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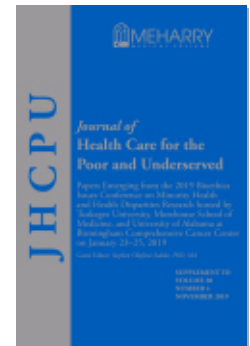
Introduction

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Introduction

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The manuscripts in this Supplemental Issue of the *Journal of Health Care for the Poor and the Underserved* are from the Second Conference on Bioethics Issues in Minority Health and Health Disparities Research hosted by Tuskegee University at the Auburn Marriott Opelika Hotel and Conference Center, Opelika, Alabama, from January 23–25th, 2019. The conference theme was “Effective Health Care and Inclusion: Growing the Next Generation of Researchers for Bioethics, Behavioral, and Health Disparities Research.” This conference was based on our belief that: (1) scholars ethically working to reduce cancer health disparities must be celebrated, (2) they must be given space to pass on enabling tools to the next generation of health scientists and researchers, and (3) that the new generation can anticipate, critically examine, and reflect on how to resolve ethical issues raised by their caring or research efforts. We expected them to emerge equipped to propose more effective, reasonable, and ethically defensible changes to methods and policies.

In planning the conference, we reasoned that vulnerability is an ontological condition of our humanity and that inherent, situational, and pathogenic vulnerabilities exemplified as health inequalities, disparities, and inequities remain legitimate concerns.¹ These factors reflect an injustice due to the unequal burden of suffering and preventable deaths experienced by minority populations.^{2,3} Furthermore, in view of efforts to confront the ethical challenges of the new personalized medicine initiatives, such as the All of Us Research Program, and the returning of genomic research results to patients for clinical care, the life-affirming field of bioethics should address these matters.^{4–10} Therefore, the Bioethics Shared Resource Core of the Morehouse School of Medicine/Tuskegee University/University of Alabama at Birmingham Comprehensive Cancer Center Partnership collaborated with the research community and adopted a holistic approach to create the necessary reflective space to address relevant ethical issues.¹¹

The conference had three parts. The first part considered the philosophical accounts of vulnerability and ethical obligations in addition to why collaborative efforts from bioethics and public health matter in attempts to break the cycle of health inequities. We examined current intervention research on improving minority health, standards and models, and promises and perils. This first part concluded with discussions on the obligations and challenges of translating research findings into practice—from bench to bedside to the community and everything in-between.

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Martha Albertson Fineman's paper, "Vulnerability in Law and Bioethics," set the tone of the conference. Fineman's insights represented a moral grounding for the subsequent discussions on health disparities and the obligation to achieve equity. The author opined that "recognition of universal vulnerability reveals the ways in which all human beings are inexorably dependent on social relationships and institutions throughout the life course."

Winn and Milligan's work on the connection between health and place-living in neighborhoods (affluent versus poor) called attention to how ZIP code or neighborhood of association (ZNA) and immutable community history are relevant in the quest to break the cycle of inequities. The authors suggested that, unless we are vigilant, some communities could be overlooked and remain invisible, particularly in the era of big data and a personalized approach to medicine.

Current intervention research on improving minority health included the work of Wilson and colleagues. The authors discussed their work with the Tuskegee/Macon County Diabetes Coalition as a case study for ethical community engagement to empower communities in an attempt to promote healthy living and habits in communities that suffer from this disease.

Payne-Foster and colleagues conducted a survey on racial anxiety among medical residents. The authors found that participants scored less on their workplace skills and actions. They concluded that training programs for physicians must "incorporate more skill development around handling racial anxiety." They raised the ethical question of social accountability of medical schools in building a culturally competent workforce.

Hernandez explored the concerns and needs related to maternal mental health with a population that is often stigmatized and inadvertently neglected. She noted that traditional institutional review board (IRB) forms and processes focus on individuals, but there is a need to include considerations of community; thus, she argued, researchers should use a community-based participatory research (CBPR) approach that is inclusive and respectful of community views and realities. Otherwise, research efforts will inadvertently expose communities to exploitation.

Mayfield-Johnson described her Photovoice project on the vulnerability and resiliency of the Mississippi Gulf Coast Vietnamese community. She identified, through content analysis, six categories of the sources of strength for this vulnerable population in the context of their history, culture, and experience. Her findings support the use of Photovoice that employs photography as a research tool for community engagement and self-empowerment.

The theme of the obligations and challenges of translating research findings into practice—from bench to bedside to the community and everything in-between—featured the works of four authors and their colleagues. Grizzle's insights on the ethical and regulatory issues in the use of human tissues to support precision medicine suggested that, even after taking care of all of the ethical issues for the benefit of the medically underserved populations and the focused research necessary, the cost of planning and execution may be out of reach for these populations.

Crook and colleagues identified four factors that potentially limit the translation of research findings to the achievement of health equity. They include: (1) expansion of basic science definition to include the science of health disparities, (2) understanding

factors that support community well-being, (3) inclusion of diverse populations in clinical trials, and (4) training scientists to move discovery to community applications. The authors argued that clearing these huddles would have a great impact on achieving health equity.

Zekeri's work on food insecurity and maternal mental health among African American single mothers living with HIV/AIDS in the Alabama Black Belt raised the issue of the obligation of clinicians to consider the seriousness of food insecurity in this population. He argued that the effects of prescribed medications diminish if activity depends on having food to eat when the population cannot afford food.

Kimberly's insights on translating research into practice, from individuals to community, indicate that the present potential for translational research to improve human health is unprecedented. However, in the era of big data and artificial intelligence, integrating data on genetic risks with other available health information in a fair manner will pose a challenge that may force a rethinking of the fiduciary relationship between physicians and patients. He raised pertinent bioethical issues and questions worth considering in efforts to ensure health equity. He suggested that while opportunities and challenges in translational science abound, it is the coming together of communities to address the challenges that will serve the public good.

The second part of the conference focused on the theme of the unnatural causes of health inequalities. Hull's work with tribal communities suggested an approach that would change the conversation about genomics and health disparities research. She suggested that tribal communities must be engaged in conversations that respect their rights to share the values they would prioritize in conducting collaborative genomic research. To her, the concepts of reciprocity, transparency, and cultural competency that indigenous researchers have articulated as important are absent from the current regulations.

This second part concluded with a film, viewing of exhibits, and poster presentations. Dr. Lonnie Hannon, Associate Professor of Sociology at Tuskegee University, facilitated what turned out to be a passionate discussion on the vulnerability of the Flint, Michigan community, particularly when the city officials defended their decision to change the water supply for economic reasons and presented it as good when the water turned out to be bad for human consumption. The audience watched the film, "Deadly Deception," a documentary about the United States Public Health Service (USPHS) Study of Untreated Syphilis in the Negro Male and viewed the exhibit at the Tuskegee University Legacy Museum. Dr. Lauren Powell, who is affiliated with the Virginia Health Department, and the director of the Health Equity Program, facilitated the debriefing session along with Mrs. Kimberly Carr, a doctoral candidate from Tuskegee University's PhD in Integrative Biosciences Program. Two poster sessions featured the research activities of early career scholars as well as undergraduate and graduate students from the three partnering institutions.

The third part of the conference focused on envisioning future research and clinical practice with a bioethics lens with a word for the next generation of researchers, "All of Us Research Program, Activism, and Policy Implications." Dr. Dara Richardson-Heron, the Chief Engagement Officer of the All of Us Research Program, a program created by the National Institutes of Health, provided a talk on precision medicine and how the

NIH All of Us Research Program can facilitate the initiative with purposeful inclusion and engagement of diverse communities. In her talk and paper, she cautioned that to rebuild trust and move forward to action would require having difficult but necessary conversations with communities that have been historically medically underserved or underrepresented in biomedical research.

In response to the theme of what should change and what should remain the same to promote health equity, Espinoza's work offered a reflection on the idea of "Vulnerability, Allyship, and the Researcher-Subject Relationship." She proposed *allyship* as an alternative model of the researcher-subject relationship that can protect vulnerable subjects while supporting them in growing in their autonomy. Her approach is in line with those elaborated by Martha Fineman and empirically demonstrated by Susan Mayfield-Johnson's work with the Mississippi Gulf Coast Vietnamese community.

Rivers argued for the use of an implementation science framework and translational science models to enhance the state of readiness of medically underserved populations to engage in research. Sodeke and Powell co-authored the Heroes and Great Ideas column written to preserve the legacy of Henrietta Lacks, whose immortal cells contribute to scientific advancements and medicine. They concluded that the legacy of Henrietta Lacks lives on.

What makes the manuscripts so striking is the way in which the discussions embrace the concepts of vulnerability and stress the importance of solidarity, interrelationships and interconnectedness, empowerment of communities, and allyship. Furthermore, they emphasize the need for all sensitive means possible, including being mindful of conflicts of interest in non-experimental studies and in our research efforts as moral agents to continue work on eliminating health disparities. Readers will find that these articles illustrate the hallmarks and the spirit of solidarity, inclusiveness, and diversity. We offer the manuscripts as instructive tools, not just for the next generation of researchers who attended the conference, but also for those who will read the proceedings thoughtfully. We must display the courage that will achieve dismantling of health disparities and experiencing of health equity.

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