connected community” that share similar experiences and relationships among its community members (Damianakis and Woodford, 2012). In regards to CBPR, there are different participatory levels categorizing interactions between the researcher and the community which is shaped by narrative ethics. The CBPR participatory categories available for descendant family members to re-define the legacy of the USPHS Syphilis Study include: 1) Family members as research leaders and researchers as ongoing advisors, 2) Researchers and family members as co-researchers or, 3) Researchers as leaders and family members as ongoing advisors (Turnball, Friesen, and Ramirez, 1998). Additionally, to incorporate and accommodate younger descendant family members in the narrative and possibly older, disabled descendant family members, the use of Photovoice (use of cameras to take pictures to document experiences and uncover themes used for qualitative research) can be explored (Hergenrather, Rhodes, Bardhoshi, 2009). There is no specific way to conduct CBPR. To help facilitate CBPR and narrative ethics, an ethical framework is proposed, specifically between descendant family members of the Study and researchers. Also, the ethical framework proposed is adapted from other CBPR principles. These include:

1. Acknowledging power differentials intergenerationally between descendant family members (older vs. younger descendant family members) and between descendant family members and researchers
2. Fiduciary transparency regarding funding and budget between researchers and descendant family members
3. Transparency between descendant family members and researchers.
4. Continual dialogue and equitable dissemination to make joint decisions about data, dissemination of results, project development, time constraints, feasibility, and acceptability to minimize and avoid “hidden voices” (Wallerstein and Duran, 2006; McDavitt et al., 2016)
5. Mutual trust, truthfulness, respect, and patience between descendant family members and researchers
6. Intellectual humility demonstrated by researchers. Learning to appreciate the expertise produced by both researchers and descendant family members
7. Humility
8. Freedom of self-expression, values, and identity through narratives
9. Reflectivity. Being able to recollect and reflect on experiences to draw conclusions about the legacy
10. Continual identification of descendant family leaders and family
11. Establishment and representation of younger, descendant family leaders present at leadership meetings
12. Informed consent between researchers and descendant family members. Verbal consent between descendant family members
13. Co-learning between descendant family members and co-learning between descendant family members and researchers
14. Empowerment
By incorporating these ethical principles to guide CBPR and narrative ethics in identifying and understanding the legacy of the Study, there will be a generation of increased relevance of this type of qualitative research, increased rigor of research (improvements on research protocol and instrumentation), increased research utilization (increased productivity of research and reduction of time constraints) (Turnball et al., 1998). Additionally, new qualitative perspectives regarding the legacy of the Study may be generated from identifying and recognizing attitudes among the younger generation. On a larger scale, these perspectives may reveal underlying themes in chronic and sexually transmitted diseases, risky behaviors, and health disparities that significantly affect younger individuals.

Conclusion

The legacy and truth of the USPHS Syphilis Study at Tuskegee are still held by living, descendant family members. Until that truth is fully revealed, the legacy of the USPHS Syphilis Study at Tuskegee will remain in question. CBPR and narrative ethics provide a foundation and safe environment for descendant family members to reveal their truths and human experiences about the legacy in hopes of prompting a paradigm shift on how the legacy is perceived.
References


Katz, R. (2016). Was the development of the Mistrust-In-Research (MIR) field of study yet another ‘Legacy of the USPHS Syphilis Study at Tuskegee’? A case study in passing ethics research from ‘generation to generation’. *Journal of Healthcare, Science, and The Humanities, 6*(1), 21-35


Secondhand Smoke in the Workplace

Suvag Patnaik, MD, MPH
Resident, Occupational Medicine
Family and Community Medicine
Occupational and Preventive Medicine Residency
Meharry Medical College
1005 D.B. Todd Blvd.
Nashville, TN 37208
(615) 327-6782 Office
(615) 327-6131 Fax
Email: spatnaik@mmc.edu

Mitali Nanda, MD
Pediatrician
Capstone Pediatrics
1015 Hanson Ct, Suite 101,
Murfreesboro, TN 37127
Tel: (615) 203-0566 office
Email: mnanda@capstonepediatrics.com

Francisco Tejeda, MD
Resident, Preventive Medicine
Family and Community Medicine
Occupational and Preventive Medicine Residency
Meharry Medical College
1005 D.B. Todd Blvd.
Nashville, TN 37208
Tel: (615) 327-6782 Office
Fax: (615) 327-6131
Email: ftejeda@mmc.edu

Muktar Aliyu, MD, DrPH
Assistant Professor Occupational Medicine
Vanderbilt University
21st Avenue South, Suite 640
Email: muktar.aliyu@vanderbilt.edu
Nashville, TN 37208
Tel: (615) 327-6782 Office
Fax: (615) 327-6131
Author Note

The following work was produced to meet the requirements of the Preventive Leadership Advocacy Rotation (PLAR) project for the Preventive and Occupational Medicine Residency Programs at Meharry Medical College. The focus of PLAR is to research laws, policies, and/or guidelines within the context of evidence-based medicine and provide this information to advocacy organizations with the intent to improve the care and health of all affected. The authors have no conflicts to disclose.

The project described was supported by grant number D33HP29248 from the Health Resources and Services Administration (HRSA), operating division of the U.S. Department of Health and Human Services (DHHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of HRSA or DHHS.

Abstracto

El humo de segunda mano (secondhand smoke o SHS) se inhala involuntariamente por los no fumadores y a veces se le llama humo de tabaco en el ambiente (Environmental Tobacco Smoke o ETS). Este tipo de humo es una mezcla de humo indirecto (lateral) y humo de la corriente principal o directa. El SHS causa enfermedades cardiovasculares y respiratorias en adultos y niños no fumadores, que afectan la salud y pueden causar la muerte. El propósito de este artículo es enfatizar los varios efectos adversos causados por la exposición al humo de segunda mano, enfocándose en técnicas para medir el SHS ambiental y los patrones de exposición al SHS a través del tiempo. Se realizó una búsqueda en PubMed usando los siguientes términos clave: “humo de tabaco”, “humo de segunda mano”, “efectos en la salud” y “leyes sobre el tabaquismo”. Se usaron 25 artículos relacionados al humo de segunda mano y se compararon respecto a los conocimientos actuales y las recomendaciones sobre las medidas sobre tabaquismo en los centros laborales. Los resultados de la búsqueda revelaron que los efectos que perjudican significativamente la salud están directamente relacionados a la exposición al humo de segunda mano, y afectan a todas las razas, etnias y grupos ocupacionales. Si bien hay varias leyes en vigor, la mayoría se proponen separar a los fumadores de los no fumadores. Los resultados requieren que las leyes se cumplan para que la prohibición de fumar se aplique de manera uniforme en los centros laborales y se desincentive el incumplimiento. Se debe proporcionar a todos los trabajadores información sobre los efectos adversos del tabaquismo y sobre clases para dejar de fumar. Las leyes deben requerir la designación de zonas restringidas a fumadores mientras las leyes avanzan hacia la prohibición total. La ventilación de la zona para
Abstract

Secondhand smoke (SHS) is defined as the smoke inhaled involuntarily by nonsmokers, often also referred to as Environmental Tobacco Smoke (ETS). SHS is a mixture of side-stream (side stream smoke) smoke and mainstream (main stream smoke) smoke. SHS exposure causes cardiovascular and respiratory diseases in nonsmoking adults and children, resulting in significant morbidity and mortality. The purpose of this article is to emphasize the various adverse health effects of second hand smoke exposure, focusing on environmental SHS measurement techniques and patterns of SHS exposure through time. A PubMed search was performed using the following keywords: “tobacco smoke”, “second hand smoking,” health effects,” and “smoking laws.” Twenty Five articles were used pertaining to secondhand smoking were compared against current knowledge and recommendations for workplace smoking policies. Results from the search revealed that significant adverse health conditions are directly related to second hand smoke exposure, and prevail across different races, ethnicities, and occupational groups. Whereas numerous legislations are currently in place, most aim to separate smokers and nonsmokers. These findings require that Legislation be enacted to uniformly ban smoking from workplaces and provide disincentives for non-compliance. Information about the harmful effects of smoking and smoking-cessation classes should be offered to all workers. Legislation could require designated restricted smoking areas for workplaces as they move towards a complete ban. Ventilation of the smoking area should meet general standards, and the smoking area should have a slight negative pressure to ensure airflow into the area.

Keywords: Secondhand smoke, workplace, smoke-free laws

Introduction

Cigarette smoking and exposure to secondhand smoke (SHS) became highly prevalent in most developed countries during the 20th century. The United States (US) Surgeon General reports provided an expansive amount of evidence and authoritative synthesis that led to definitive conclusions concerning smoking as a cause of disease. Despite growing evidence of the association of tobacco smoke with disease, a lot of work still remains to be done to protect vulnerable population against the harmful effects of cigarettes. Since evidence surfaced relating tobacco use to direct adverse health effects, extensive research has ensued exploring all possible routes of exposure. Current emphasis revolves around the effects of tobacco smoking on those that are indirectly exposed by being in the vicinity of active smokers. As more and more evidence has surfaced about possible adverse effects from indirect exposure, smoke free laws in public places and worksites has become a priority among advocacy groups.

What Is Secondhand Smoke Exposure?

The term “secondhand smoke” refers to cigarette smoke that others are exposed to involuntarily by sharing the same environmental airspace. There are two components to SHS: 1) main stream smoke, which is the exhaled tobacco smoke of active smokers, and 2) side stream (side stream smoke) smoke, that comes off of the burning cigarette. Both main stream smoke
and side stream smoke have components that are harmful to the health of exposed persons, although there might be quantitative differences. This has led to research being directed into the health effects of side stream smoke just as intensely as main stream smoke. Side stream smoke is generated under lower temperature conditions, but may have significant amounts of toxic compounds, sometimes in higher concentrations, than main stream smoke. Main stream smoke usually gets quickly diluted as it disperses into the ambient environment, but still contains significant amounts of potential carcinogens (Mannino, 2012).

The morbidity and mortality related to SHS exposure can be attributed to cardiovascular and respiratory illnesses. A report from the Surgeon General in 2010 estimated that approximately 46,000 cardiovascular deaths and 3,400 respiratory deaths occur among the non-smoking population in the US each year (Morbidity and Mortality Weekly Report [MMWR], 2011; U.S. Department of Health and Human Services [DHHS], 2010). The primary locations where exposure to SHS is likely to occur are in homes of active smokers, public places such as restaurants/bars, and workplaces that do not have smoking policies. Cars and other vehicles in which active smoking takes place are a source of SHS exposure, as well (DHHS, 2014).

Measurement of Secondhand Smoke Exposure in the Environment

Components of tobacco smoke can be measured in the environment while an individual is actively engaging in smoking, as well as after the event. Tobacco smoke contains various measurable components like carbon monoxide, nicotine, and benzene. These components are present in concentrations that depend on various factors, such as the area of the space that smoking occurs, the duration of active smoking, the numbers of smokers in the vicinity, as well as the ventilation system of the airspace, including the type and efficiency of air cleaning mechanism in place.

The principal metabolite of nicotine (cotinine) is the most studied and followed biomarker for qualitative and quantitative measurement of tobacco smoke. There are various ways to measure tobacco smoke components in smokers, as well as non-smokers. Measurements include analyzing samples from blood, urine, saliva, and hair to assess the body burden of tobacco smoke. Study of tobacco smoke components have clearly shown that they are absorbed by non-smokers, further justifying the health hazard that SHS poses for this subset of the population (National Institute of Occupational Safety and Health (NIOSH). As per the National Research Council (NRC), the estimated average urine cotinine level in a smoker is about 1825 ng/ml, while a non-smoker averages about 25 ng/ml. Nicotine is almost exclusively attributed to tobacco smoke and has been shown to be prevalent in the ambient atmosphere where tobacco is smoked, as well as in non-smokers.

Trends In Secondhand Smoke Exposure

Another way second hand smoke can be assessed is by the urinary metabolite of nicotine, cotinine. Tobacco smoke exposure can be quantified by evaluating the urine cotinine levels. A study conducted by the CDC showed that in a select population from 1988-1991 nearly 90 of 100 (87.9%) non-smokers had a measurable level of cotinine. This was followed in later years (2007-2008) by a decrease in measurable cotinine to about 40 of every 100 people (40.1%). The most current period studied was from 2011-2012, where about 25 of every 100 (25.3%) non-smokers had a measurable level of cotinine, refer to figure 1.
Growing regulations and more strict laws about smoking in public and at work have contributed to the decline in cotinine levels described above. Additionally, current societal norms view smoking less and less as an acceptable practice, in addition to increased awareness of the harms of passive tobacco smoke exposure. These changes have led to a conscious effort to avoid passive and active tobacco smoke exposure (DHHS, 2006).

Demographic Differences in Second Hand Smoke Exposure

Overall, there was a general reduction in cotinine levels across all racial and ethnic groups, higher cotinine concentrations were found in specific groups Non-Hispanic Black Americans had a higher level of cotinine when compared to non-Hispanic White Americans and Mexican Americans. Data from 2011-2012 suggest that SHS exposure among Black nonsmokers was 46.8% compared to non-Hispanic White nonsmokers (21.8%) and Mexican American nonsmokers (23.9%) (MMWR, 2015).

A difference in cotinine levels was also found with varying levels of socioeconomic status. Greater than two out of every five nonsmokers exposed to secondhand smoke were living below the poverty level over the 2011-2012 time period. Additionally, various occupational profiles (i.e. white collar, blue collar, and construction workers) were found to have significantly higher exposures to secondhand smoke. Specifically, blue collar workers and construction workers were exposed to secondhand smoke in greater quantities than white collar employees (MMWR, 2015).
Third Hand Smoke: Another Aspect of Passive Smoke Exposure

Third hand smoke (THS) refers to tobacco smoke particles that stay behind on indoor surfaces, even after majority of it has dispersed out of the environmental airspace (Matt et. al., 2010). THS is sometimes defined using three R’s; how it remains, how it re-emits toxicants, and how it reacts with air pollutants. THS includes not only smoke particles on hard surfaces, but also smoke particles that adhere to clothes, the body, and hair of smokers allowing it to re-enter the ambient air and expose non-smokers to SHS (Matt et. al., 2011). This process is referred to as stale smoke and is a growing public health concern. As THS can be a potential health hazard for non-suspecting persons from the inadvertent exposure to tobacco smoke, the public health threat is even greater (Sleiman et. al., 2010). Efforts may be made to ventilate the environment that has been exposed to THS, but harmful components have a potential to persist, despite major efforts at elimination (Matt et. al., 2011).

Environmental Tobacco Smoke (ETS) and Mainstream Smoke (main stream smoke): A Chemical Comparison

Secondhand smoke (SHS) is defined as the smoke inhaled involuntarily by nonsmokers, often also referred to as Environmental Tobacco Smoke (ETS). SHS is a mixture of side-stream (side stream smoke) smoke and mainstream (main stream smoke) smoke. ETS has been found to contain many of the same toxic and carcinogenic agents as are found in main stream smoke, but in lower concentrations (DHHS, 2016). The major differences in the contents of side stream smoke versus main stream smoke come from the fact that main stream smoke is generated at higher combustion temperatures, which produces stronger reducing agents in the backdrop of oxygen deficiency due to the cigarette cone burning (DHHS, 2016). Burning cigarette has a peak combustion temperature of 900°C during puffing, but only 600°C in between puffs. ETS gets diluted in the air whereas exposure to main stream smoke entails direct exposure to the concentrated form of the tobacco smoke. However, exposure to ETS is a prolonged exposure as compared to main stream smoke which is limited in time (DHHS, 2016).

Health Consequences of Environmental Tobacco Smoke (ETS) Exposure.

Lung cancer

Second hand smoke exposure is a recognized risk factor for development of lung cancer (DHHS, 2006). There is a very small, but established, dose-dependent association between SHS carcinogens with lung cancer. This association is important, as ETS exposure can span the entire life from childhood to adulthood (DHHS, 2006). A meta-analysis in 2006 of 25 studies found a pooled relative risk of 1.22 (95% CI 1.13-1.33) for lung cancer in a study population of non-smokers exposed to SHS (DHHS, 2006). Another meta-analysis of 18 case-control studies showed increased overall odds for lung cancer in non-smokers exposed to SHS of 1.31 (95% CI 1.17-1.45) (Kim, et. al., 2006). In understanding these risks, there were 7,300 lung cancer deaths that can be attributed to secondhand smoke exposure among adult nonsmokers in the United States from 2005 - 2009 (DHHS, 2014). Figure 2 illustrates the multipronged effect of secondhand smoke exposure on the development of respiratory pathologies.
Cardiovascular disease

SHS exposure also increases the risk of cardiovascular disease in non-smokers. Pooled relative risks from meta-analyses indicate a dose-response relationship from SHS exposure, with a 25 to 30 percent increased risk of coronary heart disease (He et. al., 1999; Law, Morris, & Wald, 1997). Various mechanisms by which SHS has been shown to cause cardiovascular morbidity include endothelial dysfunction and increase of inflammatory markers (He et. al., 1999).

In a study including healthy young volunteers, exposure to SHS was found to compromise coronary artery endothelial function in the same way as in active smokers (Panagiotakos et. al., 2004). SHS is also associated with increased inflammatory markers, like increased white blood cell counts and increased levels of C-reactive protein, homocysteine, fibrinogen, and oxidized LDL cholesterol (Panagiotakos et. al., 2004). Some studies looking at serum cotinine concentration to assess SHS exposure found that in a 20 year follow-up of non-smoking men, coronary heart disease (CHD) risk was directly proportional to serum cotinine concentrations. Compared with men in the lowest quartile of serum cotinine concentration, the risks in the second, third, and fourth quartiles were 1.45, 1.49, and 1.57, respectively (Whincup, et. al., 2004). Figure 3 illustrates the commonest pathologies and clinical conditions of the cardiovascular system that stem from exposure to secondhand smoke exposure.

Other respiratory tract illness

Asthma and chronic obstructive pulmonary disease (COPD) are associated with SHS exposure (Menzies, et. al., 2006). Several studies have shown improvement in the status of people with asthma after the implementation of workplace bans on smoking (Menzies, et. al., 2006).
Advocacy and Policy

Banning smoking in the workplace is the only way to eliminate smoke exposure to non-smoking workers. Physical segregation of smokers and non-smokers, however, will not completely eliminate smoke exposure as they share the same airspace. Depending on the extent of the exposure, SHS exposure of the non-smoking population may be comparable to that of a person sharing a house with a smoker.

Tobacco smoke exposure and cardiac disease risk association was studied in Scotland where the outcome suggested a reduction in risk for developing heart disease (Pell, et. al., 2008). This reduction was most likely attributable to the nationwide ban on smoking at work and in public spaces. Part of the study collected data about the number of admissions secondary to acute coronary syndrome 10 months before and 10 months after the passage of the smoking ban in work and public places. A 17% (95% confidence interval [CI], 16%-18%) decrease was found in the number of admissions over the time period studied. A reduction was also seen in the hospitalization numbers for smokers, former smokers and non-smokers by 14%, 19% and 21% respectively (CI given for these %?). A decrease in serum cotinine levels was found in the group reporting decreased exposure to SHS in non-smokers, from 0.68 to 0.56 ng/ ml (P<0.001)(19).

In another study by Hammond et al, airborne nicotine concentrations were found to be less than 1 mcg/m³ in both restaurants and offices with a smoking ban, as compared to 2-6 mcg/m³ in offices that allowed smoking, and 3-8 mcg/m³ in restaurants that allowed smoking. These findings are comparable to mean nicotine concentrations of 1-3 mcg/m³ that have been measured in the homes of smokers (Hammond, 1999).
An increasing trend in adopting non-smoking policies in workplaces has been observed. A model workplace is one that completely bans smoking with consideration also given to policies that outline designated areas for smoking. It is important to not only implement non-smoking policies, but also help smokers to quit. This should include opportunities to participate in smoking cessation programs to promote long-term cessation efforts (Hammond, 1999).

Smoke Free Workplace Laws: The Current Trends in the United States

Since the turn of the century, there has been a drive to limit the general public’s exposure to SHS. The Department of Health and Human Services (DHS) included objective 27-13 in Healthy People 2010 which called for laws to eliminate smoking in public places and worksites in all 50 states plus the District of Columbia (DC), but we as a nation were unable to reach our goal in 2010 (Healthy People 2020). Healthy People 2020, objective TU-13 no aims to complete the task of its predecessor. Too meet this objective, the CDC reported changes that have been made to state laws in a Morbidity and Mortality Weekly Report (MMWR). This report discussed 26 states (including DC) which enacted laws banning smoking in indoor areas, including worksites, restaurants, and bars by 2010 (MMWR, 2011). The first law was enacted in Delaware in 2002, which included a comprehensive smoking ban throughout the state. The report also noted regional discrepancies; for example, southern states are slow to adopt the prohibition of smoking in public places.

In 2007, Tennessee enacted the Non-Smokers Protection Act, which made smoking in enclosed public spaces illegal, with a few exceptions; most notably private companies and worksites (TN State Legislation SENATE BILL NO. 1325, 2007). Since Healthy People 2020 seeks a smoke-free policy adoption nationally, and the CDC considers a state smoke free law to be in place only when comprehensive, it has served as an inspiration for this advocacy effort to promote the facts related to the harms of environmental smoke and exposure (Healthy People, 2010). The CDC considers a state smoke free law comprehensive to be in effect when it protects three sectors from ETS; private sector worksites, bars, and restaurants. In Tennessee, the laws do not completely prohibit smoking in private-sector worksites or bars; therefore, these laws do not fully protect a non-smoker and may not be considered comprehensive under the CDC rules. As time passes, some states have expanded their laws to create coverage of these sectors specified by the CDC strengthening the protection for non-smokers to ETS.

Recommendations for Companies in a State/City Without a Smoke Free Policy

The best overall method for eliminating tobacco smoke in the workplace is a complete ban on smoking and implementation of smoking cessation programs to assist with workers’ cessation needs. Ideally, workers should not be forced to breathe in tobacco smoke just because they work in occupations that support their essential life needs.

A publication released by NIOSH outlined steps by which a workplace can eliminate tobacco use in the workplace. The publication noted that employers have to work with all parties in implementing non-smoking policies from the labor force to the management. All stakeholders should be brought into the decision making process. The article further discussed
how strategies developed by schools of public health could be tailored to suit each workplace. Four steps were outlined; 1) Offer incentives to stop smoking, 2) Offer cessation classes or counseling to the workers, 3) Distribute information among workers about the harms of smoking, and 4) Implement disincentives for those who continue to smoke after non-smoking policies have been implemented.

When there is physical separation of smokers and non-smokers, a false sense of security prevails (DHHS, 2016). If the same airspace is shared, it is not possible to completely eliminate passive exposure of smoke for the non-smoking population of workers. Any area within the building where smoking is permitted, the smoke will have a tendency to spread through the shared airspace. In order to ensure complete separation, the designated smoking area should be outside of the building and operate under a separate ventilation system that does not allow the smoke to flow back into the common workspace or public walking areas. This consideration was reiterated in the 1986 Surgeon General’s report on involuntary smoking, which concluded that by simply separating smoker and non-smokers complete protection from SHS is not possible for non-smokers. Implementing this mechanism can reduce the exposure to ETS, but due to the ability of smoke particles to spread through the common airspace exposure to all workers is very likely (DHHS, 2016).

The only satisfactorily proven method of ETS elimination is completely prohibiting smoking in the workplace (DHHS, 2016). However, the current industrial culture dictates a lack of ability to implement such laws in the workplace. Until then, the most effective way to keep non-smoking working class from being exposed to ETS is to ensure smoking areas are completely separate from the general workplace and operate under its own ventilation system. In addition, it is necessary to ensure that the exhaust system does not intermix with the general circulation. As additional precautionary measures, workplaces should put up warning signs to indicate that designated areas are in place for smoking and smoking on premises are allowed only in such areas. Such signs should be put up in English, as well as Spanish, or any other predominant non-English language that is used by a majority of the working population.

Benefits of Comprehensive Smoking Bans

There have been studies made to look at the impact of a comprehensive smoking ban on the healthcare utilization and admission rates. One such study focused on the state of Arizona following the comprehensive ban enacted in May 2007. They evaluated the rate of admissions for asthma, stroke, chest pain, and acute myocardial infarction from January 2004 until May 2008. They matched corresponding months before and after the smoking ban to find a statistically significant decrease in admissions for these diagnoses (Herman & Walsh, 2011). There have also been studies evaluating the effect of a comprehensive smoking ban by counties following implementation of a ban for 12 months, one study showed both a 20% percent reduction in hospital admission rates for heart attacks and 11% reduction for COPD (Barr et. al., 2012).
Conclusion

This country has a long history steeped in the use of tobacco, being one of our first cash crops and cornerstone in the forming of the republic. The Tobacco Industry also has a long history of bullying and manipulation that still casts a shadow on public health. A history not easily forgotten, the formation and implementation of tobacco control laws is not easy, and neither is quitting. By bringing growing fields of evidence we can offset the influence of big business forcing law makers to seek better controls for the general public. Given the growing number of states to ban the use of tobacco products comprehensively there is pressure on many state legislators to protect the general population from the effects of ETS exposure. Since, there is clear evidence of the negative effects of smoking on the health of the public, we should analyze the financial benefits to enact laws to better protect our citizens. Since it has been shown to reduce hospital admissions and exacerbating a number of chronic condition we can therefore see a reduction in health care spending. We should promote the programs to reduce tobacco use in new consumers and provide resources to help old consumers cut out the habit. It’s not easy to quit tobacco use and it requires strong reinforcement to keep from returning to tobacco use. It is the right of any mature adult to enjoy tobacco products- if they desire to do so, but it also the right of everyone to be protected from carcinogenic compounds.

References


Menzies D., Nair, A., Williamson, P., A., Schembri, S., Al-Khairalla, M., Z., Barnes, M., ... Lipworth, G., J., Respiratory symptoms, pulmonary function, and markers of inflammation among bar workers before and after a legislative ban on smoking in public places. **JAMA.** 2006; 296(14): 1742


BLACK LIVES MATTER!
Book Review

**White Rage: The Unspoken Truth of Our Racial Divide**

Carol Anderson, Author

Rueben Warren, DDS, MPH, DrPH, MDiv
Professor and Director of the National Center for Bioethics in Research and Health Care at Tuskegee University
Tel: (334) 724-4554
Email: warrenr@mutu.tuskegee.edu

*White Rage* by Carol Anderson is a chilling account of the freedom struggle of African Americans and the historic white backlash directed against the efforts for human rights assurance by African Americans. Dr. Anderson is the Samuel Candler Dobbs Professor and Chair of the Department of African American Studies at Emory University in Atlanta, Georgia. The book developed from her op-ed published in the *Washington Post*, following the killing of Michael Brown, in Ferguson, Missouri, helped to bring national media attention to, what seemed to be, recent injustices against African Americans. However, a broader and historic lens was necessary to document trends and patterns of injustice. Dr. Anderson provides a scholarly account of the *Truth* regarding the African American struggle for freedom and justice in the United States from the period of enslavement until today.

The book consists of the following sections: Kindling, Reconstructing Reconstruction, Derailing the Great Migration, Burning Brown to the Ground, How to Unelect a Black President and Imagine. I use the following topic areas: situation, analysis, and conclusion or resolve to provide the reader with a systematic way to approach the salient issues in each section. For example, Kindling begins with a reflection on the killing of Michael Brown by the police and a reminder about the death of Amadou Diallo, another Black man killed in New York City in 1999. Diallo, a West African immigrant, stepped out of his apartment and the NYPD mistakenly, fired 41 bullets; 19 of them hitting their target and killing him. In response, the local community and the nation also expressed outrage over racial profiling, stop-and-frisk, and police brutality in Black and Hispanic communities. However, then Mayor Rudy Giuliani, responded by highlighting the reduction in the New York City crime rate and emphasized that the real issue was the “community’s racism against the police.” (p.157) He also chastised community residents for their unwillingness to take responsibility for the issues plaguing their neighborhoods. In 2014, unarmed Michael Brown was killed by a white police officer and the media’s response to the Black community’s outrage was reframed as Black rage by the op-eds and news commentators instead of acknowledging the systemic white rage that kills Black people with impunity.

The Kindling section of the book emphasizes that while much attention is placed on what is publicly visible (the flames of a fire), little attention focuses on the kindling or white rage, which is the manipulation and maneuvering of whites to avoid addressing the salient issues of racism; as Anderson writes, “white rage… it works its way through the courts, legislatures and government bureaucracies.” (p.3) Anderson “make(s) white rage visible . . . blow(s) graphite
onto that hidden fingerprint and trace its historic movements over the past 150 years.” (p.3) She argues that white rage is triggered by Black advancement.

White rage presumes the moral high ground. White rage is a sickening false narrative about a culture of Black poverty that implies that Black people devalue education, hard work, family and ambition. The truth is that enslaved Africans worked hard and without remuneration to build this country. They fought in the Civil War and in every war in which the United States has engaged, built their own schools, worked the land, and built their own cities and amassed some wealth. The forty acres and a mule promised to Black people by the federal government were never fully realized. Even with the Thirteenth, Fourteenth and Fifteenth Amendments, Black progress was denied. World War I provided opportunities in the North that the South would never provide. Yet, the truth is that the North was no panacea. In many ways, it was just like the South, just in a different location. The Great Migration North resulted in uninhabitable slums for Black people. The hard-fought battles against segregation, Jim Crow, unequal education, mass incarceration and other human rights violation continue, despite the election of a Black President. The truth is white rage undermines democracy. This section concludes with a profound statement, “...these seemingly isolated episodes [of racial violence] reach back to the nineteenth century and carry forward to the twenty-first, once fitted together like pieces in a mosaic, reveal a portrait of a nation: one that is the unspoken truth of our racial divide.” (p.6)

Reconstructing Reconstruction opens with several quotations/statements by U.S. Presidents that warrant repeating:

James Madison called [chattel slavery] America’s “original sin.” (p.7)

Thomas Jefferson prophesied that [chattel slavery] would bring down a wrath of biblical proportions. He wrote, “I tremble for my country when I reflect that God is just: that his justice cannot sleep forever.” (p.7)

Abraham Lincoln wrote that the Civil War was God’s punishment for, “All the wealth piled by the bondsman’s 250 years of unrequited toil.” (p.7)

What appears to be regret and repentance for slavery was short lived; Thomas Jefferson advocated for expulsion of Black people from the U.S to save the nation. Kentuckian Henry Clay established the American Colonization Society to move thousands of Black people to Liberia, and even Lincoln himself, wanted Black people to move to South America. Nonetheless, the contributions that Black people have and continue to make in the building of the U.S. are immeasurable. In 1860 for example, Dr. Anderson reports that 80% of the U.S gross national product was tied to slavery. Ten percent or 179,000 Union Army soldiers and 19,000 Navy men were African Americans. Nonetheless, Lincoln is quoted as saying, “I am not, nor ever have been, in favor of bringing about any way the social and political equality of the white and black races.” (p.14)

Andrew Johnson, who became President after Lincoln’s assignation, was even less supportive. In 1865 the Freedman Bureau was created. Part of the Bureau’s responsibility was the reallocation of Southern land to newly emancipated citizens; forty acres were the parcels
supposedly allocated. The head of the Freeman Bureau was General Oliver O. Howard. However, as General Howard allocated the land for emancipated Black citizens, President Johnson rescinded the order commanding the army to throw tens of thousands of Black people off the land and returned it to the plantation owners.

Following the end of slavery, physical violence by white people toward Black people, was perpetrated on women, men and children, alike. Stabbing, lynching, clubbing, burning and other mutilations continued prompting many Black and some white people to request greater federal presence. But President Johnson chose not to increase the federal presence, which encouraged white southerners to continue their rampage on Black life. Black Codes were enacted throughout the South. Black people were required to sign annual labor contracts with plantations and mills. If they refused they were charged with vagrancy, put on the auction blocks and sold to the highest bidder to work in the convict-lease system.

Northern congressmen vigorously opposed the Black Codes, which slowed, but did not stop the injustices imposed by the Black Codes. President Johnson opposed every effort by Congress to correct the injustice created through the Black Codes. In fact, the authors of the Black Codes also designed the criminal justice system. Education for Black people was a part of the responsibily of the newly formed Freeman Bureau to correct some of the injustices that resulted from enslavement. However, President Johnson, for example, rejected the idea of the federal government building schools for Black people. Nevertheless, by 1866, Black people had built, staffed and run at least 500 schools, for themselves. The federal government that was supposedly passing and enforcing law to protect the rights and assure justice for Black people was, in fact, doing just the opposite. The roll-backs continued as late as 1942, when only 3% of the voting-age populations cast a ballot in the 7 poll tax states. Anderson paraphrasing historian Fredrick Maitland writes, “The slave law of the South may have been dead, but it rules from the grave.” (p.38)

Derailing the Great Migration chronicles how southern white men responded with merciless forms of terror to Black people migrating to the North, Midwest and West. Black men and women were mob lynched. For example, a Black pregnant woman whose husband was lynched responded by saying that, “If she knew the parties who were in the mob she would have warrants sworn out against them” (p.40). Soon after making this statement, she was dragged to a tree; stripped, tied by her ankles and strung upside-down. The woman was set a fire and her unborn baby was slit from her stomach. When the baby fell to the ground one of the mobsters smashed the baby’s head with the heel of his boot. Publicly elected officials such as governors, mayors, police chiefs also responded with subtle, but clear and effective strategies to stop the Black movement from the South.

While migration was common for millions of people coming to the U.S, elite southern white men used every means conceivable to prevent Black people from moving North. The Great Migration was not great for Black people. There were few illusions among Black people about the North. However, it was better than being in the South. World War II created jobs in the North for Black people. Maneuvers by northerners to facilitate Black people moving from
the South to assume these jobs were subverted by southerners stopping and/or derailing trains and using other subversive actions. Black people nonetheless, continued to go North. Fears about Black people competing for jobs, seeking housing, schooling and other positive living conditions emerged in the North, which resulted in so-called race riots and other forms of violence. These occurrences were not race riots. There were, in reality, white people rampaging and killing Black people. As Black people fought back, questions were raised in the courts if Black people had the same rights as whites, particularly in instances of self-defense.

Burning Brown to the Ground focuses on the NAACP’s fight to destroy Jim Crow and overturn the Plessy v. Ferguson decision which made separate and equal legal in the United States. The separate was unequal. One glaring example was reflected in the student to teacher ratio, as well as the dollars spent to educate each child in the public-school systems. Segregation in the South was blatant and the law of the land, but de facto segregation was subtler, yet as harmful in the North. From 1935 to 1950, the NAACP with brilliant lawyers like Charles Hamilton Johnson, Thurgood Marshall and many others repeatedly went to court to demonstrate that southern governments could not verify that separate was equal. On May 17, 1954, the Brown vs. the Board of Education U.S. Supreme Court case, concluded that Jim Crow schools violated the equal protection clause in the Fourteenth Amendment. Charles Johnson wrote, “if segregation is unconstitutional in educational institutions, it is no less so unconditional in other aspects of our national life.” (p.75)

In subsequent years, the Brown decision resulted in furious reactions throughout the country, particularly in the Deep South. Both overt and covert white rage appeared in the North and the South in all sectors of national life. Emmett Till’s murder in Mississippi was but one example of the white reaction to Black progress. White rage was so strong that in 1955 the Supreme Court handed down Brown II, which stated that desegregation must happen “with all deliberate speed.” Southern states chose to continue to defy and resist the federal laws by passing unconstitutional laws. But Black parents fought back, and in Cooper vs. Aaron, it was unequivocally stated, Brown was the supreme law of the land and had to be obeyed. Yet, in 2017, the public schools throughout the country are probably more segregated and unequal than they have ever been.

Rolling Back Civil Rights makes clear there was much more to the Movement than Rosa Parks refusing to give up her seat in Montgomery, Alabama, or Martin Luther King Jr.’s iconic “I Have a Dream” speech on the National Mall before 25,000 people (p.98).” The Civil Rights Movement was a series of engagements ranging from locally organized, planned nonviolent strategies to expose inequities in housing, employment, schools, health and other so-called guarantees of “citizens” of the U.S. led, in many instances, by the Southern Christian Leadership Conference (SCLC). The challenge was, “to redeem the soul of America.” (p.98) It was not until the triple murder of civil right workers in Mississippi that the 1964 Civil Rights Act was passed. It was not until Bloody Sunday in Alabama that the 1965 Voting Rights Act passed. Repeatedly, white rage provided kindling for overt violence by white people. Black People have only received temporary anecdotal remedies to assure their civil rights by the various branches of the federal government.
Because of what seemed to be progress in assuring civil rights for Black people in the 1960s, white rage began to coalesce. The Nixon and Reagan administrations in the Executive Branch of government, and the Burger and Rehnquist Supreme Courts, in the Judiciary Branch, issued two pivotal decisions related to the Civil Rights Act of 1964 and the Voting Rights of 1965. By 1965, Nixon said that, “almost every legislative roadblock to equality of opportunity for education, jobs, and voting had been removed. President Lyndon Johnson’s Great Society and affirmative action reversed the years of discrimination against working-class white people and oppression and racism against Black people. Nixon also redefined racism for the public by focusing in on overt racism as demonstrated by organizations like the Ku Klux Klan. The overt form of racism overshadowed other forms of racism such as systemic and institutional racism, which are equally, if not more devastating. While the Voting Rights Act was clearly working, the first piece of civil right legislation that President Nixon sent to Congress was to eliminate Section 5, which targeted the areas in the country, “where potential for discrimination to be the greatest.” (p.107) President Nixon also wanted to stretch the act to the entire country. Section 5 of the Civil Rights Act continued until 2015. The Nixon administration set the stage for much of the reversal of civil rights gains that would later be realized during the Reagan administration.

Today, Ronald Reagan is regarded as one the great U.S. Presidents, despite the rollback of many of the civil rights gains during the early 1960. For example, Reagan reconfigured grant and loan packages for colleges and universities, which resulted in large cuts in funds available for students. While the cuts hurt all low-income students, Black students were 5 times more likely to have parents whose income was below the twelve thousand dollars’ threshold. Thus, in part, Black enrollment in college dropped from 34 to 26 percent. Similar cut backs occurred in grades K-12. During the 1960s to 1970s, the Black unemployment rate declined. However, Reagan’s policies increased Black unemployment and widened the gap between Blacks and whites to unprecedented levels. Additionally, there was a massive lay off federal job resulting in nine hundred workers being furloughed, 60% of whom were Black.

President Reagan also engaged in a national drug abuse program to warn young people about the dangers of drug use instead of focusing on narcotic smuggling. He asserted, in 1982, that there was a crisis, despite no evidence that such a crisis existed. Interestingly, in 1979, in support of the Sandinista guerrillas, known as the Contra, Reagan provided $19.3 million for the Contra to oppose the Marxist Nicaraguans who had recently overthrown long time U.S. ally and dictator Anastasio Somoza.

President Reagan had boasted the importance of cutting of drugs to the U.S., while at the same time, cocaine imports in the U.S. increased by 50%. With the massive influx of cocaine, came the introduction of crack in the Black community. Unlike in 1981, when Reagan’s response was treatment for addiction, he shifted to law enforcement and punishment. In the 1970s, cocaine use in the Black community was minor, but by 1984, crack use in the Black community was out of control. Also, the explosion of AK-47s, assault weapons and homicide rates in the Black community exponentially increased. Anderson succinctly summarizes this section when she writes, “The United States did not face a crime problem that was racialized; it faced a race problem that it criminalized” (p.137).
How to Unelect a Black President opens with Anderson stating, “On November 4, 2008, the United States seemed to be crossing the racial Rubicon” (p.138). Desmond Tutu agreed and said, “Obama's victory told, People of color that for them, the sky is the limit” (p.138). Obama had 66 percent of the Hispanic vote, 62 percent of the Asian vote, 56 percent of the women's vote and 95 percent of the Black vote. Historically, the Democratic Party benefits as the percentage of voters goes up. The strategy for the GOP was to suppress the vote. Obama had outmaneuvered Clinton by energizing youth and poor people, along with the Democrat's usual allies. The frustration by the GOP soon transformed into a strategy of voter intimidation and suppression. At the state level Photo ID laws across the country became an effective strategy used by the GOP both in Northern and Southern states. Another strategy was to limit or eliminate early voting. The GOP learned the pattern of Black voting and created strategies to block them. In 2010, Shelby County, Alabama challenged the Voting Rights Act by suing the federal government and in a 5-4 decision the court concluded that the law is obsolete. They kept Section 5 of the Act, but ruled Section 4 was unconstitutional.

White Rage is an excellent resource for scholars, students and the public. The book provides a ready reference for a plethora of historical information about the challenges and successes in assuring justice for Black people in the United States. The book also does an extraordinary job in synthesizing efforts that continue to strive for freedom and justice for Black people in the U.S. It is indexed and well documented.
Author Requirements

The Journal of Healthcare, Science and the Humanities
June 2014

I. General Information

The Journal of Healthcare, Science and the Humanities (JHSH) publishes a wide variety of articles intended to enrich and advance the knowledge of health and health care, science and the humanities, as well as the art and science of health care delivery and the health professions.

Program or project summaries/exemplars, formal case studies, or case scenarios are acceptable, but must be carefully constructed to avoid any subtle commercialization or politicization. Authors are free to submit academic manuscripts that present differing or alternative views to current issues and debates. The Editor will make final decisions regarding these issues after consultation with the members of the Journal Executive Leadership, including Intellectual Property Counsel if so required.

JHSH will not consider manuscripts that are being submitted or considered elsewhere simultaneously. If an author wishes to have a work rescinded from JHSH consideration for submission to another publication, the author must request in writing and be granted an official written notification regarding the same from the Editor or Senior Associate Editor.

Unless there is clear justification, and only with the written permission of the previous publisher, JHSH will not accept manuscripts published elsewhere, or that will be published prior to appearing in JHSH. Authors must inform the Editor of such matters at the time their manuscript is submitted; review by Intellectual Property Counsel may be required. Such matters must be acknowledged in the Author Note.

II. Representative Manuscript Categories

JHSH encourages authors to choose from a wide range of subject matter categories. Authors may explore various categories and possibilities with the Senior Associate Editor, who will subsequently discuss with the Editor. The Editor has responsibility for final decisions in this area. The following are representative categories.

a. Research papers, theoretical investigations.

b. Scholarly critiques and commentaries on various topics.

c. Formal case studies and program/project reports.

d. Reaction papers and editorials.

e. Book, film, media, law, education or other reviews.

f. Other academic or professional articles related to the JHSH interdisciplinary mission.

g. Creative work, including poetry and short fiction relevant to the JHSH mission.
Author Requirements

III. Submission Review Processes

Submissions undergo a four-stage process of rigorous review, discernment, evaluation, and approval. The Editor may adapt these processes to meet specific circumstances.

Stage 1:

Authors submit full manuscripts or manuscript concept proposals to both the Editor and Senior Associate Editor. The Editor, Senior Associate Editor, and Associate Editors will conduct a preliminary assessment for relevance to the JHSH mission. The Senior Associate Editor will provide guidance to the corresponding author about shaping the manuscript for JHSH readers. All manuscripts, including all figures and graphics, must be formatted correctly and comply with JHSH Author Requirements before manuscripts will be allowed by the Editor to progress to Stage 2. Compliance with this requirement is mandatory. Exceptions will not be granted.

Stage 2:

After the Senior Associate Editor determines that all Stage 1 requirements are met and that all manuscript and graphics/figures formatting is in compliance, the Senior Associate Editor forwards the manuscript to the Chairs of the Academic Review Committee (ARC) for rigorous peer review. Also, at the time of Stage 2 submission, all authors must submit their completed Author Agreements and Copyright Release Forms. No article can be published unless this requirement is met by all authors. All journal peer reviewers have executed non-disclosure agreements and conflict of interest declarations to protect an author’s rights and academic property. Peer review routinely results in manuscript revision. The first author and the ARC Chairs work together to address matters stemming from peer review and to ensure that the manuscript is revised accordingly.

Stage 3:

After successful peer review and revision, the ARC Chairs send the revised manuscript to the Chairs of the Manuscript Editorial Committee (MEC) for rigorous editorial and formatting review, revision, and critique of actual content and language. This also includes careful review of all figures, graphics, and other related elements for compliance with requirements. The MEC also reviews, critiques and recommends minor formatting needs. The author and the MEC Chairs process and finalize the manuscript. When this process is completed, the MEC Chairs send the final manuscript back to the Senior Associate Editor as certified ready for final review.

Stage 4:

Upon receipt from the MEC Chairs, the Senior Associate Editor sends the final edition of the manuscript to the Journal Associate Editors for a final qualitative review. Any additional changes required are completed between the author and the Senior Associate Editor. Upon successful final qualitative review by the Associate Editors, the Senior Associate Editor sends the final edition to the Editor for final review and approval. If all items are in order, the Editor formally approves and accepts the manuscript for a future edition of JHSH. The Editor notifies the author of final acceptance.

Note: The Editor may make further determinations regarding requirements or revisions to manuscripts. In the event of circumstances, the Editor may disapprove a final edition.
IV. Style Requirements


APA Style Web Resources: The URL links below provide additional information and assistance for APA style requirements.

http://owl.english.purdue.edu/owl/resource/560/01/
http://www.apastyle.org/elecref.html
http://www.psychwww.com/resource/apacrib.htm

Formatting Specifics:

In addition to meeting APA style requirements, articles must be organized according to the format below. All papers must be divided into appropriate, titled sections and subsections based on subject matter.

a. Introductory Material. Each manuscript must begin with the title, name of author(s) with current title(s) and institutional affiliation(s). With the exception of creative essays pre-approved by the Editor, manuscript titles shall be consistent with the scholarly and professional nature of the Journal. Informality, a casual tone and colloquialisms must be avoided. When using degrees after an author’s name, periods are omitted. (e.g., PhD, not Ph.D). Contact information for the corresponding author is to be included, either in the introductory material or as part of the Author Note. Authors are to provide complete, precise information for themselves and each co-author, to include street address, phone, fax and e-mail address (see example below):

Mary Smith, MD, PhD, CPI
Chair, Department of Surgery
University of Smithville
301 Smithville Road
Smithville, MD
Tel: (301) 456-1234
Fax: (301) 456-1235
Email: Mary.Smith@smithville.edu

b. Author Note. Immediately following the title and author information, each manuscript must include a brief, un-indented paragraph containing important preliminary and/or disclaimer information. This paragraph, called an Author Note, will state the source of the subject material (e.g., preliminary presentation or doctoral dissertation). If the work was supported by a grant, contract, or similar instrument, proper credit must be given. In the Author Note it is required to place the information about IRB and IACUC review and approval with relevant protocol identification numbers and dates of approval or determination. The Author Note should include any required institutional disclaimers. The author/authors must declare any and all financial conflicts of interest (or lack thereof) in the Author Note. The Author Note shall include information regarding contributors.
Author Requirements

See Section VII below concerning requirements for designating authorship as opposed to contributors. Acknowledgments are placed in the Author Note.

c. Abstract. Immediately following the Author’s Note and without any page break, all articles will have an abstract of approximately 200 words. The abstract is a single, unindented paragraph of plain text without bullets or subsections. The abstract must use key information from the text to provide a clear, concise and unbiased summary. Review Articles or Creative Writing submissions do not have an abstract.

d. Keywords. Immediately following the abstract and without any page break, list at least three key words to facilitate electronic searches of the manuscript. The choice of key words will depend on the subject matter. Review Articles or Creative Writing submissions do not include key words.

e. Introduction. Immediately following the Keywords and without any page break, the text must begin with a section entitled “Introduction.” In the Introduction the author should preview what is about to be presented, and may chronicle the past history of the subject under discussion with appropriate use of references from the literature. Both the content and length of the introduction will vary according to subject matter. Review Articles and Creative Writing must include an introduction explaining the intent and providing important background to what follows.

f. Middle Sections. Based upon subject matter and methodology, the middle portion of the manuscript is to be divided into appropriate sections and subsections, each of which must be appropriately titled. See Section V for the formatting of section and subsection headings.

g. Conclusion. This section provides a concise summary of the materials previously presented, and points toward future or practical implications and/or implementation. Review Articles and Creative Writing should include a conclusion that points out the benefit of what has been presented to the reader and to the JHSH mission.

h. References. For those manuscripts requiring them, references will be listed on a separate page following the text. Accuracy is the responsibility of the author; references will not be validated in editorial review. The APA publication manual provides detail on the correct format for references. Review Articles do not require references, unless deemed by the Editor as essential. However, if useful Review Articles, Commentaries, Academic Reflections and other non-research presentations strictly speaking may offer Select Bibliographies or listings of works as For Further Reading.

V. Manuscript Preparation Requirements

Manuscripts must be submitted (including tables and figures) in single spaced copy. Standard American or UK English usage and spelling are the norm, the latter for authors from UK English-speaking communities. Except for clearly stylistic conventions that can be reasonably justified in an academic and professional publication of this nature, authors are to avoid overly informal compositional style and language. Similarly, to maintain the highest level of academic quality, the use of the first person singular or plural is normally not accepted in JHSH research-oriented works. However it can be used in commentaries, reviews, and creative works and in those categories where its usage mirrors the style of academic/scientific papers in
scholarly publications. Contractions are not to be used except for intentional style purposes or within quoted materials. For all tables and figures, see the Graphics Section below for detailed instructions. All manuscripts must use one-inch margins throughout. Authors are to submit all material in electronic format compatible with MS Word for MacOS and Windows. It is the author’s responsibility to ensure software compatibility of both text and graphics. Manuscripts should not contain any specialized formats, automatic styles, or other features not easily translated between computing platforms or any content that cannot be shaped by desktop graphics technicians at the publishing house. For example, the use of references must not require editing or graphics personnel to obtain commercial notation software. Such editing must be able to be accomplished within MS Word. It is the responsibility of authors to require with this matter. Submission that do not comply will be returned until the matter is resolved.

**Bullets**

Bullets are not permitted within the text. Numbered or lettered lists are acceptable.

**Electronic Submission**

All manuscripts are to be submitted to the Editor and the Senior Associate Editor as an e-mail attachment. All manuscripts must be submitted in MS Word format for MacOS and/or Windows (.doc or .docx format). Do not send manuscripts using the pdf or webarchive format. Such will be returned. See Section VI regarding graphics. Authors may wish to review examples of previously published articles as guides. These can be made available upon request.

**Headings**

Each manuscript must be subdivided into relevant sections as discussed above. Sections may be further subdivided to enhance the discussion or for other editorial reasons. Major sections should use Level 1 headings. Subsections should use headings for Levels 2 through 4. Directions for formatting Headings follow:

- **Level 1:** *Helvetica* 14pt Centered Uppercase and Lowercase Heading **[Bold]**
- **Level 2:** *Helvetica* 11pt. Centered, Italicized, Upper and Lowercase Heading
- **Level 3:** *Helvetica* 14pt Flush Left, Italicized, Uppercase and Lowercase Heading
- **Level 4:** *Helvetica* 14pt Indented, italicized, lowercase paragraph heading and ending with a period.

Authors who do not have Helvetica font may substitute Arial.

**Typeface**

Except for headings as listed above, Times New Roman 12pt font is required for the body of the manuscript and references. Do not use bold or underlining for emphasis. Italics are allowed provided they fit APA style guidelines.

**Headers and Footers**

Headers or footers (including footnotes) are not permitted in the manuscript.

Pagination is allowed at the bottom center or bottom right for review purposes only. Page numbers will be removed from the final versions of manuscripts.
Author Requirements

Length

Articles are typically approximately 15-25 pages single-spaced (approx. 9,000 – 15,000 words), not including references, tables, graphics, or other appendices.

For lengthier articles, authors may arrange with the Editor for the publication of companion manuscripts in back-to-back editions of the Journal.

Review and other similar works are limited to 10-15 pages single-spaced, including references.

Punctuation

The Abstract and Author Note are single, unindented paragraphs. Indent all remaining paragraphs. Use a comma between elements and preceding the conjunction (and, or) in a series of three or more. Use a semicolon to separate elements in a series that contains commas. Use a colon between a grammatically complete introductory clause and a final clause. Do not use a colon to introduce an incomplete sentence. Avoid the overuse of double quotation marks for words. Introduce a key or new technical term in italics.

References

The APA publication manual provides detail on the correct format, including the hanging indent for the second and subsequent lines of the reference. Double-space between references. A brief list of common citation types follows. Use Arabic numbers throughout the references unless a Roman numeral is part of a title.

**Book (author):**
Hewlett, L.S. (1967). Title of work. Location: Publisher.

**Book (editor):**

**Chapter in an Edited Book:**

**Journal Article (print):**

**Journal Article, more than seven authors**

**Journal Article (electronic):**
Newspaper Article (print):

Newspaper Article (electronic):

VI. Special Manuscript Preparations

JHSH regularly includes sections dedicated to special types of manuscripts. Such sections include:

- Book, Film, or Other Reviews
- Special Technical Reports, Scholarly Reflections, or Professional Summaries
- Literary Works

Manuscripts for review and reports generally must follow all author requirements. However, such manuscripts require careful adaptation depending upon the nature of the manuscript, its intention, its place within the JHSH edition, and other factors. The adaptation of requirements for reviews and reports is subject to the direction and approval of the Editor. The Editor may delegate the same to the Senior Associate Editor.

Literary works submitted for publication must meet the highest standards for each specific literary genre. The requirements for literary works are subject to the direction and approval of the Editor. The Editor may delegate the same to the Senior Associate Editor.

VII. Graphics Requirements

All graphics must be submitted within the individual manuscript at the end of the manuscript itself. With each figure or graphic, a short, explanatory caption must be provided. The caption is to be placed appropriately.

Where they are to be placed within the manuscript are to be indicated in a centered directions such as:

*Figure 1 inserted here.*

In addition to placing the graphic at the end of the manuscript, each is to be sent as a separate file in high resolution as a JPEG, TIFF, PNG etc. If the graphic is a Table created in MS Word, it is to be provided additionally as a separate graphic file that ensures that text and other elements are spaced and formatted correctly. During publication processes, first authors are to remain available for the publishing house to contact them for additional refinements for graphic elements. JHSH Editorial Leadership and the publishing house are not responsible for errors in graphics that should have been overseen and corrected by the actual authors.
Author Requirements

VIII. Authorship

The naming of authors must conform with the “Ethical Considerations in the Conduct and Reporting of Research: Authorship and Contributorship” of the International Committee of Medical Journal Editors (http://www.icmje.org/ethical_1author.html). Authorship may only be ascribed to those individuals who personally, actually and substantively contributed to the actual writing of a manuscript, its design, conceptual development, or its academic or professional scholarship. Honorary authorship by virtue of one’s position within one’s institutional organizational structure (e.g., Department Chair) is not permitted at any time or for any reason. Authors are permitted to list other individuals as contributors in the Author Note when relevant and appropriate. However, information about contributors must be brief and relevant.

Authors submitting manuscripts must apprise the Editor immediately if controversies exist concerning authorship or other related issues. JHSH cannot take responsibility for mitigating author disputes or related controversies. If an author dispute is discovered and claimed after publication, JHSH and Intellectual Property Counsel have the right to direct retractions, errata, or other corrections in future JHSH editions in accordance with pertinent laws, regulations, federal requirements, or academic standards. These actions and others may be taken in the event of research misconduct.

IX. Responsible Conduct of Research Standards

Authors must adhere to all standards regarding research integrity and the responsible conduct of research. JHSH strictly adheres to requirements regarding research misconduct, namely falsification, fabrication, and plagiarism. Any allegation of research misconduct is immediately referred to the Editor, who will immediately refer the matter to the JHSH Intellectual Property Counsel. JHSH will support all requirements and processes for such matters to their conclusion.

Articles involving human subjects or animal research must indicate appropriate IRB or IACUC protocol determinations, reviews and approvals with dates. Authors must cite the approved protocol numbers. Any information relative to these important areas must be placed within the Author Note. When there may be questions regarding whether data/materials are determined to involve either human subjects research or research exempt from human subjects regulations, the text must clearly indicate who has made such determinations and the date of determination. It is the right of the Editor and Senior Associate Editor to ensure that all such matters comply with requisite ethical standards, regulations, laws and requirements.

Similarly, authors must disclose relevant conflict of interest information where applicable (or the lack thereof). Any information relative to this area also must be placed within the Author Note.

All questions regarding these areas and other matters related to academic, research, or professional ethics are to be referred directly to the Editor or Senior Associate Editor.

X. Intellectual Property Information

JHSH is a peer reviewed publication of international renown. As such, it upholds and complies with all requirements regarding the protection of intellectual property and copyrights as applicable. JHSH adheres rigorously to United States norms for publications and responsible authorship. JHSH furthermore honors the academic standards and expectations of other international peer reviewed publications.
When an author’s manuscript is accepted for publication, authors must sign author agreements and comply with JHSH directives. One such area is to ensure that the JHSH respects the work of authors especially if it is derived from previous efforts. Therefore, all authors must disclose such factors and work with the Editor and Senior Associate Editor for the preservation of all intellectual property and copyright issues. JHSH will not publish any materials whose authors have not completed author agreement and copyright release requirements.

The following underscores information summarized previously. Questions concerning the information below and its applicability to specific cases are to be referred to the Editor and Senior Associate Editor.

Once an author submits a manuscript, the author is not permitted to have that work under simultaneous consideration by any other publisher or organization. Similarly, if an author submits a proposal for future manuscript development and the proposal is accepted, then the proposal and its subsequent manuscript cannot be submitted elsewhere. If by chance an error has been made in these regards, the author must obtain from the other publisher or publishers a clear release and submit this to the Editor and Senior Associate Editor for consideration. If an author wishes to have a previously submitted manuscript or already accepted proposal published by another organization, the author must submit a formal request to the Editor. Permission is needed before finalization.

In addition, unless there is clear justification and only with the written permission of the previous publisher, JHSH will not accept manuscripts that have been published elsewhere, or that will be published prior to appearing in JHSH. Authors must inform the Editor and Senior Associate Editor of such matters at the time a manuscript is submitted. Such matters must be acknowledged in the Author Note.

Similarly, if an author’s manuscript is based upon one’s thesis or dissertation, the author must inform the Editor and Senior Associate Editor regarding copyright ownership. If the copyright for the thesis or dissertation is owned by anyone other than the author, such as the degree granting institution of higher learning, the author must obtain and submit to the Editor and Senior Associate Editor a copyright release and permission to publish from the copyright owner. Until the matter of copyright is completely processed and resolved successfully, the author’s manuscript cannot be published in the Journal.

**General Copyright Guidance:** Unless expressly agreed to by JHSH, the copyright (i.e., ownership) of the material belongs to JHSH itself and its publishers. Other arrangements may be made (e.g., exclusive or non-exclusive licenses) but must be proposed by the author at the time of submission. If a contributor prepared the submission in the scope of his or her employment, the employer must assign its rights, or the author must be able to prove that the employer has already ceded copyright back to the employee (e.g., through an institutional copyright policy). Government employees will be required to obtain publication clearance approvals in accordance with agency procedures for works prepared as a part of their official duties. Proof of government clearances will be required. Students submitting material from a dissertation or other academic work in development should check with their institution to confirm ownership. All authors must obtain permission for the use of any material owned by others, including tables, figures, graphs, charts, drawings, photographs and other illustrations, and digital media works.
Author Requirements

Regarding Reproduction and Copying for Private Use: JHSH encourages copying and reproduction of information appearing in its editions so long as such copying and reproduction is strictly limited to non-commercial educational and personal use. Any other use must be under specific agreement. In every case, JHSH and the original author must be prominently acknowledged as the source of the material. Furthermore, if an article were to be used for widespread educational classes via on-line forums (e.g. MOOC), permission of the Editor and Senior Associate Editor is required to ensure that no commercial use will be tolerated after on-line use. Any use in on-line courses must also, as mentioned above, credit the original author and JHSH.

XI. Contact Information

Manuscripts and/or concept proposals for articles are to be sent directly to jharrell@mytu.tuskegee.edu.

If needed, call the Tuskegee University National Center for Bioethics in Research and Health Care at (334) 724-4554.
Please join us for the 2017 Commemoration of the Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee and the Public Health Ethics Intensive Course

Monday, April 3rd to Friday, April 7th, 2017