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Tuskegee University Experience Challenges Conventional Wisdom: Is Integrative Bioethics Practice the New Ethics for the Public's Health?

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Abstract

The Tuskegee University National Center for Bioethics in Research and Health Care was established in 1999 in partial response to the Presidential Apology for the United States Public Health Service's Study of Untreated Syphilis in the Negro Male conducted in Macon County, Alabama, from 1932 to 1972. The Center's mission of promoting equity and justice in health and health care for African Americans and other underserved populations employs an *integrative bioethics approach* informed by moral vision. Etymological and historical analyses are used to delineate the meaning and evolution of bioethics and to provide a basis for Tuskegee's *integrative bioethics* niche. Unlike mainstream bioethics, *integrative bioethics* practice is holistic in orientation, and more robust for understanding the epistemic realities of minority life, health disparities, and population health. The conclusion is that *integrative bioethics* is relevant to the survival of all people, not just a privileged few; it could be the new ethics for the public's health.

Keywords

Integrative bioethics; mainstream bioethics; syphilis study; population health; public health; public health ethics; cancer health disparities research; holism; reflective equilibrium; moral vision; particularities; diversity; right action

Tuskegee University National Center for Bioethics in Research and Health Care

Tuskegee University is located in rural Macon County, in the rural Black Belt of Alabama. The University supports and recognizes the Tuskegee University National Center for Bioethics in Research and Health Care (The Center) as a scholarly environment that engages various communities in promoting bioethics and public health ethics. The Center's mission is to promote equity and justice in health and health care for African Americans and other underserved populations.

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conducted in Tuskegee, Alabama from 1932 to 1972. The negative legacy of this study has been cited as a hindrance to African Americans and other minority groups taking full advantage of medical care and participating in scientific research. Mistrust of the medical establishment has been a serious issue. Since its founding, Center faculty and staff have been working to educate researchers, empower affected communities, and build trust. The Center aims to transform the burden of the negative legacy into opportunities for collaborative research and fuller participation by African Americans and other minorities in research and in the health care system. The Center works with local, regional, national, and international communities to address the ethical and human rights issues in science, technology, and health, particularly as they impact people of color and other underserved populations. The Center's goals are to (1) promote racial and ethnic diversity in the field of bioethics and in public debates about bioethical issues, (2) conduct research and publish scholarship on bioethics and underserved populations, (3) educate students, scholars, the media, and the public about bioethical issues important to underserved populations, (4) foster effective, respectful, and mutually beneficial community partnerships to address inequities in health and health care, (5) develop bioethics training programs, and (6) advocate public policies that improve the health and health care of all Americans, particularly the underserved.

In implementing these goals, the Center employs an *integrative bioethics* approach that is informed by a unique moral vision to guide its actions. This approach has been used to address complex issues in research on the public's health, host discussions of public health ethics, promote ethical practice across the curriculum at Tuskegee University, educate various communities about conducting research with human subjects, develop community consultation and engagement regarding participating in research and clinical trials, enhance health-promoting partnerships with the school systems and various community-based organizations, maintain research partnerships with other institutions of higher learning, and conduct research workshops for students and researchers. The Center has enjoyed some successes, but there is still much to be done. In spite of the fact that, through the years, considerable revisions of the goals occurred, depending on the interests, persuasions, and areas of research of those who served as directors of the Center,¹⁻¹⁵ implementation activities have been broad, inclusive, largely interdisciplinary, and not focused on medical morality. Decidedly, the spirit behind the 1998 moral vision remains. In the section below, two instances demonstrating the implementation of Center goals with the use of the framework of *integrative bioethics* are highlighted.

The MSM/TU/UAB CCC Partnership

One example of the implementation of its goals is the provision of leadership in bio-ethics work to the Morehouse School of Medicine, Tuskegee University, and University of Alabama at Birmingham Comprehensive Cancer Center (MSM/TU/UAB CCC) Partnership. This 11-year partnership still continues today.

In 2005, Morehouse School of Medicine, Tuskegee University, and University of Alabama at Birmingham, three schools with different institutional cultures, characters, and resources, agreed to collaborate in efforts to eliminate the gaps in cancer burden. Pursuing this laudable aim predictably involved communication challenges. The Partnership is made up of eight components: (1) Scientific Research, (2) Research Training and Career Development, (3) Cancer Education, (4) Community Outreach, (5) Recruitment, (6) Evaluation, (7) Biostatistics, and (8) Bioethics. Biostatistics and Bioethics have served as shared resources within the Partnership. Guided by the ethical and bioethical expertise and conscience of the Tuskegee University National Center for Bioethics in Research and Health Care, the Bioethics Shared Resource has been instrumental in helping the Partnership endure and

progress through its growing pains. The strategies for this collaboration have been published elsewhere.¹¹[p.35–45]

The First Bioethics Conference in Cancer Health Disparities Research at Tuskegee

Another example of the implementation of its goals with the unique and holistic approach to the practice of bioethics was the hosting of a national conference, designed to assist others in addressing the ethical issues raised by research on cancer health disparities.

Research on cancer health disparities is a complex enterprise. In our view, attempts to address and resolve the enduring issues of disparities embedded in the public's health should be guided by an *integrative bioethics* approach to bioethics practice. Our sense is that, understood correctly and practiced properly, *integrative bioethics* is the science of life struggles, survival, and flourishing, particularly in the environment of the United States where the seeds of race, ethnicity, gender, class, culture, and spirituality have flourished (for good and ill). Essential to the public's realization of a humanly lived life is good health and healthy behaviors. What makes good health possible for the individual and the population amidst competing priorities in America's complex environment and structures is the ability to make individual—though sometimes collective—informed, practical, and moral choices, guided by sound ethical reflection and analysis. Essential to such mindset is the study of ethics, which provides us with the language and habits of thought for reflecting on and analyzing health and environmental issues connected with our behaviors and actions. How these behaviors and actions are framed determines how they are addressed by the field of public health informed by ethics. We surmised that an integrative bioethical blending of historical, practical, and ethical considerations of issues, behaviors, and actions is necessary to ensure defensible and appropriate responses, social policy, and law. To this end, the First Bioethics Conference on Cancer Health Disparities Research was held at Tuskegee on January 18–20, 2012. Its aims were: (1) to *broaden* participants' understanding of ethical issues specific to cancer health disparities research; (2) to *demonstrate* awareness of various stakeholders and perspectives impacting resolution of the ethical issues; (3) to *gain* a better understanding of how cancer health disparities research can be ethically conducted to eliminate disparities with due attention to contextual issues, individual interests, and entrenched community values; and (4) to *plan* to engage the knowledge and transforming experience gained to eliminate cancer health disparities in home institutions or new environments.

People attending the conference engaged in experimental and experiential learning, with the opportunity to present their experimental work and interact with peers to sort out the ethical issues raised by such work in a supportive environment. To engage the emotions and stimulate various ethical perspectives of the attendees, a theatrical presentation of the life and connectedness of Henrietta Lacks was used. This was performed by two professional actresses and by Tuskegee University students who played supporting roles. The group also visited a HeLa Cell Exhibit designed and mounted by the Legacy Museum of Tuskegee University, and then participated in facilitated reflections and ethical analyses. These immersion experiences were planned to increase the sensitivity of attendees, with the concept that such increased sensitivity to the plight of others can inform plans for improved moral judgments pertaining to ethical issues in research. The articles in this Supplement constitute the proceedings of the conference.

All that has been said up to this point generates legitimate questions: What is bioethics? How has it evolved? What is mainstream or traditional bioethics? How did the unique moral vision and beliefs inform practice of *integrative bioethics* at Tuskegee University? What is

integrative bioethics approach? How is it different from mainstream bioethics? What connection is there between bioethics and the public's health? What is the role of ethics and public health ethics in these matters? How can the practice of *integrative bioethics* help in formulating appropriate responses, policies, and laws for promoting health equity? Why should the practice of *integrative bioethics* be part of the ongoing bioethical conversations? In the sections that follow, I will try to answer these questions.

Etymological Analysis of Bioethics and Integrative Bioethics

In his book, *Word Origins and How We Know Them*, etymologist Anatoly Liberman observed that “words wither with age, but by shrinking they conceal their past and begin to look younger.”¹⁶[p.75] Like any other word that has survived through history, the sense of the word *bio-ethics* seems very familiar. However, one may speculate that its past was perhaps unintentionally concealed so that it might look younger and fit contemporary meanings.

Nevertheless, in order to stimulate reflection and increase understanding, I shall use the tool of etymology to unravel the past for the word *bio-ethics* and thereby demystify it. This analytical approach “determines the basic elements, earliest known use, changes in form and meaning, tracing its transmission from one language to the another... and reconstructs its ancestral form wherever possible.”¹⁷[p.472] So, speaking etymologically, BIOETHICS is a compound word. It is made of two words—the prefix BIO from the Greek word *bios*, which means *life*, and the root ETHICS, from the Greek word *ethike*, which means the science of morals or the study of habits.¹⁸[p.5–7] At least in Western thought, ETHICS as a subject matter has been regarded as a branch of philosophy concerned with the *rightness* or *wrongness* of actions.¹⁹[p.379] If we put BIO and ETHICS back together, BIOETHICS might appear as activities that concern the rightness or wrongness of actions for life. This concern does not only obtain in the Western world, it extends to populations everywhere, perhaps with special importance for marginalized minority populations. American bioethics, in its present incarnation, is Western in orientation. I will say more about this later. Applied in the fashion just described, an etymological approach helps to debunk the erroneous, antiquated, narrow view of bioethics as the field of inquiry directed at the doctor-patient relationship and concerned only about ethical issues that scientific and technological advancements raise. In the international arena, bioethics is not medical morality; its concerns are more far-reaching.²⁰ That broad concept is consistent with the global views enunciated by others.^{21,22}

Similarly, to continue the etymological analysis is to deconstruct *integrative bioethics* and then reconstruct it. This is possible since we now understand the meaning of *bio-ethics*. The adjective *integrative* qualifying the word *bioethics* comes from the verb *to integrate*. To integrate is “to form, coordinate, or blend into a functioning or united whole ... to end the segregation of and bring into common and equal membership in society or an organization.”²³[p.628] As we understand and apply it at the Tuskegee Center for Bioethics, an *integrative bioethics* approach is an experience-based paradigm that blends all the disciplinary fields and domains—biological, psychological, social, economical, philosophical, political, cultural, spiritual—that enable human beings to live full lives in balance with their environments. It spans the boundaries of disciplinary fields in collaborative ways to accomplish the blending. The difference in orientation between mainstream bioethics and integrative bioethics is clear. Rather than concentrate on esoteric medical, scientific, and technological issues alone to the neglect of contextual issues as mainstream bioethics does, an *integrative bioethics* approach promotes diversity and celebrates the interrelationships and interconnectedness of all human endeavors. It allows one to integrate, in a flexible way, social and cultural particularities into bioethical discourse

while making sure that these entities are not marginalized when attempting to understand and resolve perennial life problems of bioethics.²²

The next questions pertain to the origins and evolution of bioethics. I shall use a historical approach to answer these questions.

Origins and Evolution of Bioethics, and Conventional Wisdom

There are competing accounts of the origin of bioethics in the United States and the Western world. The philosopher and theologian Jonsen suggested that bioethics was born due to the advent of limited numbers of dialysis machines and the need to determine who shall have dialysis and who shall not.²⁴ Others have pointed at the heated debates about medical decision-making among physicians, scientists, lawyers, theologians, and philosophers as the source.^{25,26} One philosopher credited cultural politics as the main origin of mainstream bioethics.²⁷ However, the philosopher McCullough has suggested that bioethics originated in earlier times.²⁸ His claim is that the works of John Gregory in 1772²⁹ and Thomas Percival in 1803³⁰ are essential to the understanding of contemporary bioethics. Both Gregory and Percival documented the tensions among physicians, surgeons, and druggists that characterized their era. At that time, these professionals looked to medical ethics for resolution, hence his suggestion to understand the history as part of the bioethics story. The physician and philosopher Engelhardt pointed to the foundation of bioethics as located in attempts to resolve practical health problems brought on by new technologies of the day. At that time, bioethics functioned to legitimize bioethical decisions and provided recommendations to formulate appropriate health care policies.³¹ Philosopher Iltis observed that bioethics became prominent as a result of a “fracture in a society having to deal with cultural wars.”³²[p.630] Other commentators have claimed that the foundation of bioethics dates to the 1920s, when Fritz Jahr, a Protestant pastor, philosopher, and educator, published an article entitled “Bio-Ethics: A Review of the Ethical Relationships of Humans to Animals and Plants” in the German Magazine *Kosmos*. He proposed a *bioethical imperative* that extended Kant's moral imperative to all forms of life.³³ From the foregoing accounts, it is clear that bioethics, as we know it, had several origins, and those who practiced it must have crossed disciplinary lines to resolve bioethical issues, although they may have been reluctant to do so.

Georgetown University and the University of Wisconsin: Two Locations and Two Views

The origins of the ideas of bioethics in America have been located on two separate university campuses. One idea originated at the University of Wisconsin, the other at Georgetown University in Washington D.C. Having been influenced by the work of Aldo Leopold in 1949, Van Rensselaer Potter, a biochemist and cancer scientist at the University of Wisconsin conceived, in 1970, a new discipline that he called *bioethics*. This discipline was to help thinkers reconsider the systems of thought and practice of the era with the hope of revising deeply held values and beliefs about the world. The new concept highlighted the relationship and interconnectedness among biology, human values, the environment, and ecological systems, and served as a bridge to an understanding of the survival of the species. In a sense, it was to be an interdisciplinary ethics.³⁴ This was the first concept of this type from the Western world, but it did not gain traction.

In 1999, Philosopher William Thomas Reich characterized Andre Hellegger, the founder and first director of the Kennedy Institute of Ethics at Georgetown University, as “committed to and [having] worked toward bioethics as a self-consciously interdisciplinary field in which the contributing disciplines adapt to each other-rather than sustain themselves as

autonomous disciplines—to create a dynamic and complex, clinical, and social activity.”³⁵[p.25] But this wider view was not well received.³⁶ Nonetheless, in 1971 some physicians, philosophers, and theologians at Georgetown University came up with the term, *biomedical ethics*.^{37,38} The originally intended broad scope of bioethics at Georgetown was circumscribed to a system of thought and practice, narrowly defined in scope and strictly medical, to solve medical dilemmas. This revitalized study of medical ethics constituted the conventional wisdom and the prevailing ethos of the bioethics of the day. This view occupied the attention of bioethicists for decades. Although extensively modified, this approach has been vigorously defended over the years, and is still present today.^{22,23} One may ask: Why? The reason that this variety of bioethics, which is mainly clinical ethics, became mainstream was that it was couched as being pragmatic, giving priority to and addressing moral and ethical issues that biotechnological innovations, biomedical research, and health care raise. Dubbed *Principlism* or *the Georgetown mantra*, the minimalist theories and restricted general principles used to practice mainstream bioethics were drawn from Anglo-Saxon moral, political, and social traditions, keeping it acceptable for the dominant majority. But, in so doing, the approach marginalized other contextual issues and phenomena that are equally important in discourse, and it evaded socio-cultural issues. Thus, it failed to account for the role of emotions, feeling, religion, and other particulars. Nevertheless, this has been long-lasting in the Western world and has profoundly influenced ethical judgments, even in international contexts. Regarding this picture, Sociologist Renee Fox observed how indigenous researchers struggle to make principlism fit their contexts, almost to the neglect of their own foundation for morality.^{39,40}

In 1994, the philosopher Reichlin argued that these origins and definitions may reflect “different conceptions of the epistemic status of bioethics in that one conceives of it as an application of moral knowledge to biomedical problems”⁴⁰[p.79] that is also “connected to a methodology for working out clinical judgment;” the other is conceived as “a broad and interdisciplinary public inquiry.”⁴¹[p.79] These views may be valid (the three levels of epistemic realities certainly resonate with the African heritage of the visionary leaders at Tuskegee) if they are linked together in ways that they cannot be artificially separated, particularly when the central concern is human life, and when human wellness implies holism. *Holism* has informed the discourse and practice of bioethics at Tuskegee University National Center for Bioethics in Research and Health Care since its beginning; I refer to it as *integrative bioethics*.

In summation of this part of the evolutionary narrative, Tuskegee *integrative bioethics* embraces sound ethical method(s) for resolving complex issues related to individual and population health. It incorporates Jahr's view of respect for, and the interconnectedness and interrelationship of, all forms of life in the ecosystem; it approximates Hellegger's “wider view” of bioethics. The Tuskegee *integrative bioethics* approach broadly captures the essence of the unique moral vision and goals of the Center, as I will now explain.*

The Context of Integrative Bioethics at Tuskegee University

As indicated earlier, in the wake of the presidential apology of 1997, and in response to an executive order to establish a bioethics center at Tuskegee, the visionary leaders of the Tuskegee University National Center for Bioethics in Research and Health Care (The Center), reasoned in 1998, that it would be confining and inappropriate to adopt the narrow view of mainstream bioethics in its totality. For them, addressing the challenges faced by African Americans and other minority groups in America, and indeed the world, would

*Readers should please note that throughout the remaining sections of this paper, when I use *bioethics* without the qualifying word *integrative* it refers to mainstream bioethics or to the field in general.

require a broader, more robust view of bioethics in concept, scope, and practice. They communicated this moral vision in the founding document. Excerpts are quoted below.

Effective responses to the challenges of the most serious inequities in our nation's health and health care system requires bioethical approaches which incorporate a broad range of scientific and technological information, conceptual analyses which frame and critique information, and moral claims that arise from diverse fields, including biomedicine, ethics, history, public health, law, literature, philosophy, religion, and the social and psychological sciences. It is our view that an approach to bioethics which attempts to utilize abstract ethical theories alone to develop moral guideline to action in health care and life events is insufficient ... effective moral reasoning in health care and research requires us to employ an interdisciplinary account.⁴¹[p.31] Such an approach which brings into play a focus on the perspectives and experiences of African Americans and other minorities as well as dominant groups, would add more substance, relevance, and fairness to the presentation of formal and procedural justice. It would be a much stronger foundation for producing a more adequate treatment of African Americans as a group in bioethics than purely individualistic, minimalist methods of the more traditional approaches.⁴¹[p.32]

To my knowledge, this narrative has not been previously shared. For the first time, this analysis exposes the general public and the bioethics community to the thinking behind the establishment of the Center and its work at Tuskegee. The unique moral vision in the excerpts just presented reflects the life struggles, survival, and ongoing efforts at flourishing for a minority group of underserved people. They must continue to live in a pluralistic society structured by the powerful and majority-defined norms. Embedded in the vision is the heritage of its crafters, their sense of community, solidarity, and compassion for those similarly situated in the American society and in the world.

These visionary leaders understood the precariousness of their situation and could foresee the implications of their work. They understood that the problems of bioethics are embedded in people's lives and social world. Hence, the original Center's mission was to "become a premier provider of interdisciplinary instruction, research and community outreach for educating and training professionals in the field of bioethics both at the undergraduate and graduate levels; educating and advocating for moral progress through the empowerment of people of color and other underserved populations in the United States, the Caribbean and Africa."⁴¹[p.25] The vision has provided the context for the kind of bioethics that would be defined locally from the inside but that would have global applications and be driven by an *integrative bioethics* approach at Tuskegee. Unlike the narrow approach of mainstream bioethics that marginalizes other contextual issues and reduces attention to human dignity, a more robust *integrative bioethics* approach is needed. Such an approach is naturally sensitive to philosophical, cultural, economical, political, and religious issues present in a pluralistic society. As the physician and philosopher Leon Kass suggested, such a holistic approach allows us to reflect on "the full range of human goods at stake in bioethical dilemmas as we prudently seek the best-possible-under-the-circumstances."⁴²[p.6]

At Tuskegee University, we have reasoned that such an *integrative bioethics* approach can guide good intentions and harness the will to power. It can enable us to exercise vigilance as we watch for signs to stop, start, or go easy on apparently good but nevertheless troubling life activities in which we may find ourselves. One could say that, in the bioethics enterprise, the *integrative bioethics* approach has carved a niche for Tuskegee that needs only to be solidified. Accordingly, over the years, the vision served as a guiding light and shaped the justification for university support of, among other things, local, national, and international scholarly presentations and publications; ethics across the curriculum; intensive

discussion of the draft curriculum for public health ethics by a campus-wide interdisciplinary faculty group in 2005; the integration of bioethics into a health disparities course; a business ethics course; a professional ethics course in veterinary medicine, a new student orientation course, and an engineering ethics and society course. As mentioned earlier, *integrative bioethics* was used to implement the First Bioethics Conference in Cancer Health Disparities Research in Tuskegee in January 18–20, 2012.

Integrative Bioethics: Missing and Supportive Understandings

In their edited book entitled *The New Ethics for the Public's Health* published in 1999, Beauchamp and Steinbock concluded that, in the wake of emerging diseases and new treatments and technology, certain practices and services of the profession of public health raise ethical issues that warrant consideration from the individual as well as from the community. Without making a reference to bioethics, they insisted that a “new ethics” was needed to address the situation effectively.⁴³ Similarly, in 2003, the Institute of Medicine's Committee on Assuring the Health of the Public in the 21st Century published a seminal report entitled *The Future of the Public's Health in the 21st Century*. Remarkably missing in the report is any consideration for the role bioethics can and will play.⁴⁴ In these two seminal texts, bioethics was missing. Perhaps the idea of *integrative bioethics* did not arise at all.

At about the same time, however, the President's Council on Bioethics reconsidered bioethics. The Council lent credence to Tuskegee's original approach to bioethics (*integrative bioethics*). It redefined bioethics in its published report, *Being Human*. In his opening speech, Leon Kass, Chairman of the Council, stated, “Bioethics is not ethics of biology, but *ethics in the service of the bios*—of a life lived humanly, a course of life lived not merely physiologically, but also mentally, socially, culturally, politically, and spiritually. This means undertaking a fundamental inquiry into the full human and moral significance of developments in biomedical and behavioral sciences and technology.”⁴⁵[p.3] This is substantial support, because he concluded “In my view, such questions of the good life—of humanization and dehumanization—are of paramount importance to the field of bioethics. ...”⁴⁵[p.7] An international bioethics organization maintains that “bioethics could be defined as the study of ethical issues and decision-making associated with the use of living organisms.”⁴⁶[p.1] This organization suggests that “concepts of bioethics can be seen in literature, art, music, culture, philosophy, and religion throughout history.”⁴⁶[p.1] These concepts are consistent with those of *integrative bioethics*. The definition highlights a mode of inquiry that spans the intersection of the classical discipline of human endeavor for a sound ethical deliberation.

In 2011, a National Institutes of Health solicitation defined bioethics as “a branch of ethics that involves systematic analysis and critical reflection of ethical issues in biomedical and behavioral research, public health, and health care delivery.”⁴⁷[p.1] This is a fairly comprehensive definition because it appropriately includes public health under the umbrella of bioethics. Still missing in the definition, however, is social science and an emphasis on social justice. The danger here is that, even if the omission was inadvertent, it could lead some to believe that such considerations are not important. As Turner has suggested, it is possible that mainstream bioethics is still struggling with not only what to do with race in a pluralistic American society of today,⁴⁸ but also what to do with social concepts, community, and social justice, as philosophers Hoffmaster, Whitehouse, and Buchanan observed.^{49–51}[p.288] This leads to the question: Should the conventional wisdom of mainstream bioethics be reconsidered? This is addressed in the next section.

Should the Conventional Wisdom of Mainstream Bioethics be Reconsidered?

In view of changes in the definition of bioethics and recovery, from the Tuskegee Archives, of the vision that drives *integrative bioethics*, relevant questions are: Should the conventional wisdom of mainstream bioethics be reconsidered? Is *integrative bioethics* the new ethics for public health? Furthermore, are the moral concepts of the visionary leaders of the Bioethics Center appropriate for this day? Can something profound be learned or gained from such a vision? I answer *yes* to all these questions and argue that, although it takes patience, humility, and a collaborative spirit to practice *integrative bioethics*, the concept, when properly practiced, reflects the epistemic realities of living a full life in our pluralistic society. The concept is more advantageous to the moral sensibilities and worldviews of underserved people than the individualistic, minimalist-oriented, mainstream approach to bioethics. *Integrative bioethics*, which is interdisciplinary, is a bridge-builder and boundary spanner. It celebrates particularities and inclusiveness; it aims at holism and wholeness; it embraces community and the spirit of solidarity.^{32,52,53} Mainstream bioethics does no such thing, and although it continues to be conventional wisdom, it should be reconsidered.

Today, while the boundaries of contemporary or mainstream bioethics in the United States remain controversial, there are indications that the bioethics agenda is broadening to focus more on issues of disparities in health and wellbeing, justice, and equity.^{54–56} Mainstream bioethics is becoming an *integrative bioethics* that is consistent with the Tuskegee vision of years ago. I agree with commentators^{50,51} who have observed that the field of bioethics may be making a full-circle turn. From my standpoint, however, it will be more so if and when it is self-critical, expands its vision, and opens its way of thinking to all of humanity. Such a social and moral epistemological understanding can give *integrative bioethics* its deserved place in the bioethics enterprise.⁵¹

The Connection between Bioethics and Public Health

Integrative bioethics practice and public health: Is *integrative bioethics* the new ethics for public health?

The unfortunate omissions of bioethics and its moral sense *per se* (as stated in Beauchamp and Steinbock's book *New Ethics for the Public's Health*⁴³) from the IOM sponsored report,⁴⁴ along with a comprehensive, countering definition of bioethics in the 2003 report of the President's Bioethics Commission⁴⁵ prompt three questions: How is bioethics connected to the public's health? Why is a broad interpretation of bioethics engendered by *integrative bioethics* practice an important consideration for health equity? How will such an approach contribute to the promotion of health and wellness for minorities, particularly the underserved? These questions are now addressed.

What is the connection?

Public health, a field that has traditionally been seen as responsible for promoting health, serves to find the source of diseases and to prevent or contain the spread of diseases to maintain healthy individuals and populations. Without good health, only limited normal functioning (much less flourishing) is possible.⁵⁷ The belief that important health-related behaviors are substantially influenced by societal factors and context is established among public health practitioners. However, while public health may cite, blame, or otherwise identify the societal or contextual issues influencing individual behavior and determining health status, it does not deal directly with these factors. What identifies and effectively interrogates these factors is not the individualistic, minimalist bioethics, but the kind of bioethics practice that welcomes, blends, and accords credibility to different ways of

thinking, knowing, experiencing, and understanding the interconnectedness of all stakeholders in health matters affecting personal and community wellbeing. Thus, there is a connection between the public's health and practice of *integrative bioethics*.

Why is *integrative bioethics* practice an important consideration for health equity?

Health is a vital component of human flourishing, hence, it is a good worth pursuing for the good life, not just an ideal meant for haves that is unavailable to the have-nots. As noted elsewhere in this paper, I would argue that understood correctly and practiced properly, *integrative bioethics* in the United States should be seen more as a disciplined inquiry into experiences of real people, a science of life struggles, survival, and flourishing in the context of an environment seeded with issues of race, ethnicity, gender, class, culture, and spirituality. In such an environment, one's situation in the society is directly related to one's health and well-being. Bioethicist Annette Dula observed that African American health in the United States is related to race and socioeconomic status.⁵⁸ The Institute of Medicine Report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, confirms that observation. A core message of the report reads, "If you are Black, you are more likely to get inferior health care than if you are White. And if you are Hispanic or Native American, odds are you're also in trouble."⁵⁹[p.86] Apparently, treatment in the medical world reflects what goes on in the real world. However, the report also revealed the limited explanatory power of socioeconomic status by citing other measures, such as the extent of socioeconomic inequality within a community; the nature, level, and temporal pattern of unemployment; societal connectedness; the extent of involvement in social networks; marital status; early childhood experiences; and exposure to dignity-denying situations as dominant factors in determining the levels of preventable disease, disability, and premature death.⁵⁰

The life experiences of minorities suggest that those who have historically been in these situations—the poor and disenfranchised—have limited ability to demonstrate health-promoting behaviors, and are more likely to engage in risky behaviors and take risky actions. These private acts, which tend to have social consequences in terms of increased disparities, morbidity, and mortality, should be of concern to bioethicists, who are oriented to speak the truth to the powerful and hold them accountable for work to eliminate such disparities. In doing so, the concerns of *integrative bioethics* go beyond access to health care to include the social conditions and structures that make healthy living possible, and demonstrate how to promote such conditions for the good of all in an ethical manner.

How will practice of *integrative bioethics* contribute to the promotion of health and wellness for minorities?

People are deemed to be minorities by dint of race, ethnicity, gender, class, and sexual orientation, though of course none of these diminishes their humanity. Teaming-up to achieve living conditions that promote health and wellness for minority individuals and communities is a concern that requires collaboration and balancing in order to be just. In 2007, Hastings Center Report editor and health-care advocate, Carol Levine, wrote that bioethics could be seen as the field that "addresses critical issues affecting the way we live and die."⁶⁰[p.4] I agree that it should be. With that in mind, the idea is that the Tuskegee niche of *integrative bioethics* and public health practitioners must work together with government to make healthy living conditions possible. This notion has always had a place in the history of Tuskegee. Nevertheless, laudable as they are, such efforts may raise ethical questions: Does the government have an obligation to intercede to reduce the cost of negative externalities? Why or why not?

Promoting healthy behaviors, for instance, might involve policy interventions of restrictions, prohibitions, and mandatory behaviors that may amount to profound invasions of privacy; thus *integrative bioethics* will be concerned with the extent to which the state should get into the business of modifying human behavior, even if it does so to improve health. While *integrative bioethics* may be concerned about the demands of autonomy, equity, and community, which are central to any attempt to fashion an ethically sensitive public policy in this area, it is not oblivious to the existing oppressive structures that ferment tension and shape the responses of African Americans as moral agents. In the United States, the epistemic realities of oppression are undeniably a common experience for people of color. This may also be true in other parts of the world where people are dehumanized for whatever reasons. Nevertheless, while there may be tension between the public and private acts of individuals, the community's interest in health as an irreducible good and beliefs about the wellness of its members deserve consideration. Individual interest should not, *prima facie*, be sacrificed on the altar of community preferences without appropriate justification. Consequently, *integrative bioethics*, which is concerned about the health and well-being of all people, particularly African Americans and other minorities, can be a useful and powerful framework for hearing voices that would otherwise go unheard.

In regard to particularities, *integrative bioethics* is concerned with the potential for enrollment in research without adequate information, coercion of research subjects, exploitation of research subjects, disproportionate representation of groups, inappropriate use of study design and data, and the misuse of power, especially where power differentials exist between the researcher and the researched. It is also concerned about how such diverse disorders as toxic communication at work, toxic waste dumps, homelessness, and poverty can contribute to poor health.^{3,4} Additionally, of serious concern to *integrative bioethics* is how fat-laden, sugar-loaded, refined foods served in our schools to children contribute to their less than optimal health, diminished academic accomplishments, and reduced well-being. With due respect to distributive justice, we must do better.

Integrative bioethics, as the science of survival with concerns about social and environmental justice, urges us to develop the motivation, seize the opportunity, and demonstrate the willpower to accomplish what needs to be done. We have the tools at our disposal to reverse the trend;⁶¹⁻⁶⁴ to do otherwise would be unjust. In this sense, practice of *integrative bioethics* could become the “new ethics for the public's health,” to borrow Beauchamp and Steinbock's terminology.⁴³

What Role Does Ethics Play?

Exhibiting our moral agency contributes to healthy behaviors, as does the way the behaviors are presented and perceived. An understanding and use of ethics can make a substantial contribution in this area. Ethics, as the systematic study of morality, provides the language for reflecting on and analyzing health and environmental issues connected with our behaviors and actions. How these behaviors and actions are framed will determine how they will be addressed by public health practitioners. In this regard, historical, practical, and ethical considerations of issues, behaviors, and actions are necessary to ensure defensible and appropriate social policies and laws. For instance, for certain disenfranchised groups, behaviors and actions are not necessarily predictable. Their situations, like moving targets, may change from time to time, depending on the hand life deals them, to use a card analogy.

Any ethics that makes such a presupposition will not work for African Americans or minorities whose behaviors and actions have a history, dependent on the context in which they may be challenged to make decisions. Their experiences with the health care system have too often been demeaning and humiliating. As philosopher Leonard Harris expressed

it, even when well-developed reasoning using Eurocentric, Kantian deontological, contractarian, or utilitarian approaches can justify autonomy, expecting African Americans or any other minority group to exercise rational “autonomy under duress” is antithetical to the spirit of respect for people if they cannot first, as moral agents, be deemed by the dominant group as ontologically, intrinsically good, independent of their condition or state in life.⁶⁵

I suggest that a Western-view-only type of bioethics is not necessarily humanistic or realistic for today's pluralistic American society, and will not serve humanity effectively here or any place where foundations for morality go beyond “principlism” to broader notions of human wellness. For this reason, an unassuming, non-Eurocentric approach to bioethics—*integrative bioethics*—that is cognizant of entrenched values and beliefs about what constitutes health and wellness, and is embedded in social justice and supported by human rights and international law will be richer and more helpful. It will be consistent with the kind of ethical practice of public health that may make a positive difference to the health of all Americans.

Integrative Bioethics and Public Health Ethics: Moral Friends

Although the concerns of *integrative bioethics* extend to all lives, public health and bioethics share the responsibilities of promoting and protecting the public's health, and also protecting and promoting human rights.^{44,55} As indicated earlier, the practice of *integrative bioethics* is consistent with the bioethics definition as “ethics in the service of the bios—of a life lived humanly—a course of life lived not merely physiologically, but also mentally, socially, culturally, politically, and spiritually.”^{45[p.3]} Essential to the public's realization of such a “humanly lived” life is good health and healthy behaviors. What makes good health possible for the population amidst competing priorities in our complex environment and structures is the demonstration of moral agency in the ability to make individual (but sometimes collective), informed, blended, practical, and moral choices guided by sound ethical reflection and analysis. When such choices are compromised, good health and the right to it drift out of reach. Although the notion that health is a human right is controversial, that should not prevent us from trying, for the common good, to make it possible for everyone. Proper practice of public health requires a sound knowledge of the ethical issues and tensions that arise.⁶⁶ Framework versions of *integrative bioethics* analysis, such as those promoted by Sodeke and Price, contextualize public health ethics and can engage appropriate reflection and options with due regard for individual interest and social justice.^{7,10,67,68} To this end, public health practice is a concern of *integrative bioethics*, and the ethics of public health is its moral friend.

Fashioning Defensible Responses, Policies, and Laws

The argument has been made that the fields of bioethics, public health, and government should work together to fashion defensible responses, social policies, and laws, while being mindful of the ethical tensions posed by such efforts. Both the practice of *integrative bioethics* and the ethical practice of public health can promote sensitivity to such tensions, particularly when government makes policies that affect behaviors linked to illness and preventable early death. Such collaborative action can guide decisions about how to intervene and allay the fears of those who, rightly so at times, are afraid of government intrusion in their lives.

Conclusion

The narrative of the moral vision that informed the establishment of the Tuskegee University National Center for Bioethics in Research and Health Care in 1999, along with the ensuing

and enduring scholarly activities it guides, may have been the best kept secret in the bioethics community. Now that the story has been recovered and shared here, it will be prudent to give it its rightful place in the ongoing bioethical conversations in matters concerning our collective existence, wellbeing, and flourishing.

An account of bioethics that is narrow and minimalist does not give due attention to social justice and inadvertently legitimizes continual exclusion of voices that must be heard. Rather than enriching intellectual discourse, that practice limits and diminishes it, and is therefore unjust. An *integrative bioethics* approach is a paradigm based on lived experiences. The use of this framework to create reflective space at Tuskegee allows otherwise silent parties to speak. The holism and intellectual and spiritual richness possible with this paradigm was demonstrated during the First Bioethics Conference on Cancer Health Disparities Research at Tuskegee University in 2012.

Some people may have justifiable reasons to defend the *status quo* that has served the biomedical community for good or ill for over 30 years, because of the fear that detraction from it may not serve their own interests.⁶⁹ Others may object because the idea of reconsideration may diminish the satisfaction they relish from attacking and attempting to resolve esoteric and controversial clinical issues. Nevertheless, I have argued that the conventional wisdom perpetrated by such a mindset should be reconsidered and renegotiated in the light of the complex health issues of today's pluralistic society. My voice is joining the voices of others speaking from the margins of present day bioethics. If we can summon and exhibit the moral courage to entertain such an idea, subscribing to *integrative bioethics* can galvanize the effort to embrace inclusiveness rather than exclusiveness, and be responsive to community particularities rather than confined by supposedly general ethical principles. Effective responses to classical and enduring health disparity issues and solutions to novel problems are needed.

Integrative bioethics promotes the necessary interdisciplinary, collaborative efforts and moral sensibilities needed by all fields involved in affecting the public's health in a positive way. It gives voice to the underserved and socially and economically disadvantaged, empowering those communities by enhancing their skills in ethical decision-making. This has been the Tuskegee niche in the bioethics enterprise.

The essence of the *integrative bioethics* framework is, at least in part, remarkably consistent with the recent recommendations of the Presidential Commission suggesting how to practice moral science.⁷⁰ My synthetic conclusion is that *integrative bioethics*, as presented here, should become part of the bioethical conversations. It is relevant to all people, not just the privileged few. Failure to incorporate it would amount to a continued denial of the Tuskegee niche, although truly it has already been carved into the bioethics enterprise. It would validate charges of exclusivity, elitism, and moral imperialism that were once leveled at mainstream bioethics.^{71,72} We should not permit this to happen.

An inevitable question remains: Just how does one shape a field for the better? Allen Buchanan has suggested that bioethics should cast a critical light on itself by use of social moral epistemology.^{51[p.289]} I argue that, when this approach is conscientiously taken, the Tuskegee niche of *integrative bioethics* framework will be fully acknowledged as part of the bioethics enterprise. This may cause the field to re-examine traditional approaches to bioethics that fail minority individuals at best, and at worst, do not serve the common good. The Tuskegee *integrative bioethics* framework is conceptually *inter-disciplinary*, methodologically *multi-disciplinary*, and entirely *trans-disciplinary* in practice. It may help mainstream bioethics change course. The concern of *integrative bioethics* focuses on issues of race, ethnicity, gender, class, and diversity. It captures beliefs about lived experiences,

defined from the inside rather than from the outside, and gives legitimacy to their role in deciding correct actions. As a comprehensive way of providing justice in health and health care, and of asserting the value and priority of human life with global orientation, *integrative bioethics* could be considered an alternative model for the new ethics for the public's health.⁴³

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