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<td>Andrew A. Zekeri, PhD</td>
<td>Sociology Tuskegee University</td>
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### Academic Review Committee Members

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<thead>
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<th>Name</th>
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CONTRIBUTING AUTHORS
Preface

Contributing Authors

Zanice Bond, Ph.D., is Assistant Professor of English at Tuskegee University in Tuskegee Alabama. She received her Ph.D. in American Studies from the University of Kansas. Bond is a 2015-2016 Woodrow Wilson Fellow. In 2017 she received a Poetry Foundation fellowship which supported her participation in the Furious Flower Center’s Legacy Seminar on Yusef Komunyakaa at James Madison University. She received a 2017 Fulbright-Hays Summer Seminar grant to Chile, South America, where she studied The Construction of Chilean Identity: Socio-economic, Political, and Educational Reforms. Dr. Bond is currently co-director of the National Endowment for the Humanities (NEH) grant Literary Legacies of Macon County & Tuskegee Institute: Zora Neale Hurston, Ralph W. Ellison, Albert Murray at Tuskegee University (2019-2021). She is also revising her dissertation, Race, Place, and Family: Narratives of the Civil Rights Movement in Brownsville, Tennessee, and the Nation, for publication.

Beverly A. Ebo, EdD, M.Ed., is Public/Private School Liaison at Tuskegee University National Center for Bioethics in Research and Health Care. Dr. Ebo is also an Orientation Instructor at Tuskegee University and has worked in higher education for over 30 years. Beverly holds an EdD in higher education administration from Northeastern University and has a strong interest in adults and children with special needs and learning disabilities. Her dissertation topic: Understanding the Experiences of College Students with Learning Disabilities.

Eric J. Suba, MD earned his BA from Princeton University and his MD from Washington University in Saint Louis. Eric trained as a pathologist and has practiced with Kaiser Permanente in Northern California since 1990. He is currently Director of Clinical Laboratories at Kaiser Permanente in San Francisco. In 1996, after documenting that the burden of cervical cancer in southern Vietnam was a legacy of the Vietnam War, Eric founded the all-volunteer Viet/American Cervical Cancer Prevention Project. The subsequent introduction of Pap screening to southern Vietnam led to 50% reductions in cervical cancer incidence rates between 1998 and 2003, and provided one of the first real-world examples of successful cervical cancer prevention in a contemporary developing country. Eric’s commitment to rapid, effective cervical cancer prevention is inseparable from his role as a leading critic of unethical U.S.-funded cervical screening research in India.

Andrew A. Zekeri, Ph.D. is professor of sociology and graduate faculty in the Department of Psychology and Sociology at Tuskegee University. His research focuses on rural poverty, family well-being, food insecurity and nutrition among single mothers in Alabama Black Belt, and conspiracy theories about HIV/AIDS and food insecurity among HIV-positive patients. Dr. Zekeri also studies social and behavioral sciences perspective on rural health disparity issues, community and economic development in the rural South. He has published articles in several international refereed scholarly journals. In 2015, Zekeri’s book, “Issues and Challenges of the American Rural South,” was published by Cognella Academic Publishing. He holds a PhD in rural sociology from The Pennsylvania State University.
### 2018 Public Health Ethics Forum: Minority Elders and Healthy Aging

Presented by: Centers for Disease Control and Prevention and the National Center for Bioethics in Research and Health Care at Tuskegee University  
September 14, 2018, 8:00 a.m. – 4:15 p.m.  
CDC Roybal Campus, Building 19 – Auditorium A  
1600 Clifton Road NE, Atlanta, GA 30329

#### Program Agenda

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<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker/Position (City)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 a.m. – 2:00 p.m.</td>
<td>Registration, Student Poster Exhibits Open</td>
<td>Conference Lobby Area</td>
</tr>
<tr>
<td>8:00 a.m. – 8:45 a.m.</td>
<td>Welcome</td>
<td>Leandra Liburd, PhD, MPH, MA, Director, Office of Minority Health and Health Equity (OMHHE), Centers for Disease Control and Prevention (CDC)</td>
</tr>
<tr>
<td></td>
<td>Rupen Warren, D.D.S., M.P.H., Dr.P.H., M.Div</td>
<td>Director, National Center for Bioethics in Research and Health Care at Tuskegee University</td>
</tr>
<tr>
<td>8:45 a.m. – 9:30 a.m.</td>
<td>Opening Plenary: Health Ethics and American Indian/Alaska Native Elders</td>
<td>Dave Baldridge, BA, Executive Director of the International Association for Indigenous Aging</td>
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<tr>
<td>9:30 a.m. – 9:45 a.m.</td>
<td>Break</td>
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| 9:45 a.m. – 11:15 a.m. | Panel: Thriving and Aging with Dignity                              | Councilman Chester Antone, Councilman, Tohono O’dham Nation; and Chairman, Secretary’s Tribal Advisory Committee, Arizona  
Mrs. Mamie H. Clemons, B.S., Retired Teacher, Director of Curriculum, and Principal, Pittsburgh, PA  
Ms. Nadinne Cruz, Advisory Board Member, Professor, Consultant, and Author, Long Beach, CA  
Mr. Elias Segarra, JD, Retired Lawyer, Duluth, GA |

#### Master of Ceremonies

CAPT Craig Wilkins, OMHHE, CDC
Message from the Editor

Rueben C. Warren D.D.S., MPH, Dr. P.H., MDiv.
Professor and Director of the National Center for Bioethics in Research and Health Care at Tuskegee University
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The December edition of the Journal of Healthcare, Science and the Humanities usually includes selected articles from the Annual Public Health Ethics Forum co-sponsored by the National Center for Bioethics in Research and Health Care, Tuskegee University (National Bioethics Center) and the Office of Minority Health and Health Equity at the Centers for Disease Control and Prevention (CDC). Other peer-reviewed articles, a commentary and reflections from an elders’ panel are included to commemorate National Minority Health Month, which occurs in April every year. Since 2015, the National Bioethics Center and the CDC have co-hosted this forum. This year the forum focused on elders and was held in September during Senior Citizens Month instead of April, which limited the time needed to translate and transform the excellent presentations into peer reviewed articles. Thus, there are no original articles from the 2018 Public Health Ethics Forum published in this edition. However, the Program Agenda from the forum is included, as well as a narrative from an extraordinary elders’ panel that highlighted the entire forum.

In April 2015, National Bioethics Center, CDC and the Morehouse School of Medicine co-hosted the first Public Health Ethics Forum. This first forum commemorated the 100-anniversary year of the death of Booker T. Washington (April 5, 1856—November 14, 1915), Founding President of Tuskegee University. Interestingly, in April 1915 Booker T. Washington established National Negro Health Week. In 1895, the National Negro Health News reported that, “Forty-five percent of all deaths among Negroes were preventable; there are 450,000 Negroes seriously ill all the time; the annual cost of this illness is 75 million dollars; that sickness and death cost Negroes annually 100 million dollars.” Selected articles from that forum were published in the Journal of Healthcare, Science and the Humanities (JHSH) Volume V, No. 2, Fall 2015. Again, during April, National Minority Health Month, the 2016 and 2017 Public Health Ethics Forums took place on the main campus of CDC. The attendees from across the U.S., and participants from the Dominican Republic, focused on Hispanic/Latino Health (2016) and on Women’s Health (2017). Selected articles were published in English and Spanish in Volume VI, No. 2, Fall 2016; Volume VII, No 2, Fall 2017 published articles from the forum on Women’s Health.

This edition of the JHSH includes the agenda from the 2018 Public Health Ethics Forum, “Minority Elders and Healthy Aging.” Dave Baldridge, Executive Director of the International Association for Indigenous Aging, gave the keynote address at the opening session and highlighted some of the assets and challenges related the Native American and Indigenous
From the Editor's Desk

Aging. That morning also included an extraordinary elders’ panel entitled, “Thriving and Aging with Dignity.” The panelists included, Councilman Chester Antone, Tohono O’odham Nation, and Chairman, Secretary’s Tribal Advisory Committee, Arizona; Mrs. Mamie H. Clemons, B.S., retired teacher, Director of Curriculum and Principal, Pittsburgh, PA; Ms. Nadine Cruz, Advisory Board Member, professor, consultant, and author, Long Beach, CA; Mr. Elias Segarra, JD retired lawyer, Duluth, GA. Be sure and note the Reflections narrative from the panel that is included in this edition.

Several very exciting concurrent sessions provided engaging discussions about the lived experiences of elders of color. Ethical Dilemmas in Serving Diverse Elders, Framing Aging as a Positive Experience/ Promoting a Healthy Mindset Among Minority Elders and Healthy Aging and the Built Environment/Ethics of Social Policy and Healthy Aging were the titles of the sessions. There was a diverse audience that participated in the sessions, representing CDC, academia and various advocacy groups. Each session had a speaker, discussant and lively audiences that brought a vast array of experiences and perspectives. There was time for open dialogue and discussion following the presentations.

The student poster session included several very interesting research projects. Five students displayed their posters and were well prepared to discuss their research. All the poster presentations focused on the health and well-being of elders. The students who presented had the option of transforming their poster presentations into manuscripts that would be peer reviewed and, if accepted, their manuscripts would appear in this edition of the journal. Mr. Weiwen Ng, University of Minnesota, presented a poster entitled, “Racial Disparities Among Minnesota Nursing Facility Residents Are Inextricably Linked to Serious Mental Illness: A Latent Class Regression.” Kamaria Bricso Tulane University presented "The Association of Herpes Virus Type 1 And Alzheimer's Diseases Development." The poster by Lan Doan, from Oregon State University, was entitled, "Health-related Quality of Life Among Asian American & Pacific Islanders Medicare Beneficiaries." The poster by Danielle McDuffie, from the University of Alabama, Tuscaloosa, was on, "The Role of Religion and Spirituality as Protective Factors Against Depression in an African American Bereavement Populations." The poster by Yolanda Pettty from the Interdenominational Theological Center in Atlanta GA, and Ashanti-Ali Davis, from Tuskegee University in Alabama, was on, "Promoting Fresh Fruits and Vegetables for Elders in a Food Desert." The Journal of Healthcare, Science and the Humanities provides a unique opportunity for students to learn the intricacies of scientific writing and publishing.

This edition also includes several original papers. Andrew Zekeri, Ph.D., Professor of Sociology in the Department of Sociology and Psychology and Adjunct Professor in the National Bioshics Center at Tuskegee University, has two original papers in this edition. The first article is entitled, “Racial-Ethnic Disparities in HIV/AIDS” and the second is “Health Care in the United States: Evidence from a Sociological Field Research in Alabama’s Black Belt and Smoking Behavior, Demographic Factors and Smoking Cessation Among Rural and Urban Residents.” The first article examines African Americans’ belief in psychosocial factors associated with racial HIV/AIDS and health disparities using an exploratory qualitative study methodology. Dr. Zekeri focuses much of his research on health disparities among African Americans living in the Alabama Black belt counties. In this article, he asked several empowering questions on how African Americans define their health and disease burdens, reasons for their plight, problems they face, their coping strategies for providing daily necessities of shelter, transportation, and healthcare. Dr. Zekeri argues that without hearing the voices of African Americans about issues that affect their health, well-being, and social life, health disparities will worsen. He concludes the article by writing, “Health care is a by-product of the distribution of power and the organization of the society.” His lens as a sociologist emphasizes the importance of factors outside of the health care system that have a direct impact on health care. Professionals working within the system must listen to those whom they serve. In the second article, Dr. Zekeri focuses on smoking as a persistent health problem and leading cause of morbidity and mortality worldwide. Using a telephone survey, he examined the relationship between health status, age, gender and smoking among samples of 150 rural and 150 urban adults in Pennsylvania. He also examined reasons why some respondent quit smoking and who encouraged them to quit. Dr. Zekeri’s results found male, female, and age differences in smoking behaviors. Interestingly, there is no relationship between health status and smoking. However, those who stopped smoking for health reasons did so with support of family. In these two articles, Dr. Zekeri shares the range of social issues that influence health and suggests that people have much to share about their health and health care needs, if they would only listen.

Eric Suba, M.D., Director of Clinical Laboratories, Kaiser Permanente Medical Center in San Francisco, Robert Ortega, M.S., Senior Writer, CNN in Phoenix AZ, and David Mutch M.D., Professor of Gynecologic Oncology, Washington University, School of Medicine in Missouri, use documents obtained from the US National Cancer Institute (NCI) funded 18-year randomized controlled trial in Mumbai for their article. Their clinical trial compared a discredited cervical screening test to “no-screening whatsoever.” The Mumbai trial required Indian and global health leaders to assume “no-screening whatsoever” would remain “standard care” throughout India for the duration of the trial, and thereby delayed the implementation of routine cervical screening among the general population of India for 18 years. During those 18 years, 1-2 million women died from cervical cancer in India, while Pap screening became “standard care” in developing countries such as Vietnam. Paradoxical beliefs in the non-feasibility of Pap screening in developing countries, which rationalize the staggering opportunity costs associated with the Mumbai trial, have corrupted World Health Organization policy guidelines. They recommended revising the guidelines to acknowledge that good-quality Pap screening can be implemented, even in a rural setting in a developing country, with reasonable investment. Tata Memorial Hospital and the US Office for Human Research Protections determined that the Mumbai trial was unethical. The authors suggest that the Mumbai trial was effectively covered-up by false and misleading statements from US medical leaders. They also recommend that all surviving Mumbai trial participants, from both intervention and control arms, should finally receive good-quality cervical screening tests. They argue that NCI leaders should publicly acknowledge that the Mumbai trial was unethical, and they should publicly apologize to trial participants and their families. Otherwise, the global public may reasonably conclude that conscience has died at NCI.
Preface

The year 2019 marks 400 years since the Middle Passage brought enslaved Africans to Virginia (1619–2019). April 9–12, 2019 the National Center for Bioethics in Research and Health Care will host the 23rd Annual Commemoration of the 1997 Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee on the historic campus of Tuskegee University. This year’s theme is, “400 Years—1619-2019: The Ethics of Reparations and Reconciliation.” Among the events during the Commemoration is the sixth Annual Public Health Ethics Intensive course. There will be keynote presentations by national scholars from across the country who will address topics ranging from Ethics of African Spirituality, to Ethics of Slavery, to Reparations and Reconciliations, ending with a presentation on Optimal Health.

From the Editor’s Desk

Dr. Beverly Ebo, Public Private School Liaison at the National Bioethics Center, writes on, “Constructivism or Behaviorism: What is the Best Method to Teach Special Needs Students?” Consistent with her work with the Macon County Public School System, Dr. Ebo is responsible for coordinating public health ethics activities between school students in Macon County and the National Bioethics Center. Her article examines the best method(s) to teach pre-kindergarten, kindergarten, elementary and secondary students with special needs. She explores constructivism and/or behaviorism methods to teach students with special needs. In her paper, Dr. Ebo defines, compares, and contrasts the constructivism and behaviorism in the context of students with special needs. While some educators are unclear about which method is most effective, others are unsure and recommend integrating both. Dr. Ebo concludes that special needs students learn best when constructivism and behaviorism approaches are integrated. It is more effective to make instructional and curricular decisions based on the individual child, tasks and the setting than to use strategies representing only one theory. Moreover, the integration of components from both approaches could help special and general education teacher’s work more effectively as a team to teach children with learning disabilities.

Zanice Bond, Ph.D., Department of Modern Languages, Communication, and Philosophy at Tuskegee University completed a commentary on Mend, which is the debut collection of poetry by Kwoya Fagin Maples, a creative writing instructor at the Alabama School of Fine Arts in Birmingham. Her collection of poems honors and acknowledges several Black enslaved women by calling their names, as she describes their suffering from Dr. J. Marion Sims’ unethical, gynecological surgeries. Sims, known as “the father of modern gynecology,” acquired enslaved women to conduct his unethical research, many times without using the available anesthesia. In her book, Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present, Harriet A. Washington writes that while Sims was a plantation doctor treating a black infant boy, he tried to “pry [the infant’s] skull bones into new positions. Bond also includes poems by Natasha Trethewey, “Miracle of the Black Leg,” and “Knowledge,” and “Dr. Samuel Adolphus Cartwright on Dissecting the White Negro,” who examines race and gender in medical transplants and dissection procedures. Poetry by Nikky Finney, “The Greatest Show on Earth,” is dedicated to enslaved Black women. Sylvia Plath’s poem, “Fever 103,” are words of advice to slave masters regarding “distinctive diseases of the negro.” The Preface to Kwoya Fagin Maples’ Mend, published in October 2018, ends with an appeal. Bond ends her book review essay with a wish written by Maples, “that you would consider how this story relates to now. Presently in 2018, Black women are three times more likely to die after childbirth than white women, regardless of ability to pay and regardless of prenatal care.” She writes about a health condition that disproportionately and adversely impacts Black women, particularly Black women with limited access to health care. She concludes by writing, “The women who are suffering from it [fistula] are often ostracized by their families and communities. Maybe, reader, you will see how you are connected to this story. Maybe you will honor what you come to know by sharing it.”
Smoking Behavior, Demographic Factors and Smoking Cessation Among Rural and Urban Residents

Andrew A. Zekeri, B. Sc, M.Sc., Ph.D.
Professor of Sociology
Department of Psychology and Sociology
Adjunct Professor of Sociology
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Author Note
The opinions expressed in this articles are solely those of the author and do not necessary reflect those of the institution where he is employed. The author wishes to express gratitude to the anonymous reviewers for their helpful comments.

Abstract
Smoking remains a leading cause of morbidity and mortality worldwide. Though age and gender differences in smoking in the United States population have been documented, data about these differences and smoking cessation among rural and urban residents is limited. The purpose of the research is to examine the relationship between health status, age, gender and smoking among samples of rural and urban adults. The paper also examined reasons why some respondents quit smoking and who encouraged them to quit. Data for this analysis were obtained by a telephone survey of two samples of adults 30 years of age and older: 150 residents from an urban county and 150 from a rural county in Pennsylvania. Data included information on health status, a number of health behaviors (including smoking cigarettes), age, gender, and smoking cessation. The results indicate that for respondents residing in the rural county, whether a person is a male or female is statistically related to smoking. Age is statistically related to smoking. There is no relationship between health status and smoking. Those who quit smoking did for health reasons and were more likely to had support from family members (spouse and children). Smoking (smoke now, used to smoke and never smoked) did not relate consistently nor strongly to health status when residence and gender were controlled. Programs promoting smoking cessation might benefit by involving family or other household members.

Keywords: Smoking behavior, smoking cessation, Health Status, Rural and Urban residents
Introduction

According to the World Health Organization (2015), nearly 6 million people around the world die each year from tobacco-related causes. In the United States, the death rate among smokers is 2 to 3 times higher than that of nonsmokers (Carter et al., 2015). Cigarette smoking is responsible for about 480,000 deaths a year (Center for Disease Control and Prevention, 2016). Tobacco significantly increases the risk of respiratory disease, cataract, stroke, and low-birth-weight babies (Newman, 2019). More people die from smoking related causes than from HIV/AIDS, illegal drugs use, alcohol use, motor vehicle injuries, suicide, and murders combined (Newman, 2019). Some Healthy People 2020 national health objectives address smoking and smoking cessation.

Tobacco is a clearer health risk. Therefore, the purpose of this analysis is to examine the relationship between health status, age, gender and smoking among samples of rural and urban adults. Research in this area is of paramount importance in that it enables researchers and policy makers to identify groups or individuals who are particularly vulnerable to poor health behaviors, and who should, therefore, be the focus of special intervention. It also provides an insight into the factors that may influence health behaviors, so that these factors may be considered in policy formulation analysis at the state and federal levels. Series of questions were posed to sharpen the research objectives: How do people who smoke or do not smoke perceive their health status? Do rural and urban residents differ in the extent to which they smoke? Is gender a good predictor of smoking? Do men and women in the middle years differ in the extent to which they smoke? Addressing these questions will extend our knowledge of the relationships between some demographic variables and cigarette smoking. The adverse health effects of smoking and the benefits of quitting are well documented. Many smokers who try to quit cite a desire to improve their health as the main reason. In this study, I also examined smoking cessation. Identifying those who successfully quit smoking, why they did, and who supported them in quitting will help to target smoking cessation programs and interventions in the United States.

Literature Review

One health behavior as a risk factor needing greater control and attention worldwide is smoking. Smoking remains a leading cause of morbidity and mortality. Previous studies have shown that smoking is more common among men than among women (Newman, 2019; Waldron, 1983; 1986; Waldron et al., 1988). Furthermore, evidence indicates that concerns about health consequences of smoking have not had a greater influence on women's smoking than on men's smoking. Women who smoke have higher burden of smoking related diseases than men who smoke (Fisher et al., 1993; Hugh et al., 2013; Hymowitz, 1991; Venters et al., 1990). Furthermore, some studies have demonstrated the additive effects of smoking on bad health outcomes. (Hill & Gray, 1984; Waldron et al., 1988). Though age is not related to health behavior in any consistent way, there is a strong evidence that some health-damaging habits (for example, smoking) begin in early adolescence (Newman, 2019; Norman, 1988; Hugh et al., 2013). No one factor has been found to provide a sufficient basis for predicting all health behaviors. Our health habits and practices are often daily actions which have been influenced by a host of demographic, social, cultural and biological factors (Newman, 2019). Understanding factors affecting smoking behavior of men and women may guide targeted gender-specific intervention programs and more effective policies, smoking cessation efforts and counselling programs.

Many studies have addressed factors associated with quitting attempt or with successful smoking cessation. Some examined such demographic variables as gender, age, marital status, income and education to determine whether they differed between smokers who tried to quit and those who did not, as well as between successful and unsuccessful quitters (Lee & Kahende 2007; Stueve & O’Donnell, 2007; Venters et al., 1990; Hymowitz et al., 1991; Fisher et al., 1993; Newman, 2019).

In this study, I also examined why smoking cessation and type of cessation assistance used by individuals with successful smoking cessation. Such knowledge could help public health policy makers and medical care systems develop effective targeted interventions.

Methods and Procedures

The data for this analysis were obtained by a telephone survey of two samples of adults 30 years of age and older: 150 residents from one urban county and 150 from one rural county in Pennsylvania. Selection of the counties was based on the county classification scheme developed by Hines et al. (1975). One of the counties selected for this research had all of its population characterized as rural in 2010 and was not adjacent to any metropolitan county. The second county had 100 percent urban population in 2010 and was classified as a metro county.

The questionnaire used in the study was designed to obtain information on health status, a number of health behaviors (including smoking cigarettes), age, gender, and place of residence. Health status was derived from the question “How would you rate your health at the present time? Would you say it is (1) very poor; (2) poor; (3) fair; (4) good; (5) very good. Responses were dichotomized to separate those with poor health status (responses 1 & 2) from those in good health status (3-5). Self-rated health has been shown to be a valid and reliable measure of general physical well-being (Idler & Benyamin, 1997; Fosse & Haas, 2009) and is predictive of chronic and acute disease, physicians’ assessments, physical disability, and health behaviors (Idler & Benyamin, 1997).

Smoking data were derived from the following questions: “Have you smoked at least 10 packs of cigarettes in your entire life? Responses categories were 1) yes 2) no. “Do you smoke cigarettes now?” Responses categories were 1) yes and 2) no. Respondents who had not smoked at least ten packs of cigarettes in their entire life were coded as never smoked. Those who smoked at least ten packs of cigarettes in their entire life but did not smoke at the time of the interview were coded as “used to smoke” while those who had smoked at least ten packs of cigarettes in their entire life and were smoking at time of interview were coded as “smoking now.” Gender data was obtained from the question: “Are you a male or female?” Place of...
residence was derived by classifying respondents according to the county of residence. Age data was obtained from the question: "How old are you?" Responses range from 30 to 90 years. This was coded into young (30-44), middle aged (45-64) and older adults (65-90).

To determine if any observed relationships were greater than chance or random occurrences, statistical significance was assessed using Chi-square analysis procedures. The .05 level was selected to determine statistical significance. Analyses were performed using Statistical Packages for the Social Sciences (SPSS) version 21.0 computer software program (SPSS Inc., IL: Chicago, USA).

Study procedures were reviewed and approved by the author's University Office of Research Compliance prior to the collection of any data.

**Results**

The relationship between health status and smoking for both rural and urban residents is presented in Table 1. Whether a person is in poor or good health was not statistically related to smoking. Thus, there was no evidence or any statistical reason from the data to conclude that there was a meaningful relationship between health status and smoking in this sample.

*Table 1. The relationship between health status and smoking by residence.*

<table>
<thead>
<tr>
<th>Residence</th>
<th>Health Status</th>
<th>Health Status</th>
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<tbody>
<tr>
<td></td>
<td>Poor</td>
<td>Good</td>
</tr>
<tr>
<td>Smoke now</td>
<td>40.5</td>
<td>25.9</td>
</tr>
<tr>
<td>Used to smoke</td>
<td>24.3</td>
<td>29.6</td>
</tr>
<tr>
<td>Never smoke</td>
<td>35.2</td>
<td>44.4</td>
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<td>Total percent</td>
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<tr>
<td>Number</td>
<td>37</td>
<td>108</td>
</tr>
<tr>
<td>( X^2 )</td>
<td>2.728</td>
<td>1.591</td>
</tr>
</tbody>
</table>

The extent to which the relationship between gender and smoking differs according to residence was also examined in Table 2. For respondents residing in the rural county, whether a person is a male or female is statistically related to smoking.

*Table 2. The relationship between gender and smoking by residence.*

<table>
<thead>
<tr>
<th>Gender</th>
<th>Rural</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoke now</td>
<td>31.0</td>
<td>28.0</td>
</tr>
<tr>
<td>Used to smoke</td>
<td>47.3</td>
<td>14.7</td>
</tr>
<tr>
<td>Never smoke</td>
<td>25.4</td>
<td>57.3</td>
</tr>
<tr>
<td>Total percent</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Number</td>
<td>71</td>
<td>75</td>
</tr>
<tr>
<td>( X^2 )</td>
<td>20.389*</td>
<td>2.492</td>
</tr>
</tbody>
</table>

Males were more likely than the females to smoke now or used to smoke. For the urban residents, the differences between males and females smoking were small and not statistically significant. However, for rural residents the relationship between gender and smoking behavior was statistically significant: males were much more likely than females to smoke “now” or to have smoked in the past.

*Table 3. The relationship between age and smoking by residence.*

<table>
<thead>
<tr>
<th>Age</th>
<th>Rural</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoke now</td>
<td>40.0</td>
<td>33.3</td>
</tr>
<tr>
<td>Used to smoke</td>
<td>22.0</td>
<td>29.4</td>
</tr>
<tr>
<td>Never smoke</td>
<td>38.0</td>
<td>37.3</td>
</tr>
<tr>
<td>Total percent</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Number</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>( X^2 )</td>
<td>9.399*</td>
<td>14.641**</td>
</tr>
</tbody>
</table>

*Significant .05  **Significant .01
Data showing the relationship of age to smoking by residence are presented in Table 3. For both rural and urban residents, age was statistically related to smoking. Those who have never smoked in their entire life or used to smoke were more likely to be older adults while those who smoked at the time of interview were most likely to be younger and middle aged. These patterns by age and smoking behavior are similar to what Norman (1988) found in his studies.

**Table 4.** The relationship between age and smoking by gender.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>30-44</td>
<td>45-64</td>
</tr>
<tr>
<td>Smoke now</td>
<td>49.0</td>
<td>38.8</td>
</tr>
<tr>
<td>Used to smoke</td>
<td>22.4</td>
<td>40.8</td>
</tr>
<tr>
<td>Never smoke</td>
<td>28.6</td>
<td>20.4</td>
</tr>
<tr>
<td>Total percent</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Number</td>
<td>49</td>
<td>49</td>
</tr>
</tbody>
</table>

X² = 14.702***

*Significant .05
**Significant .01

The relationships between age and smoking were assessed for both males and females in Table 4. For both males and females, age is significantly associated with smoking. For males, those who used to smoke and those who have never smoked were most likely to be older while those who smoke at the time of interview were the younger ones. Similar patterns were found for the females.

The relationship between health status and smoking was assessed for both males and females, Table 5. Regardless of gender, there is no evidence from the data to conclude that there was a meaningful relationship between health status and smoking. Differences between men and women in regards to health status and smoking were not statistically significant.

**Table 5.** The relationship between health and smoking controlling for gender.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Status</td>
<td>Poor</td>
<td>Good</td>
</tr>
<tr>
<td>Smoke now</td>
<td>36.4</td>
<td>34.3</td>
</tr>
<tr>
<td>Used to smoke</td>
<td>38.6</td>
<td>35.3</td>
</tr>
<tr>
<td>Never smoke</td>
<td>25.0</td>
<td>30.4</td>
</tr>
<tr>
<td>Total percent</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Number</td>
<td>44</td>
<td>102</td>
</tr>
</tbody>
</table>

X² = .449

Finally, the data in Table 6 about smoking cessation indicate that family members and significant others (spouses) play a big part in helping a person become smoke free.

**Table 6.** Respondents who quit smoking: reasons and who supported them to quit.

<table>
<thead>
<tr>
<th>Reasons Respondents Quit Smoking (N= 108)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnancy</td>
</tr>
<tr>
<td>Bad for others</td>
</tr>
<tr>
<td>Doctor's advice</td>
</tr>
<tr>
<td>Health problems</td>
</tr>
<tr>
<td>Read</td>
</tr>
<tr>
<td>Decided not good</td>
</tr>
<tr>
<td>Family pressure</td>
</tr>
<tr>
<td>Cost</td>
</tr>
<tr>
<td>Others</td>
</tr>
</tbody>
</table>

**Who Supported Quitting (N = 97)**

| Spouse | 24.7 |
| Daughter | 21.6 |
| Son | 13.4 |
| Mother | 4.0 |
| Father | 3.0 |
| Friend | 17.5 |
| Neighbor | 3.0 |
| Co-worker | 3.0 |
| Others | 9.0 |
Summary and Conclusions

This analysis examined the relationships between residence, health status, age and smoking and smoking cessation among a sample of Pennsylvania. The relationship between health status and smoking was not statistically significant. Expected differences in health status between rural and urban residents were not found. Moreover, a number of other variables thought likely to relate to health status did not. Thus, smoking (smoke now, used to smoke and never smoked) did not relate consistently or strongly to health status when residence and gender were controlled. Indeed, age was the only variable found to be significantly and consistently associated with smoking; the younger respondents were more likely to smoke now than were the older respondents. I did find that gender made a statistical difference in smoking. Rural males were much more likely to have previously smoked while rural females were much more likely to have never smoked. It may well be that in rural areas smoking is not accepted for the females.

While other research found a similar relationship between age and smoking, the overwhelming importance of this variable in the present analysis was not anticipated. All other explanatory variables paled in importance relative to the person’s age. Expected differences in smoking rates between males and females were not found. The decision of a male or female to smoke or not depends more on his or her age. Apparently, expanded socialization contacts that occur within age groups are likely to lead to smoking. There is a high and increasing rate of smoking among young adults.

Despite the large number of research studies that have dealt with consequences of smoking, there is still much that is not fully understood. The present study extends the existing log of smoking research in at least one way. Unlike most studies on smoking, this research has focused on rural-urban differences. It suggests that the relationship between perceived health status and smoking is not statistically significant for residents of either area. The need for further studies of differences in smoking is underscored. Findings from the research indicate that younger adults should be the target group for smoking cessation programs. These new data can be strategically used by health providers and public health officials to communicate the benefits of quitting, increasing motivation to quit, and engage young smokers in supportive services to help them quit and stay quit. The older adults in this sample changed their lifestyles consistently associated with smoking; the younger respondents were more likely to smoke now than were the older respondents. I did find that gender made a statistical difference in smoking. Rural males were much more likely to have previously smoked while rural females were much more likely to have never smoked. It may well be that in rural areas smoking is not accepted for the females.

Finally, the study suggests that cessation program need to take a holistic approach including social support from spouse or partner, children and friends. The health concerns reported by participants as important motivators for quitting indicate that much more attention should be given to health care related interventions.

Limitation of the study

The findings in this manuscript are subject to two major limitations. The smoking data in this study relied on self-reporting. Participants might under-report smoking and over-report quitting smoking. Race was omitted in the analysis because of low percentage of some groups of interest (e.g., African American and Hispanics) do not live this rural part of Pennsylvania.

References


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Articles


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Author Note

The opinions expressed in this article are solely those of the author and do not necessary reflect those of the institution where he is employed. I want to thank Prof. Rueben C. Warren who inspired and motivated me, and has supported my inquiry into the concerns of poor African Americans struggling to survive in Alabama’s Black Belt. I want also to express my deep and sincere gratitude to the African Americans who participated in the focus group sessions. You are truly remarkable people. All study procedures were reviewed and approved by the Tuskegee University Office of Research Compliance prior to the collection of any data. I wish to express gratitude to the anonymous reviewers for their helpful comments.

Abstract

This paper examines African Americans' beliefs of psychosocial factors associated with racial HIV/AIDS and health disparities using an exploratory qualitative study. This research was conducted to determine how African Americans define their health and disease burden, the reasons for their plight; the problems they face; their coping strategies for providing daily necessities of shelter, transportation, and health care. If we ignore the voices of African Americans, we have dehumanized them, making their humanity invisible. Without hearing the voices of African Americans, our understanding of their social life and health issues is incomplete. Analyses from the top down miss the insights that only those experiencing racial health disparities can articulate. Their voices have important implications for policymakers interested in eliminating racial health disparities and promote equity in health. The focus groups discussions in the paper provide the voice, the presence, and the perspective of African Americans who live on the margins and are generally invisible to the rest of us. Issues surrounding racial health disparities are complex, difficult, and controversial. Results indicate that health insurance, lack of access to quality health care, environmental hazards in neighborhoods, poverty, lack of medical practitioners, unhealthy eating habits, poor life style
choices, lack of African Americans in health care professions, lack of trust in white health care professionals and unemployment contribute substantially to racial health disparities in America. Health care is a by-product of the distribution of power and the organization of the society.

Keywords: Racial-Ethnic Disparities, HIV/AIDS, Health Care, Sociological Field Research, African Americans, Alabama’s Black Belt

Introduction

Equity in health care is a major public health issue in the United States. The disadvantaged groups are negatively impacted. The first HIV infection cases were documented in the United States in 1979 (Newman, 2019). The disease was originally referred to as the “gay plague” because the first group to be identified with the disease was gay men from San Francisco, Los Angeles, and New York (Newman, 2019). The identification of HIV/AIDS with this group led to it first being defined as a sexual epidemic rather than a public health threat. Gay activists and public health officials mobilized to increase awareness and began to change the public’s perception of the disease in the early 1980s (Newman, 2019).

Today, HIV/AIDS disproportionately affects African-Americans more than any other racial or ethnic group in the USA (CDC, 2017). Currently representing only 13% of the US population, African-Americans now comprise close to half of the total reported HIV/AIDS cases in the USA according to the Centers for Disease Control and Prevention (CDC, 2017). The situation remains dire and broader attention is necessary from the public health and medical sectors who serve the majority of African-American populations and the community at-large to work towards closing this health disparity gap because good health is a fundamental right for every human being without distinction of race, religion, and political belief, economic or social conditions (WHO, 2015). There is a need to improve equity in health.

Therefore, the purpose of this research was to add insights about disparities in HIV/AIDS and health by focusing on the voices of African Americans who are the most affected. We sought to know how they define their health and disease burden, the reasons for their plight; the problems they face; their coping strategies for providing daily necessities of shelter, transportation, and health care. If we ignore the voices of African Americans, we have dehumanized them, making their humanity invisible. As Eric Alterman argued in an essay for The Nation (Alterman, 2000:12), “While we hear that 43 million Americans lack health insurance, rarely do we read or hear about what it’s like to raise a sick child without it.”

Without hearing the voices of African Americans, our understanding of their social life and health issues is incomplete. Analyses from the top down miss the insights that only those experiencing racial health disparities can articulate. Their voices have important implications for policymakers interested in eliminating racial health disparities and promote equity in health. The focus groups discussions provided the voice, presence, and perspective of African Americans who live on the margins and are generally invisible to the rest of us.

It is the hope of the author that the analysis and suggestions presented in this research, as well as further work stemming from this research, will enhance understanding of HIV/AIDS and health disparities in the rural south, that they will contribute to better understanding by the public in general, and contribute to better understanding by planners, public health practitioners, and policymakers. The sociological tradition used in this research stresses the need to see a situation from the point of view of the people who are in it. Thus, it directs the investigator to seek out and listen to African Americans own statements of their experiences.

The Study Area

Alabama’s Black Belt is easily identifiable to even a casual observer driving through the South. The concentration of rural African-American communities in the South is not accidental. Most of these places are directly connected with the abolition of slavery. There are rural African-American communities in other parts of the United States but they are relatively few compared to the number located in the South. Reconstruction and the implementation of Jim Crow laws ensured that these communities were socially and economically isolated (Zekeri, 2015). Economic arrangements, such as sharecropping and employment discrimination have made these places among the poorest in the nation (Zekeri, 2003; 2015). The area is one of the poorest in the nation and the majority of the residents are welfare dependent (Zekeri, 2015). The residents are, as the President's National Advisory Commission on Rural Poverty put it in 1967, “people left behind.” It is also one of those categorized by the United States Department of Agriculture as counties of “persistent poverty” in 2017 (Zekeri, 2018).

Despite their persistence, rural black communities have become “places left behind” in many respects. Although much has been written about the return of African-Americans to the South, and the southern economic boom of the 1970s and 1980s, these developments have not rejuvenated rural black communities. There is ample evidence that economic development in the South is highly uneven, concentrated in urban areas, bypassing African-Americans in rural places (Falk & Lyson, 1988; Lyson 1989; Zekeri, 2003; 2015). The poverty-stricken character of these places contrasts sharply with the affluence of white society. This disparity reflects in some respects the stratification of African-Americans, namely the division between middle-class African-Americans and the so-called underclass.

Although the area was the cradle of the civil rights movement, the poor residents are still faced with many of the same inequities of years past. Living in the area has not been idyllic experience. Residents are still living in the same shacks and shanties described in numerous reports during the 1960s, only now, in 2018, there have been more years of deterioration. The Black Belt’s remote location, paucity of employment opportunities, and other requirements for industrial development are detrimental to both in-migration and population retention.

Research Method

Qualitative and quantitative methods were used for the study. The study focus groups are widely used in health research as well as in sociological research to gain perspectives,
enlightenment, and insight into the minds of participants as they discuss topics of interest to the research (Wilkinson, 2003a). A focus group study is a structured series of group discussions designed to reveal perceptions and opinions on a defined issue involving carefully selected participants who share common characteristics (Bloor et al, 2001; Krueger & Casey, 2000; Seale et al., 2003; Silverman 2000; 2001; Wilkinson, 2003a; 2003b).

The objective of the focus group interviews conducted in Bullock, Dallas, Lowndes, Macon and Wilcox Counties was to study the underlying beliefs and opinions on psychosocial factors and their impact on HIV/AIDS and health disparities. As Berg (2004) noted, focus groups are not intended to statistically represent the study population, but are an appropriate technique in situations where highly efficient collection of exploratory data is necessary.

African American participants that were HIV-positive were recruited from a HIV/AIDS clinic in Alabama. Others were recruited using a variety of methods, including community liaison recruitment, and a snowball technique where African Americans from churches, barber shops and beauty salons were encouraged to use their personal network and bring a friend to the focus groups. The community liaison was asked to recruit individuals to participate in the focus groups. This approach for recruitment was selected because individuals within the community have better access to residents and more credibility than a person outside the community.

Potential participants were advised that: (1) focus groups would last one to two hours and be held at varied times during the day and evening; and (2) they would be served a light meal during the meeting. They were advised that participation was optional and that they had the right to refuse to answer any questions and withdraw from the focus group anytime.

Follow up contacts with some individuals who had agreed to participate but did not show up revealed that the topic was perceived as a particularly sensitive one that individuals felt reticent about discussing, with their lack of knowledge about the issue at hand being offered as the most frequent explanation.

Written consent was obtained before starting the focus groups, and participants were provided light refreshments. The consent form and questionnaire were approved by Institutional Review Board at Tuskegee University. Before the focus groups sessions began, participants were asked to complete a questionnaire. The questionnaire included questions on demographics and psychosocial variables. The demographic information allowed for a better snapshot of the focus group participants. The questionnaire also stated the purpose of the session. Twenty focus group interviews were conducted over two years focusing on general perceptions of health and medical care; general perceptions of health care provider; general perceptions of medical care system. In America, race-ethnicity bias may be somehow a subconscious motivation for health outcomes. For example, in one study, doctors described African American patients no matter their education and income levels as less intelligent, likely to follow medical advice, and less likely to participate in rehabilitation, and as more likely to abuse alcohol and drugs than white patients (Van Ryn & Burke, 2000). Thus, we can list individual racial bias and bigotry as factors contributing to racial imbalances in the health care system. In America, race-ethnicity bias may be somehow a subconscious motivation for health outcomes.
in giving or denying access to advanced medical procedures. Racism continues as a regular feature of the American society, often something that whites, not subjected to it, are only vaguely aware of. African Americans, are however, on the receiving end, racism is an everyday burden.

**Health Insurance**

One of the many reasons given for the racial disparity in HIV/AIDS and health is lack of health insurance. Most of the focus group participants (83%) believed that lack of health insurance by African Americans explains a significant part of the health disparities (Table 1). They believed that a high percentage of African Americans in the Black Belt are uninsured or underinsured. African Americans are the least able to afford regular medical checkups, prescription medicines, and even over the counter medications (Zekeri, 2015). Although African Americans are aware of early detection and screening of cancer, they tended to have a fatalistic view of their health outcomes once they have cancer (Zekeri, 2015). Because of fatalistic views and lack of health insurance, African Americans are less likely to take advantage of preventive services (Zekeri, 2015).

**Table 1. Reasons given for Racial/Ethnic Disparities in HIV/AIDS and Health Care in the United States by Focus Group Participants.**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>85.6</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>83.0</td>
</tr>
<tr>
<td>Unequal access to quality health care facilities</td>
<td>75.0</td>
</tr>
<tr>
<td>Poverty</td>
<td>77.0</td>
</tr>
<tr>
<td>Not enough medical practitioners in black communities</td>
<td>85.0</td>
</tr>
<tr>
<td>Unhealthy eating habits</td>
<td>80.0</td>
</tr>
<tr>
<td>Dieting, Exercise, and Lifestyle Choices</td>
<td>88.0</td>
</tr>
<tr>
<td>Environmental Racism</td>
<td>56.7</td>
</tr>
<tr>
<td>Under-Representation of Blacks in Health Care Fields</td>
<td>85.0</td>
</tr>
<tr>
<td>Unemployment</td>
<td>73.3</td>
</tr>
</tbody>
</table>

Another finding from the sessions is that uninsured African Americans are less likely to seek medical help until their illness has progressed to a serious state. For an example, from previous research in the Black Belt, uninsured African Americans are more likely than those with insurance to be hospitalized for avoidable complications of conditions such as hypertension and diabetes – problems that could be managed in a doctor’s office (Zekeri, 2013; 2015). Therefore, financial concerns, not outright racial prejudice, may lie at the heart of health policies.

Some focus group participants talked about how they reduced their medications (cutting their pills in half or taking medications every other day) or stopped taking their medicine altogether (those who could no longer afford their medications). Although some of the women in the group received Medicaid for their children, most had no health insurance for either their children or themselves. As one single mother reported,

I do not have health insurance except for my baby. She is on her father’s plan. When anybody is sick, we go to the doctor and pay for it. Health insurance would cost more than $300 a month for us.

What was also evident from the focus meeting is that the cost of medical care, particularly out-of-pocket expenses is a financial burden even to some African Americans with health insurance. Some participants said that illness or medical bills can lead to bankruptcy.

**Unequal Access to Quality Health Care Facilities**

The distribution of and access to health services for the African Americans in the Black Belt are significantly uneven. For many who lived in this poor geographic region, they have no adequate health care coverage package. More than half of the group participants (75%) believed that racial disparities in HIV/AIDS and health are based, in large part, on the unavailability of quality services in black communities. The availability and quality of health care services are not equally distributed in America. Several African American women commented that the likelihood that African Americans in the Black Belt would obtain early detection and screening for cancer and HIV/AIDS is hindered by lack of access to quality primary care physicians and health facilities. These rural poor have problems of access to health care as medical facilities and practitioners are not available locally. For example, lack of access to health care contributes to a decrease in the availability and use of mammography, and an increase in diagnosis at later stages of breast cancer for black women (Zekeri, 2015). There are immense physical and psychological barriers in these areas as well. The people interviewed responded that having money and health insurance in the Black Belt are not enough to make the residents feel safe.

Increasingly, hospitals and ambulances that serve these black communities are either closing, relocating, or becoming private. In Alabama, the likelihood of a hospital closing is directly related to the percentage of blacks in the community (Zekeri, 2015). Residents of Macon County felt stigmatized and discriminated against in terms of health care because John A. Andrews Hospital closed in 1987. Residents told the investigator that geographic availability and proximity are important determinants to seeking health care services early. In the Black Belt, many patients are treated in an outpatient or ambulatory setting, including physician offices and clinics. Home health care is usually less expensive and more convenient for the patient than the care provided in a hospital or skilled nursing facility (Zekeri, 2015).

**Poverty**

Interestingly, another common context, other than health insurance and access to quality health care, that was routinely heard in focus groups, was poverty. Most participants
(77%) believed that high poverty among African Americans is another contributing factor to health disparities (Table 1). These African Americans felt that the variables that contributed mostly to their increased incidence of cancer, HIV/AIDS and other diseases were beyond control. In addition to poverty, oppressive forces such as segregation, substandard health care, and the subsequent feelings of meaninglessness, hopelessness, and social despair provide the environment for the emergence of cancer fatalism.

As one 30-year-old respondent put it “because of poverty, blacks are less likely to take advantage of preventive services and the quality of the health care they receive tends to be lower.” Participants told investigators that blacks are more likely than whites to receive treatment in hospital outpatient clinics and emergency rooms, which are more often public than private. It was their perception that whites are more likely to go to a private doctor’s office.

An African American mother of two, who works as a nurse’s aide explained that “poverty also can aggravate the hypertension suffered by African Americans, and various other acute and infectious diseases that are more common among people in the lower social classes. High rates of poverty among African Americans mean that they are less likely to receive early and adequate medical treatment.”

In the United States, health and access to health care are unequally distributed on the basis of socioeconomic status (Duncan et al., 2001; Haan et al., 1987). Money, or the lack of it, explains much of the disparity in HIV/AIDS and health of African Americans and whites.

**Not Enough Medical Practitioners**

Not enough doctors and nurses in black communities – many participants alluded to these when asked to explain racial disparities in HIV/AIDS. Eighty-five percent of the participants indicated that lack of health care providers make good health care difficult. An African American woman with four children said “many doctors do not want to practice in rural areas, leaving a doctor shortage in Alabama’s Black Belt Counties.” Some spoke of white health care providers who belittled their complaints, over-booked appointments and kept them waiting, and made it difficult for them to obtain the best care.

Physician availability fluctuates by region and type of locale. Few doctors locate in low-income rural communities like the Alabama’s Black Belt, although some foreign-born doctors have done so. Alabama’s Black Belt Counties cannot provide the expensive, sophisticated equipment and technical support personnel that many of today’s physicians prefer, and they don’t comprise enough patients to justify high capital costs (Zekeri, 2010; 2015).

**Social Health Behavior**

Approximately 80% of the participants believed that the racial and ethnic differences in health are due to African Americans’ unhealthy eating habits. African Americans are much more likely than others to eat high-sugar, high salt, and high-fat foods. Bad health behaviors mentioned during the interview include smoking, abuse alcohol or other substances, failing to use seat belt or other poor safety behaviors such as not engaging in adequate physical activity.

**Environmental Racism-Physical Environment**

Physical environment factors include health threats from exposure to toxins and unsafe conditions, particularly in residential settings. Environmental racism, the tendency for the U.S. hazardous waste sites and pollutng industries to be located in areas where the surrounding residential population is African American may also contribute to poorer health among African Americans (Zekeri and Habtemariam 2006). Although health care access and other social variables might account for some of the disparities in HIV/AIDS and health, more than half of the participants (56.7%) reported their perspective that differences in environmental and occupational exposures also play a role. A 50-year-old African American man felt that “there is a disproportionate placement of pollution-intensive industries and hazardous waste sites in African American communities.”

During the focus group discussion, someone talked about the well-known recent example of environmental danger that took place in Flint Michigan which is 57% black, with nearly 40% of the citizens live in poverty. Crises started Flint in 2016 after it was revealed that officials failed to publicly acknowledge that the water supply had been contaminated with lead and had poisoned local children. Both Michigan and the Federal government declared a state of emergency. Lead poison is associated with a variety of illnesses, developmental delays, and behavioral problems (Doleac, 2017). In Flint, Michigan, residents suffer from heightened levels of stress, depression, and trauma (Goodnough S Atkinson, 2016). In 2017, a government appointed civil rights commission issued a report blaming the crisis on “historical, structural, and systematic racism” (Almasy & Ly, 2017, p.1).

Black communities are affected by contaminated air and drinking water, the location of hazardous waste treatment and storage facilities. Furthermore, African Americans are more likely to live in polluted environments and are more likely than whites to work in hazardous occupations where they are exposed to toxic chemicals, dust, and fumes (Zekeri 2015). In the Alabama Black Belt Counties, exposure to pollutants from nearby industrial facilities, power plants, toxic waste sites present hazards for many.

**Under-Representation of African Americans in Health Care Fields**

Many of those who were interviewed (85%) believed that under-representation of African Americans in the health care fields is part of the problem. African Americans are seriously under-represented in the health care profession and this lack of representation is particularly significant for African American communities like Alabama’s Back Belt that rely on African American physicians for care (Zekeri and Habtemariam 2006). Many study participants felt that with so few African American health care professionals in the Alabama’s Black Belt, the control of the health care system lies almost exclusively in the hands of whites. One man said that “even when blacks complain of chest pains and other symptoms of heart disease, white doctors are less likely to take the complaints seriously.”
Articles

Lack of Trust in White Health Professionals

Another issue that came out of the interviews and discussions is distrust in white health professionals by African Americans. African Americans are more reluctant than whites to seek treatment for HIV and AIDS because they distrust the government (Zekeri 2013; 2015). This is because of the infamous Tuskegee experiments conducted by the U.S. government for 40 years (from 1932 to 1972). For the experiments, 399 poor black men were recruited and led to believe that they would receive free medical treatment for what they called “bad blood,” while, in fact, they were left untreated for syphilis so that the government health researchers could study the impact of the disease on them.

Unemployment

Many African Americans in the focus group interviews (73.3%) felt that unemployment makes good health care difficult and thus, contributes to disparities in HIV/AIDS and health. A lack of jobs paying a living wage and health benefits abounds in the Alabama Black Belt (Zekeri & Habtemariam 2006; Zekeri, 2015). Many participants talked about the difficulty of finding employment, particularly a job that pays a living wage. The reason for their difficulty in finding a job becomes more apparent when we recognize that certain segments of the population have extraordinarily high rates of unemployment, particularly young African Americans and other minority groups without a high school diploma (Zekeri, 2015).

Many African Americans are unemployed or employed in jobs that do not provide health care insurance (Zekeri, 2007; 2013; 2015). Yet, access to health care services is related to ability to pay, and ability to pay is related to access to health insurance. Searching for work and coming up with nothing is a demoralizing experience. Consequently, some people in the Black Belt quit looking for a job after many unsuccessful attempts.

Discussion

African Americans’ belief of psychosocial factors associated with racial HIV/AIDS and health disparities were examined in this exploratory qualitative study.

Reducing disparities in HIV/AIDS and health care between racial groups is currently a major focus of interest in the United States. In the past years, the United States Department of Health and Human Services has launched major initiatives in this area (Zekeri, 2015). Unfortunately, however, adequate information to describe social factors, most notably from African Americans’ perspective, has generally been unavailable or extremely limited in academic studies. This study contributes to this gap in research on health disparities.

Issues surrounding racial health disparities are complex, difficult, and controversial. However, health insurance, lack of access to quality health care, environmental hazards in neighborhoods, poverty, lack of medical practitioners, unhealthy eating habits, poor life style choices, lack of African Americans in health care profession, lack of trust in white health care professionals and unemployment contribute substantially to racial health disparities in America.

African Americans face many barriers in obtaining quality health care. The biggest obstacle they must overcome is the lack of affordable insurance. Lack of transportation, the location of health care facilities, the unequal distribution of health care providers in the area, inability to pay for visits to the doctor or co-payments, and referral patterns all contribute to racial health disparities in HIV/AIDS in the area.

Of the many factors contributing to health disparities discussed, insurance coverage appears to be a key. Having health insurance, more than any other demographic or economic factors, determines the timeliness and the quality of health care. One reason for lack of health insurance is the higher poverty rate among African Americans.

Among African Americans, money problems are constant in most of the families and periodic in the others. Conversations during in-depth interviews and focus group discussions frequently turn to the money problem.

As one person put it:

“Right now we’re kind of stuck for money. We’re just making it by. Like, we just keep up with the bills. I just paid the phone bill, and our money’s about all out. So, we’ll have to wait till next week before we do any work on our house. If there’s any money next week.”

The stress and worry about getting by is ever-present. Some help come from state Medicaid or the federal Medicare program for older people. But families sometimes incur medical costs when they have no insurance, and usually have to pay some portion of costs even when they are covered. There is often confusion about medical insurance or assistance – what it covers, when it expires, how far back it is effective, and whether the family is currently eligible. Medicaid is available to people with incomes below a certain level, even if they are not on welfare, but fluctuating incomes and re-certification problems leave many families without coverage.

Conclusion

A decade after the historic election of Barack Obama as president of the United States on November 4, 2008, America still struggles with the debilitating effects of personal and institutional discrimination based on race, religion, and ethnicity. Despite recent gains, African American still suffer noticeable disadvantages in health care, economic, politics, education, employment, and many other areas. When opportunities to health and health care system are unequally distributed according to race, all facets of life remain unequal.

Health care is connected to the American social structure. The political economy, corporates structure, and the distribution of resources and power influence health and illness. Health issues in the United States are an assortment of economic, political, cultural, and social forces outside the immediate control of the individual: a shortage of jobs that pay a living wage, persistence of discrimination, residential segregation, and social isolation. Health issue is a social...
problem, according to the socio-structural perspective; it is a by-product of the distribution of power and the organization of society.

Some innovative, energetic attempts are already being made in some Alabama Black Belt Counties and some communities to address the health disparity problems. However, the fledgling efforts need much more help, both financial and institutional, from outside the area, in part because the rural counties as a whole are not sufficiently affluent to combat local poverty and health care issues. The health care problems need to be better understood; and, a great deal of more resources must be devoted to them, simply to prevent health disparity from getting worse, and to hold on at present levels. Without a concerted effort in Alabama Black Belt Counties, a long-standing pattern of socio-economic and health disparity within the counties may grow much worse. Improvement will require even greater effort. Unless there is a commitment to reduce and prevent health disparities, the problem will cycle through still more generations and engulf more people and communities.

References


Articles


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Constructivism or Behaviorism: What is the Best Method to Teach Special Needs Students?

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Abstract

This review article will examine differences and similarities of constructivism and behaviorism to determine the best method(s) to teach pre-kindergarten, kindergarten, elementary and secondary students with special needs. Some educators may use constructivism methods and others may use behaviorism methods to teach students with special needs. Others are unsure what methods to use and decide it may be best to integrate the two.

“The function of education is to teach one to think intensively and to think critically. Intelligence plus character—that is the goal of true education.”—Dr. Martin Luther King

Keywords: Special Needs, Behaviorism, Constructivism

Introduction

Many states and districts are changing their style of teaching and the materials they use with special needs students, trading in traditional text-heavy materials for those created with the “universal design for learning” philosophy (CAST, 2011). Universal Design for Learning (UDL) is a set of principles for curriculum development that gives all individuals equal opportunities to learn. It provides a blueprint for creating instructional goals, methods, materials, and assessments that work for everyone—not a single, one-size-fits-all solution but rather flexible approaches that can be customized and adjusted for individual needs (CAST, 2011).
At the heart of every effective classroom is a devoted teacher, embracing the opportunity to educate the world’s next generation of citizens. Hence, teachers have a moral obligation—by virtue of achievement for all students—to develop and nurture their lifelong learning. The topic of this article is important for educators, school administrators, parents and policymakers to evaluate as the education reform movement strives to engage and prepare special needs students for a technologically-advanced and globally-impacted society. There are many methods of delivery that special education teachers can use to reach their students. I propose that special needs students learn best under a constructivism paradigm. However, this article will examine the constructivism (which focuses on how individuals learn) and behaviorism (which is a worldview that assumes a learner is passive, responding to environmental stimuli) paradigms to determine which model is more effective in the learning process of special needs students. Therefore, the guiding question for this article is: Constructivism or behaviorism, which is the best approach to use to teach special needs students?

**Definitions of Special Education and Specific Learning Disability**

Special Education may be defined as a specialized area of education which utilizes unique instructional methods, materials, learning aids, and equipment to meet the educational needs of students with learning disabilities (Special Education News, n.d.). Hasselbring & Williams (2000) articulate that students with special education needs can be defined as “those who, because of a disability, require special education and related services to achieve their fullest potential” (p.78). Students’ disabilities may range from speech and language impairments to mental retardation, and more than half have a specific learning disability due to a psychological disorder (Fernández-López, Rodríguez-Fórtilt, Rodríguez-Almendros, & Martínez-Segura, 2013).

Specific learning disability is defined as a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations (Specific learning disability, 1997).

**Constructivism Defined**

According to Thirteen, (n.d.) constructivism is a theory based on observation and scientific study about how people learn. In other words, people construct their own understanding and knowledge of the world, through experiencing things and reflecting on those experiences. When an individual encounters something new, he/she has to reconcile it with previous ideas and experiences. Sometimes, an individual may change his/her beliefs or maybe he/she will discard the new information as not important. A person has to ask questions, explore, and assess what he/she knows, hence; the individual is an active creator of his/her own knowledge. Von Glasersfeld describes constructivism as “a theory of knowledge with roots in philosophy, psychology, and cybernetics” (Glaserfeld, 1989). Constructivism has implications for the theory of instruction. Discovery, hands-on, experiential, collaborative, project-based, and task-based learning are a number of applications that base teaching and learning on constructivism.

**Contributors to Constructivism**

McLeod (2009) articulates that Jean Piaget was the first psychologist to make a systematic study of cognitive development. His contributions include a theory of cognitive child development, detailed observational studies of cognition in children, and a series of simple but ingenious tests to reveal different cognitive abilities. According to Piaget (1936), children are born with a very basic mental structure (genetically inherited and evolved) on which all subsequent learning and knowledge is based.

Piaget’s belief was that individuals learned through the construction of one logical structure after another. He also concluded that the logic of children and the way they think are completely different from those of adults. The implications of this theory and how Piaget applied them have shaped the foundation for constructivist education Thirteen, (n.d.).

Based on maturation factors Piaget came up with a developmental approach to teaching children. The approach changes as children mature as to what is taught at diverse age levels. Piaget then stressed the following maturational stages of development as the child matures:

- sensorimotor from birth to two years whereby the use of the senses and muscles are utilized in learning. The items used can be seen, manipulated by touch, and shaken
- preoperational from two to seven years of age in which the young child perceives one variable only or largely such as length, width, and height, especially when comparisons are made between objects
- concrete operations for the younger between the ages of seven and eleven. Here, the pupil needs to refer to physical objects in order that the abstraction being studied is meaningful
- stage of abstract thought after twelve years of age in which the abstract becomes increasingly meaningful without making reference to the concrete. (Ediger, 2003, p.175).

An individual can see what activities and experiences change gradually from observational methods of learning and touch/movement to the abstract with the use of words and symbols as children become mature (Ediger, 2003). Learning has to wait upon the maturational sequence and there are selected activities then which may be emphasized within the sequential stages of maturational progression. Piaget also stressed the importance of students moving forward in achievement whereby students are in charge of sequencing their own learnings, largely on an individual basis (Ediger, 2003).

Lev Vygotsky was another contributor to Constructivism. Vygotsky proposed a theory of cognitive development that emphasized the underlying process rather than the ultimate stage of development. He examined the relationship between the cognitive process and the subject’s social activities and is well known for his sociocultural theory of development that focuses on the “zone of proximal development (ZPD)” (Thirteen, n.d.). According to Ivan (1994), Vygotsky’s concept of “ZPD may be defined as the difference (expressed in units of time) between the performances of the same child working with and assisted by an adult. In this concept of the proximal zone, the view of the child as a social being engenders a methodological
The chart below depicts a comparison of four major characteristics of a constructivist perspectives. Children in building an understanding of the concept (Bransford, Brown, & Cocking, 2000). Setting with more knowledgeable or proficient people (parents, teachers, peers, others) assists is the basis for cognitive growth. Accordingly, the communication that transpires in a social setting with more knowledgeable or proficient people (parents, teachers, peers, others) assists children in building an understanding of the concept (Bransford, Brown, & Cocking, 2000).

**Comparison of Characteristics of Constructivist Perspectives**

The chart below depicts a comparison of four major characteristics of a constructivist perspectives.

<table>
<thead>
<tr>
<th>Major Characteristics</th>
<th>Piagetian Classroom</th>
<th>Vygotsky’s Perspective</th>
<th>Social Constructivism</th>
<th>Holistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal</td>
<td>Develop logical thinking</td>
<td>Develop self-regulated attention, conceptual thinking, logical memory</td>
<td>Construct and reconstruct contexts, knowledge, and meanings through discourse communities</td>
<td>Student ownership of the learning process and the outcomes</td>
</tr>
<tr>
<td>Classroom focus</td>
<td>Spontaneous, student-directed experimentation</td>
<td>Interaction with subject-matter concepts to develop advanced cognitive capabilities</td>
<td>The emergence of a community of participants that together re-create knowledge</td>
<td>Real-world communication tasks that build on children's strengths and interests</td>
</tr>
<tr>
<td>Role of the teacher</td>
<td>Create and organize challenging experiences; ask probing questions to facilitate learner rethinking of ideas</td>
<td>Model, explain, correct, and require the learner to explain</td>
<td>Participate in a system of practices that are themselves evolving; participate in the “co-construction” of knowledge</td>
<td>Interact with a variety of learning contexts to actively learn and communicate</td>
</tr>
<tr>
<td>Example</td>
<td>Some math and science curricula</td>
<td>Reciprocal teaching</td>
<td>Some elementary math and science classrooms</td>
<td>Whole language</td>
</tr>
</tbody>
</table>

Green & Gredler, 2002

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**Behaviorism Defined**

The focus of Behaviorism is on the conditioning of observable human behavior. J. B. Watson, the father of Behaviorism, defined learning as a sequence of stimulus and response actions in observable cause and effect relationships (learning-theories, n.d.).

Cherry (n.d.) suggests that behavior can be studied in a systematic and observable manner with no consideration of internal mental states. This school of thought suggests that only observable behaviors should be studied. There are two major types of conditioning:

1. Classical conditioning is a technique used in behavioral training in which a naturally occurring stimulus is paired with a response. Next, a previously neutral stimulus is paired with the naturally occurring stimulus. Eventually, the previously neutral stimulus comes to evoke the response without the presence of the naturally occurring stimulus. The two elements are then known as the conditioned stimulus and the conditioned response.

2. Operant conditioning (sometimes referred to as instrumental conditioning) is a method of learning that occurs through rewards and punishments for behavior. Through operant conditioning, an association is made between a behavior and a consequence for that behavior (Cherry, n.d.).

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**Contributors to Behaviorism**

‘Give me a dozen healthy infants, well-formed, and my own specified world to bring them up in and I’ll guarantee to take anyone at random and train him to become any type of specialist I might select – doctor, lawyer, artist, merchant-chief and, yes, even beggar-man and thief; regardless of his talents, penchants, tendencies, abilities, vocations, and race of his ancestors’ (Watson, 1930, p.82).

According to John Watson (1913), psychology should be the science of observable behavior. Behaviorists view psychology as an objective experimental part of the natural sciences. Moreover, its goal is the prediction and control of behavior.

Skinner’s views were slightly less extreme than those of Watson. Skinner believed that we do have such a thing as a mind, but that it is simply more productive to study observable behavior rather than internal mental events (McLeod, 2007).

According to Skinner, voluntary or automatic behavior is either strengthened or weakened by the immediate presence of a reward or a punishment. “The learning principle behind operant conditioning is that new learning occurs as a result of positive reinforcement, and old patterns are abandoned as a result of negative reinforcement” (Belkin and Gray, 1977, p.59). In his book entitled, The Technology of Teaching, Skinner wrote:

“The application of operant conditioning to education is simple and direct. Teaching is the arrangement of contingencies of reinforcement under which students learn. They learn without teaching in their natural environments, but teachers arrange special contingencies which expedite learning, hastening the appearance of behavior which would otherwise be acquired slowly or making sure of the appearance of behavior which otherwise never occur” (Skinner, 1968, p.64).
Skinner believed that more complex learning could be achieved by this process of contingencies and reinforcement "... through successive stages in the shaping process, the contingencies of reinforcement being changed progressively in the direction of the required behavior" (Skinner, 1968, p.10).

Differences between Constructivism and Behaviorism

Learning theories usually fall into one of several paradigms; however, for the purpose of this article, constructivism and behaviorism are examined to support the theory that special needs children learn better under a constructivism paradigm. Constructivism is often articulated in stark contrast to the behaviorist model of learning (Murphy, 1997). When a teacher uses constructivist principles for teaching children, the teacher believes that learning should be meaningful and related to real life situations. Whereas, if a teacher breaks down tasks into small and manageable portions for teaching, the teacher has taken on behaviorist principles (Grobecker, 1999). See some major differences between the two in the chart below:

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Constructivism</th>
<th>Behaviorism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic idea:</td>
<td>Learning is an active, constructive process.</td>
<td>Stimulus-response. All behavior caused by external stimuli. Behavior can be explained without the need to consider internal mental states or consciousness.</td>
</tr>
<tr>
<td>Learner viewed as:</td>
<td>Information constructor.</td>
<td>Passive, responds to environmental stimuli.</td>
</tr>
<tr>
<td>Other</td>
<td>Learners construct their own subjective representations of objective reality. New information is linked to prior knowledge, thus mental representations are subjective.</td>
<td>Behavior may result in reinforcement (increased likelihood that behavior will occur in the future); or punishment.</td>
</tr>
</tbody>
</table>

Teaching/Learning Methods for Special Needs Students

Special needs students are often the most challenging to teach yet also the most neglected by politicians and government educational policymakers. The number of students in special education has skyrocketed since the 1980s and stabilized in the last few years. During the 2008-2009 academic school year, about 6.5 million students aged 3 through 21 were enrolled in special education programs for students with disabilities in the United States (Snyder & Dillow, 2010).

During the 2008-2009 academic school year, about 6.5 million students aged 3 through 21 were enrolled in special education programs for students with disabilities in the United States (Snyder & Dillow, 2010).

Looking at techniques used by teachers in the late 20th century, Orkwis and McLane (1998) describe the potential of Universal Design for Learning (UDL) to help all students meet high standards: In terms of learning, Universal Design means the design of instructional materials and activities that allow the learning goals to be achievable by individuals with wide differences in their abilities to see, hear, speak, move, read, write, understand English, attend, organize, engage, and remember. “Universal Design for Learning is achieved by means of flexible curricular materials and activities that provide alternatives for students with disparities in abilities and backgrounds” (Orkwis & McLane, 1998, p.9).

Hallowell and Ratey (2010), specialists on adolescents with attention-deficit disorder (ADD) at Hallowell's Center in Massachusetts, emphasize structure as the key to effective teaching students with ADD. They stress the importance of creating strict guidelines for students with ADD in the classroom. For example, they believe students should have constant reminders about classroom rules and direction for assignments. Additionally, Hallowell and Ratey (2010) believe that setting limits on children is “soothing” for them, rather than constraining. They also emphasize the importance of play time and creativity for students, since many of them may become frustrated or bored with monotonous, structured work. Moreover, Hallowell and Ratey (2010) advocate fitting playtime and creative intellectual work within the boundaries of strict guidelines and disciplinary measures for students with ADD. Contrary to Hallowell and Ratey's perspectives Mookerji (2011) points out a story about Paige, a special-needs student featured in a 2005 New York Times article, who was confused and bored due to the lack of structure in her special education classroom. After Paige transferred from a southside Chicago school to one in New York, she despised her special education class, complaining that “everyone just plays around in there too much.” Her special education fifth-grade classroom did not have many assessments and assessments, and substitute teachers constantly rotated in and out of the classroom. Though Paige may have been able to do what limited homework there was, she received bad grades because of the lack of structure in class (Mookerji, 2011).

Another approach to teaching special needs students is differentiating instruction. Hammeken (n.d.) defines differentiating instruction as the process of teachers proactively planning to teach students at their current levels of ability, rather than taking a standardized approach to teaching. With differentiated instruction, classroom teachers plan what the student will need to learn, how they will learn it and how they will demonstrate what they have learned. Hammeken (n.d.) articulates that one of the most popular terms when referring to differentiating instruction is that “one size does not fit all” and it is a wonderful tool for special needs students.

According to Educating Children with Special Needs (n.d.) special education teachers use various techniques to promote learning. Depending on the disability, teaching methods can include individualized instruction, problem-solving assignments, and small group work. Other techniques special education teachers can use include remedial instruction such as repeating the information and devoting more time to working on skills. When teaching special education classes, Teaching Special Education (n.d.) suggests that educators use diagrams, graphics and pictures to augment what they are saying in words; this strategy benefits the visual and auditory learners simultaneously. If the child loses his/her place while reading, or uses his/her finger to point to the words, the teacher can place a colorful piece of plastic under the line to assist the student’s eyes to return to the right place when he/she loses focus. Swanson (1999) not only agrees with the techniques of Teaching Special Education (n.d.), the researcher also suggests that teachers break learning into small steps, administer probes, and engage students in directed response/questioning. Grobecker (1999) concurs that breaking down tasks into small, manageable segments is a strategy that is associated with a structured approach to teaching special needs students.
Using a different approach, Marcus (2001) articulates that perhaps the most unusual approach to teaching students with special needs is that of pediatrician Melvin Levine at the medical school of the University of North Carolina-Chapel Hill. "His Schools Attuned program, which so far has influenced the curricula at the Bank Street College of Education in New York and California State University-Northridge, gives students a grounding in brain research so that they'll appreciate, for instance, that a child who can't seem to comprehend information projected on a screen might comprehend when the essential points stand out in color" (Marcus, 2001, p. 4).

According to Levine, students who don't concentrate can be moved to the front of a classroom or given frequent short breaks. Or a teacher can use a prearranged hand signal to tell a child to get back to work without resorting to a public scolding (Marcus, 2001). A student teacher gave an example of how two students who kept slipping up on tasks such as preparing slides to view in a microscope. She came up with two approaches, first, she wrote and spoke the directions, one step at a time and then she paired advanced students with the ones struggling to catch on. Group learning gave the student teacher time to assist students who needed repeated explanations and she thought that kids have a certain way of explaining things to each other (Marcus, 2001).

Davis (2011) gives an example of how an eighth-grade teacher presented her students with an activity that awarded them $200 in virtual money and asked them to plan a three-course dinner party for eight friends. The students calculated food costs by using a grocery store’s website and then planned the parties. The following week, the teacher gave them the same challenge but limited their budget to $50.00.

Still examining teaching and learning methods, Sze (2009) turned her focus on students with autism. "Students with autism thrive in environments that provide structure. The language learning classroom may be structured a certain way, but the structure of language itself is ambiguous and may cause for difficulty in language learning for these students. Teaching students with autism to communicate is often done through prompting, which involves the teacher saying a phrase and the student repeating the phrase. This type of structured learning may work well for beginning language/communication skills, but educators should strive to wean students off prompting and teach them to speak at their own will" (Sze, 2009, p. 360).

Like, Sze (2009) Kagohara, Sigafoos, Achmadi, O’Reilly, and Lancioni (2012) focused on the learning that of autism, but from a technology perspective. The researchers conducted research that was designed to teach two students with autism spectrum disorders (ASD) to check the spelling of words using the spell-check function on common word processor programs. "During baseline, the participants performed less than 40% of the task-analyzed steps correctly. When the video modeling intervention was introduced via an iPad, both participants reached the 76–100% correct level on the task analysis and became more successful in using the word processor programs to check the spelling of words. Follow-up data showed 100% correct performance by both participants. The results suggest that the video modeling intervention, delivered via an iPad, was effective in teaching two adolescents with ASD to check the spelling of words using common word processing programs" (p. 304).

## Multiple Methods of Presenting Instructional Content

<table>
<thead>
<tr>
<th>Auditory</th>
<th>Visual</th>
<th>Tactile/Kinesthetic</th>
<th>Affective</th>
<th>Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lecture</td>
<td>Video clips</td>
<td>Field trip</td>
<td>Small group work</td>
<td>Digitized video PalmPilot Video Conferencing</td>
</tr>
<tr>
<td>Discussion</td>
<td>Sign language</td>
<td>Sign language Gestures</td>
<td>Cross-age tutoring Peer-mediated instruction</td>
<td>Electronic discussion boards Online chat rooms</td>
</tr>
<tr>
<td>Song</td>
<td>Watch a play</td>
<td>Drawing</td>
<td>Roleplay</td>
<td></td>
</tr>
<tr>
<td>Read aloud</td>
<td>Books</td>
<td>Braille books</td>
<td>Some elementary math and science classrooms</td>
<td>Tape recorder iPod</td>
</tr>
<tr>
<td>Questioning</td>
<td>Graph, table, chart</td>
<td>Demonstration Roleplay Dance Games Manipulatives Build an object</td>
<td>Spreadsheet PowerPoint Overhead data projector</td>
<td></td>
</tr>
</tbody>
</table>

**Summary**

A literature review presented numerous methods of presenting instructional content to special needs students. Going into this article review the thought was that special needs students learn better under a constructivism paradigm. After a careful review of the literature and case studies, it is evident that special needs students learn best when components from both the constructivism and behaviorism approaches are integrated. It is more effective to make instructional and curricular decisions based on the individual child, task and the setting than to use strategies representing one theory. Moreover, the integration of components from both approaches could help special and general education teachers work more effectively as a team to teach children with learning disabilities (Steele, 2005). However, further research in this area is recommended.
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Abstract

Documents obtained through the US Freedom of Information Act show that, in 1997, the US National Cancer Institute (NCI) funded an 18-year randomized controlled trial in Mumbai that used mortality endpoints to compare a discredited cervical screening test to no screening. The Mumbai trial required Indian and global health leaders to assume “no screening” would remain “standard care” throughout India for the duration of the trial, and thereby delayed the implementation of routine cervical screening among the general population of India for 18 years. During those 18 years, more than one million women died from cervical cancer in India, while Pap screening became “standard care” in other developing countries. Incorrect beliefs that Pap screening is not feasible in developing countries provide false justification for opportunity costs associated with the Mumbai trial and hinder cervical cancer prevention efforts in developing countries, where 90% of global cervical cancer deaths occur. Those incorrect beliefs
also undermine World Health Organization policy guidelines, which should be corrected to acknowledge that good-quality Pap screening can be implemented in developing countries with reasonable investment. Tata Memorial Hospital and the US Office for Human Research Protections (OHRP) determined the Mumbai trial was unethical. That determination has been effectively covered up by false and misleading statements from US medical leaders. All surviving Mumbai trial participants, from both intervention and control arms, should finally receive good-quality cervical screening tests. NCI leaders should accept OHRP determinations, acknowledge the Mumbai trial was unethical, and apologize to trial participants.

**Keywords:** Bioethics, cervical cancer, India

### Introduction

During the first half of the 20th Century, cervical cancer was the leading cause of cancer-related death among women in the United States(1). During the latter half of the 20th Century, the number of American women developing and dying from cervical cancer declined precipitously(1). It is widely accepted that the cause of this remarkable public health achievement was cervical screening using the Papanicolaou cytology test, or “Pap smear.” Today, cervical cancer remains the leading cause of cancer-related death among women in developing countries(2), due to lack of access to routine cervical screening services in those countries. Today, 90% of global cervical cancer deaths occur in developing countries(2).

The establishment of routine Pap screening services in southern Vietnam(3) led to 50% reductions in cervical cancer rates between 1998 and 2003(4), providing one of the first real-world examples of successful cervical cancer prevention in a contemporary developing country. The discovery of an association between the Vietnam War and cervical cancer, which was documented in 1996 but not published until 2004(5), provided compelling incentives to fix and not just study the problem of cervical cancer in Vietnam. Publication of data linking war to disease was delayed for eight years in an attempt to ease the process of reconciliation by presenting what most would acknowledge to be a remedy in advance of what some would perceive to be an accusation(4).

Cervical screening reduces cervical cancer incidence and mortality rates by detecting and treating pre-invasive cervical lesions (e.g. high-grade squamous intraepithelial lesions, or HSILs) before HSILs progress to invasive cervical cancers. A variety of cervical screening tests may be used to detect HSILs, including Pap smears, human papillomavirus (HPV) tests, and visual inspection with 4% acetic acid (4% VIA). Visual tests such as 4% VIA were introduced for may be used to detect HSILs, including Pap smears, human papillomavirus (HPV) tests, and visual inspection with 4% acetic acid (4% VIA). Visual tests such as 4% VIA were introduced for HSILs) before HSILs progress to invasive cervical cancers. A variety of cervical screening tests can be implemented in developing countries(2).

Randomized controlled trials (RCTs) are considered the gold standard for generating scientific evidence to establish the effectiveness of health interventions. However, scientific evidence comes in forms other than that of RCTs. Important examples of scientific evidence establishing effectiveness in the absence of RCTs are provided by the US Preventive Services Task Force (USPSTF), which is a highly-regarded independent panel of volunteer experts. The USPSTF has determined that the “introduction of cervical screening to populations naïve to screening reduces cervical cancer rates by 60% to 90% within three years of implementation. The reduction of mortality and morbidity associated with the introduction of cytology-based screening is consistent and equally dramatic across populations”(7). On the basis of such scientific evidence, the USPSTF assigned its highest “A” recommendation to cervical screening in the absence of RCTs comparing cervical screening to no screening(8). The USPSTF also assigned its highest “A” recommendation to “no smoking” in the absence of RCTs comparing not smoking to smoking(8). Today, RCTs testing the effectiveness of either cervical screening or not smoking would appear scientifically unnecessary.

Because cervical screening was introduced to routine clinical practice without first being tested through RCTs, the year in which the effectiveness of cervical screening was firmly established can only be estimated indirectly. One such estimate may be obtained through consideration of a study of untreated HSILs that was conducted at New Zealand National Women's Hospital by gynecologist Herbert Green from 1965 until 1974(9). Through his study, Green sought to show that untreated HSILs do not progress to cervical cancer. In 1984, whistleblowers working with Green published results from Green's study which showed that untreated HSILs progress to lethal cancers, and that cervical screening and treatment prevented that progression(10). The 1984 publication led to a governmental inquiry led by Judge Silvia Cartwright(9). Rather than being applauded as an important contribution to medical science, Green's study was censured by the Cartwright Inquiry for deliberately withholding proven life-saving interventions(9,11). Government censure of Green's study indicates that the effectiveness of cervical screening had been established well before 1984.

From 1997 until 2015, the US National Cancer Institute (NCI) funded an RCT in Mumbai, India. The Mumbai RCT was conducted by Surendra Shastri, Head of Preventive Oncology at Tata Memorial Hospital, which is the largest and most influential cancer center in India. The Mumbai RCT compared cervical cancer incidence and mortality rates among 75,360 low-income women, reportedly offered four rounds of 4% VIA, to cervical cancer incidence and mortality rates among 76,178 low-income women offered no screening(12,13).

In 2014, scientific and ethical concerns regarding RCTs conducted in Mumbai,(12,13) Osmanabad,(14,15) and Tamil Nadu(16) were summarized(17) and debated (18,19). The Osmanabad and Tamil Nadu RCTs were funded by the Bill & Melinda Gates Foundation (“Gates Foundation”) and were conducted by Rengaswamy Sankaranarayanan, Head of Cancer Screening at the International Agency for Research on Cancer of the World Health Organization (WHO). Sankaranarayanan also chaired the Data Safety Monitoring Committee of the Mumbai RCT(12,13).

In 2017, BMJ Global Health published an article reporting additional concerns, discovered through the US Freedom of Information Act (FOIA), regarding the Mumbai RCT.
RCT(20). That article was retracted for fear of defamation litigation in English courts(21,22). Because BMJ had no concerns regarding the scholarship of the retracted article(22), the retraction was appealed to the BMJ Ethics Committee(21). As a result of that appeal, The BMJ invited a commissioned article regarding the Mumbai RCT. In 2018, The BMJ rejected the commissioned article, once again for fear of legal action. The BMJ Editor-in-Chief acknowledged “The crux of the problem surrounds our perceived inability to meet the legal requirements needed to pursue publishing”(23). Herein, we update concerns regarding the Mumbai RCT, including those discovered through FOIA, together with available responses to those concerns from Indian and US leaders.

**Documents obtained through FOIA show that, in 1997, NCI funded an 18-year RCT in Mumbai that used mortality endpoints to compare a discredited cervical screening test to no screening.**

Unaided visual inspection/visual inspection (UVI/VI) tests are naked-eye examinations of the cervix performed without application of 4% acetic acid. HSILs are invisible to the naked eye unless 4% acetic acid is first applied to the cervix. Unlike VIA, UVI/VI does not detect HSILs. Therefore, UVI/VI cannot reduce cervical cancer incidence rates. The objective of UVI/VI was to detect cervical cancers at earlier clinical stages. The hope was that such “downstaging” might reduce mortality rates. However, by 1997, Sankaranarayanan had concluded that “the performance of unaided visual inspection is not satisfactory to consider this as an approach for cervical cancer control in developing countries,” because UVI/VI demonstrated unacceptably low detection rates for both HSILs and early-stage cancers(24).

As part of a journalistic investigation(25), one of the authors (REO) submitted FOIA requests that produced redacted documents related to the Mumbai RCT(26). NCI informed one of the authors (REO) that all copies of the initial grant application for the Mumbai RCT had been discarded. However, the NCI grant renewal application submitted in 1999 states “Of the 2 arms of the intervention trial, women in the study arm were to receive physical examination of the breast and teaching of BSE and visual inspection of the cervix. The visual examination of the cervix has now been modified…and the cervix is painted with 2% acetic acid before examination so as to identify more reliably acetowhite patches as suspicious. However, the modification was implemented a few months after the study was started. So that out of 21,542 women in the intervention arm who were given an examination, only 15,755 women were screened by VIA (2% acetic acid)”(26@p.43). Documents obtained through FOIA contain no evidence that re-training was provided to individuals performing screening in the Mumbai RCT following the change in the screening test.

The 1999 NCI grant renewal application establishes that NCI funded the Mumbai RCT to study discredited UVI/VI, and that 5,787 women were screened with UVI/VI before the intervention was reportedly switched to VIA (2% acetic acid). To our knowledge, the performance characteristics of VIA with 2% acetic acid have not been described. However, if 2% acetic acid does not render HSILs visible to the naked eye, then the performance characteristics of VIA with 2% acetic acid would be identical to the performance characteristics of UVI/VI. Publications from the Mumbai RCT(12,13) claim that 4% VIA was studied during all intervention rounds, and do not mention studying either UVI/VI or VIA with 2% acetic acid. In light of those omissions and discrepancies, the screening test actually studied during the Mumbai RCT is more reliably defined by characteristics other than its published name.

**Much about the cervical screening test studied during the Mumbai RCT was consistent with discredited UVI/VI; very little about the test was consistent with 4% VIA.**

As documented in Table 1 and Table 2 (both of which summarize data extracted from previous peer-reviewed publications), performance characteristics of the screening test studied during the Mumbai RCT are consistent with UVI/VI. The performance characteristics are not consistent with 4% VIA.

**Table 1. Numbers of invasive cervical cancers (ICCs) detected during each intervention round of the Mumbai randomized controlled trial(12,13).**

<table>
<thead>
<tr>
<th>Intervention Round</th>
<th>Numbers of women with biopsy-confirmed ICCs in intervention arm</th>
<th>Numbers of women with biopsy-confirmed ICCs in control arm&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>First screening round</td>
<td>20&lt;sup&gt;b&lt;/sup&gt;</td>
<td>8&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Interval cancers</td>
<td>7&lt;sup&gt;d&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Second screening round</td>
<td>12&lt;sup&gt;b&lt;/sup&gt;</td>
<td>28&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Interval cancers</td>
<td>12&lt;sup&gt;d&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Third screening round</td>
<td>17&lt;sup&gt;b&lt;/sup&gt;</td>
<td>14&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Fourth screening round</td>
<td>Not available&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Not available&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Abbreviation: ICC = invasive cervical cancer.

<sup>a</sup>Cases of cervical cancer are detected among women in the control arm when symptomatic women with invasive cervical cancer seek clinical consultation.

<sup>b</sup>Numbers of biopsy-confirmed invasive cervical cancers detected in the intervention arm were obtained from Table 4 of a 2010 publication(12).

<sup>c</sup>Numbers of biopsy-confirmed invasive cervical cancers detected in the control arm were obtained from Table 4 of a 2010 publication(12).

<sup>d</sup>Cases of cervical cancer are detected among women in the intervention arm between screening intervals when symptomatic women with invasive cervical cancer seek clinical consultation.

<sup>e</sup>Publications from the Mumbai randomized trial(12,13) do not report numbers of ICCs detected during the fourth intervention round. It is therefore uncertain whether the fourth intervention round was actually performed.
For example, as documented in Table 1, during the Mumbai RCT second intervention round, more invasive cervical cancers were detected in the control arm than were detected in the screening arm. That extraordinary finding is consistent with UVI/VI, rather than 4% VIA, being the screening test studied during the Mumbai RCT. As documented in Table 2, HSIL detection rates reported from the Mumbai RCT were 18-fold to 45-fold lower than HSIL detection rates for 4% VIA reported from a cross-sectional study conducted by Shastri in Mumbai(27). HSIL detection rates from the Mumbai RCT would be considered unacceptably low in any other setting and indicate that the screening test studied during the Mumbai RCT performed throughout the RCT as UVI/VI, rather than 4% VIA.

One of the authors (EJS) presented Mumbai disease detection rates during the 2016 Krishna Raj Memorial Lecture in Mumbai, which, along with an ensuing panel discussion with Tata Memorial leaders, was recorded by King Edward Memorial Hospital and posted online(28). During the panel discussion, Shastri falsely claimed that there were large differences in HSIL detection rates between his two studies because his Mumbai cross-sectional study was hospital-based, while his Mumbai RCT was community-based(28@1hr25min24sec). In fact, both studies(12,27) were community-based. Shastri has offered no other explanations for the unacceptably low disease detection rates documented during all intervention rounds of the Mumbai RCT.

Moreover, the design, effect, and duration of the Mumbai RCT are also consistent with UVI/VI being the screening test studied. The design, effect, and duration of the Mumbai RCT are not consistent with 4% VIA.

For example, Sankaranarayanan determined UVI/VI was “quite unlikely to achieve a stage shift as soon as it is introduced”(24), because cancers detected “in the initial rounds are likely to be relatively advanced lesions”(24). For those reasons, it appears the design of the Mumbai RCT scheduled four intervention rounds, rather than one. It is otherwise puzzling why Sankaranarayanan would initiate an RCT studying one 4% VIA screening round in Tamil Nadu(16) while the Mumbai RCT studying four 4% VIA screening rounds was already ongoing(12,13). The failure of four intervention rounds to reduce cervical cancer incidence rates in the Mumbai RCT(12,13), when one intervention round of 4% VIA reduced cervical cancer incidence rates in the Tamil Nadu RCT(16), is also consistent with UVI/VI, but inconsistent with 4% VIA, being the screening test studied during the Mumbai RCT. Moreover, if the Mumbai RCT had studied multiple rounds of 4% VIA, rather than multiple rounds of UVI/VI, then Shastri would have halted the Mumbai RCT by 2007, when Sankaranarayanan’s Tamil Nadu RCT concluded that one round of 4% VIA reduced cervical cancer incidence and mortality rates(16).

In 2017, Shastri claimed he did not halt his Mumbai RCT in 2007 because the Mumbai RCT employed lay health workers to perform cervical screening tests, whereas the Tamil Nadu RCT employed nurses to perform testing(22). Readers of this article may judge for themselves whether it is scientifically necessary and ethically humane to use unscreened control groups and mortality endpoints (rather than HSIL detection rates) to compare training requirements for cervical screening tests.

### Table 2. Detection rates for high-grade squamous intraepithelial lesions (HSILs) in Mumbai.

<table>
<thead>
<tr>
<th>Study settinga</th>
<th>Screening test studied</th>
<th>Numbers of women tested</th>
<th>Numbers of test-positive women with biopsy-confirmed HSILsb</th>
<th>Detection rates for biopsy-confirmed HSILsb</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mumbai randomized trial(12,13); First intervention round</td>
<td>Unaided visual inspection/visual inspectionc</td>
<td>5,787d</td>
<td>18c</td>
<td>0.04%</td>
</tr>
<tr>
<td></td>
<td>VIA with 2% acetic acid</td>
<td>45,358d</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mumbai randomized trial(12,13); Second intervention round</td>
<td>?f</td>
<td>41,354d</td>
<td>8e</td>
<td>0.02%</td>
</tr>
<tr>
<td>Mumbai randomized trial(12,13); Third intervention round</td>
<td>?f</td>
<td>36,643d</td>
<td>18c</td>
<td>0.05%</td>
</tr>
<tr>
<td>Mumbai randomized trial(12,13); Fourth intervention round</td>
<td>?f</td>
<td>Not availablee</td>
<td>Not availablee</td>
<td>Not availablee</td>
</tr>
<tr>
<td>Mumbai cross-sectional(27)</td>
<td>VIA with 4% acetic acid</td>
<td>4,009h</td>
<td>34h</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

Abbreviation: HSIL = high-grade squamous intraepithelial lesion; VIA = visual inspection with acetic acid.

1. The Mumbai randomized trial(12,13) and the Mumbai cross-sectional study(27) were both population-based studies.
2. So that detection rates for biopsy-confirmed HSILs from both Mumbai studies could be fairly compared, detection rates for both Mumbai studies were calculated in an identical manner, using the following formula: Detection rate for biopsy-confirmed HSILs = (# of test-positive women with biopsy-confirmed HSILs)/(# of women tested).
3. Documents obtained through the US Freedom of Information Act(26@p.43) indicate the screening tests studied during the first intervention round.
4. Denominator values for detection rates of biopsy-confirmed HSILs in the Mumbai randomized trial were obtained from the following statement, published in 2010(12): “Out of 75,360 eligible women listed in the screening arm 51,145 (67.87%), 41,354 (57.84%) and 36,643 (54.26%) women participated in the first, second and third screening rounds for cervix cancer.”
5. Numerator values for detection rates of biopsy-confirmed HSILs in the Mumbai randomized trial were obtained from the following statement, published in 2010(12): “HSIL [high-grade squamous intraepithelial lesion] and LSIL [low-grade squamous intraepithelial lesion] cases were 18 and 62 in the first round, 8 and 49 in the second round, and 18 and 24 in the third round.”
6. Publications from the randomized trial(12,13) claim that VIA with 4% acetic acid was studied during all four intervention rounds. That claim is inconsistent with documents obtained through the US Freedom of Information Act(26@p.43).
7. Publications from the randomized trial(12,13) do not report numbers of HSILs detected during the fourth intervention round. It is therefore uncertain whether the fourth intervention round was actually performed.
8. Numerator and denominator values for the detection rate of biopsy-confirmed HSILs for VIA in the Mumbai cross-sectional study were obtained from numbers presented in Row 2 and Row 3 of the table labeled “Results of screening tests compared with final disease status established by the reference standard” in a 2005 publication(27).
The discredited cervical screening test studied during the Mumbai RCT may not actually have caused downstaging, and therefore may not have actually reduced cervical cancer mortality rates.

Effects cannot result from causes that do not exist. Cervical screening did not cause incidence-rate reductions in the Mumbai RCT. Therefore, incidence-rate reductions could not have caused mortality-rate reductions in the Mumbai RCT, because incidence-rate reductions did not exist. If cervical screening did not cause downstaging in the Mumbai RCT, then cervical screening could not have caused mortality-rate reductions in the Mumbai RCT, because downstaging did not exist.

In fact, cervical screening may not have caused downstaging in the Mumbai RCT. Statistical methods used in the Mumbai RCT are not described in detail sufficient to verify whether significant downstaging actually occurred. Also, staging was missing from 59 patients. That missing data might have indicated that downstaging did not actually occur. Moreover, documents obtained through FOIA disclose substantial unexplained discrepancies, documented in Figure 1 and Figure 2, between staging data submitted to NCI in 2004 and staging data published in 2010. None of those discrepancies were acknowledged in publications from the Mumbai RCT. All of those discrepancies (instead of 50%, as might be expected) support the hypothesis that the discredited intervention studied caused downstaging. None of those discrepancies (instead of 50%, as might be expected) weaken that hypothesis. Taken together, those discrepancies suggest that data may have been manipulated to create the appearance that downstaging had occurred.

Discrepancies suggestive of data manipulation were previously reported regarding Sankaranarayanan and Shastri’s Osmanabad RCT. However, because the Osmanabad RCT was funded by the Gates Foundation, rather than by the US Government, the Osmanabad RCT is not subject to oversight by the US Office of Research Integrity (ORI). In 2015, one of the authors (EJS) communicated allegations of data falsification regarding the Mumbai RCT to ORI, which initiated an investigation. When ORI determines that research misconduct has occurred, it publishes its determinations in the US Federal Register. When there is no finding of research misconduct, there is no public notice and ORI records remain confidential. One year after ORI initiated its investigation, no determinations regarding the Mumbai RCT had been published in the US Federal Register. Subsequently, one of the authors (EJS) submitted a FOIA request that produced redacted documents pertaining to the ORI investigation of the Mumbai RCT. Those documents state that “many factors were responsible” for the observed data discrepancies. However, because all responses to ORI from Tata Memorial had been redacted from the documents obtained through FOIA, none of the “many factors” responsible for observed discrepancies are specified. NCI leaders declined to comment on those substantial data discrepancies. To date, no public explanations have been offered for the discrepancies documented in Figure 1 and Figure 2.

### Table 5: Staging of Cervix cancer cases at diagnosis (Intervention Arm)

<table>
<thead>
<tr>
<th>Screening Round</th>
<th>Stage (CIS + I +II)</th>
<th>Stage (III + IV)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Screening</td>
<td>07 (35%)</td>
<td>13 (65%)</td>
<td>20</td>
</tr>
<tr>
<td>(IC 1 - 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd Screening</td>
<td>14 (50%)</td>
<td>14 (50%)</td>
<td>28</td>
</tr>
<tr>
<td>(IC 1 - 10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3rd Screening</td>
<td>09 (60%)</td>
<td>06 (40%)</td>
<td>15</td>
</tr>
<tr>
<td>(IC 1 - 6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4th Screening</td>
<td>02 (100%)</td>
<td>–</td>
<td>02</td>
</tr>
<tr>
<td>(IC 1 - 5)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 5. Staging at diagnosis (cervix-screening arm)

<table>
<thead>
<tr>
<th>Screening round</th>
<th>Early stage (0 + I + II)</th>
<th>Late stage (III + IV)</th>
<th>Staging not available</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>16 (80.00%)</td>
<td>4 (20.00%)</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Interval cancers</td>
<td>7 (58.33%)</td>
<td>5 (41.67%)</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Two</td>
<td>10 (88.33%)</td>
<td>2 (16.67%)</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>Interval cancers</td>
<td>12 (60.00%)</td>
<td>8 (40.00%)</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Three</td>
<td>17 (100.00%)</td>
<td>0</td>
<td>0</td>
<td>17</td>
</tr>
</tbody>
</table>

Figure 1: Discrepancies in intervention arm suggestive of data manipulation. Percentages of early-stage cancers are lower in data submitted to the US National Cancer Institute in 2004 (upper table) (26; p. 255) compared to data published in 2010 (lower table; ©2009 UICC) (12). All discrepancies (instead of 50%, as might be expected) support the hypothesis that the intervention studied caused downstaging. No discrepancies (instead of 50%, as might be expected) weaken that hypothesis. Reasons for discrepancies in total numbers of cases during each screening round are unknown. In 2017, US National Cancer Institute leaders declined to comment on any of those discrepancies (22).
Percentages of late-stage cancers are lower in data submitted to the US National Cancer Institute in 2004 (upper education/surveillance round) are unknown. In 2017, US National Cancer Institute leaders declined to comment on any of those discrepancies (22). All discrepancies (instead of 50%, as might be expected) support the hypothesis that the intervention studied caused downstaging. No discrepancies (instead of 50%, as might be expected) weaken that hypothesis. Reasons for discrepancies in total numbers of cases during each health education/surveillance round are unknown. In 2017, US National Cancer Institute leaders declined to comment on any of those discrepancies (22).

<table>
<thead>
<tr>
<th>Health education/Surveillance Rounds</th>
<th>Stage (CIS + I + II)</th>
<th>Stage (III + IV)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Round 1 (IC 1 – 10)</td>
<td>03 (37.5%)</td>
<td>05 (62.5%)</td>
<td>08</td>
</tr>
<tr>
<td>Round 2 (IC 1 – 10)</td>
<td>06 (42.9%)</td>
<td>08 (57.1%)</td>
<td>14</td>
</tr>
<tr>
<td>Round 3 (IC 1 – 6)</td>
<td>06 (50%)</td>
<td>06 (50%)</td>
<td>12</td>
</tr>
<tr>
<td>Round 4 (IC 1 – 5)</td>
<td>02 (50%)</td>
<td>02 (50%)</td>
<td>04</td>
</tr>
</tbody>
</table>

Table 6. Staging of symptomatic referrals at diagnosis (cervix-control arm)

<table>
<thead>
<tr>
<th>HE/monitoring rounds</th>
<th>Early stage (0 + I + II)</th>
<th>Late stage (III + IV)</th>
<th>Staging not available</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>1 (14.29%)</td>
<td>6 (85.71%)</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Two</td>
<td>9 (37.50%)</td>
<td>15 (62.50%)</td>
<td>4</td>
<td>28</td>
</tr>
<tr>
<td>Three</td>
<td>4 (33.33%)</td>
<td>8 (66.67%)</td>
<td>2</td>
<td>14</td>
</tr>
</tbody>
</table>

Incorrect beliefs that Pap screening is not feasible in developing countries, which provide false justification for opportunity costs associated with the Mumbai trial, undermine global cervical cancer prevention efforts and WHO policy guidelines.

In order to rationalize unscreened control groups in the India RCTs, Sankaranarayanan and Shastri stated “we applied the principle that whenever a new intervention is evaluated, it is compared to the standard care existing in the country and only subsequently should it be implemented as a public health policy” (18). That principle required leaders at Tata Memorial, WHO, and NCI to assume “no screening” would remain “standard care” throughout India for the duration of the Mumbai RCT (17). In 2017, Shastri stated “We are most gratified that the Government of India has introduced countrywide [vinegar-based] cervical screening since August 2016” (21), confirming that “no screening” remained “standard care” throughout India for the 18-year duration of the Mumbai RCT. During those 18 years, more than one million women died from cervical cancer in India (2), while Pap screening became “standard care” in developing countries such as Vietnam (3,4). Opportunity costs were also associated with Herbert Green’s study of untreated HSILs conducted in New Zealand (10). Consistent with his incorrect belief that HSILs do not progress to cervical cancer, Green actively opposed a national cervical cancer screening program that had been proposed as early as 1959, thereby delaying implementation of nationwide cervical screening in New Zealand for 32 years (11). During that time, more than 3,000 New Zealand women suffered avoidable cervical cancers (11).

Economist Paul Krugman has referred to “zombie arguments” as arguments that have been proven wrong and should be dead, but that keep shambling along because they serve a political purpose (33). One such zombie is the argument that Pap screening is not feasible in developing countries. One of the political purposes of that zombie argument may be to provide false justification for opportunity costs associated with the Mumbai trial.

Any suggestion that Pap screening might be feasible in developing countries would imply that large numbers of Indian women died needlessly from cervical cancer between 1997, when the Mumbai RCT began, and August 2016, when the Government of India authorized nationwide cervical screening. Perhaps by coincidence, it has become difficult to suggest that Pap screening is feasible in developing countries. That evolution is documented in the writings of Sankaranarayanan and Shastri.

In 1996, Sankaranarayanan wrote “The logistics of implementing visual cervical inspection in public-health-service settings are considerable, and may not be much inferior to that required for a cytology programme” (34). In 2005, Sankaranarayanan and Shastri concluded, in the context of their Osmanabad RCT, “Our results clearly show that good-quality cytology can be implemented even in a rural setting of a developing country with reasonable investment” (14). Their 2005 conclusion, which is observably true, is corroborated by evidence from developing countries throughout Asia, Africa, and the Americas. Pap screening programs have been operational in Latin America since the 1970s (35). Pap screening is operational in Vietnam (3,4).
2001, African leaders concluded “95% of institutions at all health care levels in East, Central, and Southern African countries had the basic infrastructure to carry our Pap screening”(36).

Remarkably, in 2001, Sankaranarayanan summarily contradicted the conclusions of those African leaders with the zombie argument that “Many low-income developing countries, including most in sub-Saharan Africa, have neither the resources nor the capacity for their health services to organize and sustain any kind of screening programme”(37). Perhaps more remarkably, Shastri contradicted his own conclusions from 2005(14) with the zombie argument he offered in 2014 as the rationale for his Mumbai RCT: “Because Pap smear screening is not feasible in India, we need to develop effective alternatives”(13). Incorrect beliefs that Pap screening is not feasible in developing countries produce gratuitous obstacles against the transfer of lifesaving Pap screening to precisely those areas of the world where 90% of cervical cancer deaths now occur(38).

In 2009, writing in praise of the Osmanabad RCT, NCI HPV expert Mark Schiffman advocated that developing countries bypass Pap screening and VIA in favor of HPV screening(39). However, Schiffman conceded in 2011(40), and again in 2017(41), that HPV tests remain too expensive for implementation in developing countries. Schiffman does not recommend 4% VIA for developing countries “because of its inaccuracy”(42). Nevertheless, Schiffman declined an invitation to endorse Pap screening for developing countries(41,43), underscoring how difficult it has become even for global health experts to counter zombie arguments.

Zombie arguments that Pap screening is not feasible in developing countries are incorporated into WHO policy guidelines, which incorrectly claim “In low- and middle- income countries, because of the high cost of setting up screening programmes based on cytology, coverage of screening is very low and alternative screening methods are needed”(44@p.1). In truth, Pap screening is feasible in developing countries, while HPV screening is not(40,41). Nevertheless, WHO policy guidelines recommend HPV screening, but not Pap screening, for developing countries(44). By default, VIA, which the world abandoned for Pap smears during the 1950s, has become the only feasible screening test recommended for developing countries by WHO policy guidelines. During the 1950s, VIA was abandoned due to justified concerns regarding its accuracy. As documented in Table 1 and Table 2, quality management for visual screening accuracy can be problematic even in the hands of experts such as Shastri.

Both Tata Memorial Hospital and the US Office for Human Research Protections (OHRP) determined that the Mumbai RCT was unethical.

In 2009, the Tata Memorial Scientific Review Committee “expressed concern that this trial [i.e. the Mumbai RCT] is unethical for control arm in view of the report submitted by Dr. Shastri. The control arm may be stopped”(26@p.398). For unknown reasons, the control arm was not stopped. In 2011, one of the authors (EJS) submitted concerns regarding the Mumbai RCT to the US Presidential Commission for the Study of Bioethical Issues(45,46) and to the US Office for Human Research Protections (OHRP)(47). The Presidential Commission, which had been tasked by President Obama with reviewing global human subjects protections following scandalous disclosures regarding unethical studies of syphilis in Guatemala(48), did not address those concerns. OHRP conducted an investigation and in 2012 determined that informed consent was not obtained from RCT participants(49). Therefore, the Mumbai RCT was, by definition, unethical.

OHRP discovered substantial discrepancies between the informed consent form submitted with NCI grant applications and the informed consent form actually used during the Mumbai RCT(49). The informed consent form submitted to NCI included information that Pap smears are standard cervical screening procedures in “developed countries,” that Pap smears are available in India; and that women could obtain Pap smears on their own if they did not wish to participate in the Mumbai RCT(49). However, such critical information was missing from informed consent forms actually used in the Mumbai RCT(49). NCI Director Harold Varmus was copied on OHRP correspondence with Tata Memorial(49). In 2013, one of the authors (EJS) communicated additional concerns to Varmus(50).

In 2012, in response to OHRP determinations, the Tata Memorial Institutional Review Board (IRB) voted unanimously to finally inform Mumbai RCT participants about differences between Pap smears and no screening, and to offer cervical screening to women in the control group(51). The corrective actions undertaken by the Tata Memorial IRB effectively ended the Mumbai RCT and prevented the embarrassment of OHRP, rather than Tata Memorial, halting the RCT. OHRP subsequently closed its investigation after concluding its prior determinations had been adequately addressed(52). Sankaranarayanan and Shastri have defended the ethics of the Mumbai RCT by claiming that corrective actions taken by the Tata Memorial IRB adequately addressed OHRP determinations(18). Ignored by their claim is that ethical informed consent must be obtained before a study begins, and not when a study ends.

Regardless OHRP determinations, it appears that the establishment and maintenance of unscreened control groups in the Mumbai(12,13), Osmanabad(14,15), and Tamil Nadu(16) RCTs required unethical informed consent(17). If women recruited for the Mumbai RCT had been informed that UVI/VI was an unsatisfactory intervention for cancer control(24), they would have declined to participate in the intervention arm. If women recruited for the Mumbai, Osmanabad, and Tamil Nadu RCTs had been adequately informed of the simple truth that cervical screening would lower their risk for death from cervical cancer, they would have declined assignments to unscreened control groups(17). Suggestions that women would knowingly choose more death, instead of more life, are implausible(19). It is correspondingly difficult to presume that the Osmanabad and Tamil Nadu RCTs were not compromised by the unethical informed consent that compromised the Mumbai RCT(17). However, the Osmanabad and Tamil Nadu RCTs were funded by the Gates Foundation, rather than the US Government, and are therefore not subject to oversight by OHRP.
Tata Memorial and OHRP determinations have been effectively covered up by false and misleading statements from US medical leaders.

In 2012, one of the authors (EJS) shared OHRP determinations(49) with the office of US House Democratic Leader Nancy Pelosi, whose Senior Health Policy Advisor, Wendell Primus, arranged a conference call among NCI leaders and staff of the US House Energy and Commerce Committee, which oversees NCI budgets. Subsequently, one of the authors (EJS) submitted FOIA requests that produced redacted documents related to that conference call(53). Those documents indicate that NCI leaders slandered the professional reputation of one of the authors (EJS) by falsely characterizing him to Congress as a whistleblower "whose views were not in the mainstream" and who "believes that Pap smears are the only proven approach to detecting cervical cancer"(53@p.10). The ad hominem criticism may have represented an attempt to discredit otherwise plausible whistleblower allegations.

NCI leaders assured Congress "there were no issues with the science" of the Mumbai RCT(53@p.10). NCI leaders did not inform Congress that science had established the effectiveness of cervical screening, compared to no screening, long before the Mumbai RCT began, or that the Mumbai RCT studied an intervention that science had discredited before the RCT began. NCI leaders assured Congress "It is worthwhile to note that OHRP did not recommend that the trial be stopped"(53@p.9). In fact, that embarrassment was spared only because the Tata Memorial IRB stopped the Mumbai RCT in response to OHRP determinations. NCI leaders assured Congress "We have reviewed the translated version of the 14-page consent form and are confident that the women were informed to the extent possible. Most of the women were illiterate"(53@p.9). It is implausible that a 14-page written consent form can adequately inform illiterate women. Moreover, NCI leaders did not inform Congress that OHRP had discovered substantial discrepancies between the informed consent form submitted with NCI grant applications and the informed consent form actually used during the Mumbai RCT(49). Nevertheless, NCI leaders left Congressional staff "glad to be fully informed, and gratified to learn that the study has had such positive impacts"(53@p.10).

In 2013, 6 years after the Tamil Nadu RCT had reported that a single round of 4% VIA reduced cervical cancer mortality(16), the Mumbai RCT reported that four rounds of 4% VIA reduced cervical cancer mortality. Despite the superfluous nature of the Mumbai RCT results, NCI leaders declared those results to be "amazing," "remarkable," and "very exciting" (54). Shastri, who had written in 2005 "Our results clearly show that good-quality cytology can be implemented even in a rural setting of a developing country with reasonable investment"(14), declared in 2013 "It's just not possible to provide Pap smear screening in developing countries"(54). Shastri, who had written in 2005 "Our results clearly show that good-quality cytology can be implemented even in a rural setting of a developing country with reasonable investment"(14), declared in 2013 "It's just not possible to provide Pap smear screening in developing countries"(54). Although NCI Director Harold Varmus had previously been directly informed of OHRP determinations(49,50), NCI leaders in 2013 declared to mainstream media "We looked at the [Mumbai RCT] ethics very carefully and felt them to be sound"(54). The results of the Mumbai RCT were first announced at the 2013 annual meeting of the American Society of Clinical Oncology (ASCO)(54). Despite OHRP determinations, ASCO President Sandra Swain also defended the ethics of the Mumbai RCT, declaring "There really was no wrongdoing there. They have no screening anyway"(54), apparently overlooking that the Mumbai RCT required "no screening" to remain "standard care" throughout India from 1997 until 2015.

In 2014, the Journal of the National Cancer Institute published the results of the Mumbai RCT(13), with no acknowledgement that OHRP had determined that those results had been obtained without the informed consent of RCT participants. Despite OHRP determinations, Shastri received the 2014 ASCO Humanitarian Award for his role in the Mumbai RCT(55). In 2017, despite Tata Memorial(26@p.398) and OHRP determinations that the Mumbai RCT had been unethical, the Supreme Court of India declared that women had given their voluntary informed consent to participate in the Mumbai(12,13), Osmanabad(14,15), and Tamil Nadu(16) RCTs, and dismissed public-interest litigation filed on behalf of vulnerable study participants(56).

Conclusion

Although Herbert Green’s study of untreated HSILs was censured by the Government of New Zealand in 1988,9 denialism and incorrect beliefs that Green did no wrong continue to this day.(11,57) New Zealand gynecologist Ron Jones has suggested that denialism will persist until medical leaders, and not only political leaders, acknowledge and apologize for the unnecessary suffering and deaths which resulted from that study(57). In 2017, 33 years after Jones and colleagues published their whistleblowing report(10), the Royal Australian and New Zealand College of Obstetricians and Gynaecologists apologized to the women involved in Green’s study(58). It was the first public apology offered by any of the medical institutions involved in the study. Whether denialism regarding Green’s study will persist following the 2017 apology remains to be seen.

NCI leaders should accept OHRP determinations, acknowledge that the Mumbai RCT was unethical, and apologize to RCT participants. Otherwise, influential individuals and groups in the medical profession may continue to deny painful truths and perpetuate incorrect beliefs regarding the Mumbai RCT. For example, incorrect beliefs that Pap screening is not feasible in developing countries may be perpetuated, to the detriment of women’s health throughout the world. WHO guidelines should therefore be corrected to acknowledge that “good-quality cytology can be implemented even in a rural setting of a developing country with reasonable investment”(14). That correction will advance global cervical cancer prevention efforts.

All surviving Mumbai RCT participants, from both intervention and control arms, should finally receive good-quality cervical screening tests, as documented by biopsy-confirmed HSIL detection rates. In 2015, Tata Memorial did not respond to inquiries, submitted under India’s Right to Information Act, regarding how many women from the control arm were screened following the close of the Mumbai RCT(59). The science and ethics of the Osmanabad(14,15) and Tamil Nadu(16) RCTs should be reviewed. However, the Tamil Nadu and Osmanabad RCTs, because they were funded by the Gates Foundation and not by the...
US Government are not subject to oversight by OHRP, FOIA, or ORI. In 2017, the Gates Foundation declined to comment on published concerns regarding the Osmanabad and Tamil Nadu RCTs(22). Therefore, as previously suggested(19), NCI HPV expert Mark Schiffman, who praised the Osmanabad RCT(39), should be invited to explain whether the implausible conclusion of the Osmanabad RCT -- that good-quality Pap screening does not prevent cervical cancer(15) -- is scientifically valid. If that implausible conclusion is scientifically invalid, then review of the science and ethics of the Osmanabad RCT by the New England Journal of Medicine may be appropriate.

Former World Bank economist William Easterly observed “poor people die not only because of the world’s indifference to their poverty, but also because of ineffective efforts by those who do care”(60). Lessons learned in Vietnam suggest that global cervical cancer prevention efforts will become more effective if global health leaders and researchers embrace a commitment to the definitive public-health goal of “improving health outcomes as rapidly as possible among as many people as possible” and assimilate the policy implications of that commitment(4). An online Delphi Exercise may facilitate such assimilation(61).

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But never yet could I find that a black had uttered a thought above the level of plain narration. . . Misery is often the parent of the most affecting touches in poetry. Among the blacks is misery enough, God knows, but no poetry. Love is the peculiar oestrum of the poet. Their love is ardent, but it kindles the senses only, not the imagination.

– from Thomas Jefferson’s Notes on the State of Virginia, Query XIV

I have not forgotten my Khoisan clicks. . . . If he were to let me rise up from this table, I’d spirit his knives and cut out his black heart, seal it with science fluid inside a bell jar, place it on a low shelf in a white man’s museum so the whole world could see it was shriveled and hard, geometric, deformed, unnatural.

– from Elizabeth Alexander’s “The Venus Hottentott (1825)”

*Mend* is the debut collection of poetry by South Carolina native, Kwoya Fagin Maples, a creative writing instructor at the Alabama School of Fine Arts in Birmingham. Her collection pays homage to Anarcha, Betsey, and Lucy, three enslaved women called by name in Dr. J. Marion Simms’s (1884) autobiography, *The Story of My Life*. From 1845-1849, Sims, who practiced medicine in Mt. Meigs, Alabama, conducted experiments on these (and other) enslaved women, advancing what would become the field of gynecology. Sims developed the precursor of the speculum used in gynecological exams today and eventually became known as “the father of modern gynecology” (Vedantam, 2017). Scientific inquiry, advancements in medicine, and recognition for groundbreaking research were, no doubt, at the core of Sims’s work, but alongside these components were notions of Black inferiority (white superiority) and the belief in innate “racial” and biological differences that allowed scientists, such as Sims, to experiment on enslaved Black people with impunity.

In *Notes on the State of Virginia*, Thomas Jefferson (1787) claimed that Blacks were “more tolerant of heat . . . [and] seem to require less sleep . . .” He referred to their “grievances” as “transient” and attributed their bravery and “adventuresome” nature to their “want of forethought.” He also believed Blacks could remember as well as whites, [but] he claimed...
“in reason [they were] much inferior...[and] in imagination they are dull, tasteless, and anomalous” (p. Query XIV). These attributes assigned to people identified as “Black” became justification for oppression and exploitation that moved beyond plantation slave quarters and cotton fields to unethical scientific experimentation, and dissections into popular culture, circus acts, even family settings.

Charles D. Martin (2017), author of The White African American Body, “observed scientists determined to perform dissections and anatomical studies of the ‘white Negro’ to prove racial inferiority despite their white skin (p. 53). Martin has referred to these men as a ‘cabal of racial scientists.’” Sims was, by extension, a part of this cabal. He was among the scientists who owned enslaved Africans and profited both financially and professionally from the institution of slavery (Washington p. 54-55). According to Harriet Washington, “Owners boarded captive bodies of sick slaves to hospitals or hired well ones to physicians for use in experiments. Sometimes they sold a slave outright for such use, particularly if she had become too old or informed to work or to breed. (p. 54)

Sims acquired Anarcha Wescott, Betsey Harris, and Lucy Zimmerman from their masters for the purpose of medical experimentation, and “eventually hid his subjects’ race and even illustrated reports of experiments on black slaves with illustrations of bourgeois white matrons” (Washington p. 59, 256). The pro-slavery stance of Sims (whether tacit or explicit) and his contemporaries was often reflected in the theories they developed and the scientific methodologies they employed.

Despite meaningful contributions or pioneering research Sims or these scientists might have conducted, their legacies also include the perpetuation of scientific racism, which has contributed to deeply-held beliefs of white racial superiority and black inferiority, beliefs that have spilled over into decisions about medical care and mental or intellectual competencies. Through Sims, and other scientists like him, white supremacy settled into our collective psyche under the guise of objective scientific inquiry, remnants of which permeate our societies today. According to Harriet A. Washington, for example, Sims “cited the popular belief that blacks did not feel pain in the same way was whites (p. 65). While a plantation doctor, he treated a Black infant boy, by trying to ‘pry [the infant’s] skull bones into new positions.’ Washington notes: "Owners boarded captive bodies of sick slaves to hospitals or hired well ones to physicians for use in experiments. Sometimes they sold a slave outright for such use, particularly if she had become too old or informed to work or to breed. (p. 54)

Sims relied on the ‘scientific myth that the bones of the black infants’ skulls, unlike white infants’, grew together quickly, leaving the brain no space to grow and develop. This premature closing of the black skull was held to cause low intelligence and perpetual childishness in adult blacks. (p. 63)

Maples’s decision to write Mend and explore the lives of these enslaved women, our “mothers of modern gynecology” (NPR), places her in a harrowing and complicated space where literature and medical malfeasance intersect. This intersectional space is the site of white superiority and black inferiority grounded in so-called scientific evidence. This space has helped to essentialize blackness, ascribe subhuman status to African-descended people, and justify their exploitation. This site often extends from scientific research and medical clinics to circus tents, and at the center of this space are often enslaved women, women of color (and other vulnerable people) whose lack of options and agency propelled them into desperation and misery. In Mastering the Female Pelvis, Terri Kapsalis states, “What might link a surgeon-slave-master to a showman-ringmaster? Both exercise mastery over bodies...” (as quoted in Judd, 2014, p 35.) Though the circus is designed for entertainment, it is the ringmaster who leads, directs, profits, and controls, all the while helping (intentionally or not) to exploit and objectify. Thus, the role of the medical researcher and the ringmaster as “[masters] over bodies” clearly overlaps.

Still, as Maples shares in her carefully researched and beautifully written historical poems, the sum total of these women’s lives was not experimental human subject. These women were first of all human beings despite any disrespectful or inhume treatments they withstood. Consequently, this intersectional space is also a site of recovery and reclamation where the contributions of these women, and others like them, are acknowledged and their dignity reclaimed through the creative musings of sonnets, ekphrasis, historical persona poems, plays, films, and other literary works that honor the memory, sacrifice, resilience of these marginalized or forgotten figures in our history. This space is confrontational. It is intimate. It is necessary. It is healing.

“The morning I was born my mama carried me to an oak tree to let it nurse me while she went back to the fields.” —“Delia” from Mend

Kwoya Fagin Maples first heard of Dr. J. Marion Sims and his experiments on enslaved women while attending a Cave Canem poetry writers’ retreat a decade ago. Maples’s book includes sonnets, a literary form commonly used during the Antebellum period, yet most of her poems are historical persona poems, which allow the Anarcha, Betsey, and Lucy to become the narrators or speakers of their own poems. Maples recognizes poets Cornelius Eady, Cave Canem co-founder, and former Kentucky poet laureate, Frank X Walker, as important influences in her decision to use persona poems, and while Eady’s Brutal Imagination and Walker’s Turn Me Loose: The Unghosting of Medgar Evers represent this unique literary form, their collections also show how white supremacy has been normalized as notions of racial superiority and inferiority prevail. (K. Maples, personal communication, November 14, 2018).

Cornelius Eady’s profoundly political collection of poetry Brutal Imagination was published in 2001. This collection focuses on the now infamous Susan Smith case. Smith drowned her two young sons but initially claimed that an unknown Black man had carjacked her vehicle and kidnapped her young boys. The first cycle of the collection includes persona poems spoken in the voice of that imagined Black man. In Turn Me Loose: The Unghosting of Medgar Evers, Frank X Walker uses persona poems to discuss the life and assassination of civil rights martyr Medgar Evers. The persona poems are written in the voice of Myrlie Evers, Medgar Evers’s widow, as well as in the voice of Byron de la Beckwith, Medgar’s assassin, and Beckwith’s first and second wife, Willie and Thelma Beckwith respectively. Beckwith internalized beliefs of racial superiority that he learned as a white boy growing up in the south. These white supremacist attitudes were a part of the Jim Crow south that helped de la Beckwith to grow into the man who would murder a Black man seeking social justice and equality. These
same beliefs helped de la Beckwith’s wife to stand by him fully aware of his criminal acts directed at Black people (Walker, 2013). Again, these collections are cited because of their shared literary form, yet the subject matter of these collections also represent ways scientific racism and white supremacy have permeated contemporary society.

Poets continue to use creative approaches to address difficult social issues, and the emotional intimacy required to create the persona poem provides an excellent form. Maples follows a rich literary tradition of historical persona poems, poems that are glimpses into history. She provides her readers with a teaching tool used to continue (or begin) conversations about race, gender, medicine, and poetry.

Maples conducted research for six years: she read Sims’s autobiography, Harriet Washington’s Medical Apartheid, and carefully studied slave narrative narratives to better understand the lives and experiences of enslaved women in the U.S. south. No doubt Maples knew the question of consent would surface as she told these women’s stories, but she understood these enslaved women had no agency. Historian Tiya Miles (2005) told the story of Doll, an enslaved woman purchased by Shoe Boots, a war hero in the Cherokee Nation. After extensive research on enslaved women, Miles asserted:

To be an enslaved woman in America was to be utterly exposed to sustained and systemic personal violation, which was also a sustained and systemic assault on the humanity and self-determination of one’s community. . . To be an enslaved woman was to be subject, always, to the sexual will of another, a sexual will that when exercised, could serve to increase the master’s property through the reproduction of more slaves (46-47).

So, even before Anarcha, Betsey, and Lucy, enslaved girls of childbearing age, became human subjects, they were property, unpaid laborers-for-life, and very likely breeders used to increase profits with the sale or further exploitation of their offspring. Maples’s awareness and sensitivity to the young women’s plight are evident in her poems. Maples’s research took her to South Carolina, New York City, and Mt. Meigs, Alabama, all sites with statues commemorating J. Marion Sims. Maples co-organized a campaign to remove Sims’s statue from the South Carolina State House. The protest included traditional and nontraditional components. In addition to signs and flyers, providing background on Sims, Anarcha, Betsey, and Lucy, Maples and members of the University of South Carolina MFA program staged a poetry marathon. Day all participants read poems by and about black women. Sims’s statue, formerly located in Central Park (New York), has been relocated to a Brooklyn cemetery, but for now, Sims’s statue remains in South Carolina. In a telephone interview with Maples, she explained that rather than keeping the statue of Sims and adding images of the women, (“even if they were three times his size”) his statue should be replaced, given his cruel legacy (K. Maples, personal communication, November 14, 2018).

With the publishing of this collection, Maples has joined a cadre of writers who refuse to allow the erasure of enslaved and marginalized people, including those who have been exploited in the name of science. Mend puts Maples in conversation with such contemporary poets as former United States poet laureate Natasha Trethewey (2012), whose ekphrastic poem “Miracle of the Black Leg,” introduces readers to a 14th century legend in which an Ethiopian (Black) male subject becomes a disposable donor for an ailing white patient. The transplanted black leg (cut off of the Black body to the white body) miraculously saves the life of the suffering white male. Trethewey’s (2012) “Dr. Samuel Adolphus Cartwright on Dissecting the White Negro,” also an ekphrastic poem, examines a unique dissection procedure as a scientist attempts to find the empirical evidence that proves innate differences between Blacks and whites. In “Knowledge,” Trethewey, an African-descended woman, inserts her own experiences with her white father as she examines a chalk drawing that captures the dissection of a young white woman, who, like Trethewey, is unable to escape the white male gaze.

National Book Award for Poetry recipient Nikky Finney, whose poem “The Greatest Show on Earth,” dedicated to “Sarri Bartman, Joice Heth, Anarcha of Alabama, Truginini and us all”, unites exploited women from both medical and circus settings”; Chancellor of the Academy of American Poets, Elizabeth Alexander (1990), whose poem “Venus Hottentot” (1823) explores the life of Saarji Baartman; and Cave Canem fellow, Battina Judd, author of Patient, whose persona poems embolden Anarcha, Betsey, Lucy, and Henrietta Lacks to speak. Judd, a Black woman, also documents her own experiences as a modern-day patient.

When Harriet A. Washington (2008) began research on her book Medical Apartheid, a colleague responded angrily to Washington’s research efforts arguing that no such experimentation existed during slavery. Most people are aware of the unethical experiments done on Jews during the Holocaust and the Tuskegee Syphilis Study (I will use the proper title) and more recently of Henrietta Lacks, whose Hela cells have made remarkable contributions to science. Yet many individuals are unaware of the proliferation of unethical treatment prior to this period.

“Bodies above virtue are never black.”
—from Mend (the sonnet corona titled “What Yields”)

In Thrall, Natasha Trethewey introduces readers to “The Miracle of the Black Leg.” According to the legend, Damian and Cosmas, who were twin brothers as well as physicians-saints, performed a posthumous transplant that involved amputating the leg of a black man (an Ethiop) and transplanting it on to the white patient. This miracle has been depicted in paintings and sculptures since at least the 14th century, in European countries including Portugal, Germany, Switzerland, France, Belgium, Spain and Italy. As with folklore, there are different versions of the tale. In one version, the Ethiop was already dead and had been buried for four day when he was disinterred and his leg removed. Trethewey’s ekphrastic poem refers to several different artistic renderings of the “miracle,” including a wood carving from circa 1547. Perhaps the first lines are among the most telling as they continue to reverberate, even now: “Always, the dark body hewn asunder; always/one man is healed, his sick limb replaced. . . ” The black man’s life and limb are sacrificed for the white patient’s health and survival. As the poem ends, the narrator asks, “How not to see it—/the men bound one to the other, symbiotic—/, one man rendered expendable, the other worthy of this sacrifice?” In each piece of art, it is the Black man who is on the floor or absent from view, yet his leg, a part of this scientific wonder, this religious miracle, remains.
Just as the Black donor image is central in the miracle of the black leg, images of Blacks as human subjects were a very real part of plantation life in the Antebellum South. Harriet A. Washington posited as “experimental subjects, slaves did not have to be recruited, persuaded, and cajoled to endure pain and indignity; they could not refuse.” 64 Plantation doctors contributed to advancements in medicine while often perpetuating the inferiority of Blacks. In a lecture entitled “American Slave Medicine,” Katherine Bankole-Medina noted that while many of the theories and arguments grounded in scientific racism of the antebellum period have been debunked, contemporary societies should continue to discuss the context and the ramifications these ideas may have had on race relations in the south. Dr. Samuel A. Cartwright, for example, was a highly-respected medical doctor, a graduate of the University of Pennsylvania Medical School and an apprentice with Dr. Benjamin Rush, an expert in public health and an abolitionist, who enslaved only one person (an aside Bankole-Medina interjects).

Like Sims, Cartwright practiced medicine in Alabama (Mississippi and New Orleans, Louisiana too), and while his research on cholera and yellow fever was groundbreaking, he also identified several “Negro” or “slave diseases” that were, by today’s standards, laughable and quickly dismissed as quackery. Drapeotomia, he discovered, was a “mental disorder” that affected runaways. It caused enslaved Blacks to seek freedom. So, based on his medical theory, Harriet Tubman would have suffered from severe drapeotomia. He offered “prescriptions” for this disease including keeping the enslaved person in a “submissive” state so that they could not flee. He also advocated “whipping” as a possible “cure” for the disease. Dysaesthesia Aethiopica, another disease he discovered, affected both the mind and body, and it explained the “lack of work ethic” among enslaved Africans. This condition diminished the intellectual capacity of the sufferer. “Scars on the body” and skin that became “insensitive” were markers for the disease. Bankole-Medina states that Cartwright’s extensive work, often informed by the Bible, made him an “authority on African American health and medicine,” yet it was “rooted in defense of slavery.”

Many southern whites who believe that Blacks are mentally and physically inferior to them have been influenced consciously or unconsciously by the remnants of the antebellum period’s scientific racism that supported slavery and reinforced the inferiority of Blacks. Cartwright had a number of prominent supports even though his theories on Negro diseases were dismissed as “pseudo-science” by the Civil War. James D. B. DeBow, head of the census in New Orleans, published Cartwright’s research in DeBow’s Review. Dr. Josiah Nott, a surgeon who contributed significantly to yellow fever research, studied the effects climate had on race. Dr. Samuel George Morton, father of ethnography, led cranium studies in which Blacks were dismissed as “pseudo-science” by the Civil War. James D. B. DeBow, head of the census in New Orleans, published Cartwright’s research in DeBow’s Review. Dr. Josiah Nott, a surgeon who contributed significantly to yellow fever research, studied the effects climate had on race. Dr. Samuel George Morton, father of ethnography, led cranium studies in which Blacks were identified as “Negro” or “slave diseases” that were, by today’s standards, laughable and quickly dismissed as quackery. In fact, he referred women with uterine problems to other local doctors, insisting, “This is out of my line; I do not know anything about it practically…” (p. 226).

In June of 1845, Sims met Anarcha, Betsey and Lucy. These teenager girls were clearly suffering from horrible conditions that developed during childbirth. Fistulas (tears) typically occurred after difficult labor. He learned of Anarcha, an enslaved woman on the plantation of Mr. Wescott, who had been in labor for three days and still had not given birth. He describes Anarcha as “colored, about seventeen years of age, well-developed, [and having] been in labor then seventy-two hours.” He delivered Arnach’s child using forceps, and several days later learned that Anarcha had “lost control of both the bladder and the rectum.” He later explained, not to the young woman, but to “the master of the servant” that she would be “unfit for her duties required of a servant… she would not die, but will never get well, and all you have to do is take good care of her so long as she lives” (p. 227).

Soon after Sims delivered Anarcha’s baby (baby did not survive) and examining her fistula, Tom Zimmerman, master of an enslaved girl named Lucy, insisted that Sims evaluate her. Lucy arrived on a train. She, too, was about seventeen or eighteen-years-old. Lucy also suffered from this incurable condition with “urine run[ning] all the time. . .whether walking or standing, sitting or lying down” (p. 228-230). Sims confesses that he detested conducting vaginal examinations. He asserts, “If it was anything I hated it was investigating the organs of the female sex” (p. 231). Of the three girls with fistulas Sims mentions by name, Betsey was the only one of the three referred to as “married.” She was unable to “hold a single drop of water” since giving birth about a month earlier because her “bladder [was] destroyed” (p. 228).

Sims referred to the fistulas as a “surgical curiosity, although a very unfortunate one” (p. 228). He concludes, “. . .[A]side from death, this was about the worst accident that could have happened to the poor young girl” (p. 227). Of course, he had never experienced slavery nor the particular vicissitudes of enslavement for girls and women that often included raped, the removal and sale of children born to them, the separation of families (parents, siblings, children, husbands/wives), whippings, malnutrition, forced free labor for life, property and subhuman status.

Even if he had compassion for these enslaved young women, he knew to negotiate with their masters. He also knew that if these enslaved workers were unable to perform, the landowner/slave master would lose money, and profiting from free labor was at the crux of the system of slavery. Sims made it clear that Anarcha would not be able to work, and Wescott would have to take care of her for the rest of her life. The economic component, essential to the master/slave relationship, was being gravely compromised. So, neither Sims nor the “masters”
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had much to lose. Given that these enslaved girls had little, if any, power or say-so over their daily lives, their bodies, and their reproductive health, it is unlikely they had the power or agency to make decisions about whether to have surgery or serve as human subjects in medical experiments. This is in no way dismissive of the pain and agony associated with fistulas, but it illustrates the physical, emotional, and social quagmire that confronted these women. Soon Sims proposes to the enslaved women's owners that he keep them so that he could experiment and operate on them, but he promises not to "endanger their lives." He adds that he would "not charge a cent for keeping them." However, the original owners would be responsible for taxes and the women's clothes (236). With this background material in mind, we enter the pages of Mend.

Alongside Sylvia Plath's poem Fever 103 are words of advice to slave masters regarding "distinctive diseases of the negro." (no page number). These epigraphs set the stage for the inevitable tension that exists between the enslaved women represented in the collection and the human subjects they became. Plath's poem begins, "I am too pure for you or anyone./Your body/Hurts me as the world hurts God. . . . " The poems to follow show the reader that this is also true for the enslaved teenaged girls, Anarcha, Betsey, and Lucy. They were "too pure . . . for anyone." And their pain is akin to a cosmic pain that telling their stories will help to elucidate.

The collection is divided into four sections. "The Door" is the introductory poem to the first section. It begins with powerful imagery: "a naked/woman/on knees/and hands" (3). The reader is able to immediately visualize this vulnerable and submissive posture. At first glance, the girl might have been a prostitute or a maid, had she not been naked. The woman is "in the backyard of things past telling," Whether this reference is to the area surrounding the "shack" Washington used to describe the medical facility in which Anarcha, Betsey, and Lucy lived or a metaphorical backyard (back alley) that holds secrets and memory, the woman in the poem is privy to information and experiences that are "past telling" because they have been held on to for far too long. The next eight lines that are intermittently indented read: "her odor/closing the space/he taps apart her inner/ thighs/her used belly/hangs/like a sow's. Fistulas carried with them an offensive odor as women suffering with this condition were often unable to control their bladder or their bowels. In the collection are comparisons to the black female body with, the sow, farm animals, fruit, water, even butcher's meat on steel. Sims has control of their ailing young bodies and is free to prod and poke and pull apart their legs.

Unlike white female patients whose examinations were done more modestly, their ailing young bodies and is free to prod and poke and pull apart their legs.

The other poems in this section express different emotions and reactions. In "Wool Human emotions were not always attributed to enslaved Black people, but strong emotions are indeed a part of this experience. Betsey is aware of Sims's "cold hands." She is haunted by memories of an overseer beating her as her skirts are raised above her head again at the hands of a powerful white man. The italicized words are direct quotes from Sims: "learn to keep still," this is purely scientific and excuse the odor suggest that he is detached, and she is fungible. Sims is clearly more concerned about the white male spectators who are offended by the odor than Betsey, who suffers with the fistula. Harriet Washington notes in Medical Apartheid: Betsey's voice has been silenced by history, but as one reads Sims's biographers and his own memoirs, a haughty, self-absorbed researcher emerges, a man who bought black women slaves and addicted them to morphine . . . to perform dozens of exquisitely painful, distressingly intimate vaginal surgeries (p. 2).

The other poems in this section express different emotions and reactions. In "Wool Door" Betsey exclaims, "They cut me open/like a great watermelon./I am ripe and yellow-bellied/and black seeds crack in their mouths" (Maples, 2018, p. 9). In "Unfolded" she is bold and determined, trying to keep herself together: "the closer/he comes/I ball my fists/right, if I could ball my body up/this tight/ke'd never pull me/apart. . . .ke'd never/eye what/I've never/seen myself" (Maples, 2018, p. 12). In "To Bear Witness" evidence of her opium addiction appears in a hallucination: . . . I see the cow with no head./I swear it was just as real as you and
Moses who parted the Red Sea, leading the children of Israel closer to freedom. And like an impassable obstacle that stood between them and their journey to the Promised Land. It was to open her legs day-after-day, year-after-year. The children of Israel spent forty-years in the wilderness, and parting like the “red sea” was no doubt exhausting. It took every ounce of strength she had to bear the weight of her body; it walked in this here room hooves clicking, a black soot hole for a neck . . . (13). Maples notes that this reference has come directly from the slave narratives she read. Questions about conjuring and magic were often asked in the interviews she studied. Seeing a cow with no head was a “bad omen” or a sign of impending “bad luck,” similar to hearing the hoot owl or the appearance of a black cat (K. Maples, personal communication, November 14, 2018). In another narrative poem, “So Familiar He Is with Parting Her Brown Legs”, Betsey observes, “The bowls of two pewter spoons are pushed in my body, yet they are kinder than his hands . . . I uncurl dizzyly. . . .I no longer bother to cover up.” By this time, Betsey is possibly already addicted to opium. Her defenses are down. She is physically, mentally and emotionally drained, so much so that she lives “dizzily” in and out of consciousness (K. Maples, personal communication, November 14, 2018).

In the final poem of section one, “Fresh Sheets” Betsey says . . . he no longer talks./ just waves his hand toward the table/ I lay myself in the center,/ part like the red sea-/I drift” (Maples, 2018, p. 20). She has surrendered to the routine and accepted her plight. Prolonged opium use, excruciating pain, and years of medical experimentation on an already worn body have led to exhaustion, yet the reference to the Red Sea is a biblical and triumphant one. Here parting like the “red sea” was no doubt exhausting. It took every ounce of strength she had to bear the weight of her body; it walked in this here room hooves clicking, a black soot hole for a neck . . . (13). Maples notes that this reference has come directly from the slave narratives she read. Questions about conjuring and magic were often asked in the interviews she studied. Seeing a cow with no head was a “bad omen” or a sign of impending “bad luck,” similar to hearing the hoot owl or the appearance of a black cat (K. Maples, personal communication, November 14, 2018).

“These lips only move when I tell them to, if I want them to. There is so much my body can still do. Plus, I’ve got these eyes for watching you.”

— from Mend (the sonnet corona titled “What Yields”)

Among the daughter-poets already mentioned is Natasha Trethewey, the daughter of poet Eric Trethewey, a white man from rural Canada and social worker, Gwendolyn Ann Turnbourgh, an African American woman from Mississippi. The couple met in the 1960s at Kentucky State College (later Kentucky State University), a historically Black college in Frankfort. When they decided to marry in 1965, anti-miscegenation laws made it illegal for them to do so in Turnbourgh’s home state of Mississippi (Wilson, 2008). Racist science clearly extended into marriage beds and influenced family dynamics, even in otherwise loving families. In “Knowledge” an ekphrastic poem inspired by J.H. Hasselhorst’s 1864 chalk drawing, Natasha Trethewey inserts herself, a 21 century woman of African descent, into a drawing that features the dissection of a young white woman from the 19th century, who, even in death, is unable to escape the white male gaze. The drawing features the dissection of a young white woman led by German anatomist Johann Christian Gustave Luce. The deceased is lying naked on a table in a cold, dimly-lit room with her “lips parted, long hair spilling from the table . . . /nipples drawn out for inspection” (28). Foiled against four inquisitive white men, representing science and scientific discovery, she is surrounded by “objects she’ll become” — a skeleton, skulls, books.

The woman, identified in the poem as “young and beautiful and drowned,” has committed suicide, and the scientists are using this opportunity “/to make a study/of the ideal female body. . . .” (28). Thus, her premature death provides an excellent opportunity to probe her young body, cut her flesh, and fetishize the female anatomy. The scientists, dressed warmly “in coats, trimmed in velvet or fur-soft as the down of [the young woman’s] pubis” seek not to understand a pathology or eliminate human suffering—but they desire to know the proportions of ideal beauty. Trethewey notes:

[T]he artist entombs her body in a pyramid/of light, a temple of science over which/ the anatomist presides. In the service of beauty-/to know it he lifts a flap of skin/ beneath her breast as one might draw back a sheet. . . . (p. 28-29)

In this instance, scientific discovery, a site for empirical data and reason, becomes a frivolous patriarchal quest for beauty, not unheard of during this period. Trethewey, using her own experiences as an African-descended woman, shows that the consequences of scientific experiments, dissections, and discoveries are not confined to morgues or hospital and medical school labs, and certainly not to young white women as reflected in the poetry upon which this discussion centers. Trethewey identifies this dissection as “a delicate wounding” and admits “the anatomist’s blade opens a place in me,/like a curtain drawn upon a room in which/each learned man is my father” (30). The painting about which she speaks in the poem hits home, for she continues her poem with lines from a poem her father wrote that refers to her as his “crossbreed child.” She is understandably hurt when he refers to her in what she calls “the language of zoology” (30). Referring to his brown daughter in words used to classify animals is not only insulting but dehumanizing. His word choice is grounded, perhaps unconsciously, in the notion of racial purity and suggests offspring of “mixed-race” couples are inherently different, a different breed, perhaps similar to the antebellum scientists’ belief in polygenism, in which human beings were created, not with a common ancestry, but with separate racial origins. Trethewey illustrates that the family unit, a microcosm of society, is not immune from racist thinking or language as it is deeply ingrained in our culture and lexicon. In this case, Trethewey, representing the Black female of the 21st century is linked to the past through the young white female of the 19th century as they are both subjected to the white male gaze, still representing power and authority over the gendered (female) body. Trethewey’s present, however, brings both gender and race to this poem. Trethewey’s pain is personal. It is generational. She says her father becomes all of the men in the painting, “even /the dissector—his scalpel in hand like a pen/poised above me aimed straight for my heart” (p. 30).

In Trethewey’s next poem, “Dr. Samuel Adolphus Cartwright on Dissecting the White Negro,” gaze shifts from race and gender to race and color, with the foundations of racist science connecting these poems. Unlike the cadaver in the poem “Knowledge” that is dissected to identify a standard of beauty, this poem focuses on a dissection to confirm perceived racial differences between Blacks and whites. Trethewey stated in an interview with Charles deNiord, “. . . Dr. Samuel Adolphus Cartwright. . . . is dissecting a white-skinned Negro to ‘prove’ the essence of black inferiority that he is sure is there. (World Literature today.org online 5/27/2015 interview accessed November 14, 2018). The poem identifies important anatomical markers such as skin, brain, blood, feet, neck that some scientists have used to confirm differences among the “races.” The poem begins with the words, “To strip from the flesh/the specious skin…”

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Regardless of prior knowledge, curious readers enter the poem as if walking into the fun house at a circus, unaware of what awaits. Finney grapples with the exploitation of women and opens the first stanza of the poem without equivocation: Under glass and tent/ floating in formaldehyde jelly/ curled in a deadman’s float/live the split spread/unanesthetized legs/ of Black women/broken like the stirrups/of a wishbone... (p. 53). She speaks to women remembering The lilac plumage/ of our petalized genitalia/in all its royal mauve/and plum rose/with matching eggplant hips/that pull the ocean/across itself each night/ and mourns being “cut away/by pornographic hands/fascinated with difference/ and the spectacle/of being a Black woman” (Finney, 53).

This poem is painful, beautiful, and honest. It is both a praise poem and an indictment. Finney, prophetic in her work, dedicates this poem to Saartjie Baartman, Joice Heth, Anarcha of Alabama, Trugini, and us all (italics mine). Within this space is room for Henrietta Lacks, Serena Williams, unknown transgender women of color, or non-binary peoples whose lives have been or will become spectacles of modern medicine.

The poem ends with the same serious tone woven throughout each line: “Our opened pirouetting vaginas,/our African music boxes/are whittled down to perfect/change purse size;/ For the normal/who will always pay/their fifty cents/to see what makes a freak a freak...” She brings the words—modern medicine and the circus—together with the lines: “The side show/was pitched on our backs/the speculum hammered/our between our legs/modern medicine was founded/ on the operation of our hips/...” She includes a direct reference to Baartman: “Go ahead/walk around her/she won’t bite/see her protruding mass/steatopygia (Finney, 53).

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The brilliantly crafted poem, “The Greatest Show on Earth” was published in Nikky Finney’s (2013) The World is Round. This poem’s title immediately grasps the reader’s attention with the provocative words “The Greatest Show on Earth.” Hearing these words often elicits excitement, bright colors, a cacophony of accordions, horns, laughter, clowns in floppy shoes, or lion tamers defying death as they bravely put their heads into the mouths of ferocious lions. Circus goers might think of cotton candy and bearded ladies, the ringmaster wearing his top hat with whip-in-hand as he commands some dangerous animal to sit or stand and do tricks. As soon as the title invites the reader to recall fond circus memories from childhood, Finney’s poem begins with a sobering dedication “for Saartjie Baartman, Joice Heth, Anarcha of Alabama, Trugini, and us all.” It is possible that readers are unfamiliar with these women. Saartjie Baartman Joice Heth, for example, is mentioned in memoirs of P.T. Barnum, circus owner known for the greatest show on earth. Joice Heth was a part of a side-show. She was billed as the 161-year-old nursemaid of George Washington. Barnum says of Heth, “Joice Heth is not a human being. What purported to be a remarkable old woman is simply a curiously constructed automation, made up of whalebone, india-rubber, and numberless springs ingeniously put together, and made to move at the slightest touch, according to the will of the operator” (from P.T. Barnum’s memoirs as quoted in Judd, 2014, p. 42).

The poem continues with buzz words used to confirm scientific racism, including weight and size of the brain/skull, blood that can be tainted with one drop, according to the notion of hypo-descent. There are even references to “flat feet” and a “short neck,” which apparently help to determine race as well. Trethewey’s poem acknowledges the partnership between scientists and religion. For example, Christian racists have justified enslavement and other atrocities through their faith (God/Bible). Science (based on logic/reason/empirical data) and religion have been manipulated to perpetuate notions of racial inferiority. The poem references Canaan “...to make of the work of faith/the work of science, evidence/the word of God: Canaan/be the servant of servants.” (p. 33). This reconfirms the almost preordained status of Blacks, as, for example “hewers of wood.” The poem ends with the words, “thus/to know the truth/of this:[this derelict/carpus, a dark compendium, this/atavistic assemblage—flatter/feet, bowed legs, a shorter neck] so deep of tincture/—see it/—we still know white from not” (30).

The scientist is relieved that he is able to distinguish, through this meticulous dissection, the difference between Black and white. The “white Negro” phenomenon was a popular one, and these “freaks of nature” often ended up in the circus as side-shows.

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The Preface to Kwoya Fagin Maples’ Mend, published in October 2018, ends with this appeal:

Dear reader, here is my wish: that you would consider how this story relates to now. Presently in 2018, black women are three times more likely to die after childbirth than white women, regardless of ability to pay and regardless of prenatal care. Biases toward black bodies still exist within the medical profession that lead to such an imbalance in medical care. Fistula is still pervasive in impoverished countries, and the women who are suffering from it are often ostracized by their families and communities. Maybe, reader...you will see how you are connected to this story. Maybe you will honor what you come to know by sharing it (xi).
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2018 Public Health Ethics Forum: Minority Elders and Healthy Aging Panel: Thriving and Aging with Dignity

**Councilman Chester Antone**
Councilman, Tohono O’odham Nation; and Chairman, Secretary’s Tribal Advisory Committee
Arizona

**Mrs. Mamie H. Clemons, B.S.**
Retired Teacher, Director of Curriculum, and Principal
Pittsburgh, PA

**Ms. Nadinne Cruz**
Advisory Board Member, Professor, Consultant, and Author
Long Beach, CA

**Mr. Elias Segarra, JD**
Retired Attorney
Duluth, GA

The Elders panel provided an opportunity for the audience to hear from a group of elders of color to share the trials, tribulations, successes and challenges that shaped their individual lives. This extraordinary group of elders of color agreed to candidly discuss how their race/ethnicity and sex/gender provided them opportunities (or lack thereof), and how these opportunities (positively and/or negatively) influenced their lives. The Public Health Ethics Forum Planning Committee agreed on a conversation format for the elders’ panel discussions. The theme of the panel discussion was, “Thriving and Aging with Dignity.” The Planning Committee spent considerable time and energy discussing objectives befitting the breadth and depth of the lived experiences of this unique panel of elders. The objectives were:

1) Identify biases that comprise and/or compromise healthy aging.

2) Explore community understanding about the differences between being elderly, and elder, and and/or being an emerging elder.

3) Examine the ethical considerations that drive achieving healthy aging: What should public health do?

4) Assure social justice in the experience of aging.

5) Achieving healthy aging: What should public health do?
The Planning Committee agreed that most of the public health workforce are not elders, so it was important to listen without judging and discuss without debating. The format was for the Moderator to ask each panelist a series of questions and allow time for panelists to respond individually. The Moderator asked each panelist to introduce himself or herself.

**Elias Segarra**

Yes, my name is Elias Segarra.

I was born in Puerto Rico, USA, and I am 88 years old.

And it’s funny -- I have three cancers. They have been treated at Emory, and the main one that’s giving me now, like, more trouble is a bone cancer. And I’m getting chemotherapy for that, but I’m doing okay. I live in Duluth, and I am -- I’m retired. I look at what you were saying -- I mean, every day, I mean, I look at -- I live day by day, and I feel happy. I feel happy. I -- when I’m going to sleep at night, sometimes, I get a little -- and then I think of what I’m going to do the other day, what I’m going to have for breakfast. I have to prepare it myself, because I live alone. But I feel happy. I watch my TV, and my computer.

I mean, I love my computer. Because of my computer, I read papers from all over the world. I read newspapers, and then I -- if I cannot see the letters well, I put them bigger, and I am -- I could say I’m living a happy life.

**Nadinne Cruz**

Yes, my name is Nadinne Irene Cruz. I’m an immigrant from the Philippines. This year, my mother, who is alive, turned 97, and I turned 70. And our newest grandchild was born, and he’s three weeks old. So this is a good year. I don’t like credentials for myself. I think of myself primarily as a person who’s searching for different ways of looking at things that are in front of our faces, like growing old, and being at that stage in life where I think more closely or more seriously with intentionality about how to die well as part of living well. And as part of being healthy. So I’ve worked mostly in higher education over 30 years in what is called public service education, so I’ve taught service learning, civic education, public service, scholarship at various institutions in the United States, and I have also run a consortium of 18 colleges.

So I’ve been connected with education for a long time, but I’m also a very, very deep critic of the very thing that I’m associated with. So my typical way is to be a critic of the conventional way of looking at things. So I will be speaking out about how I feel uncomfortable with how elderly and elder is defined, at least as far as I can -- as far as I hear it around me. Thanks.

**Chester Antone**

My name’s Chester Antone. I’m from Arizona, southwestern Arizona, a member of the Tohono O’odham Nation. Our nation borders on Mexico, and we have been primarily involved with healthcare as a politician, I guess you might say, but I don’t lie. But yeah, I was in denial for quite a long time until CDC and Tuskegee told me I was elder -- elderly, so here I am. So, yeah, we run into a lot of the issues nationally with the Native American population elderly, and we talk about it. We try to figure our ways of -- how to serve, because in our way, and most Indian communities, the elderly are special. They’re honored, but as you’ll see, some of the conversation may turn into a gradual erosion of what we used to be. But I’m here, so I’ll be participating.

**Mamie Watkins-Clemmons**

Okay. Good morning. Good morning. My friends -- Yes, and I say you are my friends, because you’re here. My name -- I’m going to give you a long name. My name is Mamie Viola Henry Watkins-Clemmons...

And it took me a bit over 100 years to get here, to be here with you. Thank you. Thank you very much. I guess you would like to know a little something about my background, which I don’t have long enough to tell you about it, but I was born in Evergreen, Alabama—and when you think you’re in Evergreen, go a little further out to China, Alabama. And I was told by several they don’t know how we got to be there, because it was back in the woods. I was fortunate to be born of two parents that were both schoolteachers, and to be able to go to school to your relatives — it takes a bit. But I’m thankful to be here, to tell you a little something about it — my education, if you call it that, able to walk to school while others rode buses to school, but we were able to be taught of things that would concern you later on in life. Meaning that there’s no stopping place if you really want to be somebody, so to speak. So I’m very grateful this morning to be here to tell you a little about life, education a bit. Being taught by my parents, then being taught by my brother, who moved from the country all the way to Tuskegee, and after Tuskegee, many, many other places — but I’m thankful — grateful to be here now. Sound a bit repetitious, but that means that’s so I’ll be able to let you know, and you may want to ask questions after that. But able to go to school, to walk to school. After being -- finishing 12th grade, and moving to Alabama State Teachers’ College at that time, being able to teach on a provisional certificate, meaning that the community wanted you. I walked two miles to a two-room school, where two teachers taught, and kept warm by a stove that wood was cut to make fire for the children in order to study. Moving from there, being at Alabama State University now, to Tuskegee, and you’ve heard a lot about Tuskegee.

You will be hearing about Tuskegee.

Then, receiving a BS degree from the University of Pittsburgh. Now, I’m able to tell you a little about the school, and the teachers that came from that two-teacher school room. We could point them.

**Dr. Rueben Warren:**

What has most impacted your life?

**Mr. Segarra:**

I’m trying to think. I’ve already done so many things, but I believe my mother had such an important part in my life, mainly making me and my personality as a positive person. I’m an eternal optimist. I was born in -- as I told you, in Puerto Rico, at such a long time ago, and it was so, so different. We were poor, and it was different at that time. I know someone
here asked a lady that she has 101, but I have 88, and it was so different. But that was what most impacted me, was my mother.

**Ms. Cruz:**

What has most impacted me? I’m going to say it straight-up, because it’s part of what I would like to share. There’s a lot of stigma attached to it -- is that when I was three or four years old, somebody came into our house, pointed a gun at my father, and gunned him down and killed him. My mother, during World War II, saw her fiancé shot and killed by an American soldier who thought they were the Japanese enemy, because all Asians look alike. Those killings are part of -- I think of inter-generational racial -- historical racial trauma, and a lot of what I have -- most of my 70 years has been focused on the particularities of my individual family. And it has taken me a very, very long time to see my family’s health in the larger context of large swathes of history and social systems. And so, that’s what I hope to be able to share, is what I have struggled to figure out about my own life in the context of the larger historical drama, to figure out how to be a healthy, thriving older person.

**Mr. Antone:**

What has impacted me the most in education? My mother, who really didn’t know too much made sure that I sat at the table and did my homework every night under the -- there was a kerosene lamp. For her to do that made me pursue education at different times in my life, and eventually make it out of the University of Arizona, and that’s the first in our family. But the other thing that I think had more of an impact on me, as far as how I view life, right now, as being something given to you by the Creator, that you should honor it -- I came to that realization by having to have lived through many dark moments. I’m an alcoholic for maybe over -- been sober now for over 20 years. But that experience has taught me the value of life now, and I just want to be a part of it now, and be happy, and do what I can for the people. The most important thing -- the one most important -- The one most important thing in my life has been the prayer life of my parents, and the idea that was put into my head was that you can -- there’s no height that you cannot reach if you are willing to pay the price all the way. So I’ve been impacted by people, dealing with people, knowing people, and being a part of their lives. That has impacted my life, to want to be a loving person, and be loved by those.

**Dr. Warren:**

This question is a little sensitive one. Give me an example of something that’s been a bias or a prejudice to you -- something or some event, bias or a prejudice to you.

**Mr. Segarra:**

I studied in the University of Miami, Coral Gables long ago. And at that time, I remember there was still segregation, which when I came, was so strange to me. Because we didn’t have that in Puerto Rico, but I felt segregated -- what struck me -- once, it was a -- like a chauffeur of a bus. And I handed him some money, and he made some comments. I don’t even recall it now, but I felt myself -- he made some comments as to -- because he heard my accent, as to derogative, and I probably couldn’t understand part of it. But a friend of mine that was with me -- he was from Cuba, and he heard it. He knew a lot more English than I did at that time, so he answered him. And, I mean, that’s an occasion I can remember when I felt like -- like, prejudiced because of my...

**Ms. Cruz:**

There are so many that I -- throw out a few. So I used to have hair below my waist. I chopped it all off because I could never, it seemed, establish a sense of my authority with the long hair. And so I chopped it off because nobody believed I was actually the teacher in the class. “So where’s the teacher?” Well, I’m the teacher. “Oh, you don’t look like the teacher.” That was one of many. Another would be, like, oh, “why are you so emotional?” Followed with, “why are you so analytical?” And so, either I was overly-analytical, or overly-emotional, and then the last one -- example -- there are just so many, but I’ll just throw out these three -- is -- so I was invited to give a presentation on United States-Philippines relations. And at that time, it was during the dictatorship of Ferdinand Marcos, and I was working on a social justice movement on human rights violations under the dictatorship of Marcos. And then, I included why the United States was implicated in giving military aid to a dictatorship for the containment of communism in Southeast Asia. And the response at the end of my presentation was not curiosity about anything. It was, “Well, why don’t you just go back, then, to the Philippines, if you don’t like it here so much?” So, a few examples.

**Mr. Antone:**

My experience has been that a corporation in our native lives from things outside coming in has been most difficult. And I don’t want to say anything about something that’s true nationally among tribes, but in my particular tribe, it seems that a corporation has kind of led us to become like the federal government. And the same thing that oppressed us, we seem to oppress. We learned it. If you look at our system of government, ours is a three-branch government, but all that bureaucracy is the same. But we still argue with the federal government about their bureaucracy, which we inherited, and that has kind of, like, a negative effect on how we feel about Indian for our elders. Because that’s what I said earlier, that we’re seeming to lose that which we had for our elders. We have an adult protection ordinance. Why? To illustrate that how far we’ve come to get to that point where we actually need an ordinance. And long ago, we didn’t -- we didn’t need an ordinance because it was just natural. You took care of your elders like you go on a hunt and you were able to get lucky to bag a deer your first time. Take over to the elders. You don’t get nothing out of it. Then after that, you always have to give some to the elders. So it changed from that due to the time period. And I guess that’s how I wanted to answer that question.

**Ms. Mamie Clemons:**

The great part of my life has been to be happy. To be happy and to make those around me happy. And whatever I could do to see happiness even in the face of a child, if the child...
Elder’s Reflections

looked worried at school, I’d like to make him happy. And I’ve always thought of this. If you are happy, can’t anyone make you mad? If you can make me angry, then you’re smarter than I am because I believe that no way should we walk around sad even though things may not go according to the way even others around you they may go of what you have seen or what you have learned. But you become that type of person that you can climb as high as the good Lord would let you go. That’s what I think.

Dr. Warren:

I asked Aunt Mamie to give me an example of something bad or some prejudice, she would not do it. She translated happy no matter what I say. I said it about five times. It all came out happy. It all came on happy.

The last question before we open it up for you to ask them questions is what advice would you give our audience? What advice would you give our audience?

Mr. Segarra:

I would give you advice that to live this life, to live is just a miracle. And enjoy your life and do the thing that makes you happiest as much as you can. And enjoy doing that, doing what you really feel passionate about. For a long time, I tried to do what others thought I should do and it didn’t work for me. So I mean, that’s the advice. I mean, follow your -- follow your vocation, whatever you feel like. Like doing that makes you happy.

Ms. Cruz:

For me, I guess the advice is what I’d like to share as an advice. What I’ve been trying to do, which is to develop some metaphors, or pictures or visuals or vision, of what it means to become elder and in the latter stages of the life cycle. And I don’t know what it might be for you. It has helped me through a lifetime of chronic depression which I think is a much stigmatized illness. In my community of Filipino-Americans, they will cite obesity, hypertension, and diabetes and won’t say anything about the high suicide rates of females, of Filipina-Americans. So some of my visuals are two and I’d like to share that as an advice. One metaphor I think of for myself to make me feel happy as a useful person is as an old-growth tree. When you think about in the Redwood Forest, the old-growth tree with all the roots interacting underneath the soil, all we need to do as an old-growth tree is to stand tall and keep standing, because then the new growth and the seedlings and all that they are can come. And we develop a big forest. And to a great extent, it sounds like a passive thing but it’s a very active thing and it is centuries old. And so there is an inherent integral value to being an old-growth tree. And if I’m a kind of human -- the metaphor of an old-growth tree, it is important for me to stay standing. And so that gives me incentive to overcome a lifetime illness of depression. The other visual that I use and I share it as an advice is the metaphor that transition. So I transition from firefighting which is like active, heroic, risk-taking, at the barricades, physically fit, able to do lots of things, and feel useful that way. But I’m no longer firefighting in the sense that I don’t have that part of my life anymore. But I can be weaving. And weaving is integral to the value of all communities. Weaving is invisible. It’s not heroic, not seen as heroic. It’s seen as feminine. It’s every day, but all communities cannot survive without the constant weaving of

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the fabric of humanity and community and without the constant mending of that fabric. And I can do that even when I can no longer be physically fit, as long as I can interact with people, I can still have value as a weaver of society.

Mr. Antone:

My advice is to go wherever one would go when it all ends—is to make your life, your characteristics, your and traditions, you know, you leave that into memories of people that you’ve known in the hopes that you really live your life well—it would have some value. Your life had a value. And hopefully, it will pass on to the people that remember you the way they do because you have these good things about you. I think that will be the advice I would give to live your life like that, to leave a good memory.

Ms. Clemons:

I learned early in life that prayer moves mountains. And I wanted to know, “Well, what is real prayer?” So I brought to my knowledge from the Holy Spirit that I could pray in seven W’s and just about cover what God would have me be and do. The seven W’s of prayer, I will give them to you. You might want to write them down. Number one, I pray that God’s Will be done. That’s W number one. That I really don’t know everything about me but there is some higher power somewhere that knows about me. What I need, what I can do at all. So W number one, I pray God’s Will be done. Number two, I pray that it be done in His Way. You know, when I started out to school, I didn’t know exactly what I wanted to be or even what I could be. But I remember that a higher power knows all about it. So I want His Will to be done in His Way. We may not learn all that we want to know quickly. But we might have to bypass some things in order to get to the best things. I pray that His Will be done in His Way, the way He wants to do it. I may not know. I may not understand. So I pray that His Will, His Way and then His Word. We studied the Word. Everyone knows something about the word Bible. So if it’s according to His Word, I know it’s all right. His Will, His Way, His Word and then all I have to do is watch. Watch and pray. And while I’m watching, while I’m watching, I have to wait. When I was teaching all of provisional and there were two ways school, I did not know that I could be 100 and one and be here and give you some knowledge of what I have gone through. So His Way and then I have to learn to Wait. Wait till the proper time. I may not be able to do what I want to do but there is a time element. His Way, His Will, His Word, and then Wait. And while you’re waiting, don’t forget while you are waiting, there must be some Work done. There’s something you have to do. There’s something you have to know. So that’s His Will, His Way, His Word, then Wait, Watch.

Watch and then wait then continue to Work, because the Word says, “I must work the works of Him that sent me while it is day. Night cometh, no man can work.” So we don’t just sit and wait like we’re waiting on the street car or a bus. But there must be some work done. So then we work the works of Him that sent us while it’s day. Night cometh, no man can work. Moreover, after we have let His Will be done, in His Way, through His Word, while we just Watch and pray then we wait. We Wait on the Lord. But we don’t Wait empty handed. We wait while we are working. We continue to work. You know, I thought about that work part and I learned to work because I -- when I would see this elderly gentleman plowing and you may not even know what the word plow [laughter]. But he was plowing a mule in order to raise vegetables.
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I would have him sit down under the shade tree and wait while I go around a row or two and do what he did with the plow. And I was only an upper teenager at that time but I wanted to help. And while I was waiting and I saw an elderly person drawing water out of a well, turning a crank to get water. I stopped to help them draw water. And then with the drawing and the waving, I had to wait until the cows that we milked. I had to wait until they grazed in the wood and come. And I had to draw water to give the animals water. And I thought to myself, “It looked like they never would stop drinking water.” They were thirsty. So with that, and I repeat those seven times, the seven W’s --

God's Will, His Way, do His Word while we Watch and pray. Then we Wait on the Lord and while we’re waiting, we Work. And after we have done that, you can feel like worshipping. You feel like worshipping because you’ve done something that helped with it. So I am very thankful to have been able to see how to work and make vegetables grow so that we could eat properly and your health could be good. You would be strong and mighty.

Following the responses from the panelists, there was an hour question an answer period. The audience shared their stories about their engagements with elders ranging from professional to personal family stories. The entire panel discussion is available on the National Bioethics Center website at: tuskegeebioethic.org.
The Journal of Healthcare, Science and the Humanities

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.

1. Research papers, theoretical investigations.
2. Scholarly critiques and commentaries on various topics.
3. Formal case studies and program/project reports.
4. Reaction papers and editorials.
5. Book, film, media, law, education or other reviews.
6. Other academic or professional articles related to the JHSH interdisciplinary mission.
7. Creative work, including poetry and short fiction relevant to the JHSH mission.
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 must 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 Upper and Lowercase Heading [Bold]
Level 2: **Helvetica** 11pt. Centered, Italicized, Upper and Lowercase Heading
Level 3: **Helvetica** 11pt Flush Left, Italicized, Uppercase and Lowercase Heading
Level 4: **Helvetica** 11pt 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.
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.
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 retraction, 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 dhodge@tuskegee.edu.

If needed, call the Tuskegee University National Center for Bioethics in Research and Health Care at (334) 724-4554.

The 2019 Public Health Ethics Intensive at Tuskegee University will be held April 9th through 12th.