The Journal of Healthcare, Science and the Humanities

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Preface

Contributing Authors

Vivian W. Pinn, MD, was the founding and first-time Director of the Office of Research on Women’s Health at the National Institutes of Health (NIH), and was Associate Director for Research on Women’s Health (NIH), positions she held from 1991 until her retirement in 2011. During her tenure she established, and co-chaired with the NIH director, the NIH Committee on Women in Biomedical Careers. Since retirement, she has been a Senior Scientist Emerita at NIH Forgarty International Center. She came to NIH from Howard University College of Medicine where she chaired the Department of Pathology. Lectures in women’s and/or health disparities have been named for her at NIH, NIMA, Women’s Health Congress, and University of Virginia School of Medicine (UVA). In 2016, UVA, School of Medicine announced the Pinn Scholars Program and in 2017 UVA renamed a medical education and research building as Pinn Hall.

Judith Monroe, MD, joined the CDC Foundation as president and CEO in 2016. Over her career, Monroe’s professional focus has centered on the intersection of primary care and public health. Prior to joining the CDC Foundation, Monroe worked for six years with the U.S. Centers for Disease Control and Prevention (CDC), serving as director of the Office for State, Tribal, Local and Territorial Support. Before CDC, Monroe served as state health commissioner for Indiana. From 2005—2010, she was a practicing physician, a clinician educator and served in a dual administrator role as director of a residency program and primary care center.

Kathleen S. Yep, PhD, is Associate Dean of Faculty in Academic Affairs and a Professor of Asian American Studies at Pitzer College (of the Claremont Colleges). Professor Yep received her doctorate in Ethnic Studies from the University of California, Berkeley. In addition to numerous peer-reviewed journal articles, she authored Outside the Paint: When Basketball Ruled at the Chinese Playground and co-authored Dragon’s Child: The Story of Angel Island. Using oral historiography and participation action research methods, she researches community-driven palliative care practices with Asian immigrant and refugee elders and Pacific Islander communities in Southern California. Her website is: kathyyep.wordpress.com.

Rosetta E. Ross, PhD, MDiv, MA is Professor of Religion at Spelman College and restructured the Christian-centric major into a diverse religious studies program. She is a founding director of The Daughters of the African Atlantic, and coordinates the international Consultation of African and African Diasporan Women in Religion and Theology. She authored Witnessing and Testifying: Black Women, Religion, and Civil Rights, co-edited Unraveling and Reweaving: Reimagining Sacred Canon in Africana Womanhood, and essays exploring black women’s activism, womanist ethics, and religions in continental and diasporan African women’s well-being. She and her partner the Rev. Ronald Bonner live in Atlanta.
Shauntā S. Wright, MPH is a Health Scientist in the Program Development and Quality Improvement Branch at CDC. Specializing in program evaluation, Ms. Wright oversees and conducts several CDC evaluations aimed to address STD disparities among youth and MSM populations. Ms. Wright has a Master’s degree in Public Health and Bachelor’s Degree in Biology from Georgia State University. She is a member of the American Evaluation Association and the Georgia State University School of Public Health Alumni Board. Ms. Wright is a past recipient of the Atlanta Business Chronicle 40 under 40 Award. She has also received CDC’s NCHHSTP Honor Award.

Drue H. Barrett, Ph.D. and CAPT, U.S., Public Health Service is the Head of the Public Health Ethics Unit and the Chair of the CDC Public Health Ethics Committee (PHEC). The Public Health Ethics Unit has been working to strengthen infrastructure in public health ethics at CDC by sponsoring training and offering a public health ethics consultation service. Dr. Barrett received her Ph.D. in clinical psychology in 1990 from Georgia State University. She also completed two years postdoctoral training in epidemiology and public health through CDC’s Epidemic Intelligence Service in the Cardiovascular Health Studies Branch of the National Center for Chronic Disease Prevention and Health Promotion.

Kathy Kinlaw is Associate Director of the Emory University Center for Ethics and Director of the Center’s Program in Health, Science, and Ethics. She is an Assistant Professor of Pediatrics, Emory School of Medicine; and Director of the Healthcare Ethics Consortium. Kathy completed her MDiv in religious ethics and bioethics from the Candler School of Theology at Emory; interned at the National Institute of Health’s Office of Bioethics, and completed a fellowship in Perinatal Ethics through the Emory University School of Medicine. Her publications and scholarly interests are primarily in the areas of: ethics committees and ethics consultation, palliative and end of life care, faith and ethics, ethics and medical education, operationalizing ethics in healthcare institutions, pediatric ethics, and public health ethics.

Ann Gallagher, PhD, is Professor of Ethics and Care at the International Care Ethics Observatory, University of Surrey. She trained as a general nurse in Belfast during the Northern Irish ‘Troubles’ and then as a psychiatric nurse in England. Ann’s undergraduate and post-graduate studies have been in the area of applied ethics. Her PhD study, supervised by Professor Ruth Chadwick, was on the theme of ‘virtue ethics and professional education’. Recent areas of research and scholarship have included: ethics education, dignity in residential care, and compassion in the National Health Service, professionalism in paramedic practice, professional regulation and ‘slow ethics’. Ann is Editor of the international journal Nursing Ethics and a member of the Nuffield Council on Bioethics. She was a Fulbright Scholar-in-Residence at the National Bioethics Center for Research and Healthcare at Tuskegee University in 2017.
David Augustin Hodge, Sr., Ph.D., D.Min., is Associate Director of Education at the National Center for Bioethics in Research and Healthcare at Tuskegee University. From undergraduate to graduate school David’s primary work was in Christian theology, Christian ethics, and Christian education. He taught in this genre for over two decades, primarily in South Florida. Additionally, for several years he was a primary writer for the adult Sunday School lessons and one of the Townsend Press, commentary authors for the National Baptist Convention, U.S.A., Sunday School Publishing Board. He published three books, primarily for women, *God of Our Silent Tears: Women of the Bible Healing Women of Today*, *God of Our Silent Tears: A Five Week Journey*, and *In the Midst of My Tears: The Bible Speaks to Abandonment, Betrayal, Rejection and Loss*. Developing a strong desire to pursue more complex questions in ethics and philosophical theology, David pursued a second doctorate degree, earning a (secular) Ph.D in philosophy supervised by virtue and care ethicist Michael Slote. His dissertation topic: *Jesus the Virtue Ethicist: A Metaethical Anticipation of Moral Sentimentalism, Empathy and Care*. 
Preface

The National Center for Bioethics in Research and Health Care at Tuskegee University and CDC’s Office of Minority Health and Health Equity

2017 Public Health Ethics Forum

Optimal Health for Her Whole Life

May 19, 2017
8:00 a.m.—3:30 p.m.
Centers for Disease Control and Prevention
Tom Harkin Global Communications Center, Auditorium B
The 2017 Public Health Ethics Forum, “Optimal Health for Her Whole Life,” focuses on a range of health issues and actions to improve the health of women and girls in the United States. The National Center for Bioethics in Research and Health Care at Tuskegee University and the Office of Minority Health and Health Equity at the Centers for Disease Control and Prevention (CDC) host this annual event. This year’s forum explores ways to promote and protect women’s health across the lifespan by emphasizing public health ethics in the practice of public health.

In order to ensure that public health practice is ethical, it should be guided by ethical theory and an ethical analysis process. “Public health ethics deals primarily with the moral foundations and justifications for public health, the various ethical challenges raised by limited resources for promoting health, and real or perceived tensions between collective benefits and individual liberty (Stanford Encyclopedia of Philosophy). CDC defines public health ethics as “a systematic process to clarify, prioritize, and justify possible courses of public health action based on ethical principles, values and beliefs of stakeholders, and scientific and other information.”

A public health ethics lens ensures a uniquely expanded focus on population health opportunities and challenges. The 2017 forum participants will discuss the interests and health of women and girls, the extent to which resources that support their health are distributed equitably, and how best to perform work that includes both individual rights and group interests in public health interventions. For example, how can we balance the values and beliefs of stakeholders (e.g., women, families, healthcare providers, policymakers, employers) with good public health practice?

Forum participants will tackle a variety of health issues, including chronic diseases (e.g., heart disease and stroke, diabetes, breast and cervical cancer, and obesity), health issues like preventing the spread of HIV and other sexually transmitted infections, reducing violence against women and girls, and improving social and economic factors that affect women’s health (e.g., education and income).

**Objectives of the 2017 Public Health Ethics Forum**

At the end of the forum, participants will be able to:

1. Identify public health challenges and opportunities to improve the health of women and girls,
2. Describe protective factors that can be integrated into public health practice, research, and policies,
3. Articulate women’s health issues within a public health ethics framework,
4. Build multi-sectoral collaborations to enhance women's health, and
5. Develop trans-disciplinary working groups to advance women’s health.

Participants will achieve the objectives through keynote presentations and discussions by national leaders in women’s health and public health ethics, and through small group sessions facilitated by subject matter experts from Tuskegee University and CDC. In addition, graduate students will present posters on their research in women’s health.
## Agenda

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<th>SPEAKERS</th>
<th>COMMENTS/ FOLLOW-UP</th>
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<tr>
<td>7:30am-2:00pm</td>
<td>Registration</td>
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<tr>
<td>8:15am - 8:45am</td>
<td>Welcome</td>
<td>Dr. Leandris Liburd, Director, OMHHE &lt;br&gt;Dr. Pattie Tucker, Director, OWH &lt;br&gt;Dr. Anne Schuchat, Acting Director, CDC, and Acting Administrator, ATSDR &lt;br&gt;Dr. Rueben Warren, Director, National Center for Bioethics in Research and Health Care at Tuskegee University</td>
<td>Mistress of Ceremony: Ms. Shonia Zollicoffer &lt;br&gt;Dr. Warren to introduce Dr. Pinn</td>
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<tr>
<td>8:45am - 9:30am</td>
<td>Opening Plenary</td>
<td>Dr. Vivian Pinn, Director, Office of Research on Women’s Health, NIH (1991-2011)</td>
<td>Historical perspective on women’s health research</td>
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<td>9:45am - 11:00am</td>
<td>Discussion Session (Plenary)</td>
<td>Dr. Judith Monroe, CDC Foundation &lt;br&gt;Dr. Kathleen Yep, Claremont University (ethicist) &lt;br&gt;Dr. Rosetta Ross, Spelman College (religious studies) &lt;br&gt;Dr. M. Reyes (TBI)</td>
<td>Moderator: Dázon Dixon Diallo (Sister Love)</td>
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<td>11:00am-12:00pm</td>
<td>Poster Session</td>
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<td>Dr. Bouye &amp; Crystal James, Esq.</td>
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<td>11:30am-12:30pm</td>
<td>LUNCH</td>
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<td>Food allowed in Aud. B &amp; Rms 245-248</td>
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<td>12:30pm – 1:30pm</td>
<td>Concurrent Break-out Sessions</td>
<td>A. Identify and address barriers to reduce diabetes, obesity, heart disease, stroke, and cancer prevalence &lt;br&gt;Facilitators: Dr. Lisa M. Lee &amp; Nilka Rios Burrows (Nilka), NCCDPHP/DDT &lt;br&gt;Session Recorder: Dr. M. Duckworth, OMHHE</td>
<td>CDC SMES &lt;br&gt;Dr. Gloria Beckles, NCCDPHP/DDT &lt;br&gt;Dr. Wayne Giles, NCCDPHP/DHSDP &lt;br&gt;Dr. Jacqueline Miller, NCCDPHP/DCPC</td>
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<td>B. Improve individual and sexual health and preventive care practices</td>
<td>CDC SMES &lt;br&gt;Scott Campbell, NCBDDO/Dr. Sherree Boulet, NCCDPHP/DRH</td>
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<td>Facilitators: Ms. Kathy Kinlaw &amp; Ms. Shautna S. Wright, NCHHSTP/DSTDTP</td>
<td>Session Recorder:</td>
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<td>C. Decrease intimate partner violence and human trafficking against women and girls</td>
<td>Community Expert &lt;br&gt;Sharon J Brown, Ambassador</td>
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<td>Facilitators: Dr. Rochelle Rollins (TBI), HHS/OASH/ODPH &amp; Ms. Melissa Merrick, NCIPC/DVP</td>
<td>CDC SMES</td>
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Preface
### Agenda

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<td>12:30pm – 1:30pm</td>
<td>Break-out Sessions</td>
<td>CDC SMEs</td>
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<td>1:30pm – 1:45pm</td>
<td>Break</td>
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<td>1:45pm – 2:15pm</td>
<td>Break-out Session Summary</td>
<td>Sessions A–E Facilitators</td>
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<td>2:15pm – 2:30pm</td>
<td>Poster Awards</td>
<td>Dr. Karen Bouye, Health Scientist, OMHHE</td>
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<tr>
<td>2:30pm – 3:15pm</td>
<td>Closing Plenary</td>
<td>Dr. Claire E. Sterk, President, Emory University</td>
<td>Dr. Liburd to introduce Dr. Sterk</td>
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<tr>
<td>3:15pm – 3:30pm</td>
<td>Adjourn</td>
<td>Drs. Warren &amp; Liburd</td>
<td>Student and speaker photo</td>
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FROM THE EDITOR’S DESK
Preface

Message from the Editor

Professor and Director of the National Center for Bioethics
in Research and Health Care at Tuskegee University
Telephone: (334) 724-4554
Email: rwarren@tuskegee.edu

This edition of the Journal of Healthcare, Science and the Humanities includes selected articles from the May 2017 Public Health Ethics Symposium entitled, “Optimal Health for Her Whole Life.” The symposium was held May 19, 2017 on the main campus of the Centers for Disease Control and Prevention (CDC) in Atlanta, GA. The symposium was intentionally scheduled in May, Women’s Health Month, and focused on the health of women and girls. In April 2015, the National Center for Bioethics in Research and Health Care (National Bioethics Center) co-hosted the first Public Health Ethics Symposium, which was held on the main campus of CDC. The co-sponsors of the symposium in 2015 were the National Bioethics Center, Morehouse School of Medicine and CDC. This first symposium was scheduled during 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.” The 2015 symposium was held in April, which is National Minority Health Month, and focused on the health of African Americans. Selected articles from that symposium 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 Public Health Ethics Symposium was held on the main campus of CDC and focused on Hispanic/Latino Health. The attendees were from across the U.S. and also included participants from the Dominican Republic. Selected articles were published in English and Spanish in Volume VI, No. 2, Fall 2016.

As previously indicated, this edition of the JHSH includes selected articles from the 2017 Public Health Ethics Symposium and highlights salient articles on the health of women and girls. The participants, mostly women, represent a cross section of people who shared their expertise and experiences, their thoughts and advice and their recommendations to improve the health of women and girls across their life span. As Editor, I usually comment on the articles included in each edition. However, I asked Ann Gallagher, PhD to provide a Commentary focused on the manuscripts included in this edition. Dr. Gallagher is Professor of Ethics and Care at the International Care Ethics Observatory, University of Surrey, United Kingdom. This Fall Dr. Gallagher spent several months as a Fulbright Scholar-in-Residence, at the National Bioethics Center. During her time at Tuskegee, she was able to fully engage in the various activities at the University, in the City of Tuskegee and in Macon County.
The Journal of Healthcare, Science and the Humanities has a new Senior Associate Editor, David Augustin Hodge, Sr., M.Ed., M.T.S., D.Min., PhD, and a new Assistant Editor, A. Delores Alexander PhD, MS. Dr. Hodge is a native of St. Thomas, U.S. Virgin Islands. He earned his Bachelor of Arts degree in Bible, Theology and English from American Baptist College in Nashville, Tennessee; his Master of Arts in Education degree from Oral Roberts University in Tulsa, Oklahoma; his Master of Theological Studies degree from Candler School of Theology, Emory University, Atlanta, Georgia; his Doctor of Ministry degree from Columbia Theological Seminary, Atlanta, Georgia; and his Ph.D. in Philosophy degree from the University of Miami. Dr. Hodge now serves as Associate Director of Education at the National Center for Bioethics in Research and Health Care. Dr. Alexander is originally from Tuskegee, Alabama. She earned a BS in Biology from Alabama State University, MS in Environmental Science from Tuskegee University, PhD degree from Meharry Medical College. She was a post-doctoral fellow at the University of North Carolina at Chapel Hill. Dr. Alexander is an Associate Professor and the Director of the Integrative Bioscience PhD Program at Tuskegee University. She is also on the faculty in three Departments: Agricultural and Environmental Sciences, Pathology, and Biology. She has a large undergraduate research lab. Please join me in welcoming Drs. Hodge and Alexander to leadership roles with the Journal of Healthcare, Science and the Humanities.

Lastly, the 2018 Annual Commemoration Events is scheduled April 9-13, 2018 on the historic campus of Tuskegee University. The forum acknowledges and honours William Jefferson Clinton’s 1997 Presidential Apology for the U.S. Public Health Service Syphilis Study at Tuskegee. The 2018 theme for the Commemoration Events is, “Ethics Across Generations.” The Commemoration Events includes a one day healing session for the descendant family members of the men who were in the U.S. Public Health Service Syphilis Study at Tuskegee, the Public Health Ethics Intensive Course, and the Annual Apology Luncheon and Banquet honouring the men who were in the Syphilis Study and their families. While the men are no longer physically with us, we honour the legacy through their families.
The healing session has been conducted for 5 years. The one day session is for descendant family members only and is conducted by Drs. Edward and Anne Wimberly. Edward Wimberly has an earned PhD in Pastoral Care and Counselling and Anne Wimberly has an earned PhD in Christian Education. The session have focused on allowing the descendant family members to share their story of how the U.S. Public Health Service Syphilis Study at Tuskegee impacted, and continues to impact, their lives. The Wimberlys have provided an extraordinary service which has aided the “individual and collective healing process.” This Public Health Ethics Intensive hosts a cadre of invited keynote speakers to address issues across the life span. Small group discussions will be held after plenary session. This year’s attendees will visit, Shiloh Baptist Church in Notasulga, Alabama, actual site, where the men in the Syphilis Study were picked up. The attendees also visit the cemetery where some of the men in the Syphilis Study are buried. A visit to the Tuskegee History Museum will host Attorney Fred Gray, Sr., the lawyer representing the men who were in the Syphilis Study. The attendees will have an opportunity to discuss the Syphilis Study and other civil right cases he has tried throughout the State of Alabama. Finally, a tour will be conducted of Mouton Field, the airfield where the Tuskegee Airmen worked on and flew airplanes during World War II. Please go to https://tuskegeebioethics.org/ or www.tuskegee.edu to find out more and to register.

Thank you, Rueben C. Warren
Lifespan Issues of Health for Girls and Women in the 21st Century: A Personal Perspective

Vivian W. Pinn, MD
Founding Director, (Retired), NIH Office of Research on Women’s Health
Washington, D.C.
Email: vwpinn@gmail.com

Author Note
This scholarly reflection is a modification of my presentation delivered at the 2017 Public Health Forum: Optimal Health for Her Whole Life at the National Center for Bioethics in Research and Health Care, Tuskegee University and the Office of Minority Health and Health Equity, CDC on May 19, 2017 in Atlanta, Georgia. The views expressed are mine and are not intended to represent the views of any organizations or agencies mentioned herein with which I was formerly or am currently affiliated.

Introduction
In the context of the current socio-political environment of the 21st century, how we discuss healthcare in the United States and against the backdrop of this conference’s theme, I reflect upon health issues of girls and women throughout their lifespan, with the theme of ‘Optimal Health for Her Whole Life.’ How the comprehensive health of women and girls is defined, studied and practiced has changed tremendously over the past 30 years. Grassroots led advocacy combined with science based legislative policies, an understanding of basic biological contributions to human health, attention to the approach to standards for health care practice, and human rights considerations have assisted in promoting change in public law for this country, a achieving a magnitude of difference in the design of biomedical research, and resulting in changes in expectations of health care to include a sex and gender lens.

A Historical Review
My perspectives are derived from entering the field of medicine in the 1960’s, when the traditional interpretation of women’s health centered on the reproductive system during women’s reproductive years. Neither conditions that affected women across the lifespan nor conditions that affected both women and men received significant recognition as an integral part of women’s health. In my career trajectory from a medical student to my former position as the first Director of the Office of Research on Women’s Health (ORWH) at the National Institutes of Health (NIH), I have observed and helped lead some of the essential changes in biomedical research to give attention to the importance of sex and gender in human health and the expanded concepts of women’s health. The concerns regarding whether standards of medical practice were being based on information that came from the study of women, beyond reproductive health, or were based on studies using men exclusively, with health issues faced by both women and men, precipitated and helped drive the biomedical research community toward much needed change.
The ORWH was established in 1990 to respond to concerns of the women’s health advocacy community that women were not systematically included in clinical trials of conditions that affect both women and men, such as heart disease about which most research was conducted in men in spite of this condition being the leading cause of death of women. After the ORWH was launched, the NIH put forth a policy that recommended the inclusion of women and minorities in clinical research. In 1993 what had been public policy became a matter of public law as part of the NIH Revitalization Act, strengthening the ability of NIH to enforce inclusion requirements. NIH implemented the new inclusion policy, now based in law, that women and minorities must be included in clinical research studies if the condition under investigation also affected them. This policy not only addressed gaps in scientific knowledge but also the ethically driven purpose to ensure that the results of research would be applicable to all segments of our population.

When we began to implement the mission of the ORWH in 1991 to increase research on women’s health and to ensure the inclusion of women in clinical research, one of the first and most obvious biological principles was emphasized, i.e., that males and females (men and women) are not the same, which the new inclusion requirements would help to document when differences in responses were determined through analyses of results by sex and gender. We also put forward the consideration that the entire lifespan of women, from childhood into the reproductive years, the post-menopausal years, and the elderly and frail elderly years required the attention of the biomedical research enterprise. Just as there may be sex and gender differences, not all women are the same, so health disparities should be better defined by studying differences or inequalities of health status, health outcomes, and responses to interventions among different populations of women (and men). The inclusion policy requiring minorities would provide valuable data that could be used to delineate approaches to health inequities.

The previous practices of exclusion of some populations from research studies, especially those considered vulnerable such as women, minorities, or prisoners, in an effort intended to protect them, had now shifted to policies of inclusion, particularly of women and minorities, so that the results of research could be applied to the diversity of the affected populations based on scientifically derived information. With the required broadened inclusivity, the principles of justice and equity must continue to be recognized both in providing access to participation for previously understudied population groups and in protecting them from unnecessary risks of unethical research design and in the health care they receive. These same principles of justice and equity must also recognize the multiplicity of factors that contribute to, or prevent, good health and wellness in girls and women across their life continuum.

Discussions of health disparities and inequalities usually refer to differences between racial/ethnic groups and/or different socioeconomic groups, but also may refer to differences in health status between men and women. Disparities commonly include, but are not limited to, shorter life expectancy, higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke, and sexually transmitted diseases. Disparities are believed to be the result of interactions among biological factors, the environment, cultural factors, discrimination, socioeconomic factors and health behaviors. Inequalities in income and education also appear to underlie many health disparities. That disparities exist between populations of women underscores the awareness that gender equity is a social determinant of health. The awareness that these factors generated unique variations in women’s health status and health outcomes created the challenges of addressing those differences in order to learn what they were and what further research was needed, driven by quality fact seeking science.
Ultimately, gaining that information from research, then having that information incorporated into health professional education, healthcare delivery, as well as into public policy could result in changes in standards of healthcare delivery. Additionally, this new information could be utilized to inform women, men, and their families to be enabled through lifestyle changes to preserve their own health.

Building on expanding knowledge, improved public health policies, the availability of health care, and being able to obtain state of the art health care must occur with knowledge about prevention, personal behavioral modifications, and reasonable expectations of what health care should provide. In the current sociopolitical environment, we must clearly identify the distinctions between having access to this state of the art health care and being able to take advantage of that access. This trajectory shift in approaching health care policies and practices emphasizes the continued need for sociopolitical awareness and actions to solidify the improvement of health across the lifespan for girls and women.

Women’s and Girls’ Health – Lifespan Continuum

Women’s health was one of the first areas to emphasize that genetic and biological factors alone are not the only bases for health, but that also behavioral and social factors, social and family roles, ethnicity, race and culture, how women relate to their bodies and gender identification, environmental exposures, occupational factors, effects of poverty, and access to medical care services (i.e. insurance, community resources, public health policies) are among other contributing factors to health status. In these foci it is important to recognize the interrelated continuum of the stages within the life span. Twenty first century women’s health and health care is addressing contributing factors from preconception (maternal health and intrauterine environment) to the frail elderly, conveying a comprehensive continuum concept of ‘life span’ or ‘life course.’ The Barker hypothesis is a theory that links disturbed intrauterine growth to the later development of cardiovascular disease. The original hypothesis was based on epidemiological findings that low-birth-weight offspring, whose mothers were severely malnourished during the third trimester, had increased risk as adults for cardiovascular disease. A more general extension of the hypothesis – to include other environmental stresses in utero—has also gained scientific currency. In this model, maternal stress triggers a chain of events, leading from increased fetal exposure to catecholamines and altered fetal neuroendocrine activity to changes in the epigenetic expression of key genes. Changes in epigenetic programming provide the developmental link between prenatal risk of exposure and later behavioral outcomes: activity rhythm dysregulation in infancy; poor inhibitory control and emotion regulation in childhood; and behavioral phenotypes that confer vulnerability to substance use in adolescence. Given these variables, supporting maternal healthcare expresses a concern for the health of both men and women in their later years.

A slight shift occurs from the Barker Theory, when observing the morbidity rates among adolescents and young adults as much of the morbidity stems from behaviors rather than intrinsic disease. Substance abuse, binge drinking, cigarette use and unhealthy dietary habits are among some of these behavioral choices, which we now know can affect health in the postmenopausal or elderly years. In the adolescent age group, seven out of ten deaths are related to unintentional deaths like motor vehicle accidents, homicide, and suicide. Early puberty transition and how it influences risk-taking behaviors, sexually transmitted diseases,
exposure to intimate partner violence, obesity, eating disorders, gender identity, roles, and formation are all areas that need attention within the lifespan continuum of healthcare for girls and women. Medical researchers and health care practitioners should be asking "How good are we at delivering healthcare? Are teenagers going to see the pediatrician? Are they seeing a gynecologist? Do they go to the family practitioner?" Delivery of health care services to adolescents and young adults is and must remain a priority. Current delivery models have substantial gaps in terms of prevention, screening, referral, and early intervention with behaviors. These gaps often place these populations at increased risk for current and future negative outcomes.

The reproductive aspect of the life continuum of health care for girls and women generally approaches reproduction as a part of middle years’ concerns. It is aptly noted that reproductive health, at an earlier period in medical research and health care, constituted almost the entirety of women’s health. Nevertheless, there remains much more we need to know about the reproductive system including fertility issues, fibroids, endometriosis, healthy pregnancies, full term babies, etc. There are a myriad of diseases and health issues associated with this part of the lifespan continuum, to include breast and cervical cancers, cardiovascular disease, intimate partner violence, and obesity. Drug overdose is also a prominent health concern in today’s society. While fatal overdoses are more common among males than females in this age group, women and families are affected in this increasing public health crisis spreading across the United States. And, current research is defining that approaches to addiction, both alcohol and substance abuse, differ for women and men.

The health of women in the post-reproductive, post-menopausal years had not been given much attention in the past. But as women are living longer and are having active and productive lives into later years, post-menopausal health has become an area of research and health interest. The benefits of research on behavioral and lifestyle choices in the early years have improved the status of health of post-menopausal and older women. But the areas of most concern for women approaching menopause were, and continue to be, the menopause transition and questions related to post-menopausal hormone therapy (MHT). The Women’s Health Initiative (WHI), a landmark 15 year study begun in the early 1990’s, was designed to study the major causes of death, disability and impaired quality of life in post-menopausal women, including cardiovascular disease, osteoporotic fractures, and breast and colon cancer. The WHI provided much needed information for women and their physicians to make decisions about MHT use. The perhaps most important yet controversial component of the WHI was a randomized estrogen-plus-progestin clinical trial for women with a uterus which was stopped prematurely in 2002 because the study demonstrated that the risks from use of hormones outweighed the benefits. The combination therapy increased the risk for heart attack, stroke and blood clots but did reduce the risk for hip and other fractures and for colorectal cancer. These results resulted in changes in the clinical approach of using combined MHT for the prevention of cardiovascular disease and other conditions for which it had been previously considered as routine therapy. The U.S. Preventive Services Task Force, in an announcement on its website May 16, 2017, stated: “Based on its review of the evidence, the Task Force recommends against the use of combined estrogen and progestin for the prevention of chronic conditions in postmenopausal women... The Task Force also recommends against the use of estrogen for the prevention of chronic conditions in postmenopausal women who have had their uterus removed.”
These aspects of the menopausal transition often segue into conditions more frequently associated with the elderly and frail elderly years. During these advanced years emphasis is on promotion of biological, psychological, and social wellness in elderly women, recognizing that vitality in old age has important antecedent predictors that operate throughout the lifespan. Cardiovascular disease, osteoporosis, cancer (breast, colon, lung, etc.), dementia, arthritis and other musculoskeletal conditions, depression, urinary incontinence, and the effects of caregiving are among the specific health concerns. In summary, when women get older they are more apt to have complex chronic diseases -- an interaction of chronic diseases -- that can be a major issue for healthcare.

**Conclusion – Moving Forward**

The lifespan continuum health issues and health care concerns, from in utero to the frail elderly years, identify the need to create interventions to counter health disparities among women, women of color in particular, from midlife forward. Medical research and health care practitioners should have among their primary aims the promotion of longer lives, preservation of mental acuity, the prevention of functional physical decline, and the improvement of life quality. Achieving these aims is especially important as women live longer and are a part of what has been referred to as the ‘sandwich generation’ – those who are midlife and older taking care of aging parents, as well as the young, sometimes their grandchildren. One in ten caregivers in the United States is 75 years or older; and women are the majority of caregivers to their families. Consideration needs to be given to the impact of stress, unpaid work and effort for women, as well as emphasis being placed on the need for women to ‘care for themselves as caregivers’ while keeping their children, spouses, parents, and community healthy.

Another component of the ethics of eliminating health disparities involves evaluating the leading causes of death among women, noting the variations between race and ethnicity. These types of focused research efforts and assessments will aid in the preventive aspects to address those health issues with strategic planning around future research, treatments, and education of women about these health concerns, with unique attention to socio-cultural factors that influence each of these areas. This approach is in concert with what is referred to as Precision Medicine, defined by the NIH as: “...an emerging approach for disease prevention and treatment that takes into account people’s individual variations in genes, environment, and lifestyle. The Precision Medicine Initiative will generate the scientific evidence needed to move the concept of precision medicine into clinical practice.”

The ethical and social implications of this emerging approach must remain central to all efforts, while addressing the whole health of the individual across the lifespan. In the eagerness to proceed, attention should be given to the ongoing major challenges to overcome political biases about what constitutes women’s health. The pursuit of scientific, ethical and community based interdisciplinary biomedical and biobehavioral research with fairness of principles and justice for all segments of our peoples can improve the health status of girls and women – and their families and communities. In the 21st century, we need to continue to deliver the message to research funders, political decision makers, medical researchers, health care practitioners and the larger populace, that women’s health involves reproduction but begins and extends far beyond; that women and their families must be well informed; and, that the
socio-political and socio-cultural variations of women are relevant to all health care policies and practices. Efforts must continue to provide advances in basic knowledge, prevention strategies, effective information dissemination, and more effective cures and interventions, while applying ethical principles and common-sense approaches for health equity in lifespan issues for the diversity of girls and women in the 21st century.
For Further Reading


Articles


Rural Women’s Health

Judith A. Monroe, MD
President and CEO
CDC Foundation
600 Peachtree St. NE, Suite 1000
Atlanta, GA 30308
Tel: (404) 653-0790
Fax: (404) 653-0330
Email: jmonroe@cdcfoundation.org

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Abstract
Women in rural communities face numerous challenges that impact their health, ranging from socioeconomic disadvantage and limited access to healthcare to placing others’ needs before their own. In this article, Judy Monroe, MD, president and CEO of the CDC Foundation, highlights critical issues raised during the May 2017 Public Health Ethics Forum, presented by the National Center for Bioethics in Research and Health Care at Tuskegee University and the Office of Minority Health and Health Equity at the Centers for Disease Control and Prevention (CDC). Through Dr. Monroe’s unique perspective as a practicing physician in rural America, state health officer in Indiana, a CDC president and CEO of the nonprofit CDC Foundation, she proposes ethical practices and practical solutions that can improve health and healthcare for women living in rural areas in America and throughout the world.

Keywords: Rural, women, health, ethics

Introduction
Women living in rural America and in rural communities across the world face numerous challenges that negatively impact their health. These challenges are wide reaching and include socioeconomic disadvantage and limited access to healthcare. Beyond the specific challenges facing women in rural America, all women face primary challenges that should be acknowledged and understood to make a significant positive impact on the lives of rural women. This article highlights critical issues raised in remarks related to rural women’s health during the 2017 Public Health Ethics Forum plenary panel discussion entitled “Women’s Health at the Intersection of Context, Inclusion, and Public Health Practice—A Dialogue.” As this article illustrates through a true story of a friend’s life, there are health consequences when
women put their own needs on the backburner, even for women who many would consider unlikely candidates for premature death. Building upon career experiences as a practicing physician, state health officer, CDC leader and president and CEO of the CDC Foundation, this article offers ethical practices and solutions to improve public health and health care received by women, particularly women living in rural areas.

Women’s Health in Social and Cultural Context – Real Women, Real Lives

It was Mother’s Day weekend in the mountains of North Carolina, where the sun danced across the lake in celebration of the wedding taking place on the hillside. Family and friends told stories of the bride and groom as children growing up, and acknowledged how they were just right for one another. The mother of the groom told the most entertaining and heartfelt stories and brought both laughter and tears to those embraced in the moment. Young children, dressed in their finest, frolicked with the family dogs in attendance and the great pine trees reached to the heavens as the couple took their vows.

The celebration continued throughout the evening and into the early morning hours, filled with laughter and food, music and dancing, friends and family. The groom and his mother were the most amusing when they danced and laughed together, and their deep love for one another was evident for all to see. The next morning at brunch, the guests sat in rocking chairs on the great porch of the lodge overlooking the lake and the pine trees. It was the perfect Mother’s Day.

Five weeks later, I had just arrived at my office to start a new week when my husband called. He got right to the point. The groom’s father had called with the news that his wife had suffered a massive heart attack and had died. I could not hold back the wave of emotion that swept over me.

My friend and colleague was gone? I could still feel the big hugs she had given me just weeks before and her unabashed “I love you” that she offered with each embrace. Did she have any idea that her life would end prematurely?

My friend was a physician who was actively practicing medicine in rural North Carolina when her life ended abruptly. She had financial means, education, a network of professional colleagues and access to healthcare. She was known for her big heart and genuine care for all people, and her willingness to fight for the underserved. Her love for her own children was unconditional, and when she gave them more than they might deserve, she would shrug and say, “But they’re my kids!” She was dedicated to serving her patients at the expense of her own health and well-being. In her sixties, she was still “on call” every third night.

Challenges to Optimal Health for Women

What are the primary challenges that impact our ability to address the behavioral tendency for women to put their own health on the backburner? What are the factors that negatively impact the health of women and girls across the United States?
At a macro level, the challenges and factors impacting women’s health range from biological factors to cultural issues. Studies on maternal hormones and functional neuroanatomy help to shed light on understanding common maternal behaviors. Yoshiaki et al conclude that there is a highly elaborate neural mechanism mediating maternal love and diverse and complex maternal behaviors for vigilant protectiveness.¹ A specific peptide in the brain may explain why mothers will put their own lives in jeopardy to save their offspring.² These, and other studies, suggest that some challenges facing all women are deeply rooted in evolution and our DNA.

Women serve as primary caregivers for their families and assume added caregiver responsibilities when there is illness or disability. Studies show that 25 percent of women caregivers have health problems as a result of their caregiving activities. Women who spend nine or more hours a week caring for an ill or disabled spouse increase their coronary heart disease risk twofold. Other health effects include elevated blood pressure and increased risk of developing hypertension; lower perceived health status; poorer immune function; slower wound healing; and an increased risk of mortality.³

Rural elders in general have significantly lower incomes and higher poverty rates than their urban peers, particularly women and rural elders of color. Many rural areas have experienced depopulation and economic distress, resulting in shrinking informal and formal support networks, particularly for rural elders who are left behind. The current opioid epidemic affecting many rural communities is a major contributor to the growth of grandparents assuming the role of parents.⁴ This places additional burden on women and makes them less likely to care for themselves.

Overcoming Cultural Beliefs that Undermine Women’s Health

Cultural and social norms have a strong influence on behavior and beliefs. I recall as a young girl sitting in the kitchen of my grandparents’ farm house in rural Kentucky. My mother and grandmother spoke frequently about how we lived in a man’s world and my grandmother expressed her pride for her grandsons’ accomplishments. As her first granddaughter, I remember listening with frustration—and resolving not to own the story she and my mother told. When I expressed an interest in science and spent time exploring the hidden life of her pond under my microscope, my grandmother told my parents not to encourage my interests. My grandmother maintained a rigid schedule of cooking, cleaning, canning and sewing. She maintained that these were the skills that I needed and that I should “grow up to be a good wife and make my husband toast.”

Luckily, we lived in the city and my teachers encouraged me, noting that I could be anything that I wanted to be. My public education rewarded questioning and independent thinking, and my friends’ parents were professionals. My father worked third shift in a factory, and I longed for the family discussions of world affairs that I glimpsed during sleepovers at friends’ homes. To this day, I am baffled by the gender bias expressed by my own grandmother and mother.

I am not alone. Cultural and gender misconceptions affect women across America—and across the globe—but these ingrained beliefs take an especially heavy toll on women in
rural communities. Understanding the narrative imposed by various rural cultures must be understood and respected before it can be changed.⁵

To that end, the United Nations created a new sustainable development agenda in 2015. As part of this agenda, countries adopted a set of goals to end poverty, protect the planet, and ensure prosperity for all on September 25, 2015. There are 17 Sustainable Development Goals (SDG) and each goal has specific targets to be achieved over the next 15 years.⁶ SDG 5 is to achieve gender equality and empower all women and girls. There has been progress towards gender equality and women’s empowerment under the Millennium Development Goals, but women and girls continue to suffer discrimination and violence in every part of the world, including those who live in rural U.S. communities.⁷

**Empowering Rural Women to Attain the Best Health Possible**

In rural America, women can be empowered with the help of government, the private sector, nonprofits and peer support. Women in rural communities can, and should, participate in local political and economic decision-making processes and find a path to raise their voices at the state level.

Often, women in rural communities unknowingly put their own health on the backburner. I saw this firsthand when I practiced family medicine in rural Tennessee after completing my residency training. As the first female physician to practice in the county, I became a curiosity to those living in the impoverished mountain community.

In my first few weeks of practice, several women came to see me with varying complaints. I had a particular interest in women’s health and was thorough in the fundamentals of taking patients’ history and performing physical examinations. I vividly recall a woman in her 40s who came to see me when I first started practicing in the county. She complained of feeling fatigued but had no other specific complaints. When I performed my physical examination, I quickly discovered a large firm breast mass that clearly indicated a serious malignancy. I asked her how long she had had the mass and why she had not told me about it.

Her reply was very innocent and shocking to me. She did not think that the mass was anything to worry about and had barely noticed it. After several more women presented to me with advanced breast cancer, I fully understood the importance of health literacy and education, especially in the rural community where I lived and worked.

Word spread in the county, and beyond, that there was a new female doctor in town who would take time to talk with her patients and explain their health issues. I saw cases of advanced cervical cancer, untreated depression, hypertension and a multitude of other diseases that could be prevented or cared for more effectively if diagnosed early. I performed more pap smears in my first month than had been provided over the past two years.

It became clear that beyond caring for individuals in this rural county, a population approach to health was essential to making a real difference. Through partnership and advocacy, we introduced mobile mammography for the first time. I partnered with the local media to get the word out and spoke at local churches and schools. Word of mouth served as a powerful
influence. By my fourth year in practice, mammograms helped diagnose all new cases of breast cancer in the early stages, and I no longer saw end stage cases presenting for the first time. Thanks to an increase in the number of pap smears performed, cervical cancer followed the same course with results allowing for early detection.

McAlearney et al, explored Appalachian women’s perceptions of trust and distrust of healthcare providers and the medical care system in a qualitative study looking at women’s views about cervical cancer and screening. They found that patient-centered communication and encouragement from a healthcare provider led women to trust their physicians and the medical care system. Lack of patient-centered communication by providers and perceptions of poor quality of care led to distrust. Women also reported trust of female physicians and distrust of male physicians in the study.⁸ These findings are consistent with my practice experience, and are important considerations for physicians who work with women in rural settings.

**Toward an Ethical Approach to Public Health and Other Considerations for Achieving Optimal Health Among Women**

*What are the most ethical approaches for modifying these patterns of behavior and other factors in order to improve women’s health across the lifespan?*

The ethical principles of respect for autonomy, patient welfare and justice guide recommended approaches to health among women.

Respecting women’s autonomy requires physicians and others to respect the decisions individual patients make about their lives. Treating everyone with dignity and honesty is critical to an ethical approach to overcoming detrimental patterns of behavior.

Recognizing physician bias is the cornerstone to respecting the autonomy of rural women. Ideally, the medical profession strives for equal treatment of all patients, but cultural stereotypes exist and decisions are influenced by unintended biases. This can lead to differences in making medical decisions based on race, ethnicity and gender. All physicians should acknowledge their susceptibility to implicit bias and be deliberate in viewing the individual objectively.⁹

I was taught in primary care that you should start “where the patient is at” in their beliefs and readiness for change. In the earlier example, it was clear to me that I could not have a significant impact on the health of individuals in the rural community I served without taking a population-based approach to health. Therefore, beginning “where the community is at” in its culture and beliefs is important to caring for individuals in rural communities. Understanding begins with listening. Taking action that will have a positive impact requires collaboration and leadership.

The challenge of health illiteracy must be approached with respectful education. The power of stories should be harnessed for both understanding and action. To reach a community, the media should be involved. As one example, I partnered with the local radio station, newspaper and community groups in rural Tennessee to educate through stories. Today, social media opens up additional opportunities for networking and sharing. Nationally, there are opportunities to partner with the film industry and songwriters to help educate America’s rural women.
The principle of beneficence requires our actions to bring about good and prevent harm. Respecting the autonomy of the individual who has little understanding of the harm that may come from their behaviors or decisions must be balanced with beneficence. This can be challenging for providers with limited time or patience to manage patients' health concerns. Balancing this ethical dilemma can be facilitated with a population approach to health literacy and education.

The principle of nonmaleficence is the obligation to “above all, do no harm” and to minimize harm if it cannot be fully avoided. Ethical approaches to reducing harm to women include calling out and fighting the unethical practices of others.

For instance, the tobacco industry for years denied the harm of tobacco use and implemented clever marketing campaigns to increase the appeal of smoking. During my tenure as the state health official of Indiana, a campaign directed toward young women was launched to promote a new brand of cigarettes, Camel No. 9.10 During the launch, young women were invited to Camel No. 9 parties and given free manicures, facials, “Martini No. 9’s” and gift bags that included free packages of the new cigarettes in teal and pink packaging.

When news of this marketing campaign targeting young women came to my attention I asked my team at the health department to move quickly toward a countermeasure. Our approach was to develop within weeks an initiative called INFluence Women’s Health and convene women leaders from business, government, education, media and nonprofits to educate them about Camel No. 9 and mobilize them to take action. We sent invitations encouraging women to “Come Dressed in Black and White and Leave Seeing Red.”

We convened at the Indiana Historical Society and all women who attended wore black and white, which gave the event an immediate energy and solidarity. The first lady of Indiana gave the welcome. We reviewed the history of addiction in women and the forces that prompted women to misuse substances. Tobacco Free Kids gave a presentation on the history of the tobacco industry and their methods to increase the use of tobacco. Most importantly, we ended the meeting with nine action steps that the participants could select from to help fight the tobacco threat to young women.

The women of the Indiana Senate united against the deceptive cigarette ad campaign and signed onto a letter to the editor that was distributed to newspapers throughout the state.11 Girl Scout troops searched adolescent magazines for cigarette ads and wrote letters to the editors asking them to stop taking tobacco money for advertising. Butler University required its pharmacy students to embark on a project to counter tobacco. We also garnered enough support to pass an increase in the cigarette tax that year, with all revenue targeted to health-related programs.

Communities can and should mobilize against unethical practices and threats to health. In the example of fighting tobacco in Indiana, the initial convening of women leaders was followed by grants that were available to local health departments to convene women leaders in their communities. Many small rural counties modeled the approach taken in Indianapolis. State health departments, along with their partners, can help rural communities by developing programs and initiatives to drive change and then supporting program implementation.
Treating all people fairly, equally and impartially embodies the principle of justice. To improve women’s health across the lifespan requires particular attention to mental health. Research suggests that women are 40 percent more likely than men to develop mental illness but the stigma associated with mental illness is a barrier to care.

My practice experience in Appalachia is consistent with studies from community health centers. One study in the rural South estimated that 44.3 percent of female clients suffered from major depressive episodes. Another study at a rural community health center in Central Virginia found that 41 percent of female clients were suffering from depression, compared to the typical urban prevalence rates of 13-20 percent. Suicide rates are also higher in non-metropolitan areas; one study estimated that suicide rates among rural residents are 37 percent higher than the rate among suburban residents.

Rural residents are less likely to receive mental health services than urban populations. Obstacles preventing people from seeking and receiving mental health care include the cost of treatment, lack of awareness of mental illness, not trusting that treatment is necessary, lack of time, not knowing where to go for services and stigma surrounding mental illness. Rural communities are small and individuals lack the anonymity of their urban counterparts. Concern that their privacy is in jeopardy keeps many rural women from seeking mental health care.

Ensuring a Culturally Competent and Inclusive Practice of Public Health and Medicine

How can women across the lifespan have a stronger voice in decisions affecting their health? How can decisions made about their individual health impact the larger community of women?

Women in rural communities experience geographic isolation, fragmented services, limited transportation, educational limitations and disproportionate poverty. Gaining a stronger voice in decisions affecting their individual health and the larger community is possible with effective leadership. State health departments can encourage and support local health departments to convene women in rural communities. Churches, local nonprofit organizations and community health centers can also lead the way. Local schools can play a critical role and inspire youth leadership.

In 2015, the largest HIV outbreak in the history of Indiana occurred in a small town in a rural county. Student high school leaders decided to do something to help educate other students. These leaders rushed to release a special edition of the student newspaper that focused on the outbreak. Articles profiled at-risk residents, dispelled rumors and discussed the impact of the outbreak on the town. Students also started a group called “Stand Up” to educate younger kids about the HIV virus and staying healthy.

This example can be replicated across rural high schools as the opioid epidemic affects women and girls in rural communities and is on the verge of being declared a public health emergency. Other risks to women’s health can be the focus of mobilizing local leaders and engaging the broader community. Involvement with these types of efforts can also give women a purpose that can be empowering.
Elected leaders should be invited to participate and support women in their quest for a stronger voice. Rural communities can learn from urban communities and design programs to overcome their unique barriers.

To overcome the barrier created by lack of public transportation options, for instance, rural communities can learn from the example of Liberty Mobility Now, founded by Valerie Lefler. Lefler grew up on a dairy farm and worked on rural transportation issues at the University of Nebraska before creating an online business where rides can be booked in rural communities to help solve transportation challenges. The business is built on the premise of neighbors helping neighbors and seeks altruistic individuals who can provide transportation support. Fees are intentionally low to increase affordability in rural communities.

The power of stories can help rural women gain a stronger voice. Success stories need to be told and shared in local media to help inspire other women to create new possibilities for their lives. Social media binds together communities today that once were geographically isolated. New online connectivity offers the opportunity to greatly increase the pace and intensity of collaboration.

To give voice to rural women requires working with women in their own communities and on their own terms. This approach will pave the way to acquiring the data and information needed to develop and improve policies that better serve their needs.

**Creating Change, Saving Lives**

*What must be emphasized or changed in our current practice to ensure that public health practitioners, researchers and policymakers plan and implement ethical public health interventions, policies and research?*

The curricula of health professionals needs to include early exposure to rural communities and a multidisciplinary approach to health and medical care. Exposing students studying to be health professionals to vulnerable populations and their day-to-day lives, cultural traditions and belief systems will better prepare health professionals to understand and manage the challenges they face. Standardized public health and medical ethics courses should be required and woven throughout the curriculum to remind students that ethics must be applied to all aspects of health and medical care. Requiring nonmedical staff and others to participate in ethical case studies can help create a team approach and an open, honest culture.

To foster continuity and comprehensiveness of care for vulnerable populations, regionalized medical care systems must be upgraded to include better linkages with local providers while expanding partnerships with other care-giving organizations and locally-based infrastructures.

It is vital to contextualize research and educational programs to create models that can be evaluated and replicated within rural populations. This approach may yield new measures to better inform our knowledge and value their differences. Research should have social value for the communities that take part in the studies. Subgroups of participants should be treated fairly and the question of who benefits from the research should be a question answered at the start.
of any new research endeavor. It is essential to muster the political will needed to change public policies that inhibit our success and design new policies to enable our success.

**What resources are needed to build capacity for addressing ethical issues that impact public health practice, research and policies relating to women’s health issues?**

Resources needed for capacity building include people, processes and technology. These resources require funding, which should come from both public and private sources. More importantly, a strategic plan for wisely building the capacity for addressing ethical issues impacting women’s health is needed.

Effective capacity building requires people with leadership skills, knowledge of women’s health issues and systems. Universities can play a role in developing the needed workforce by including biomedical ethics courses, and integrating policy and public health principles into broader fields of study. Public health programs should incorporate “systems thinking” and include ways that processes and technology can incorporate ethics.

Philanthropy is being disrupted by new thinking and new approaches. These approaches reflect a desire for program and policy impact and evidenced-based solutions. Rural community leaders should look for opportunities to make high-impact cases to philanthropies.

**Conclusion**

While rural populations face numerous challenges that impact health, there are promising solutions. When health professionals and community leaders listen to individuals without bias, implement ethical interventions, focus on community engagement, collaborate across all sectors, and empower individuals to share their success stories, powerful changes can occur. The examples shared in this article are proof that effective outcomes can address gaps in health and healthcare, particularly for women who are challenged by social and economic barriers in rural communities.
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Women’s Health at the Intersection of Context, Inclusion and Public Health Practice

Kathleen S. Yep, PhD
Associate Dean of Faculty
Professor, Asian American Studies
Pitzer College of Claremont Colleges
1050 N. Mills Avenue
Claremont, CA 91711
Tel: (909) 607-2645
Fax: (909) 621-8481
Email: kathleen_yep@pitzer.edu
Twitter: kathy_yep

“You ARE Worth Something”: Feminist and Community-Driven Palliative Care
Among Asian Immigrant and Refugee Women Elders

Author Note
The views and opinions expressed here are those of the author alone. The content of this article is documented through the author’s experience. There are no financial conflicts of interest. This subject material is a reflection and projection of ideas evolved from the author’s participation on the 2017 panel titled “Women’s Health at the Intersection of Context, Inclusion and Public Health Practice” at the 2017 “Optimal Health for Her Whole Life” forum sponsored by the Centers for Disease Control and Prevention’s Office of Women’s Health, the Office of Minority Health and Health Equity, and the National Center for Bioethics and Healthcare

Abstract
This essay stems from the panel titled “Women’s Health at the Intersection of Context, Inclusion and Public Health Practice” which was one segment of the 2017 “Optimal Health for Her Whole Life” forum sponsored by the Centers for Disease Control and Prevention’s Office of Women’s Health, the Office of Minority Health and Health Equity, and the National Center for Bioethics and Healthcare. Drawing from an interdisciplinary feminist perspective and qualitative research with Asian immigrant and refugee women elders, this essay looks at gendered patterns of illness such as arthritis and ways to engage with gendered social determinants of health. It also discusses the importance of centering voices of marginalized women since they disrupt false beliefs that deleteriously impact health such as the model minority myth or essentialist notions of culture and gender. In doing so, we may address gendered health inequalities through spaces like feminist, community-driven palliative care efforts.

Keywords: Model minority myth, asian, public libraries, palliative care, culture of health
**Introduction**

All of society benefits when everyone is healthy and well. Health and wellness are a human right for all. However, some navigate structural barriers to health and wellness outside of their individual choices. Social processes (e.g. cisgender privilege, heteronormativity, patriarchy, socioeconomic status, citizenship, language politics and the social construction of race, etc) disrupt and enable why some are and some are not able to exercise this right to be healthy and well. In May 2017, the Centers for Disease Control and Prevention (CDC) convened an interdisciplinary and cross-sectoral panel titled “Women’s Health at the Intersection of Context, Inclusion and Public Health Practice” as one component of the “Optimal Health for Her Whole Life” forum. The organizers from the CDC circulated discussion questions prior to the panels. My contribution to this discussion stems from being a feminist scholar trained in participatory action research, social stratification, and theories of race and ethnicity. My areas of research include cultural politics, feminist pedagogies, oral historiography, and critical public health. Using feminist research methodologies, I asked my collaborators in my research and teaching, Asian immigrant and refugee elder women, the discussion questions in various ways. What follows is what they want you to know as interpreted by me.

**Context**

In this essay, I draw from eight years of participant observation research alongside Asian immigrant and refugee elder women with an adult literacy program at a public library located near a suburban area around Los Angeles in Southern California. I am a professor of Asian American Studies at the Claremont Colleges, a consortium of liberal arts colleges (e.g. Claremont McKenna, Harvey Mudd, Pitzer, Pomona, and Scripps), located in Southern California near Los Angeles, California. I teach college classes such as community health, health inequities, nonviolent social change, racial politics of teaching, sociology of education, and contemporary social theory. In these classes, my college students provide immigrant and refugee elders English-As-A-Second-Language support. Simultaneously, the elders teach the Claremont College students about language ideologies, gendered and classed immigration adaptation contexts, and agency. Working with one of the college’s Community Engagement Centers and funded by the Weingart Foundation, I initiated a partnership with Literacy for All of Monterey Park (LAMP) starting in the fall of 2009. A small suburban community in the heart of San Gabriel Valley east of Los Angeles in Southern California, Monterey Park is 95% non-white and 54% foreign-born. Seventy-six percent of the city’s population speak a language other than English at home. (Stanford Center for Longevity, 2011). Located in Monterey Park’s public library, LAMP is an adult and family literacy program that furnishes language classes, computer classes, citizenship classes, and individual tutoring. LAMP supports a growing immigrant population, with many migrating from China, Hong Kong, Indonesia, Korea, Myanmar, the Philippines, Taiwan, and Vietnam. Most of the LAMP learners have resided in the United States for over ten years and are over the age of sixty. Many have had life experience with war, colonialism, and/or major upheaval.

The responses to the CDC’s discussion questions for the panel from my colleagues, the Asian immigrant and refugee women, at the library should be placed in context. The mostly elderly immigrant women that we work with and learn from in our partnership are part of a significant demographic group. After the 1965 National Origins Act ended almost 100 years
of racialized exclusion targeting Asians, Asian American populations are now one of the fastest growing racial/ethnic populations in the United States. It is expected to almost quadruple in size from 14 million in 2005 to 41 million in 2050. (Passel & Cohn, 2008). In addition, immigrant and refugee elders are a significant demographic group in the United States. In 2010, one in eight elders were foreign-born. Moreover, the U.S. elderly immigrant population increased 70 percent from 1990 to 2010, increasing from 2.7 million to 4.6 million. This trend is expected to continue with the number of immigrant elders in the United States predicted to quadruple by 2050. (Scommegna, 2013) The number of elders from historically marginalized populations is slated to increase. In 2050, blacks and other minorities are projected to make up 42 percent of people aged 65 and over, up from 20 percent in 2000. (Vincent & Velkeff, 2010).

Why Gender, Race, and Class Matter in Health Inequities

In the evenings, my college students and I walk up the lengthy staircase to the second floor of the well-lit public library. We pass by the chatter and busy-ness of the children’s section and make our way towards the adult literacy section of the public library that holds many offices, small study rooms, and large classrooms. Under the florescent light, a group of female elders are huddled together talking animatedly and waiting for us. Others are sitting by themselves studying the material or sitting nervously while clutching a bag on their lap. For two hours, college students from a liberal arts college and immigrant and refugee elders dialogue about their life stories. Over the last eight years, a small group of elders gathered for creative writing and another group regularly met to practice spoken English at a public library in Monterey Park. College students have taken Asian American Studies classes alongside LAMP students that involve social autobiography and other forms of critical pedagogies.

One elder is repeatedly late for our combined class of college students and elders. She always enters in meekly and embarrassed. During one class, she and another student are arguing about something in hushed tones with their heads turned away from me. As I smile toward them, one student, Evelyn, says that her friend is too shy to share with me. The other elder, Lisa, who is red-faced, turns away and waves her hand to deflect attention. Slowly, Lisa’s story tumbles out. Lisa has debilitating arthritis. She takes a bus from downtown, where she is a garment worker, to home. She prepares food for her family and then catches a bus to the library for our class. Her arthritic pain prevents her from walking, catching public transportation as she wishes, and getting to class on time from the bus stop. I assured her that she is always welcome in the class then we opened a conversation about arthritis as a way to identify vocabulary words for the class lesson.

Lisa shows us that in order to engage with gendered barriers to health equality for women and girls we must examine the gendered patterns of disease. An estimated eleven percent of Americans experience severe pain, and a disproportionate number of them are women and older individuals. (Nahin, 2012). While reproductive health is a significant issue with respect to women’s health, arthritis is the most common cause of disability among adults in the United States. It is the leading chronic condition for women. Sixty percent of all women in the United States suffer from arthritis and almost 26 million women are impacted. (Centers for Disease Control and Prevention, 2017).

Arthritis involves the inflammation of the joints and it impacts surrounding tissues and connective tissues. While there are many forms of arthritis, the two most common are
osteoarthritis (OA) and rheumatoid arthritis (RA). OA is one the most common forms of arthritis. RA is long-term condition that causes pain, stiffness, and swelling in the joints. It is an autoimmune disease that occurs when the immune system starts to attack the joint tissue mistakenly.

Arthritis impacts women in disparate ways. Women in the United States have higher rates of OA than men, and the joints impacted by OA tend to have gendered patterns. Whereas men tend to experience OA in their hips, women experience symptoms of arthritis in their knees and hands. Of the 1.3 million adults who manage from RA, the majority are women. The prevalence of RA among women in the United States is approximately more than double that of men who have RA. Studies show that women experience pain from RA more severely than men. (Science Daily 2008).

Lisa’s resilience and determination to attend the class despite the barriers she faced illuminates the fact that we must look at not only the gendered patterns of disease but also gendered social determinants that exacerbate health inequalities. A major barrier to addressing health disparities facing women and girls is looking at other scales in addition to self-management programs such as medication, exercise, and anti-inflammatory diets. Upstream factors, such as gendered labor market segmentation, disrupt the efficacy of disease and pain management.

For women like Lisa, the ability to be healthy and well, and to manage the pain associated with arthritis, interact with gendered patterns of poverty and labor market segmentation. “Sex” refers to the biology and genetics. “Gender” is a social construction of masculinities and femininities, whether norms and roles in society or an individual’s identity or expression. (Kirk & Okazawa-Rey, 2012). Poverty and ill-health are mutually constitutive. For the total population of elderly living in the United States, eight percent live below the poverty line. However, for the foreign-born elderly, the number living below the poverty line in the United States doubles to sixteen percent. Immigrant and refugee women make up 51% of the overall foreign-born population in the United States. Immigrant women tend to be more uninsured than native-born women and immigrant men. In addition, they tend to be covered under public health insurance more than native-born women and immigrant men. And, immigrant women tend to be in poverty more than immigrant men and native-born women. (Ruiz, Zong, & Bartalova, 2015). Moreover, under-resourced, immigrant and refugee women are often tracked and trapped into certain labor sectors for structural reasons and this labor participation impacts their health. (Benner, 2015; Garment Worker Center, 2015). Decades of repetitive labor involving the hands, such as garment work, piece work in electronic industry, restaurant work, and nail salons exacerbate and negate any self-management programs for arthritis. (California Healthy Nail Salon Collaborative, 2011; Foo, 2002). A 2015 study of garment workers in Los Angeles found that workers confronted wage theft, low wages, and poor working conditions. The surveyed workers in the study did not have access to paid sick leave, wage and hour standards, and health and safety conditions in the workplace. Several of the women in the adult literacy class reflected on their work in these low-wage, menial labor industries whether assembling clothing pieces and the dull pain in her wrist, working as a poker dealer and as a dishwasher in a restaurant and the pain in her legs from standing, or the fumes and finger swelling from the nail salon.

In addition to labor conditions, a myriad of aspects in daily life combined to worsen their arthritis. After a few weeks, a comfortable rhythm was established in the dialogues among the immigrant elders at LAMP, myself, and my college students. Slowly, the stories began
Volunteer or forced migration may be a stressful life event for anyone of any age. However, for elders specifically, the process of mediating the racialized, gendered, linguistic and cultural logics and barriers of the new country may bring about new financial, medical and psychosocial issues that exacerbate chronic conditions like arthritis. A recurring theme as a barrier to wellness was the chronic stress from creating a new life in the United States. Many talked about the accumulative stress from the myriad of barriers to creating new life in a new country. For one writing exercise, a Chinese women, Joan, wrote about the multiple stresses that prevented her from working outside of the home and that worsened her arthritis pain. She wrote an imaginary letter from her husband to herself:

Dear Niu,

I like calling you “Niu,” a nickname used only between two of us. You know the meaning of “Niu” right? Simply call a girl in Chinese in a loving tone. It wasn’t easy to live in a new country but we both have tried very hard to help each other and make our life filled with harmony, care and fun. I so appreciate your efforts, courage, diligence, intelligence and positive attitude towards life.

...after a while you started feeling uncomfortable both physically and emotionally somehow. The symptoms were fast heartbeat, neck stiffness, slight fuzziness. You felt so lonely when I was at work. You tried to watch TV but could not stand the noise. You also easily felt fatigue though not really doing much. As a result you didn’t want to do any exercise any more. .... We realized that many things here were actually all stress on you: driving, language, food, home, no job, no friends, no income, etc, etc. I didn’t truly understand the impact or the shock you had gone through until the doctor suggested. I’m so sorry that at that time I didn’t know how to handle the situation. I thought you might have to go back to (Asia) and that could help you out. But, you didn’t because you knew I would miss you badly.

Lower socio-economic status, gendered income inequality, and chronic stress, like Joan faced, are major challenges to women and girls health. The stress of poverty shapes the health of women and girls. Psychological stress is a common trigger for inflammation associated with chronic conditions such as RA. A continuous cycle of stress and flares can make living with RA a challenge. (Hassett & Clauw, 2010). The image of daily interactions as scraping away their dignity became clear. Their conversations revealed how mental health is frayed by the pile-up of risk due to generational status, gender expression, socio-economic status, and language politics.

To address the health inequalities confronting women and girls, we must engage with gendered barriers. Transportation vouchers, on-site child care, and institutional translators all play a role in mediating gendered barriers to access. The immigrant and refugee women at the library all discussed the triple shift of paid labor, childcare, and family care. The surveyed garment workers in the Los Angeles 2015 study indicated that one-third of their income went towards childcare. In addition, increased resources for women and girls health should involve a variety of sectors. For example, in a 2017 Pew Research study, women are more likely to visit a library than men. With 54% of the women said they visited a library in the last year compared to just 39% of men. (Geiger, 2017). Public libraries may be more than learning how to look up information about health conditions. Adult literacy programs at public libraries offer a myriad of programming that address health literacy (e.g., bilingual staff, computer classes, speakers, free
wi-fi, free meeting spaces) and gendered social determinants of health (e.g. free legal clinics, ESL classes, community speakers, study and job search materials in multiple languages).

Why We Need to Listen

One ethical approach for improving women’s health across the lifespan is *listening* to the voices of women and girls about the health inequalities they encounter and their strategies of healing. This textured understanding may assist in the efficacy of ethical practices, policies, and research.

The voices of the women at the library point to the possibility of feminist and community-driven forms of palliative care to address women’s health. Palliative care may be a means to engage with gendered patterns of illness and social determinants of health. Shifting to patient-centered care, palliative care addresses the quality of life with people who have chronic conditions, such as arthritis. In this way, care includes many elements—the physical, psychological, social, and spiritual problems associated with curable, chronic, and life-threatening illnesses. Studies show that palliative care improves patient-centered outcomes such as pain, depression, and other symptoms; patient and family satisfaction; and the receipt of care in the place that the patient chooses. (Meier, 2011). However, research shows underutilization of palliative care by historically marginalized populations and some studies indicate the same for some women. Scholarship also indicates the need for documenting the attitudes and beliefs of women, particularly historically marginalized and under-resourced populations, towards palliative care as a means to improve the quality of life of people who have chronic conditions. Moreover, the literature tends to depict “cultural” barriers towards palliative care in flat and static ways that may diminish the efficacy of outreach to historically marginalized groups (Born, Greiner, Sylvia,...Ahluwalia, 2004; June, A., Segal, D.L., Klebe, K., Watts, L.K., 2012).

Through key informant interviews, and focus groups, the women in the adult literacy classes shed light on attitudes and beliefs towards pain management and emotional support when managing chronic conditions. And what they tell us reveal something different than commonly held beliefs about Asian immigrant and refugee women which often fall into the category of the model minority myth or essentialist beliefs of Asian culture and gender. This difference between commonly held perceptions about the perspectives of Asian immigrant and refugee women on pain management and palliative care impacts the efficacy of practices, policies, and research geared towards this group of women.

Anchored by the Robert Wood Johnson’s Culture of Health framework, our class talked about how they foster a “culture of health” in their communities given the challenges they faced. After brainstorming sessions, each group created a project to articulate their existing group practices. One small group turned to music and faith and made a playlist of songs with some of the women singing spiritual music. Another group emphasized medicinal foods and wrote an illustrated cookbook that included recipes and food memories related to the recipes. Whereas some had superstitions about talking about death, they all talked animatedly about prevention, diet, and exercise to manage their arthritis, chronic pain, and/or cancer. Since all could not afford the arthritis medicine, they shared resources about natural medicines and exercises. Yet, the women expressed interest in and took the lead in creating resources for non-pharmacological pain management and symptom treatment as well as their practices of linking spirituality and wellness.
To hear the voices of marginalized women is to understand the ways they produce knowledge and create community support. In doing so, we may refine our practices, policies, and research to be more inclusive and effective. Whereas Asian women are depicted as reticent to talk about their feelings, the women in the adult literacy class demonstrated their interest in talking about feelings to cope with chronic conditions, their environment, stressors, and strengths related to their arthritis and serious illnesses. (Yoo, Levine, Aviv, & Au, 2010). However, they did so in their own form and on their own terms. One night at the library, four immigrant elder women and I were in a discussion about a writing prompt. The four LAMP learners for that night included Emma who was working as a housekeeper and now exploring her experiences through writing and speaking in English. Another woman in the group, Amy, worked several low-skilled jobs and was a quiet but engaged participant in the discussions. The other two women, Joan and Ellie, were a generation younger than Emma and Annie and had immigrated more recently than the older women. However, all four navigated some chronic condition with at least two-thirds of the group managing arthritis. On one evening, I invited them to respond to educator Michael Jame’s prompt: “I am a woman and one thing you need to know about me is...” Each participant would complete the sentence. I gave them the prompt and discussed it with the four. At first, they huddled together to talk about the prompt in their native language. After a few minutes, they popped their heads up and they decided as a group to ask me for clarification in English. They designated one person the advocate; and as she told me the prompt was too vague and too confusing, the others nodded their heads in agreement. And, they were right.

I listened to them intently and thankfully, the four women continued to discuss the prompt and try to improve it. We discussed how their audience was someone who did not understand their perspective. We proceeded to analyze together how the word “need” was important. We defined the word and brainstormed various situations where the word “need” was relevant such as when do you need food or when do you need sleep. The word “need” signaled necessity or something essential. It was not something frivolous. By discussing the word “need” and highlighting its role in the writing exercise, it was asking them to write what do people not know about them that was vitally important that they learn. It was about voice rather than “need.”

Interestingly, in response to this prompt and the discussion, one of the younger participants asked the elders about whether she “needed” to give input into her family if she were not working outside of the home. She wrung her hands and looked down as she asked this question. We asked for more clarification. She was too ill to work. She struggled with inner turmoil about whether she was contributing to her family. The two older women in the group reacted immediately. They spoke vehemently. Emma said: “You ARE worth something. You NEED to tell your husband.” Amy, the other elderly woman quietly nodded her head and whispered: “You NEED to tell your husband.” Then, the four proceeded to debate the topic animatedly. Amy quietly asked who needs to know. She wanted to know who was the audience for the poem. Another passionate discussion followed. Amy said she would like her husband and son to be the audience for the poem. She went on to talk about her knees and how after paid work, she grocery shops and then has to clean the house and cook. Another participant decided she wanted her parents to be the audience and discussed how she earns money in a job, cares for her children and her parents. As the four women wrestled with the ideas and their feelings, I was struck and moved by the passion, the conflict, and the compassion. I kept on hearing their use of the word “need” in various ways in English.
At one point, one person said “we need” to do our homework. After the heated discussion, the group of four decided they wanted to write a collective poem based on the prompt. Each of four women wrote one line to form the following collective poem in English:

I am a woman and one thing you need to know about me is...
I earn money myself, I am independent so I can decide everything, which I like
I can travel if I have free time and I don’t need to ask anybody to agree
I am a housewife. I can’t earn money, Now I depend on my household. In China, I earned money myself.
I feel very independent, strong, and free

The poem asserts longing. It indicates a yearning for control and agency while at the same time revealing the reality of powerless feelings about their current environment. In this way, the poem, the writing of the poem, and the discussion around the poem created a shared space to talk about feelings and to give and receive support. Classes at the library like this one became a collective space to navigate challenges and strengths in living situations, medical decisions, pain management treatment plans, and family roles and responsibilities in relation to their chronic conditions. During classes at the public library, they talk about their families and illnesses. They keep each other in the loop about missed classes and resources. At the library, the women created their own community for resources and emotional support, their own form of culturally-relevant and feminist palliative care.

Understanding the attitudes, beliefs, and social conditions of women and girls must be understood in our current practices to ensure we plan and implement ethical public health interventions, policies and research. We must understand the patients and the communities they come from in order to create more culturally-relevant and inclusive practices, policies, and research. Although the literature tends to characterize Asian immigrant and refugee elder women as unwilling to talk about feelings due to patriarchy and cultural shame, the library group indicates something more nuanced. And this multilayered understanding of how women experience illness and strategize around the barriers they face is significant for our understanding of tackling health inequities effectively. In addition to listening to the voices, we must also make space for women and girls to set the terms of the asking, listening, and sharing for our practices, policies, and research. For example, the community of women at the library played a key leadership role in crafting their own palliative care resources at the public library. This marks a significant shift to patients/patrons and to shared decision-making power over creation of and access to services. For example, the city librarian at the public library framed the library as a community space. When a group of Asian immigrant and refugee elder women approached the city librarian about space usage, the city librarian recognized that each sector (e.g. the government, the community, and the service providers/partners) have something to learn from each other. What ensued is over fifty women gathering every week in the library parking lot at dusk to dance or practice tai chi as a form of palliative care. Driven and motivated, they are self-organized and create their own curriculum for the dances. They all pitch in money for a low-cost amplification system and for the music. They bring their tea and snacks and share with each other during breaks. The partnership among a college and a public library is built on and framed by ethnic studies and gender studies principles. This mutually-respectful model draws from social justice community-based learning that positively impacts the quality and
efficacy of the cross-sector partnership. The community partnership started from where the community is and the different forms of knowledge such as fan dancing and *tai chi*. To foster a culture of health, the collaboration at a public place other than a hospital, clinic, or community-based organization uses an assets-based approach to co-create programming that is more skills-based and community-centered as a *de facto* form of culturally-relevant and feminist palliative care.

**Closing**

This is a call to recognize the role of gender in health inequalities and in ethical considerations for public health practices, policies, and research. The women of the adult literacy program in Monterey Park invite a broader vocabulary of gender-specific and culturally-relevant services and research that address gendered social determinants of health and coming up with gendered solutions. On a Sunday evening if you drive by the public library you will hear the faint sounds of amplified music and a chorus of voices counting in Cantonese, Mandarin, and Vietnamese. As you walk closer, you see rows and rows of women line dancing to a pop song. And, you might see the women discussed in this essay. The intersections of gender and community health provide us with a lens to look at the extraordinary things people with little resources do in daily life to not only survive but to thrive. Having lived through historical trauma like war, colonialism, and poverty, the immigrant and refugee elder women at the library show us the potential of under-resourced women to manage their chronic conditions and the power of public spaces like libraries to foster health literacy and community wellness. The practices of the Asian immigrant and refugee women elders is an invitation to document and nourish these cross-sector ways of fostering health, well-being, and healing. In addition to addressing gendered social determinants of health like poverty, language access, and labor market segmentation, creating structured spaces for and listening to the voices of historically marginalized women and girls in a variety of sectors are essential for addressing ethical issues that impact public health practice, research, and policies relating to women's health issues. Understanding our biases and essentialist framing of culture and women and girls will contribute to more ethical and effective practices, research and policies such as fostering culturally-relevant and accessible palliative care to women and girls.
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Articles


Optimal Health for Their Whole Lives: Reflections on Social Ethics, Freedom, and Black Women’s Health

Rosetta E. Ross, PhD
Professor of Religion
Spelman College
350 Spelman Lane, SW
Atlanta, GA 30331
Tel: (404) 270-5527
Email: rross@spelman.edu

Author’s Note

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Abstract

This reflection argues that public health ethical analysis which centralizes choice and agency as a form of the US conception of liberty or freedom will support consideration of black women and girls’ health on par with any other citizens of the United States. Responding to five questions aimed at improving women’s health across the lifespan, the reflection argues for public agency and private entity participation in producing the public health common good. It recommends challenging theo-cultural ideas that subordinate all women, and encourages Black women and girls to exercise choice and agency to overcome limits on their freedom arising from inherited or established patterns, habits, and relationships. Asserting that community partnerships enhance public health work, the reflection encourages federal health agencies to collaborate with unlikely partners to affirm black women and girls’ health and to counter cultural legacies that support exclusion of persons and groups on the basis of sexual identity, religious affiliation, social class, educational achievement, race, and other factors.

Keywords: Choice, agency, common good, theo-cultural, queer theory, liberty, freedom, ethics

Background

The most desirable health condition for women – as for any persons – includes full well-being and flourishing in body and mind. In the United States, exploration of optimal health conditions for women is necessarily a public health concern, since women and girls constitute approximately one-half of the country’s population and a very substantial portion of the country’s diversely situated labor force. As public health relates to health of the society, including, according to the American Public Health Association (APHA), working “to assure the conditions in which people can be healthy” (APHA, nd), attending to the well-being
of women is an issue of ethics, because women’s health conditions often reflect inequalities related to both women’s lower health status and women’s higher health costs. When the impact of factors such as race, class, sexual identity, and others are combined with gender, health disparities and the need for ethical analysis becomes even greater.

In a very general sense, “ethics” is a term that identifies both the process and result of reflection on practices to determine an appropriate course of action. Insofar as ethics is concerned with reasons for practices occurring as they do, technically, ethics is reflection on morality. Ordinarily, ethical reflection emerges as a corrective process in response to a challenge, problem, crisis, injustice, etc., that requires attention and change. Ethical reflection entails critically considering what is being done — or in the words of social ethicist H. R. Niebuhr (1978), considering “what is going on” — and determining appropriate behavioral and policy adjustments in the light of a goal, norm, or value. An ethicist asks, “What is the current practice, behavior, or situation?” and “What do my (or our) goals, norms, and values suggest is the desired practice, behavior, or situation?” From reflection on such questions to discern the good, the right, or the appropriate response,¹ an ethic emerges indicating what should be enacted and that toward which an agent or group should strive. In addition to reflective analysis to discern what constitutes the good, ethical reflection considers what relevant responsibilities pertain to achieving the appropriate situation and who is responsible for seeking to achieve it. The annual CDC Public Health Ethics Forum is an example of reflection about “what is going on” in US health realities. The forum exists, at least in part, to take account of the current state of health affairs and to explore some reasons to change practices to enhance the overall health of the population.

Social ethical reflection occurs within the context of a society and often seeks to overcome inequities and injustices among groups in society. Persons, private entities, and the state (include the state’s agents) are all responsible for achieving what often is called “the common good” of societies. Recent discursive practices in the United States have gone a long way toward de-legitimizing the view that private organizations have any responsibility toward achieving the common good. Additionally, the narrowing of social responsibility of private entities has occurred at the same time that public policy changes, such as the US Supreme Court’s Citizens United² ruling, position incorporated entities and individual citizens as competitors in seeking to influence state conceptions of and policies aimed at enhancing the common good. In spite of changing ideas about the roles of private entities and disagreement about how to define “the common good,” the idea of persons, private entities, and states (or state agencies) having joint responsibilities in behalf of individual and social well-being is a well-established way of identifying how to achieve the common good.

The state of health conditions within the country is a social ethics issue. The 1946³ creation of the Centers for Disease Control and Prevention (CDC) reflects the US government’s concern with “social ethics” insofar as the CDC began and continues with a

¹Strictly speaking, “the good,” “the right,” and “the appropriate” are distinct referring, respectively, to a conception of a desired goal or situation, that which accords with law or policy, and that which is best suited and/or most possible in response the current situation.

²The milestone 2010 Supreme Court ruling in Citizens United v. Federal Election Commission held that constitutional safeguards allowing freedom of speech forbid government restrictions on the amounts associations may expend independently in relation to political campaigns.

³The agency opened in 1946 and was originally named the “Communicable Disease Center,” begun to prevent the spread of malaria. See https://www.cdc.gov/about/history/index.html.
mission to protect the society against health threats. Acting in behalf of the federal government, the CDC’s charge includes protecting the population as a means of protecting the country. Carrying out its mission with equity and justice relates much of the CDC’s work to public health ethics. Faden and Sirine (2015) say public health ethics “deals primarily with the moral foundations and justifications for public health, the various ethical challenges raised by limited resources for promoting health, and real or perceived tensions between collective benefits and individual liberty.” The United States Centers for Disease Control (2017) defines public health ethics as “a systematic process to clarify, prioritize, and justify possible courses of public health action based on ethical principles, values and beliefs of stakeholders, and scientific and other information.” Both definitions suggest that ethical public health practice is guided by a theoretical basis and processes of ethical analysis since each identifies conceptual principles for reflection (“moral foundations and justifications” and “ethical principles, values and beliefs”) and circumstances of reflection (“various ethical challenges ... real or perceived tensions” and “a systematic process to clarify, prioritize, and justify”) as bases upon which public health ethics are determined. According to Dean (2017), two central public health ethics question related to CDC work are: Why do health inequities exist? and What considerations, such as overlapping social structures, contribute to health inequities?

Introduction

The recent CDC Public Health Forum, entitled “Optimal Health for Her Whole Life” (2017) considered health inequities related to gender identity and explored “a range of health issues and actions to improve the health of women and girls in the United States,” including “ways to promote and protect women’s health across the lifespan by emphasizing public health ethics in the practice of public health.” One element of the Forum, “Women’s Health at the Intersection of Context, Inclusion, and Public Health Practice,” aimed at considering ways race and ethnicity, class, sexual identity, age, and other social markers intersect with a variety of realities to impact women and girls’ health. Five areas in this discussion were: caregiving and women’s health, ideas for ethical modification of practices that relate caregiving to women’s lower health condition, enhancing women’s voices in decisions about their health, enhancing ways practitioners/researchers/policymakers interact with and attend to women’s health, and consideration of what resources are needed to improve women and girls’ health across the lifespan.

I propose using the idea of “liberty,” a central conception for defining individuality in the United States, as the primary theoretical consideration to reflect on these five areas in relation to black women and girls’ health. While the common good is taken into account in this discussion, privileging liberty or freedom in regard to black women and girls seems more meaningful because the common good may be restrictive in regard to seeking particular individual and sub-population health outcomes. When the idea of the common good is defined as maximum well being for the society, tension may arise between protecting the society and affirming the well being of a sub-population. The challenge in prioritizing or centralizing the common good as theoretical foundation for ethical consideration of black women and girls’ health is the statutory legacy and continuing ideational construction of gender- and race-based disadvantage. This reality could cause policy makers and health care providers to lean more in the direction of restriction of focus on positive outcomes during ethical reflection on black women and girls’ health. The lens of social justice is another theoretical consideration often used in public health ethical reflection, since it aims at overcoming inequalities and injustices. While the perspective of social justice is helpful, the potential to limit ethical consideration of
black women and girls’ health to correcting disadvantages and discrimination raises questions about focus on consideration of “optimum” health for such persons. It is possible that some policy makers and health care providers will view the determination to address any deficits as a worthy goal and achievable goal (without regard for whether all deficits are fully overcome or whether there is room for even greater positive health outcomes). In this case there may not be sufficient attention given to transcending the corrective focus of a social justice lens by also prioritizing enhancement of the overall well being of black women and girls above and beyond challenges confronted as a result of historic disadvantage and discrimination. Again, social justice is an important consideration; however, when taken alone as the theoretical foundation for ethical reflection on the health of black women and girls, it may be insufficient. Still another theoretical view might be to focus on the Christian concept of neighbor love. The widespread assertion of Christianity as the predominant religious lens of the United States (notwithstanding the diminishing numbers of active adherents to Christianity and the reality of a wide variety of religious traditions and practitioners in the United States) means that ideas drawn from this tradition’s framing of social life is discursively predominant in the imagination of many persons in the United States. Conceiving of ethical interventions in behalf of black women and girls’ health from the perspective of this theo-cultural disposition is challenging because Christianity structures caring for the neighbor as a paternalistic relationship of persons with more advantages providing for persons with fewer advantages. Breaking out of this dynamic, a defining characteristic of US culture, in regard to the position of black women and girls, seems too enormous for this theoretical paradigm to work even when, as Isasi-Diaz (1996) has written, love for the neighbor is reframed as “solidarity.” While Isasi-Diaz argues for viewing neighbor love only through the lens of mutuality and commonality, her limiting the basis of solidarity to “commonality of interest” leaves intact the “more advantaged”/“less advantaged” dichotomy, even though there may be ongoing relationality.

For public health ethical analysis of the well being of black women and girls in the United States, I recommend centralizing the US focus on “freedom”/liberty (while drawing on elements of these other theoretical perspectives). There is no concept that is more central to the identity of citizens of the United States than the concept of freedom or “liberty.” Among the country’s founding documents, the Declaration of Independence (1776) identifies freedom as one of the “self-evident,” “Creator”-given, “inalienable” rights – “Life, Liberty, and the Pursuit of Happiness” – that have their persistence in governments created “to secure these rights.” The “Preamble” to the Constitution of the United States identifies the intent to “secure the Blessings of Liberty to ourselves” as a reason for founding of the country. While the precise meaning of “freedom” or “liberty” in the United States remains fluid, for purposes of this paper, the concepts “choice” and “agency” are constituent elements of liberty and the basis for defining what is ethical in regard to black women and girls’ health. Choice exemplifies freedom as both the act and option of selecting according to one’s desire. In this regard, choice is a constituent element of freedom because it reflects the ability of persons to autonomously conceptualize their yearning. Agency, the ability to act with purpose, also is a constituent element of freedom because it represents the capacity to realize or to seek to actualize that for which one yearns. In this regard, choice is a constituent element of freedom because it reflects the ability of persons to autonomously conceptualize their yearning. Agency, the ability to act with purpose, also is a constituent element of freedom because it represents the capacity to realize or to seek to actualize that for which one yearns. In the context of the United States having free choice relates to volition and opportunity, while having agency (to pursue happiness, or to pursue one’s self-determined sense of fulfillment and flourishing, for example) suggests authority to enact freedom. In a context where resources and technologies necessary to secure physical well being are bountiful and where the state of one’s health ordinarily is seen as essential to human fulfillment, analyzing black women and girls’ well being in relation to the liberty of US citizens means public health ethical reflection
on black women and girls’ health must necessarily consider access, opportunity, options, and prohibitive circumstances that interact with choice and agency. What follows are reflections on the five areas discussed in relation to “Women’s Health at the Intersection of Context, Inclusion, and Public Health Practice,” using “liberty” as the primary lens to inform analysis of what constitutes ethical public health practices in relation to black women’s and girls’ well being.

1. Caregiving and Self-Care: Realities, Challenges, and Possibilities⁴

The social construction of gender roles and expectations has a direct bearing on the likeliness of women being the primary caregivers in US families. Pervasive ideas about gender include an understanding of “care” as falling within the domain of “women’s work.” Often women are expected to bear the emotional and physical responsibility of love by having and demonstrating concern for those needing care. In general, propagation of the idea that it is women’s responsibility to give care does not describe the intense physical labor often required nor the emotional toll “care work” takes on caregivers. The view that men are excluded from “care work” contradicts one element of the traditional logic that defines gender roles: the idea that men’s physical strength is a factor is assigning gender responsibilities. The physical labor of giving care may be quite grueling (lifting bodies, changing and cleaning child and adult diapers, bathing, ensuring proper sanitation and nutrition, etc.); however, in general, women are expected to perform such work. The conversion of traditional logic when caregiving responsibilities are considered magnifies one central area of challenge related to the caregiving and women’s health. Conceptualizing women as primary caregivers contradicts the traditional view that men’s strength is anticipated to attend to physical labor of ordinary life. This contradiction in regard to the physical labor of caregiving privileges men (who are not expected to perform care work), while making women secondary (since care work is expected of them), and points out not only how conceptions that sustain patriarchy and sexism are socially constructed and not tied to biology, but also exhibits the illogic of social construction through inconsistent reasoning.

Often ideas about women’s roles in the United States derive from (or are linked to) religious norms that inform the structure of family and social life. In Christian tradition, for example, the concept of being a servant – “a suffering servant,” to be exact – frequently is promoted as an exemplary model of what it means to be a “good” person; traditional practice and Christian scripture often relate this virtue especially to women. This conception of the “good” is propagated theologically by normalizing sacrifice and encouraging persons to consider the self in the last place, or to ignore the self entirely. Operating alongside religious and theological ideas about “service” (i.e., caregiving) is the reality of white supremacy as a persistent element of the social imagination in the United States, wherein a servant is primarily conceived as a raced and often a gendered body. Both ideations – women as exemplars of Christian sacrificial service and women of color as US social servants – are affirmed by women and men of all races, ethnicities and classes. For black women, the negative health impact of providing care is socially conceived as normal to their lives not only on the basis of gender, but also on the basis of race. This has occurred historically and continues currently through cultural

⁴This topic relates to Discussion Question One: “According to the 2017 Presidential Proclamation for National Women’s Health Week: ‘Women are more likely to be the primary caregivers for their families; caring for their children, spouses, partners, parents, and caregiving especially when a family member falls ill. Women also make approximately 80 percent of health care decisions for their families. In doing so, many women tend to put their health needs on the backburner. What are the primary challenges that impact our ability to address this behavioral tendency and other factors that negatively impact the health of women and girls across the United States?’ See Panel Discussion Guide, 2017 Public Health Ethics Forum, Centers for Disease Control and Prevention.
and economic policies and practices that limit choices and depress wages for “unskilled” service work, making, as Grant (1993) writes, people of color, especially women of color, prone to be identified “as” servants and identified “with” the concept of servant in the larger society. To help mitigate this, Grant advocates a moratorium on use of the term servant as an acceptable Christian designation in referring to women of color.

In regard to their health, of black women and girls’ experience of these theo-cultural ideas in everyday life is intensified through the historical legacy that conceives of the black body as chattel to be used in “service” of other persons. This means the widespread theology that affirms “servanthood” is combined with an historical past of being legally defined as “servants” and the socio-cultural conception that caregiving is the work of women and/or persons of color. Determining how to address negative effects of these intersections in the immediate experiences of black women and girls as well as how to change the attitudes of persons who affirm and reproduce these ideas through learned expressions of sexism and anti-black racism is a pivotal challenge for public health ethics in regard to this population. Dwyer (2011) and Bulato and Anderson (2004) argue that black women and girls ordinarily confronting such attitudes is one cause of racialized stress, a factor that likely compounds the negative impact of caregiving (and other realities) on their health.

2. Ethical Reflection on Modifying Patterns, Behaviors, and Ideas⁵

Identifying to who is responsible for modifying behaviors and patterns is important in determining appropriate ethical responses to ways caregiving affects women’s, particularly black women and girls’, health. This is the case for two reasons. First, and perhaps most obvious, is our knowledge that women alone, and, more specifically, black women and girls alone, do not bear all responsibility for modifying behaviors that have resulted from historical, social, and material contexts over which they often have no control. Second, and related to this, is the vision of a society in which the well being of all persons predominates discussions of health care ethics. When the idea of liberty is introduced, historical, social, and material realities that impinge on black women and girls’ health become impediments to their choice and agency as citizens in the United States. It is not possible to have free choice or to act as free agents in a manner consistent with that of other citizens under the weight of an overwhelming popular conception of being viewed as the servant who enhances the freedom of others. Among other social entities responsible for helping modify behaviors to improve black women and girls’ health, the roles of three parties are considered in this discussion: the roles of the state and the roles private entities, taken up in this section, and the role of black women and girls, discussed in the succeeding section.

Restrictions on liberty to pursue optimal health occur whenever public policies and private entity decision-making limit individuals’ health choice opportunities. State and private entity responsibilities overlap in some areas related to optimal health choices. For example, tax structures imposed by local and state governments determine private contributions to funding for public education, and federal policies on health care access may define insurer structures of access or require private agencies to provide minimal levels of coverage. Public policies and private industry practices that restrict liberty include federal budget expenditures, location of health care providers and facilities, location of food markets, and state/local/federal funding of

⁵This topic relates to Discussion Question Two: “What are the most ethical approaches for modifying these patterns of behavior and other factors in order to improve women’s health across the lifespan?” See Panel Discussion Guide, 2017 Public Health Ethics Forum, Centers for Disease Control and Prevention.
public education. These all have direct bearing on the available range of choices of health care insurance coverage, quality health practitioners and facilities, fresh and high quality produce and proteins, and education about and exposure to ideas related to conceiving a superior quality of life. When limits on these choices are considered in relation to the idea liberty as a central element of US citizenship, the role of the US government (and its agencies) becomes prominent. At the most basic level, ethics is about keeping faith with predetermined goals, norms, and values. An ethical response to the question “What are the most ethical approaches for the US Department of Health and Human Services and its divisions such as the Centers for Disease Control and the National Institutes of Health to participate in modifying patterns of behavior and other factors in order to improve women’s health across the lifespan?” should begin with the mission of these agencies.

The normative duties and obligations of US health entities follow: (a) “It is the mission of the US Department of Health & Human Services (HHS) to enhance and protect the health and well-being of all Americans. We [employees of HHS] fulfill that mission by providing for effective health and human services and fostering advances in medicine, public health, and social services.” (b) The Centers for Disease Control work “24/7 to protect America from health, safety and security threats, both foreign and in the [United States].” (c) “The National Institutes of Health (NIH), a part of the US Department of Health and Human Services, is the nation’s medical research agency — making important discoveries that improve health and save lives.”⁶ Although the NIH statement is less precise in identifying to whom it is obligated, duty to the people of the United States is presented clearly in statements from HHS and the CDC. In view of this, what follows considers the most ethical approaches for HHS, the CDC, and NIH, among other federal agencies, to participate in modifying patterns of behavior and other relevant factors to improve women’s health. The immediate responsibility of HHS and its divisions in determining ethical approaches for modifying patterns of behavior to improve women’s health is to interact with policy makers in development of legislation that is consistent with and supportive of the agencies’ missions.

In other efforts to modify the behavioral patterns of women putting their health needs on the back burner, it is important to address the political and socio-cultural context that informs and influences their behavioral choices. While women are agents of their own health decisions, factors influencing their decisions are often complex, and, for many women, their choices have implications beyond themselves as individuals. This is not to say that women should not choose themselves. Instead, the point is to direct focus on the complexity involved in some women making the choice to subordinate their own health. Time and resources also are significant factors. In addition to women’s frequent inadequate compensation, other important resource issues are access to fresh, healthy foods; access to first rate health care; and access to quality public education. To what extent do HHS, the CDC, and NIH focus efforts on the intersection of these realities with the well being of black women and girls? How can partnerships and collaborations be structured to centralize black women from all social strata in these agencies’ work? One approach might build on and expand work through some relationships that already are in place, in view of the roles of religious institutions among some black communities. A new area of collaboration should include HHS entities and other health care providers engaging religious leaders and communities to not only access and provide services to black communities, but also to help ritualize the traditions with words and practices that positively

affirm black women’s embodiment. Collaborating to develop liturgical elements that re-frame human and community identity away from normative ideas of heteropatriarchy and anti-black racism, and that present alternative conceptions of the good to include care for others without being tethered to raced and gendered ideas about service or “servanthood” (Townes) could go a long way in re-educating persons to think differently about women’s roles and ultimately about the impact of caregiving on women’s health. In expanding the reach of HHS entities into black communities, it will be important to enhance engagement with black leaders and practitioners of Islamic and African-derived religious traditions whose numbers of practitioners in the United States steadily are growing. Creative strategies might also include building unusual relationships, such as, for example, engaging urban garden programs and farm cooperatives to not only increase access to fresh fruits and vegetables in areas called “food deserts,” but also to conduct public health work, disseminate information, and demonstrate relationships of food and health.

Another significant issue for HHS entities is continuing to seek to overcome the legacies of distrust of health care institutions within black communities. Recent popularization of the Henrietta Lacks story is a reminder of persisting perceptions of black bodies as chattel or as having subordinate importance related only enhancing the lives of others in the society. Health care policy makers and personnel who hold these perceptions may participate in generational degradation and deceptions. In regard to the health decisions of black women and girls, an important factor in accessing and trusting health care agencies is to overcome attitudes of, stigmatization by, and unethical practices of persons that result in inhospitable, unsympathetic, and even hostile experiences with health care contexts. Taken-for-granted views about racial privilege, gender construction, and sexual identity often seep into reflections of policy makers and interactions of providers with clients resulting in a range of negative experiences. Attending to this involves awareness of the issue, reorientation of the consciousness of public health policy makers and practitioners, and definition of a public relations process directed toward both black communities and the larger society. Anti-racism work and anti-black racism work also are needed at all levels of health care service and policy making to increase the choices and agency of black women and girls in interaction with health care agencies and systems.

3. Black Women and Girls’ Voices in Their Health and Health Care

The popular statement “Knowledge is power!” is appropriate and significant when considering how to strengthen women and girls’ voices in decisions about their health. Public health partnerships that share knowledge which enables informed decision making is essential to enhancing women’s agency in relation to their individual health determinations. In addition to knowledge, health care access also is an important factor in women’s decision making agency. Finally, exercising choice and agency in safeguarding one’s own health is essential.

The National Centers for Chronic Disease Prevention and Health Promotion (NCCDPHP) (2009) reports, “The World Health Organization has estimated that if the major risk factors for chronic disease were eliminated, at least 80% of all heart disease, stroke, and type 2 diabetes would be prevented, and more than 40% of cancer cases would be prevented.” The options provided by knowledge of and familiarity with “the major risk factors,” and access to affordable health care policy (which enhances access to regular medical exams and screenings)

7This topic relates to Discussion Question Three: “How can women across the lifespan have a stronger voice in decisions affecting their health? These are decisions made about their individual health as well as for the larger community of women?” See Panel Discussion Guide, 2017 Public Health Ethics Forum, Centers for Disease Control and Prevention.
means a much larger number of women will have the agency to make a range of choices that strengthen their “voice in decisions affecting their health.” Building relationships with a variety of communities and organizations to develop contexts for sharing knowledge as well as to strengthen public health advocacy is an important strategy. In pursuing a relationship-building strategy, engaging communities and organizations whose voices are less frequently central to these conversations is important. This includes black women in queer and trans communities, black women living in poverty, and less mainstream advocacy organizations such as local #BlackLivesMatters chapters. Coordinated efforts to engage and influence policy may be strengthened by greater numbers of persons engaging policy makers and through testimonials of women about their specific health and well-being experiences. It would be especially useful to develop relationships and mechanisms that seek to involve the less regularly engaged populations in discussions of policies that attend to their health and well-being. A high quality of such engagement would entail not only identifying specific communities, but also developing strategies to make certain that contexts of engagement are hospitable, including ensuring that communication actually occurs between participating parties.

The recurring idea that moving beyond traditional practices and traditional collaborative partners has implications for health entities as well as communities. The tendency to act against freedom occurs not only through limits imposed on choice and agency, but also through limits arising from boundaries and inherited or established patterns, habits, and relationships. For example, in addition to theo-cultural ideas about gender and cultural constructions of service as intersecting with race and gender, theology and culture combine as a roadblock to inclusively addressing factors that negatively impact black women and girls’ health by impeding collaborations and alliances. Women and girls’ acceptance and affirmation of ideas about the “normal” construction of womanhood is detrimental when cis-gendered women and girls fail to see their health and well-being are interconnected to queer and trans-gendered women and girls’ health and well being. Since normative binary constructions of gender privilege the well being of all men and make the well-being of women and girls secondary, the ability of cis-gendered, queer, and trans-gendered women to collaborate and develop alliances is impeded by the failure to critique binary theo-cultural ideas about gender construction. Consenting to compulsory heteronormativity and heteropatriarchy, whether through actions or silence, limits choices and expressions of agency of black women and girls by curtailing potential collaboration among women and by collusion, through action or silence, with entities opposed to recognition of full human and citizenship rights of some persons based on their sexual identities. Incorporating queer theories into public health reflection can serve as a reminder to challenge exclusion based on traditional thinking and ideas. This would help overcome tendencies to erase some queer subjects completely and help overcome patterns of relying on traditional, comfortable, and, often, exclusionary practices and thinking. Charania (2016) writes that although the interrogative disposition of “queer reading/viewing practices alone cannot prevent the violence of hetero/homonormativity, they do intervene in dominant formulations of dangerous subjects and desirable citizens, enabling a more critical reading of state-based freedom practices.” Black women and girls’ employment of queer theories may be especially supportive of realizing their freedom to choose and agency to act, since a “central task in queering popular ways of seeing ... necessitate[s] a queering and querying of affect, desire, embodiment, and power.” Limits arising from boundaries and inherited or established patterns, habits, and relationships do not emerge only in relation to sexual identity. Reliance on established ways of thinking and acting may impede collaborations and alliances of black women and girls beyond Christianity and across social classes, and may result in black women
and girls’ colluding with other groups to exclude black persons who do not identify as Christian or who are situated in differing social class locations, or who may be “different” as a result of any of a number of other social and identity markers. “Queering and querying” established ways of thinking and acting could be a means of black women and girls enacting their freedom by breaking apart the limits imposed by traditional conceptions because stigmatizing persons based on sexual identity, religious affiliation, social class, educational achievement, and in other ways is a socio-cultural reality, federal health agencies and other entities in society share responsibility with black women and girls to overcome these impediments to their having a stronger voice in decisions affecting their health.

4. Conclusion: Ethical Interventions of Public Health Practitioners, Researchers, Policymakers

To summarize, determining the changes and resources need to overcome inequities related to black women and girls’ health in comparison to other populations within the nation includes:

(a) Centralizing the experience of freedom, understood as having choice and agency, combined with conceptions of the common good, social justice, and queer theory, to inform reflection on public health ethics in regard to black women and girls.

(b) Countering theo-cultural ideas about women’s roles and persisting conceptions and practices of anti-black racism, giving special attention to dismantling ideation of black women as servants.

(c) Federal health agencies and private entities undertaking practices that support policymaking that is ethically relevant to ensuring the well being of black women and girls; federal health agencies collaborating with significant entities in black communities to develop strategies that counter traditional ideas about roles of women and girls, including looking beyond habitual alliances and partnerships; and federal health agencies countering reasons for distrust of health care institutions among black communities.

(d) Black women and girls exercising choice and agency to overcome limits on their freedom arising from boundaries imposed by inherited or established patterns, habits, and relationships.

(e) Federal health agencies and other social entities seeking to counter cultural legacies that support exclusion through stigmatization of persons and groups on the basis of sexual identity, religious affiliation, social class, educational achievement, race, and other factors.

In addition to what has been stated above, the call to do things differently and develop new, creative approaches to public health work is an ever present challenge as new

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Footnote:

⁸This topic relates to Discussion Questions Four and Five: “What must be emphasized or changed in our current practice to ensure that public health practitioners, researchers, and policymakers plan and implement ethical public health interventions, policies and research?” and “What resources are needed to build capacity for addressing ethical issues that impact public health practice, research, and policies relating to women’s health issues?” See Panel Discussion Guide, 2017 Public Health Ethics Forum, Centers for Disease Control and Prevention.
realities delegitimize once successful older strategies. Ongoing work to build relationships with and receive insights from persons who do not ordinarily participate in public health ethics conversations is important. Ensuring this should include both developing personnel responsible for building relationships with such persons and groups, and developing contexts of hospitality and mutuality with a view toward expanding both insights from diverse communities and the impact of the community’s insights on ethical public health practices. It may not be taken for granted that personnel with public health competencies also have appropriate cultural competencies. As indicated earlier, significant resources are needed to address gaps in culturally relevant knowledge and sensitivity among traditional as well as non-traditional public health workers. Moreover, relationship building need not be limited to information gathering or dissemination of agency resources and work.

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Centers for Disease Control and Prevention. (2017). *Public health ethics forum: optimal health for her whole life*, flyer. The forum is hosted jointly by the National Center for Bioethics in Research and Health Care at Tuskegee University and the Office of Minority Health and Health Equity at the Centers for Disease Control and Prevention (CDC).


Articles


Women’s Sexual Health: Ethical and Health Equity Considerations in Assessing Public Health Interventions

Shauntā S. Wright, MPH
Health Scientist
Program Development and Quality Improvement Branch
Division of STD Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
1600 Clifton Road, Mail Stop E-27
Atlanta, GA 30329-4027
Tel: 404-639-6209
Email: sswright@cdc.gov

Drue H. Barrett, PhD
CAPT, US Public Health Service
Lead, Public Health Ethics Unit
Office of Scientific Integrity
Office of the Associate Director for Science
Centers for Disease Control and Prevention
1600 Clifton Road, Mail Stop D-50
Atlanta, GA 30329-4027
Tel: 404-639-4690
Email: dbarrett@cdc.gov

Kathy Kinlaw, MDiv
Associate Director
Program Director, Ethical Engagement in Health and Science
Emory University Center for Ethics
Assistant Professor, Pediatrics
1531 Dickey Drive
Atlanta, GA 30322
Tel: 404-727-2201
Email: kkinlaw@emory.edu

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

In the United States disparities exist in many areas related to women’s sexual health throughout the lifespan. This paper reports findings from a conference session on women’s sexual health at the 2017 Public Health Ethics Forum on women’s health, “Optimal Health for Her Whole Life,” hosted by the National Center for Bioethics in Research and Health Care, Tuskegee University and the Office of Minority Health and Health Equity, Centers for Disease Control and Prevention (CDC). The session and the overall conference emphasized the concept of health equity and the value of utilizing public health ethics frameworks in addressing women’s health. In this paper, we discuss the need for accurate, engaging information about sexual health, focusing on two components of women’s sexual health: sexually transmitted diseases (STDs) and unintended pregnancy. Short and long-term options for addressing this need are considered, with a particular focus on the utilization of social media campaigns. An initial analysis of the ethical considerations in the use of social media campaigns is provided. The importance of a commitment to community engagement in the context of such interventions is also discussed. Sexual health concerns, such as STDs and unintended pregnancy, and public health interventions being considered in addressing these concerns would benefit from an ethical analysis of short- and long-term intervention options, with particular attention to issues of health equity and disparities.

Keywords: Women’s sexual health, health equity, health disparities, public health ethics, public health, social media

Introduction

In order to further discussion about women’s health issues, on May 19, 2017, The National Center for Bioethics in Research and Health Care at Tuskegee University and the Office of Minority Health and Health Equity at the Centers for Disease Control and Prevention (CDC) hosted the 2017 Public Health Ethics Forum, “Optimal Health for Her Whole Life.” The goals of the Forum were to highlight public health ethics challenges associated with improving women’s health, particularly women vulnerable to health disparities; examine the unique health needs of women at all stages of the life cycle; and identify protective factors that support holistic health across the life span. The Forum also focused on reframing public health approaches to women’s health to ensure that a health equity framework is applied and that ethical issues, social determinants of health, and systems barriers are considered as part of public health interventions. The Forum tackled a variety of women’s health issues and held small group sessions to further explore these issues. The small group session on women’s sexual health included seven women’s health subject matter experts, two facilitators and one recorder. The seven participants included representatives from public health nonprofits, community based organizations, academic institutions and a public health contracting agency. The session was co-facilitated by Kathy Kinlaw, an academic ethicist from Emory University’s Center for Ethics, and Shauntá Wright, a Health Scientist from CDC. Dr. Drue Barrett, lead of CDC’s Public Health Ethics Unit, served as recorder for the breakout session. This paper provides a summary of the breakout session discussion of women’s sexual health.

The World Health Organization (WHO) defines sexual health as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” and “requires a positive and respectful approach to
sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled (WHO, 2008).” In the small group session, we focused on sexual health issues related to sexually transmitted diseases (STDs) and unintended pregnancy.

Utilizing a health equity framework to address optimal sexual health in women warrants an understanding of the social determinants that influence women’s health. The WHO Commission on Social Determinants of Health Conceptual Framework accounts for the impact of socioeconomic and political contexts associated with ethnicity/race, social position, education, occupation, income and gender on the health care system, in relation to the distribution of health and well-being (Solar & Irwin, 2010). Social determinants of health and health disparities add to the complexity of both understanding and implementing public health actions. For example, in the area of STD prevention, it has become clear that social factors such as poverty, lack of access to quality STD services, homelessness and unstable housing join individual risk behaviors such as inconsistent condom use to increase a woman’s risk for acquiring a sexually transmitted infection (Hogben & Leichliter, 2008).

In the United States, there are glaring disparities related to women’s sexual health, particularly in adolescents and African Americans. According to prevalence and incidence estimates, adolescents and youth aged 15-24 years account for half of all new STD cases (Satterwhite et al., 2013). It is estimated that 1 in every 4 sexually active adolescent females aged 15-19 years has an STD (Forhan et al., 2009). This has substantial implications for women’s health. For example, cervical complications including Pelvic Inflammatory Disease (PID), are a major cause of infertility, chronic pelvic pain and ectopic pregnancy (Oakeshott et al., 2010; Scholes et al., 1996). Adolescents and young adults aged 15-24 years have the highest reported cases of gonorrhea. Surveillance data show that chlamydia rates are 5.4 times higher in African American women than in non-Hispanic Caucasian women. Gonorrhea rates in African American women are 9.6 times higher than in non-Hispanic Caucasian women (CDC, 2016). Young non-Hispanic Caucasian, non-Hispanic African American and Hispanic women aged 18-24 have the highest rates of unintended pregnancy (Finer & Zolna, 2014). Negative outcomes associated with unintended pregnancy include premature delivery (Kost, Landry, & Darroch, 1998), low birth weight (Orr et al., 2000), and physical violence in pregnancy (D’Angelo, et al., 2004).

Public Health Ethics Forum Sexual Health Session

The goals of the sexual health session were to identify potential issues, risk factors, harms and concerns impacting the sexual health of women and girls in the United States; to begin to consider short- and long-term options for addressing these impacts; and to identify and discuss ethical considerations relating to the intervention options. The session began with the facilitators providing an introduction to the field of public health ethics and the process of ethical analysis, as well as information on two sexual health topics: STDs and unintended pregnancy. The facilitators then guided a discussion of potential issues which may be impacting women and girls’ sexual health.

The issues identified by the meeting participants fell into three broad categories - health-related concerns, the impact of social media and other communication sources for
accessing information about sexual health, and the impact of cultural norms. A variety of health-related concerns were identified. Topics of most concern were the impact of unintended pregnancy and teenage pregnancy, STDs, and sexual violence. Participants felt that social media could be an effective strategy in the effort to effectively communicate to adolescents and young adults about STDs and unintended pregnancy. Also mentioned were the impact of menopause on the sexual health of older women and issues surrounding access to contraception for women of childbearing age.

The discussion of social media and communication issues focused on the need for reliable and trusted sources of information about sexual health, especially for young adults. There was concern about where information is being obtained, and a sense that many parents are uncomfortable talking about sex with their children, who then turn to other sources for this information, typically social media sources. The session participants agreed that there is an important role for public health in ensuring access to sexual health information that is conveyed in a manner that is understandable, relatable, and engaging. It is also important to ensure that the appropriate science is conveyed and translated so that the information is useful for a broad range of ages.

The role of culture, including peer pressure, was also explored. This included a discussion of how cultural norms impact sex education and how messages about healthy sexual behaviors are communicated. However, the impact of culture was also explored more broadly in terms of how societal or cultural norms impact sexual behaviors and societal expectations regarding appropriate gender roles. The discussion focused on the impact of peer norms and peer pressure. It was pointed out that adolescents and young adults are heavily influenced by their peers and that this presents opportunities as well as risks for conveying information about healthy sexual behaviors. Questions were also raised about the role of governmental policy and the impact of religion on messages related to women's sexual health. Participants were concerned about judgmental messages from religious leaders and how those messages may shape the behavior of adolescents and young adults.

**Ethical Analysis**

The session emphasis on individual sexual health and preventive practices led to a broad conversation about risk factors and issues of concern, such as access to care, cultural norms around sex education, faith-based approaches to sexual health, peer norms and influence, and information-seeking behavior of adolescents and young adults. Session participants then utilized a public health ethics framework to further analyze these issues.

CDC defines public health ethics as “a systematic process to clarify, prioritize, and justify possible courses of public health action based on ethical principles, values and beliefs of stakeholders, and scientific and other information” (CDC, 2015). A public health ethics framework ensures that public health actions are not only ethical, but also includes scientific information to support the approach. Health equity is defined as existing when all populations have “the opportunity to attain their full health potential” and no one is “disadvantaged from achieving this potential because of their social position or other socially determined circumstance” (Braveman, 2003). Utilizing a health equity lens to view women’s sexual issues places public health advocates in a unique position to address this complex issues in an equitable manner.
Numerous methodologies exist for ethical analysis in clinical ethics decision making (Beauchamp & Childress, 2012). The evolution of frameworks for ethical analysis in public health has occurred more recently, with an increase in proposed approaches over the last 2 decades (Marckmann et. al., 2015; Upshur, 2002). Public health ethics frameworks typically share elements that focus on identifying the public health goals, considering stakeholder values, identifying the risks and the harms and balancing them against the benefits, ensuring that benefits and burdens are fairly distributed, and respecting individual as well as community interests (Kass, 2001; Bernheim, Neiburg & Bonnie, 2007; Ortmann et al., 2016).

During the discussion about sexual health, facilitators and participants adopted a process of identifying possible short-term and long-term options for action around a specific issue impacting the health of women, including adolescents, in the United States. Meeting organizers requested that this approach be utilized to ascertain whether the group could identify short- and long-term intervention options that reflect particular public health ethical principles in a 60 minute discussion session (see Figure 1). To guide discussion, facilitators asked participants questions to garner ideas about potential benefits, harms, utility, health equity and distributive justice.

**Figure 1.** Process for ethical analysis of proposed options for addressing public health issues.

The example discussed by the session participants focused on concerns about unintended pregnancy, sexually transmitted diseases, and sexual violence. Though these were identified as distinct issues, the group identified that one general option for response to all of these issues was the need for accurate, engaging information about sexual health, especially for young adult women.
Identification of Short-term and Long-term Options

The discussion of short- and long-term options focused on one suggested response - to convene a wide range of stakeholders who are committed to improving access to information about sexual health. The stakeholders would be tasked with developing a common language, identifying communication gaps, and developing a targeted social media campaign about sexually transmitted illnesses and healthy sexuality for adolescents and young adults.

Several possible short-term intervention options were explored. These included use of a social media messaging campaign in schools where an increase in sexually transmitted illnesses has been identified. One advantage of this approach is that it would allow targeting of young adults who are most in need of information. Social media offers a promising avenue to deliver public health information, particularly for disease prevention (Stockwell et al., 2012; Wong, Merchant, & Moreno, 2014). However, social media platforms may have a negative outcome if it results in a false sense of privacy leading to riskier behaviors and discussion about sex, violence and drinking, combined with less parental monitoring (Borzekowski, 2006). There are potential harms and ethical implications associated with targeted communication strategies (e.g., privacy issues, stigmatization). Thus, participants felt that use of this strategy would need to be carefully considered and justified. Participants indicated that it would also be important to engage the community to obtain their input on the communication strategy.

A second short-term intervention option was to develop a parent-child communication program that would help parents talk with their children about sex. This approach emphasizes the importance of the role of parents in providing a foundation for healthy sexuality before their children are bombarded by other sources of information. Many parents do not take an active role in discussing sexual health with their children and often do not begin discussions until after puberty (McNeely et al., 2002). Parents are reluctant to discuss sexual health with their children for several reasons, including fear that discussing sex will encourage sexual activity, the child is too young to discuss it and the parent may disclose too much about their own sexual past as a result of the discussion (Schuster, Eastman, & Corona, 2006). An example of a communication intervention is the “Parent University” which is a community-based project that focuses on helping parents overcome barriers so they can communicate more effectively with their children (Reform Support, 2014).

A third short-term intervention was to build a discussion of healthy sexuality into information that pediatricians discuss during office visits. If this approach was pursued, there would need to be a consideration of whether physicians are considered to be trusted sources of information about sexual health. Use of this approach would raise health equity questions for young women without access to routine medical care.

Participants felt that long-term options should focus on learning from efforts that have examined effective communication approaches and conduct studies that identify messages that will have long-term impact. Participants expressed that in order to have a lasting impact, public health advocates should use terms such as “employment” and “education” instead of “health equity” and “health disparities”, which may not be relatable to adolescents and young adults. Participants also indicated that more research is needed to identify culturally appropriate messages that will work for adolescents and young adults. Due to time constraints, group
discussions did not identify a list of long-term options. Participants stated that they needed more time to thoughtfully consider the ethical implications.

**Ethical Considerations for Social Media Campaigns**

The session participants explored the ethical considerations for using a social media campaign “targeting” young adult women. The initial ethical principles identified for analysis by session participants included: beneficence, non-maleficence, equity, and utility. A social media campaign approach could then be assessed according to the effectiveness of the campaign in addressing each ethical principle. How effective would the social media campaign be in providing benefit, both to the individual young adult woman and to the larger population or community of young women addressed? Would a social media campaign have potential for causing harm? What campaign components would cause the least harm or risk of harm to the individuals “targeted” in the social media campaign? What would be the risk for harm from the campaign to the community of young adult women as a whole? From a utility perspective, would a social media campaign be effective in providing a greater balance of benefit over harm? And would a campaign promote just and fair inclusion? Inherent in this analysis is the ability to balance individual and community interests, respecting individual interests and decision making while promoting the good of the community at large. Figure 2 the group’s initial discussion/ethical analysis of the use of a social media campaigns to target healthy sexuality messages to young adult women.

**Consideration of Relevant Principles:**

**Beneficence** *(effectiveness of the option in providing benefit):*

- The intervention would be a community-based effort with a large outreach that could be delivered in a short amount of time at a relatively low cost
- It would provide young adults with access to relevant and accurate health information that they can use for decision making about healthy sexual choices
- Young adults are familiar with and extensive users of social media

**Non-maleficence** *(risk of harm):*

- Possible risk of increasing distrust in public health messaging if the intended audience suspects or fears that they are being unduly influenced or that their behaviors are being monitored
- Social media messages on healthy sexuality may not be effective for young adults with low health literacy

**Equity/Justice** *(health equity advanced/benefits and burdens fairly distributed):*

- It may be difficult to target all relevant groups due to uncertain access to social media (e.g., homeless youth)
- It is important to ensure that messages are linguistically and culturally-appropriate for all audiences
- It will be important to provide messages about health sexuality early and often

**Utility** *(balance of benefits over harms):*

- Use of social media could be a powerful intervention for increasing healthy sexuality if it is combined with other approaches that improve health literacy and it reaches groups who do not have access to social media
- The benefits of the social media intervention could be increased by including young adults in planning and implementation efforts

*Figure 2. Process of ethical analysis for use of a social media campaign to target healthy sexuality messages to young adult women.*
Structural interventions, such as technological, policy, economic and environmental changes have been employed to address complex factors that influence sexual health (Satcher, Hook, & Coleman, 2015). Social media platforms and information technology have been used as strategies to implement sexual health behavioral interventions in adolescents (Lassi et al., 2015). Innovative digital media remove geographic barriers and provide opportunities for sexual health education programs to be performed using websites, text messages and apps (Guse et al., 2012).

For adolescents and young adults, access to relevant and accurate health information can aid in decision making (Eng et al., 1998). The benefit of using social media campaigns is that it would be a community based effort that would allow for a large outreach at a relatively low cost. Social media has the potential to reach thousands, if not millions of users in a short time span (Jones et al., 2014). A potential risk would be the possibility of lack of adolescent participation if there was concern that the social media site was being used to collect data about their behaviors. The group raised concerns about equity issues, suggesting that it may be difficult to target all relevant groups as some may not have access to social media, particularly homeless youth. While access to social media in homeless youth was a concern for session participants, technology-utilizing HIV interventions have been used to reach homeless adolescents (Arnold & Rotheram-Borus, 2009). Young people between the ages of 12 and 24 years are the most extensive users of new technology, in comparison with adults over 25 years, and are more likely to be connected to virtual environments, regardless of race, ethnicity or socioeconomic status (Berry, 1997; Landry et al., 2015). For adolescents and young adults to make effective use of sexual health information from social media, they must have appropriate health literacy (Gray et al., 2005); thus, the intervention would need to be part of a larger approach that included other ways of educating and reaching adolescents. One primary takeaway was the importance of using language that young women understand and that messages need to be given early.

A commitment to community engagement was a recurrent theme in the discussion. Involving women, including young adults and adolescents, in the discussion, planning and implementation of options for addressing sexual health is an essential component to an ethical response. Having the voices of those most affected “at the table” from the beginning is critical in building a partnership of change that has integrity. Additionally, staying in partnership and developing trust through respectful relationship-building and transparent communication provide a potential foundation for exploring the sensitive issues and real life complexity of an issue such as sexual health. Respect for those most affected by the potential options for change requires eliciting what aspects of sexual health are of most concern and value to members of the community. What options for action seem most relevant and feasible for the women involved? Where would there be lack of consensus about this among women in the community? Any real sustainability of resulting recommendations will be informed by this level of engagement, discussion and growing trust.
Conclusion

The session on women’s sexual health at the 2017 Public Health Ethics Forum on women’s health highlighted the impact of sexual health disparities in women and pointed to the need to include sexual health as part of the overall discussion about the health of women. Most importantly, the discussion highlighted the benefits of applying an ethical analysis framework when interventions are under development to ensure fairness and to proactively address ethical issues.

This paper highlights one process that can be used to initiate an ethical assessment of options for addressing sexual health issues. Additional public health ethics frameworks can be utilized to deepen this analysis. The short time duration of the session (60 minutes) limited the ability of the group to delve into the ethical issues. With more time and meaningful discussions, the group could have identified potential intervention implementation partners, assessed intervention feasibility and proposed short- and long-term outcomes for the intervention options.

Most public health initiatives in communities are built on relationships and trust. The ethical analysis process should entail a community-engaged approach, involving community members most affected by the public health issue. Meaningful community engagement is essential for implementation of any option. This ethical analysis framework can be used across various public health programs to examine proposed public health interventions. Further exploration is needed to apply the model and to identify practical examples of how public health professionals balance programmatic needs with ethical considerations.

The discussion also highlighted the important role of social media in our daily lives, and perhaps especially in the lives of adolescents and young women. The prominence of social media offers important opportunities for general health and sexual health messaging to adolescents and young adults and needs to be further explored as a powerful public health tool. More information is needed to ascertain whether, and how, social media communication has a long-term impact on health behaviors, especially among young adults.

The authors hope this discussion will encourage others to continue exploring how applying public health ethics and health equity perspectives can enhance public health interventions and improve women’s health outcomes.


Intersectionality, Dignity and the Value of Stories

Ann Gallagher, Ph.D, RN
International Care Ethics Observatory,
University of Surrey, Guildford, Surrey, GU2 7XH, United Kingdom
Phone: 01483 68 9462
E-mail: a.gallagher@surrey.ac.uk

‘There is no agony like bearing an untold story inside of you’ (Maya Angelou)

It is not, in my view, possible to think about women’s health without thinking about care. Care is both an attitude and an activity. It is something we feel and something we do. All of us have had experience of receiving care, even if the care was not ideal. Many of us have been care-givers informally (in families) or formally in care services. Women have a particularly important role in care-giving and, whilst this is a privilege, there are also challenges in terms of the cost to women’s own health and the societal devaluation of care work.

I was invited to submit a commentary to this special issue as I was coming to the end of a two month sabbatical in the National Bioethics Center for Research and Healthcare at Tuskegee University. My experience has taught me to appreciate the significance of history and culture and the value of scholarship relating to intersectionality, identity and privileged irresponsibility. These topics are central to much of the discussion in the articles here.

My area of expertise is in ethics as applied to health and social care. I coined the term ‘careism’ to refer to ‘negative and devaluing attitudes’ directed towards those who work in care services (Gallagher 2017). I argued that:

…care workers are diverse in terms of culture and race, but they are mostly female and working class. There is a view that anyone can deliver care (particularly if a woman). This group of workers is in a unique position to experience the quadruple-whammy of sexism, racism, classism and careism.

I am a white Irish woman from a working class background, living in England and working as a Professor of Ethics and Care. I have engaged in research and scholarship relating to topics such as dignity in care, professionalism and fitness to practise. There are a wide range of philosophical options regarding approaches to ethics in care. One which has gained momentum in recent years is ‘care ethics’, also known as ‘ethics of care’. This approach focuses on the quality of relationships and on concepts such as vulnerability, dignity and care (Gallagher 2017). American philosopher, Joan Tronto, has argued that ‘we cannot understand an ethics of care until we place such an ethic in its full moral and political context’ (1993 p.125).

A concept that Professor Tronto develops in her work, that has much resonance here, is that of privileged irresponsibility. By this is meant ‘ways in which the majority group fail to acknowledge the exercise of power, thus maintaining their taken for granted positions of privilege’ (Bozalek 2014). Tronto (1993 p.120-1) writes of privileged irresponsibility as:

Those who are relatively privileged are granted by that privilege the opportunity simply to ignore certain forms of hardship that they do not face.
She goes on to argue that the privileged do not feel the need to know about the lives of those who are ‘subjugated’. People who are privileged do not take responsibility for caring practices getting, what she refers to, at a ‘free pass’ out of taking care responsibilities for themselves or others (Tronto 1993 p.70).

It has been suggested that privileged irresponsibility is maintained by processes of inferiorisation, interiorisation and othering. By inferiorisation is meant that “marginalised groups are constructed as mentally, physically or emotionally inferior to the accepted norm, and found to be ‘wanting’ or ‘less than’ the norms in various ways” (Bozalek 2014 p.59). Interiorisation happens when people ‘who are subjugated accept, uncritically embrace and collude with the way that they have been negatively construed by those in privileged positions/dominant culture’ (ibid). By othering is meant the ‘way in which the marginalised are illegitimated by being regarded as ‘them’ (objects) rather than as ‘us’ (subjects)” (ibid). To address privileged irresponsibility, Vivienne Bozalek (2014) (Professor of Social Work at University of Western Cape, South Africa) describes the implementation of educational projects that brings together Black and non-Black students so they can see each other as ‘both similar and different’ (p.65) and where privileged groups can overcome ignorance ‘of the suffering of these groups, due to their remoteness from these groups’ (p.67).

The stories that are the focus of most of the articles in this special issue have the potential to enhance knowledge of the predicament of women who are marginalised. If reflected upon meaningfully by privileged readers, they also have the potential to reduce privileged irresponsibility.

Philosopher, Alasdair MacIntyre (1981) wrote that ‘I can only answer the question “what am I to do?” if I can answer the question “of what story or stories do I find myself a part?”’ The stories inform us as to how things are for some women as well as how things could and should be. Sociologist, Arthur Frank (2010), commented on the value of stories as follows:

Stories animate human life; that is their work. Stories work with people, for people and always stories work on people, affecting what people are able to see as real, as possible, and as worth doing or best avoided.

This special issue showcases some of the many interesting contributions to the May 2017 Public Health Ethics Forum which had the theme of ‘Optimal Health for Her Whole Life’. The six articles in this issue focus on stories about women, stories that illuminate the diversity, complexity and the dignity of women’s lives in America.

Dr. Vivian Pinn gave the keynote lecture and provides a personal perspective in this issue, on the topic of ‘Lifespan Issues of Health for Girls and Women in the 21st Century.’ Her discussion is wide-ranging and reminds that women’s health status differs depending on their race, culture, class and immigration status. Dr. Pinn rightly points to the limitations of the ‘traditional biomedical model and to the need to understand interactions amongst disparities related to biology, environment, discrimination and health behaviours, She draws to our attention the development of ‘precision medicine’ which considers variations and interactions amongst individuals’ genetics, environment and lifestyle. We are left in no doubt as to the complexity of public health challenges and of the need for a range of preventive and information interventions to respond adequately. An important argument she makes is that
'women must learn to be ‘self-caregivers’ as well as ‘caregivers’. That is, they need to learn to look after themselves if they are to have the capacity to care for others.

The next three articles are based on the plenary session entitled ‘Women’s Health and the Intersection of Context, Inclusion and Public Health Practice’. Dr. Judith Monroe’s article illuminates ‘Rural Women’s Health’. She is an authoritative voice given her credentials as a practicing physician in rural America, as state health officer in Indiana, as a CDC leader and CEO of the nonprofit CDC Foundation. Dr. Monroe details challenges encountered by women in rural communities. She shares the story of a much loved physician friend who died of a heart attack and who, along with many other women, had put her own health ‘on the back boiler’.

Dr. Monroe’s practice, working with women in rural areas, highlights the importance of cultural and biological explanations for ill-health and the disproportionate responsibility assumed by these women for the health of others. She notes the gender bias of women in her own family who had different expectations of boys and girls. In drawing attention to Goal 5 – achieve gender equality and empower all women and girls - of the United Nations Sustainable Development Agenda 2015, Dr. Monroe connects the American to the global women’s health agenda (see http://www.un.org/sustainabledevelopment/gender-equality/ ). She also emphasises the importance of patient-centredness (‘start where the patient is at’ ) and discusses the values and principles that underpin public health practice. Values that include: respect for autonomy, patient welfare, justice, beneficence and non-maleficence. Dr. Monroe’s article promotes the importance of collaborative and empowering approaches that require the engagement of government, church, private and non-profit organisations and peer and community support initiatives.

The article by Dr. Rosetta Ross, Professor at Spelman College, is entitled ‘Optimal Health for Their Whole Lives: Reflections on Social Ethics and Black Women’s Health’ assumes an approach to public health ethical analysis that ‘centralises choice and agency.’ Her responses to five question areas highlight concerns and constructive analyses that have both local and global importance. Dr. Ross helpfully discusses public health ethics as a ‘social ethics’ and reminds readers of the CDC definition of public health ethics as ‘a systematic process to clarify, prioritize, and justify possible courses of public health action based on ethical principles, values and beliefs of stakeholders, and scientific and other information.’ Her article integrates practical and philosophical issues relating to health inequities and social structures. Dr. Ross introduces additional values for consideration such as freedom, solidarity and neighbourly love. She critically discusses the perceptions and impact of Black women’s caregiving and makes connections with ‘service’ and ‘servanthood’. Dr. Ross also highlights the detrimental consequences of women putting their own health needs ‘on the back boiler’ and the historically exploitative nature of some health care agencies (giving the example of Henrietta Lacks). Her arguments focus on the need for Black women and girls to exercise choice and agency and to challenge stigmatising and stereotypical assumptions about, for example, servanthood and binary approaches to sexual identity.

The third contribution from the panel is from Dr. Kathleen Yep, Associate Dean of Core Faculty and Professor at Pitzer College of the Claremont Colleges, and is entitled “You ARE Worth Something”: Feminist and Community-Driven Palliative Care Among Asian Immigrant and Refugee Women Elders. Dr. Yep draws on 8 years of participant observation research with elder immigrant and refugee women attending an adult literacy programme at
a public library in Los Angeles. The story of ‘Lisa’ illuminates most clearly and poignantly the everyday issues that arise for women as they negotiate the intersection of gender, race, class, ageing and disability. Similarly, the story of Joan who wrote an imaginary letter to her husband reflecting on the challenges and efforts required to move from Asia to live in a ‘new country’. Dr. Yep’s ethical focus is on listening ‘to the voices of marginalised women.’ The collective women’s poem included by Dr. Yep demonstrates the courage and determination of these women of different cultures and the value of being together. As she concludes: ‘Understanding our biases and essentialist framing of culture and women and girls will contribute to more ethical and effective practices, research and policies such as fostering culturally-relevant and accessible palliative care to women and girls.’

The article by Ms. Shauntā Wright, Dr. Barrett and Ms. Kinlaw, was derived from the concurrent session on the theme of ‘Improve Individual and sexual health and preventive care practices.’ Ms Wright is a Health Scientist at the CDC National Center for HIV/AIDS, Viral Hepatitis, STD and Tuberculosis Prevention in the Division of Sexually Transmitted Disease Prevention. The article ‘Women’s Sexual Health: Ethical and Health Equity Considerations in Assessing Public Health Interventions’ focuses on two aspects of women’s sexual health: sexually transmitted diseases (STDs) and unplanned pregnancies. Dr. Wright and colleagues cite statistics that demonstrate a significantly higher rate of STDs and unplanned pregnancies amongst African American and Hispanic women. The article details findings from a public health forum that brought together seven public health officials and two facilitators (one an ethicist). Dr. Wright and colleagues discuss three themes from the discussion: health related concerns, the impact of social media and other communication, and the role of cultural norms. The authors supplement the CDC approach to public health ethics with a ‘health equity lens’ which relates to people’s opportunity to ‘attain their full health potential’ unhindered by disadvantage from their social position. Innovative interventions, utilising social media, are detailed to reach young people in need of information. The development of a ‘parent university’ to facilitate conversations between young people and parents is also discussed. Regarding ethical considerations relating to the social media intervention, the values of beneficence, non-maleficence, utility and equity are applied. The authors suggest the benefits of more time being devoted to the discussion of ethical aspects of sexual health issues. Although there is no reference to explicit stories of people, there is emphasis on tailoring interventions to the needs of particular people in terms of age and housing situation.

The fifth article in this issue is by Dr. Moni MacIntyre and is entitled ‘Religion, Ethnicity, and Identity: The Role of Race/Ethnicity, Sex/Gender and Class in Identity Formation’ begins by focusing on what humans have in common – membership of the earth community - as opposed to the ways in which they are different. Dr. MacIntyre highlights the importance of ‘identity’ in giving our lives meaning and details the process of identity formation that includes elements of race/ethnicity, class, sex-gender and gender which overlap. The systems of stratification is called ‘intersection theory’ by sociologists and can include, MacIntyre points out, a ‘consideration of colliding identities’. She discusses aspects of gender diversity and how this might intersect with the racial identity of young people. She adds to this the impact of social class on these other aspects of identity. Dr. MacIntyre concludes that a focus on materialistic success is likely to be short-lived and, echoes Junger, in arguing for humans to get back to their tribal identity. She writes "To look beyond and appreciate our differences as we recognise our common origin is perhaps our only hope".
All six articles in this issue illuminate important aspects of women’s health. They urge us to reflect sympathetically on the predicament of younger, older, marginalised and seemingly privileged women. They remind us of the self-sacrifice of women who put others before themselves and who put their own health on ‘the back burner’, sometimes with fatal consequences.

The stories shared reveal the dignity or worth of all of the women who engaged with the authors and of the many referred to whose life stories had been heard and who may have struggled to reconcile the intersecting components of their identities. The dignity that is writ large in these stories is ‘human dignity’ (what Nordenfelt refers to as menschenwürde), the dignity that underpins international human rights declarations and is the intrinsic value placed on all humans just because they are human. A second type of dignity that is most prominent here is ‘dignity of identity’. Nordenfelt (2004) writes of this type of dignity as particular to the individual and to the integrity of their body and mind and can be dependent on self-image. Respecting dignity of identity involves finding out what matters to a person and what enables and inhibits their feeling of worth and value. To find out what matters to women we need to take the time to ask. In one of the earliest dignity studies we conducted in England, I asked an older woman ‘what does dignity mean to you?’ She said ‘it means having a saucer with my cup’. This culturally specific response could not have been guessed at. The moral is, if you want to know what matters to people, ask them.

The authors of the six articles demonstrate a high level of sensitivity to the specific situations of the women and girls they write about and to their dignity. They are very obviously committed to improving the individual and social circumstances of the women and recognise the importance of individual values of autonomy and freedom communitarian values of utility, solidarity and social justice. The theme of the 2017 Ethics Forum ‘Optimal Health for her Whole Life’ stimulated high quality outputs with a high level of ethical analysis.

As Frank suggests, the stories here do ‘animate human life’ and it seems likely that they will ‘work with people, for people’ and it is hoped ‘on people, affecting what people are able to see as real, as possible, and as worth doing or best avoided.’

The contributions suggest gaps in health provision for women, particularly those in rural areas and those who are considered marginalised. The contributions also suggest innovations and strides that have been made to improve health.

Bioethics has potential to offer further illumination of the issues focused on in these six powerful contributions. It has been suggested, for example, that the activities of bioethics could include the 3 A’s of: academia, advocacy, and activism. This can be traced to a bioethics blog in 2015 drawing from a talk by Mimi Arbeit which was entitled ‘What are we ready to risk? Academia, advocacy, and activism’. These concepts are also discussed by Eckenwiler and Cohn (2009) in The Ethics of Bioethics: Mapping the Moral Landscape and in Ten Have’s (2016) Global Bioethics: An introduction. He writes of ‘advocacy and activism’ as follows:

These activities were until recently not condoned in bioethics (as political not academic). Now they are necessary if global bioethics wants to be more than studies and books. They are often initiated by a few individuals (like most NGO’s
have started). They help to transform moral dissatisfaction into movements and organisations that structurally challenge existing practices. Systemic failures cannot be addressed by individuals alone. Sometimes, advocacy and activism require blaming and shaming, leaving aside nuanced and subtle language, to identify the root causes of global problems.

Insights from academia in bioethics and related disciplines provide the means to reflect critically on the stories relayed in the six articles. In some articles reference to bioethical principles and values (for example, respect of autonomy, beneficence, justice and solidarity) is made explicit. Drawing on human rights theory and principlism has then particular value in providing direction for ethical responses to disparities in health. Sociology and feminist theory also illuminates issues that are related and yet, too often, considered to be disconnected. Intersectionality, as discussed by Dr. MacIntyre in this issue, is a particularly helpful lens that draws attention to how gender ‘intersects with other identities and how these intersections contribute to unique experiences of oppression and privilege’ (Association for Women’s Rights in Development – AWID - 2004). In addition to the intersection of race/culture, class and gender it is also necessary to consider the experience of being, for example, older, disabled, lesbian and poor. It is helpfully pointed out that:

Intersectional analysis posits that we should not understand the combining of identities as additively increasing one’s burden but instead as producing substantively distinct experiences (AWID 2004).

This underlines the importance of the research and scholarship that underpins the six contributions to this special issue. Listening to and retelling the women’s stories both acknowledges the value of intersectionality as ‘a tool for gender and economic justice’ (AWID 2004) and also underlines the importance of both human dignity and dignity of identity.

The articles also cause us to reflect on our privilege and to consider, if, in our sphere of practice and influence there exists privileged irresponsibility. Are we aware, for example, of processes of inferiorisation, interiorisation or othering? Is there need and potential for us to follow the example of Vivienne Bozalek (2014) and bring together Black and non-Black students and practitioners so they can see each other as ‘both similar and different’? (p.65). We should consider also what educational and practice innovations are best placed to develop empathy in those who deliver care?(Gallagher et al 2016). None of us should claim ignorance of the suffering of these groups, due to their remoteness from these groups'(Bozalek p.67).

As I draw this commentary to a close I am reminded of the initial quotation from Maya Angelou – ‘There is no agony like bearing an untold story’. Stories of women who are marginalised and who struggle, as in these articles, need to be told. And more, they need to be acted on. Activism and advocacy are two concepts too little referred to in mainstream bioethics and yet they present here in abundance. All of the contributors demonstrate a commitment activism and advocacy to improve the health of women.

The articles in this special issue should be read and taken seriously by all. The optimal health of women throughout the lifespan is of the utmost importance. The consequences of bringing it about will not just benefit women but rather whole populations – women and men - around the globe. Everywhere, the attitude and activities of care are required.
References


Gallagher A. (2017a) ‘Care Ethics and Nursing Practice’ (Chapter 15) in Scott A. Key Concepts and Issues in Nursing Ethics, Springer


Book Review

Economic Ethics & the Black Church
Wylin D. Wilson, Ph.D., Author

David Augustin Hodge, Sr., D.Min., Ph.D.
Associate Director of Education and Senior Associate Editor of the
Journal of Healthcare, Science and the Humanities at The National Center for Bioethics in
Research and Health Care at Tuskegee University
Tel: (334) 724-4564
Email: dhodge@tuskegee.edu

Wylin Wilson’s nascent attempt at putting forth a normative ethical argument that intersects economics and the Black Church stands at the precipice of being both a black theology of liberation and a Christian ethics manual. She borrows from both to construct a social scientific exposition and commentary on black rural America. Wilson skillfully uses the tools of the social sciences to analyze and evaluate the present state of affairs of rural Macon County, Alabama, while offering a critique of how the Black Church has either employed (or resisted) charity or liberation models. By choosing rural Alabama, an American sector that’s both poor and black, Wilson ideologically cements herself similarly to the Latin American milieu of a half a century ago when Gustavo Gutierrez, Jose Miguez Bonino, Juan Luis Segundo, et. al. wrote prolifically about the economic perils of the poor and the base-Christian communities’ response. Without stating this directly, she enjoins herself as a defender of the poor, “needy,” economically oppressed, with the Latinos mentioned, the 8th and 7th Century prophets, black and womanist theology and Jesus as she posits the salient questions: “How are we to care for the most vulnerable citizens who cannot contribute to production and are limited in terms of consumption? Who owns and controls the means of production? What are our responsibility to the poor?” (p.72). Although she gives no metaethical argument for how the reader should formulate a theory that would respond to these questions, Wilson does craft a normative “Christian economic ethic” that seems to be an amalgamation of Christian ethics, virtue ethics, and care ethics. But this is my read—certainly there are times when her critique seems rather friendly to relativism, cultural relativism in particular. I turn now to an objective/analytical assessment of Wilson’s Economic Ethics & the Black Church to evaluate its structure, organization, methodology and ethical theory.

In chapter one Wilson hints at what will become the tension she wishes to ethically unpack: “Unfortunately, most congregational efforts continue to focus on charity instead of justice” (p.5). Using three quite diverse black churches from her target community of Macon County, Alabama, she first derives similarities and dissimilarities by attending their Sunday morning worship services, Bible studies, and other events where the congregants gather. These churches are as unique as their perspectives on economics, but one thing germane to each is the “self help/social uplift” (SHSU) tradition that was espoused by this county’s most famous resident, Booker T. Washington, former slave and Founding President of Tuskegee Institute (now and hereafter, Tuskegee University). This notion of self-help and self-determination, which was (and remains) the bedrock of Washington’s social, political and individual philosophy, is not inconsistent with modern republican political ideology, and remains paramount even if the contemporary context is too complex for its utility, which is a phenomenon that doesn’t escape Wilson as she avers, “The Black Christian identity is complex.”
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This complexity—and perhaps ambivalence—is clearly seen in the way the three different congregations face and “experience social and economic exclusion.” Further, states Wilson, “poverty must continue to be addressed, not merely with a view toward charity but with a view toward justice in Black faith communities” (p. 68-9).

Significant to the SHSU tradition is the educational development context, which is another tension in and of itself. The brutality of slavery fostered both a pragmatic genius, as freed men and women sort the education denied to them in slavery, and an institutionalized psychology, as freed men and women subsumed to an unrepentant white supremacy/anti-black value system. Wilson argues that these early educational institutions were characterized by paternalism and threats to African American self–esteem as students were not taught to embrace their bicultural identity as African Americans” (p. 15). The poignancy of this claim lies in the resultant affection black middle-class have for the values of those who created the hegemony, while at the same time losing touch with their black counterparts who still find themselves in a deep impoverished state. It seems rather normal for any human person to aspire to, and even prefer, a comfortable economic stratification, and any calm, rational person of average intelligence should be able to appreciate this mindset. But what is not so appreciable is when that economic stratification loses its capacity for empathy and “distorts perspectives of reality.” This sanguine observation is helpful in discerning perspectives on the poor, but I am not sure that the variables used are as straightforward or as persuasive as Wilson would like. To be sure, there might in fact be jealousy from the bottom up, and there might be hubris from the top down, but I am not convinced that the middle class values are wrong. If the middle class values are such that they are the motivation for caring, then how could this value be off-center? For example, if a person is poor due to irresponsible behavior, family members, friends and others may be justified in being a miffed, especially if the “poor” person had the same or similar opportunities. My caution here is less of judgement, or prescriptivism, and more of a quest to be more analytically surgical to avoid romanticizing poverty. Describing what counts for being poor is debatable and needs clarification in Economic Ethics—especially since the ongoing binaries of charity versus liberation is poor-contingent.

The precision of chapter two lies in Wilson’s break down of the bifurcated ethical theories that she counts as being accentuated in her case churches: accommodation and liberation. She defines these polarities in the following way: “accommodation relates to the acceptance of economic norms as principles that legitimate a system of inequality, where charity is set over and above justice seeking...” (p. 46). It is “the acceptance of the American economic order as is” (p. 47). This accommodationist philosophy of many in the case churches is seen as non-disruptive and normal, especially since Macon County is (if not the birthplace) almost synonymous with Tuskegee and the Tuskegee Institute where Washington defended and industrialized this idea. The brilliance of Wilson’s point requires slow (as opposed to fast) thinking. The Black capitalistic mantra of “Pulling yourself up by your own bootstraps,” though pragmatic at the beginning of the twentieth century, has little to no fecundity at the beginning of the twenty-first century. The reverse migration of blacks coming home to Macon County is not fast enough to offset the brain drain and migration outward. Thus the bootstrap metaphor is a myth if there aren’t any bootstraps—even worst if there aren’t any boots.

On the other hand, liberation ethics (the economic ethics Wilson is defending) is less of a cultural relativism and more of a theological ethics and a Christian ethics, on her account (Wilson doesn’t develop this language so I will set it aside. Suffice to say, the former is far...
broader than the latter). Wilson says, “by contrast [to accommodationist ethics], expressions of Black religious experience that are revolutionary and whose economic ethic can be considered liberationist come from either marginal sects or were efforts of leaders, typically Black activist clergy, who many times did not have the backing of their congregation or denomination” (p. 46). This was true of Dr. King and others. Why would a black mainline protestant congregation, filled with middle class congregants, have a need for a liberation ethic? In their minds, they have already been liberated, so-to-speak, or if not liberated they have arrived at or have accessed a comfortable place. But liberation ethics is not a proponent of ethical subjectivism or any other social or political philosophy that grants ascendancy to (what the Reagan conservative republicans termed) “rugged” individualism. Liberation ethics, derived from liberation theology, is an other-regarding ethical theory. It conveys the idea of less of me and more of others.

In contrast to the accommodationist “uncritical acceptance of economic capitalistic rationality...,” “…it advocates expending intellectual and physical energies in community empowerment, knowing that because poverty is external (as opposed to an internal character or cultural flaw), it can be removed” (p. 51). Though the rationality for a liberation ethics is quite justifiable, noble and admirable, and for reasons I’ve already stated above, I think this way of defining poverty needs more showing. Wilson makes the assumption, following Muhammad Yunus whom she cites, and probably because she herself (like we all are) are susceptible to capitalistic and democratic biases, that poverty is wholly structurally based. Poor and poverty are used synonymously in this work, but are they synonymous? To what extent is economic “poor” relativistic? For example, a Jain may appear poor, but it is not structural—it is minimalism. Liberation ethics would do nothing to enhance their “poor” (?) way of life.

I found chapter three very helpful in terms of clarifying and reminding the reader of the source already identified—Macon County, Alabama. Wilson’s narrative style, and derivative narrative ethic, is ingratiating for at least two reasons: 1) it offers an interlude to the more intellectually tedious deciphering and teasing out of what makes for good ethics—metaethically, with respect to “right” and “good” —and normatively, with respect to “charity” and “justice”; 2) it reminds the reader that there are real people behind the accommodationist and liberationist ethical theorizing. I do find one consideration troubling, but I am not sure how Wilson would respond: Lincoln and Mamiya’s classical text is used authoritatively, as it should be, but it was published in 1990—25 years after the Voting Rights Act of 1965, and 15 years after James Cone’s most definitive work on Black liberation theology, God of the Oppressed. Wilson’s Economic Etic was published in 2017, 27 years after Lincoln and Mamiya. Therefore, it seems to me, that their analysis has closer relevance to the period when blacks were restrained from voting than a year after the closing of America’s two-term black presidency. Although their work has valuable insight, using their data seems less relevant today (p. 65-6). Once again, as Wilson herself states at the end of the chapter, “The Black Christian identity is complex.” Comparisons should be made with respect to the present data, not with respect to data that (I believe) has lost its significance.

As Wilson moves through chapters four through seven, her liberation ethics becomes even more developed and clearly articulated. If the reader harkens back to her defining of the Black Church in chapter two, and if this definition is correlated with her notion of religious identity, the pragmatic of her economic justice nicely unfolds. There is no way to define the Black Church and economic justice in the twenty-first century without referring to one of its most polarizing features: the prosperity gospel. Up to this point I’ve made no reference to this
account, but its preoccupation with teaching personal money management is a good feature. On the other hand, the prosperity gospel’s relative inattention to the economic injustices historically compounding poorer black communities represents an in principle contradiction. I share with Wilson a deep “skepticism of prosperity theology.” I fully agree that “such a theology leads to an acceptance of the world as is offering hope that, I fear, is fleeting in the face of the reality of the lives of many who long have been experiencing economic crisis. Furthermore, it is a theology that has an accommodationist economic ethic” (p. 77). Prosperity theology offers an ethic based upon complacency and, a fortiori, should be rejected as a viable economic ethic. The mentality that God is going to prosper the poor, and that God wants Christians to be rich (whatever that means) through some mythical, mystical and anachronistic concept of sowing and reaping, fosters a market driven economy that makes the rich benefit and the poor falter. Wilson defends a liberation system of economic justice that encourages the “Judeo-Christian notion of restoration and restorative justice” (p. 83).

I conclude this review of Wylin Wilson’s Economic Ethics & the Black Church in the same way I began—with praise. As Wilson points out (pp. 94-96), the prosperity gospel was borne with the teachings of white evangelicals who prioritized evangelism and personal salvation over the economic realities of slave descendants who were thrust into segregation, jim and jane crow manipulation, domestic terrorism, and a continuance of social and economic inequities. White evangelicals teach that black concerns should be with prayer and allowing God to make a difference. They further teach that saving the lost, which it takes money to do, should be the priority of all Christians; their economic situation can be resolved by pulling themselves up by their own bootstraps. This sounds good, philosophically, as perhaps, to teach one’s children personal responsibility. But as an economic system for folks having no foothold, no cup to hold water—or no bootstraps—it is quite scary to hear (as Wilson quotes Pastor Fred Price) “The Church that Jesus set up was not to be a welfare agency. It was to be a channel through which He could pipe the wealth so that the lost could be sought and brought into the knowledge of Him” (p. 94). The contrast is far more revolutionary, though not at all perfect.

Black liberation theology take its cue from the need for social justice: it has been a major critic of the policies of our market-driven economy that preys on the poor and vulnerable. This is Wilson’s tradition. She’s a third generation liberation theology thinker who is making both a theoretical and practical contribution to black and womanist theology as well as ethics. James Cone has said that any theology that doesn’t take seriously the plight of the poor and the oppressed is not Christian theology. Clearly he’s not in favor of a prosperity gospel. His most formidable interlocutor in the early years of doing constructive black theology was J. Deotis Roberts, who differed from Cone in his (early) vie for reconciliation with whites, which was a clearly a conviction Cone lacked. But central to their thesis was the notion of justice for the poor—not through an otherworldly, apocalyptic agenda, but now, through distributive justice. Institutions have facilitated the lack that blacks and other poor have undergone, and this can only be corrected by a reversal of trajectory. As Wilson says, “individuals [are] children of God, made in God’s image” (p. 122). There is an associated dignity that undergirds this premise, one that prioritizes “access to resources for sustenance and human flourishing” (p. 123). Economic ethics is justice driven, aligning itself with Jesus’ mission statement “The Spirit of the Lord is on me, because he has anointed me to proclaim good news to the poor. He has sent me to proclaim freedom for the prisoners
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and recovery of sight for the blind, to set the oppressed free, to proclaim the year of the Lord’s favor” (Luke 4:18-19). Wylin Wilson is most definitely on the right side of the gospel, history, and the impact of economic ethics and the black church.
AUTHOR REQUIREMENTS
I. General Information

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

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

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

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

II. Representative Manuscript Categories

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

a. Research papers, theoretical investigations.

b. Scholarly critiques and commentaries on various topics.

c. Formal case studies and program/project reports.

d. Reaction papers and editorials.

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

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

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

III. Submission Review Processes

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

Stage 1:
Authors submit full manuscripts or manuscript concept proposals to both the Editor and Senior Associate Editor. The Editor, Senior Associate Editor, and Associate Editors will conduct a preliminary assessment for relevance to the JHSH mission. The Senior Associate Editor will provide guidance to the corresponding author about shaping the manuscript for JHSH readers. All manuscripts, including all figures and graphics, must be formatted correctly and comply with JHSH Author Requirements before manuscripts will be allowed by the Editor to progress to Stage 2. Compliance with this requirement is mandatory. Exceptions will not be granted.

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

Stage 3:
After successful peer review and revision, the ARC Chairs send the revised manuscript to the Chairs of the Manuscript Editorial Committee (MEC) for rigorous editorial and formatting review, revision, and critique of actual content and language. This also includes careful review of all figures, graphics, and other related elements for compliance with requirements. The MEC also reviews, critiques and recommends minor formatting needs. The author and the MEC Chairs process and finalize the manuscript. When this process is completed, the MEC Chairs send the final manuscript back to the Senior Associate Editor as certified ready for final review.

Stage 4:
Upon receipt from the MEC Chairs, the Senior Associate Editor sends the final edition of the manuscript to the Journal Associate Editors for a final qualitative review. Any additional changes required are completed between the author and the Senior Associate Editor. Upon successful final qualitative review by the Associate Editors, the Senior Associate Editor sends the final edition to the Editor for final review and approval. If all items are in order, the Editor formally approves and accepts the manuscript for a future edition of JHSH. The Editor notifies the author of final acceptance.

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


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

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

Formatting Specifics:

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

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

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

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

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

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

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

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

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

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

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

V. Manuscript Preparation Requirements

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

**Bullets**

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

**Electronic Submission**

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

**Headings**

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

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

Authors who do not have Helvetica font may substitute Arial.

**Typeface**

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

**Headers and Footers**

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

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

Length

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

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

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

Punctuation

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

References

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

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

Book (editor):

Chapter in an Edited Book:

Journal Article (print):

Journal Article, more than seven authors

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

Newspaper Article (electronic):

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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 direction such as:

Figure 1 inserted here.

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

VIII. Authorship

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

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

IX. Responsible Conduct of Research Standards

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

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

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

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

X. Intellectual Property Information

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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.
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