RICE UNIVERSITY

“‘At the Cross-Roads’: African American Spirituality, Clinical Trials, and Patient-Subject Decision-Making”

by

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Abstract

Published assessments of religion and health scholarship observe the substantial need for the study of African American spirituality, and that what is available has implicated this cultural production as helpful and supportive of good health yet inhibitive in end-of-life decision making. This qualitative study from semi-structured interviews with African American prostate cancer patients finds spirituality as helpful to sustaining patients in their decisions to risk medical research, although patients determine their decision to accept risk based on their understanding of the medical science presented to them. They are comforted by the agency available to them through bioethical principles and practices, most notably, informed consent. The findings of this study contest the centrality of the Tuskegee narrative popularly believed to be inhibitive to African American clinical trial participation as well as the over-simplification of the relationship between religion and African Americans’ cancer fatalism widely held among members of the health professions. The study acknowledges that structural issues prevent too many African Americans from access to the option of clinical trial participation. Two constructs are offered: a cultural sociological approach (Jeffrey Alexander; Gordon Lynch) to re-imagining Tuskegee as a sacred rhetoric, and a sociological approach to risk acceptance and risk taking referencing institutionalized religion; both constructs are derived from Durkheimian theory. These solutions are offered as responses to the data that emerged through the qualitative research and existing treatments of religion and health in African American religious scholarship. This study suggests that there is a shifting paradigm in which more African Americans will merge their spirituality with scientific knowledge to increase medical research participation with the long term aim of
reducing health disparities. In turn, additional theoretical frameworks will emerge beyond the closed loop epistemology inherent in Durkheim’s theory. The research agenda began here points to implications for theory and practice in fields including African American Religions, pastoral theology, health policy, health services, and bioethics.
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Introduction

The study of African American religion and health is at a cross-road positioned to head in a new direction, and clinical trials and experimental medicine are the signposts. This dissertation examines the role of religion and spirituality in the lives of African American men, who, diagnosed with prostate cancer, are presented with participation in a clinical trial as one among a number of options for care within a U.S. cancer treatment and research institution. It examines these decisions in light of literature in African American religious studies and public health research about African Americans’ attitudes and behavior about clinical trial participation. Much of the narrative of the relationship between African Americans and the U.S. medical establishment is fraught by a history of neglect through experimentation. This dissertation is not a recitation of that history; rather it is an examination of particular social processes within this fraught relationship through the cultural gaze of African American religious response to and examination of it. The work provides an opportunity to re-consider deeply held cultural beliefs about American and African American culture, and how these patients engage as agents interacting within and between two iconic American institutions: African American Religion and the U.S. health care system.

Stephanie Y. Mitchem and Emilie M. Townes stand at the forefront of the academic religious response to and examination of issues related to health and the U.S. health care system. In the disparate texts of these two Womanists, I detect theoretical foundations that lie in social theories closely related to or derived from Emile Durkheim’s famous examination of religious life as “eminently social.” In Mitchem’s and
Townes’s work, the “social” places emphasis on the identity function of religion and the ways that culturally connected individuals, African Americans, know how to exercise agency. “Knowing” is key component of decision making. The primary data in this project seeks to understand how African American male patients tease out their “knowing” in order to exercise their sense of agency and how their religious sensibility informs this knowing and, ultimately, their treatment decision. But these men do not exist in a vacuum. A prominent aspect of the world they have constructed for themselves is their engagement with religious practices and religious institutions. It is in institutions where, according to Mary Douglas and Aaron Wildavsky, individuals are oriented to how to process the “knowing” that is at the heart of their decisions: risk acceptance. This theoretical framing, too, is derived from Durkheim. Within institutions, including religious communities and religious beliefs, individuals share information and gain a risk orientation. I examine the orientation to risk taking presented in African American Religion and compare it to the risk acceptance experience of patients who participated in the clinical trial I studied.

In chapter one, “What Meaneth This?: African American Religion and Health, The Terrain and Field and Project,” I outline the various branches of academic literature related to African American Religion and Health. The terrain required to present this overview moves from religious scholarship to public health studies to bioethics. The majority of work published about African Americans’ religion and spirituality and health behaviors and attitudes has been developed in disciplines other than religious studies.

In chapter 2, “Religion, Black Bodies, and Clinical Trials: Good and Evil, Sacred and Profane,” I provide an in-depth interpretation of the problem of African American
clinical trial participation in religion and health by examining the work of two key producers in the field: Stephanie Mitchem and Emilie Townes. Townes, unlike Mitchem, acknowledges medical research, especially for women for whom public policy was changed in an attempt to increase research designed for women’s health issues. Townes’ primary monograph on health focuses on the social problem of the U.S. failure to provide adequate health care access to all of its citizens. In her view, a Womanist response requires naming this failure as a lament, repentance, and construction of an ethic of care; Townes sees each element of this trajectory as communal or community-based. Stephanie Mitchem’s religion and health research agenda is nearly twenty years long. She has established a record of African American epistemological perspectives on health issues with the overwhelming majority of her work focused on the women’s sense of religiously influenced agency. In the chapter, I also establish that narrative is an important form through which the general public gains a perspective of issues related to health and social groups.

But before discussing elements of narratives from the primary data, I outline a key component that shapes all of the narratives: knowledge. Chapter 3, “‘I Don’t Care How Much You Know, Until I Know How Much You Care’: Religion, African Americans, and the Sociology of (Medical) Knowledge” hones in on the different forms of knowledge that make it possible to be willing to take various sources of information into consideration. Scientific knowledge is accepted in Western cultures as objective and neutral, in part, because the methodology of its production requires it to have the capacity to be empirically replicated. However, sociologist and philosopher Bruno Latour, writing in the 1970s, introduced the idea of the social construction of scientific knowledge and
the social mechanisms that help scientific facts to be argued and replicated. This knowledge making process is also present in the work of Peter Berger and Thomas Luckmann in the sociological and religious realms of knowledge. This chapter lays the groundwork for the possibilities of how patients could choose to use the information they gather and from what knowledge communities. A primary inquiry in the chapter is whether patients’ religious knowledge or religious community will be sufficient to sustain the Durkheimian paradigm of social adherence or whether, in the language of Michel Foucault, there would be an irruption or discontinuity that shifts toward defect to the scientific community.

In Chapter 4, “‘That’s My Story and I’m Sticking to It’: Illness Narratives of African American Men, Their Spirituality, and Prostate Cancer,” I begin to identify specific aspects of the patients’ narratives that respond to the primary query in chapter three. In brief, the men make their decision based on knowledge shared by the medical science community while maintaining their relationships within their religious community affiliations. As they straddle both communities, risk emerges as the theme that points toward extra-health implications for African American religious scholarship.

“The Anatomy of African American Religion, Resistance, and Risk” is the subject of chapter 5. There I construct a sociological theory of risk applicable to African American religion and health using work from Durkheim successor, Mary Douglas and her writing partner Aaron Wildavsky. Sociological risk theories emerged during the late twentieth century when sociologists observed threats that could not be contained by nation-state borders such as nuclear accidents. But understanding the scope of these potential dangers is dependent on issues in the realm of the sociology of knowledge and
the manner in which experts’ knowledge impacts lay persons and lay persons’ decisions including risk identification. During this period, Mary Douglas, alone and with Wildavsky, undertook the role of morality and culture related to risk. They establish the role of institutions in shaping the individual’s orientation to risk acceptance. I argue that culturally, African American religious scholarship is inherently orientated to the past while risk is an inherently future oriented cognitive and affective decision and experience. The Durkheimian socio-religious frame brings some of the disparate, most prominent literature in the field into a single framework for examination as a means of re-orienting the clinical experience for future extension of African American religion and health discourse. My hope is that as I continue to develop the related research agenda it will contribute to this discourse in ways that help all who are determined to advocate for the reduction and elimination of health inequities through the reforming of the most beneficial elements of African American religions that can be explicated to guide individuals as well as for collective agency in risk acceptance and risk taking when warranted.
Chapter 1
What Meaneth This?:
African American Religion and Health - The Terrain of the Field and Project

Introduction

The literature in the field of religion and health that is drawn from the social and cultural experience of African Americans is scant.¹ A growing body of literature is documenting a relationship between religion, spirituality and health. Some of this literature falls within the realm of bioethics, some within medical humanities or religion and medicine, and yet more in an area sometimes referred to as spirituality/religion and health. My focus is on religious experience within the biomedical setting amongst the persons, social activity, and rational and nonrational or affective considerations and expressions.² I am focusing on what is often termed the Western medical enterprise of diagnosis and treatment of body systems where scientific discovery and technology are


²Refer to Renee C. Fox and Judith P. Swazey, “The Coming of Bioethics,” in Observing Bioethics (New York: Oxford University Press, 2008), 37-40. Generally, bioethics can be related to cultural expectations for the standards and principles used in the provision and evaluation of biomedical treatments and research within a particular society. According to Fox and Swazey, the field of medical humanities focuses on the education and training of medical students, training physicians, and practicing physicians. This field is addressed through the expanse of the humanities and the social sciences with the goal of expanding medical professionals’ approaches to patients beyond the view of essentially “fixing” or restoring the bodily systems impacted by a particular illness or disease process. The scope of the field, according to the mission statement of the New York University School of Medicine emphasizes the illness experience – from the physicians’ performance through literature as well as through the expanded learning of medical professionals especially as more and more technology has become available that narrows considerations of the whole of the patient experience. The overall goal of medical humanities is to improve the provision of compassionate care. See also David J. Hufford, “An Analysis of the Field of Spirituality, Religion and Health,” http://www.templetonadvancedresearchprogram.com/pdf/TARP-Hufford.pdf, (accessed 15 February 2011); New York University School of Medicine, “Mission Statement,” http://medhum.med.nyu.edu/ (accessed 29 November 2010).
able to enhance, sustain, and extend life—with all the moral implications in the giving and accepting of these technologies. For all their focus on technology in modern medicine, an estimated 100 of 146 U.S. medical schools require at least one course in the role of faith in medicine. An emerging portion of the spirituality/religion and health literature seeks to understand how cultural components of health care, in general, and patients’ participation in clinical trials, in particular, fit into the larger body of work. This project fits within this emerging part of the field. The majority of this chapter presents an overview of the various fields that needed to be reviewed in order to demonstrate fit for the project. These fields include African American religious studies; the nature of healing; public health and medical sociology; topics within bioethics; the psychology of spirituality/religion and health; and clinical trial decision making. First, I present definitions that will be used throughout the project and then move into the overview of the literature.

Definitions

It is helpful to define a number of terms that appear frequently throughout the project. These terms include: “African American,” “spirituality,” “religiosity,” “clinical trial,” and “health,” and “medicine.”

Whenever I refer to “African Americans,” I mean the descendants of Africans who have lived in America since the sixteenth century. A small number of African Americans have lived in the U.S. without a slave family heritage; however, the foreparents of the overwhelming majority of African descendants came to what became the United States of America during the transatlantic slave trade. This slave heritage is noted because

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religious studies scholarship emphasizes its importance within the cultural mechanisms that formed “the something new” that forms the object of study in African American religions. Occasionally, I will use the term “black” interchangeably to refer to the same group. However, predominantly, the use of “black,” in this thesis refers to the origin of persons from the African continent and their cultural frame as well as to the embedded experience of oppression and discrimination that came as a result of their skin color.

“Medicine” in this project will refer to biomedicine, the study of disease and biological science. Webster’s Medical Dictionary defines it as: “the science and art dealing with the maintenance of health and the prevention, alleviation, or cure of disease; the branch of medicine concerned with the nonsurgical treatment of disease.”

Like so many terms germane to this discursive context, “health” has a broad, culturally relevant body of literature out of which one must select an operative definition. Here, health simply refers to the status of normative function—normative for the individual or as determined within a particular culture. Although it is contested in some quarters, the definition of health written in the Preamble to the Constitution of the World Health Organization is widely accepted as a cross-cultural concept of health. “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease.” Note that medicine is distinguished from health. Medicine is the set of actions that seek to achieve, sustain, or restore health; health is measured in the site of

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4 For a full history, see the seminal work by Albert J. Raboteau, *Slave Religion: The ‘Invisible Institution’ in the Antebellum South* (New York: Oxford University Press, 1978). Raboteau describes the social, economic, political and cultural factors that shaped the religion of African slaves in the United States as well as in other parts of the New World.


individuals’ bodies with public health being these measurements and widespread measures taken to assess, sustain, and restore well-being across a specified population.

The National Institutes of Health (NIH) web site clinicaltrials.gov acknowledges that there are a variety of definitions for the phrase, but that “clinical trials…are generally considered to be biomedical or health-related research studies in human beings that follow a pre-defined protocol.”  This website is intended to be “user-friendly” for the general public who usually do not have specialized scientific training; this includes patients who may be searching for a trial that addresses their health problem or condition. The protocol refers to the process of the investigation. It is an outline of the elements of the study and the way the experiment will be conducted. There are various levels of clinical trials. Phase I trials are those in which the device or medication in the trial is being tested in humans for the first time; the test is to identify issues of tolerance in the human body. Phase II trials are being tested in humans in order to determine appropriate dosage, in the example of a medication. A Phase III trial is conducted in order to compare current standard medical practice against the one being tested; it often involves several hundred consenting participants and can facilitate changes in standard medical practice and health policy. 8

The most difficult of the key definitions to clarify are “spirituality” and “religiosity;” these terms are used within a shifting descriptive debate. There are two aspects to the debate: the terms themselves and the methodologies for the study of spirituality and religiosity, and especially important to medicine and health, the means to measure

spirituality and religiosity.\textsuperscript{9} This is, in part, so that the health professions, including policy makers, can make the topic measureable in order to empirically determine effects, for example, from a beginning point then measure again after some sort of intervention. This, seen as scientific process, requires religiosity/spirituality to be something observable.\textsuperscript{10} There is significant literature in the social sciences, religious studies, and the health professions that seek to define these terms. Here I will address only the general parameters regarding the two aspects of the descriptive debate as they are pertinent in the discourse about health and clinical trials.

Religious scholar Ann Taves places use of the term “spirituality” within the academic discourse of religious experience.\textsuperscript{11} This placement is helpful in locating the discussion of the project within the field of religious studies. In her interpretation of this discussion, spirituality “has variously been subsumed under, equated with, or distinguished from religious experience.”\textsuperscript{12} Psychologists Charles Mindel and C. Edwin Vaughan argued for a broadened use of the term “religion.” In their study of religious involvement among geriatric patients; they address what was being interpreted as disengagement from religious involvement.\textsuperscript{13} Mindel and Vaughan found that physical limitations of growing older might impact the ability of their participants to engage in “nonorganizational” religious activities, but that participants’ involvement in private religious behaviors were not diminished as participants aged. In fact, some patients became more individually

\textsuperscript{10}The need for observable measures helps to explain why religiosity and spirituality are often measured by activities such as church attendance, the frequency of reading sacred texts, and participation in ritual prayer.
\textsuperscript{11}Taves, 7737.
\textsuperscript{12}Ibid.
religiously-involved when they were unable to do so socially. This was an important argument to begin to acknowledge a variety of expressions of religion, intrapersonally.

Mindel’s and Vaughan’s research contributes to “multidimensionality” that we now often think of in the use of the concept and term “spirituality.”

Sociologist Robert Wuthnow similarly describes a shift toward spirituality beyond “the dwelling;” that is, spiritual expression outside the ritual practices of formal institutions. The move away from institutions began after the 1950s, the height of U.S. church attendance.\textsuperscript{14} Wuthnow distinguishes spirituality of dwelling from spirituality of seeking and spirituality of practice. He notes that a spirituality of dwelling is neither necessarily outmoded nor an irrelevant expression. One may envision someone who carries the values of a stable home—from the spirituality of dwelling. Although spirituality of practice occurs beyond institutional walls, it is not without knowledge. It may include knowledge from a variety of sacred texts, and incorporate activities intended to enhance or express relationship with God—“activities such as prayer, meditation, and acts of service.”\textsuperscript{15} Spirituality of practice is taken into self; it has a moral dimension that is internalized and binds together various facets of one’s life.\textsuperscript{16} For Wuthnow, spirituality of dwelling and spirituality of practice are not exactly the same, but they are related, and they are not valued against one another. Spirituality is a term, then, that can be used in a variety of settings.

\textsuperscript{14}Robert Wuthnow. \textit{After Heaven: Spirituality in America after the 1950s}, Berkeley, CA: University of California Press, 1998, 9. For Wuthnow a spirituality of dwelling can be thought of as a stable home and life; it includes formal dress and performance; that is, rituals. In the mode of spirituality of seeking, one may be between homes; that is, moving to a new place. The act of the move and the experience of the new place may impact identity formation.

\textsuperscript{15}Wuthnow, 186.

\textsuperscript{16}Wuthnow, 186.
Pam McCarroll, Thomas St. James O’Connor, and Elizabeth Meakes also determine that spirituality incorporates religiosity. In a search of five databases, they located 76 publications that had researched definitions of spirituality. These authors reviewed 68 of these articles and identified twenty-seven (27) definitions of spirituality. Within those 27 definitions, they located eight themes within spirituality:

1. Meaning and purpose (23)
2. Connection and relationships (22)
3. God/god(s)/Transcendent Other (12)
4. Transcendent self (11)
5. Vital Principle (10)
6. Unifying force or integrative energy (7)
7. Personal and private (7)
8. Hope (4)

These are rank-ordered only in the sense of the number of times that the identified dimension was mentioned among the twenty seven definitions as a central aspect of spirituality. The number behind the phrase shows the number of times that dimension was listed. The dimension is not described the same way in each article. For example, spirituality as “meaning and purpose” was described in nine articles as that which “shapes one’s values and approach to life and orientation to the universe.” The connection and relationships dimension could have been described as relationship within self, with the natural world, others, and/or the Transcendent Other.

The availability of these themes is important for a number of reasons. For one, by its very methodology as a literature review, the list points out that the research to define

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19 Ibid.
spirituality (as well as its counterpart religion) is an ongoing endeavor. McCarroll’s, O’Connor’s, and Meakes’ review of articles that simply seek to define the terms of the discourse and Mindel’s and Vaughan’s early work to expand the activities one expects within religiosity show that the discussion that began thirty years ago is continuing. The expanded list of dimensions will also be helpful to identify the aspects of religiosity/spirituality that may be operative in the clinical trial decision. During the patient interviews for this present project, I had rules of thumb to follow in distinguishing patients who preferred one term over the other. I was also able to listen for some of these themes in order to identify how they might be academically distinguished apart from patients’ perspectives.

Researchers Taylor, Chatters, and Levin have considered the discourse around definitions for religion and spirituality for use in the clinical arena. They note that “There is no agreed upon common understanding or definition of religion and spirituality and their distinctions [...] Among social scientists and the general public alike, there is a tendency to use these terms interchangeably.” However, they, as do many researchers operating within the field, settle on using the work of Harold Koenig, a Duke University psychiatrist who has been a leader in the development of contemporary research on spirituality, theology, and health. In the handbook he co-authored with McCullough and Larson, religion is more community focused and institutional, and spirituality is a more individualistic and behaviorally oriented. Taylor, Chatters, and Levin augment Koenig

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21Ibid, 15.
with Mattis, whose work has often focused on African American women. Interpreting Mattis, Taylor, Chatters, and Levin, conclude that “spirituality” and “religiosity” among black women are distinct constructs but are intertwined. For them, then, traditionally, “religious participation [has been] a conduit for achieving spirituality.” “Religiosity [is the adherence to predefined rituals and beliefs whereas spirituality [is] the internalization and consistent expression of positive values and the effort to manifest goodness in daily life.” “Spirituality [refers to the operating] relationships with God, with self, and with transcendent forces, including nature.”

To summarize, in this project, I employ the definitions of religiosity and spirituality that are gaining the broadest support in the field of spirituality/religion and health: both religiosity and spirituality are a measure of personal relationship with a divine entity (entities), figures or principles of transcendence. Generally, in religiosity this relationship of transcendence functions through a formal institution with a governing structure that develops and teaches doctrinal content and practices. Spirituality involves much more fluid content and practices that are used to facilitate connection with divine or the transcendent meaning-making figure that may operate within or outside a formal structure, including combining practices and beliefs from a variety of formal faith systems. Spirituality incorporates religiosity.

Literature Review


“Religiosity [is the adherence to predefined rituals and beliefs whereas spirituality [is] the internalization and consistent expression of positive values and the effort to manifest goodness in daily life.”

“Spirituality [refers to the operating] relationships with God, with self, and with transcendent forces, including nature.”
David J. Hufford has conducted an extensive assessment of the field of Spirituality/Religion and Health. As with any assessment, the aim of his study is to identify “current limitations, key problems, methodological shortcomings of current research and related issues relevant to moving the field forward.” He writes that there was an assumed link between spirituality and health throughout human history. This relationship continued in the Western world until the late nineteenth century when the notion of scientific medicine and standardized medical education became the predominant model. Hufford emphasizes the point that little of this emerging scholarship has come from religious specialists:

The field of SR/H research is quite new…but growing rapidly. The study of religion, of course, has existed since ancient times and is well represented in several contemporary fields. But those fields, such as theology, religious studies, and the sociology and history of religion have paid relatively little attention to healing, almost none to issues of direct clinical relevance.

Medical anthropologist Linda Barnes makes a related observation when she notes that much of the discourse between religion and biomedicine has been led by medical professionals. In addition to convening sessions on religions and healing for the American Academy of Religion, Barnes has taught religion and spirituality to medical students. In her essay “A Medical School Curriculum of Religion and Healing,” Barnes outlines a comparative studies approach to the study of religion/spirituality and medicine based on the increasingly diverse and pluralistic religious landscape in the U.S. In her view, physicians need training to address this diversity among patients. She observes, that “the current frame of reference for such training is ‘culturally competent care’ or ‘cultural

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27Hufford, 2.
28Hufford, 3.
29Hufford, 4-6. Hufford abbreviates the field as “S/RH”: spirituality/religion and health.
30Barnes has taught at the Boston University School of Medicine and at Harvard.
competence’ – the ability to serve as a competent provider in response to cultural and religious diversity.”  

She goes on to promote an approach to medical humanities that helps humanities faculty understand the structure of graduate medical education and to highlight that medical faculty should obtain training regarding the various ways that they could be called upon to work with patients who seek healing in biomedicine as well as in “cultural versions of religious therapies.” Besides advocating teaching physicians and medical students about religion, she argues that healing lies at the center of the dialogue between religion and medicine. This healing focus is also present in the work of Stephanie Mitchem, one of the primary scholars of African American religious studies and health. As part of a developed research agenda, the research trajectory into which the current project fits complements teaching modules for researchers who wish to understand culturally based clinical trial accrual and patient-subject dynamics especially as patients implicitly or explicitly indicate connections to their religiosity or spirituality.

As I move into the details of the literature review, Barnes’ (and Elias K. Bongmba’s approach to which I will soon come) contributions help to frame how I determine that there are gaps in the germane African American religious scholarship.

Scholars of African American religions entered the critical discourse of their object of study over a century ago. These scholars have not been merely apologists; they have articulated positive and negative effects of religion in the vast myriad of social, political, and economic issues of concern to American blacks. Yet few scholars of African

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32 Barnes, 308-9.
American religion engage aspects of institutionalized medicine in their work; and even fewer do so in a discursive format – in their form of argumentation or in their disciplinary distribution points— accessible to medical providers and researchers. This gap creates an opportunity for the current study.

**Literature Review: African American Religious Studies**

Scholars of African American religious studies have offered a view of health related issues using methodological approaches such as theology (Sanders), theological social ethics (Townes), and interdisciplinary approaches that focus on cultural analysis (Mitchem, Sanders). Primarily, these scholars have argued that the cultural expressions they study shaped and were shaped by color-based oppression of Africans involuntarily brought to what would become the United States as free labor and exploited black bodies. Four hundred years later, public health statistics document ongoing impacts of color-based racism at individual and systemic levels. African American religious scholarship places racism and race-based oppression and discrimination as the essential experiences with which persons of African descent living in the United States must cope on a daily basis.

In this vein, Cheryl Sanders provides a theological-ethical interpretation of data from research by Howard University renal transplant surgeon Clive O. Callendar on

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35I have chosen to withhold from this discussion Yvonne Chireau’s work in Black Magic as a historical-cultural analysis of spirituality in both conjure and Christianity. I read her work as a comparative analysis of diverse spiritual practices within a cultural group; I am interested how spirituality engages a different cultural form – medicine--for the sake of achieving health.

36Brian D. Smedley, et al, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (Washington, D.C.: The National Academies Press, 2002), 1. This is a study by the Institute of Medicine of the National Academies. The volume was unprecedented in its comprehensive scope and bold assertions. “Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients.”
African Americans’ perspectives on kidney donation. Callendar’s patients held expectations of racism in the harvesting and transplantation of organs (This is the surgical removal of organs and tissues in a manner that will preserve them so they can be surgically placed into another human.). He interpreted that they perceived that racism manifested as the disproportionate harvesting of donations from blacks to give to white patients, and the premature taking of organs or the withholding of life supportive or life saving measures in order to make African Americans’ kidneys available for transplantation into non-African Americans. Sanders interprets that these patients decision to decline organ donation reflect their theology of the body: they believe they will need a fully-intact body when they are resurrected in the final earthly reign of Jesus Christ in accordance with the Book of Revelation in the Christian Bible.

Sanders renders a Christian theological interpretation for both sets of issues (racism and theology) identified in Callendar’s encounters. She recommends that ministry praxis, through preaching and teaching can be assistive in creating a new paradigm. For example, preachers and teachers could address when the soul leaves the body as a means of assuaging fears that medical pronouncements of death may be premature. Sanders also sees theological ethics as useful in ministry to address organ transplantation. Religious leaders could teach about faith, hope, and charity as the virtues that cultivate an ethic of (organ) donation. Sanders implies, but does not directly employ the language of risks and benefits that are central to the mainstream of bioethical discourse. She limits her arguments to the case of organ transplants rather than any theoretical projections. Sanders also focuses largely on intervention level discourse.

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between physicians, ethicists, and chaplains. Her process is helpful as an example of the types of work that would be instructive in a content course in medical humanities. However, in this essay, her intended audience consists of teachers of current and future patients rather than medical practitioners. In my pedagogical vision her work has additional usefulness in its theological interpretation. She provides an additional resource to medical professionals working with a family member who would like to donate to a sibling, for example, but who is concerned about bodily resurrection. It is best used as a particular example of how religious beliefs may inhibit the use of medical technology to enhance or sustain life, but it does not offer additional insight into patients’ decision making about innovative medicine since her work was published in 1995 and the first U.S. kidney transplant in an African American in New York was performed as early as 1965, nine years after the first recorded successful kidney transplant in the country.\textsuperscript{38}  

Emilie Townes engages religion and health as a social ethical problem. In \textit{Breaking the Fine Rain of Death}, she proposes a womanist ethic of care to overcome the lack of access that impacted too many women and African Americans when she took a snapshot of the status of the U.S. healthcare system at the turn of the twenty-first century. Townes includes a chapter on Tuskegee, for its historical, educational, and ethical analytical value. Her 2001 volume was published a few years after the NIH guidelines for the inclusion of women and racial and ethnic minorities had been adopted. In her chapter on women’s health, she projects hope for an improvement in the status of women’s health through medical research. She sides with those of a political mind who connect

underrepresentation in clinical trials as the missed opportunity to create better science and better health outcomes, notably because research can bring increased attention to diseases that most impact women. She notes that white males and diseases important to their health status were being given priority for medical research—at the expense of other groups such as women, and suggests more attention to the health status gap for all women will be helpful to African American women. In her chapter on HIV/AIDS, she illustrates how the medical community, including its research arm, overlooked the health of women and blacks. White gay males were included in clinical trials at rates that soon reflected race, gender, and class factors as measures of “social wealth.” Townes includes a very brief section in which she explains that Christian theology that elevates the soul over the body contributes to less emphasis on physical health in orthodox Christian thought. In the HIV/AIDS chapter, she notes that cultural norms that repress sexuality and sexual health education contribute to ignorance and, in turn, facilitate the spread of infections through lack of protection and undisclosed risky sexual practices. Townes’ broad scale solutions include the religious activity of lament, accepting fault for having excluded too many from access to health care (and I would add medical research), and repentance by correctively including all in health care as well as for a community-based approach to solving public health problems.

In agreement with the intent of Townes’ suggestions, in my dissertation, I wanted to develop data in order to research the assertions Townes was only able to suspect or project. It is interesting that she sees the link between health disparities and women’s

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40 Ibid, 128-134. Here, Townes describes sexual practices such as the willingness to discuss legislation for mandatory HIV testing for prostitutes, but not their male clients, and the cultural rejection of gay males which led some of these men in the African American community to “masquerade” being straight.
participation much more clearly in women’s health than she does in the case of African Americans—even though she notes that both groups have been excluded from medical research. She even asserts that social ethicists have been less likely than medical ethicists to enter the health and health care debate. She thinks that “the concerns of social ethics—structures, institutions, processes, systems, and the ways in which individuals and groups both respond and shape them – provide a helpful lens to consider the nature of health and health care.”

In the years since Townes’ book was published, research interest in and funding for cultural mechanisms related to health have increased significantly. The social scientific study of these cultural mechanisms is one branch of hope to reduce health disparities. My investigation enters the gap that Townes sees, however, not from within social ethics – although there are ethical questions and concerns raised and answered in my project. Instead I respond to this gap from a sociology of religion frame by examining the components she suggests: “structures, institutions, processes, systems, and the ways in which individuals and groups both respond and shape them.” Examining the religious factors that may influence medical research participation is not, as one may infer from her chapters on women and African Americans, an attempt to place all of the responsibility on the individuals in these groups for which she advocates, and who also experience disparate health status and medical research attention. Rather, it is an attempt to understand beyond the historical reality that the research structures that produced the Untreated Syphilis study was egregious. It was egregious, and its mechanisms are

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41 Townes, 2.  
42 Townes, 2.
indefensible, despite the attempt by some to say that the study met the standards of research during its time.43

Easily, Stephanie Mitchem has produced the largest corpus devoted to religion/spirituality and healing among African Americans; it begins with her dissertation filed in 1998. In that project, her primary research question involves investigating the holistic nature of African American women’s spirituality. Mitchem sees spirituality and healing operative in a broad scope of personal and healing situations from incest to who provides healing arts to social roles; any of these issues fit into her perspective of the vastness of health issues. Throughout her work, black women are always the moral agents whose experiences are necessarily central; Mitchem has undertaken the project, in part, to extend the reaches or subject matter of womanist theology.44 The violence of incest against black women is facilitated by the invisibility of females within the African American community and a distorted vision of black sexuality portrayed by whites. Additionally, she juxtaposes the contribution of “untrained” “granny midwives” with the medical establishment, including African American physicians who would rather ignore midwives and their contributions to the spiritual and physical healing of members of their communities. Mitchem uses participant-observation (for example, attending meetings and events) and personal interviews with eleven members of a volunteer African American women’s health education and advocacy group to collect data about the women; she asks the them to define health, healing, and spirituality. Mitchem’s constructive project highlights how black women have used their agency to seek healing for themselves and


their communities. Mitchem reports how the women in her project, despite oppression, reimagine themselves as activists who seek healing for themselves and their communities. She offers a reconstruction of the doctrine of salvation; her aim is to “take these women off the cross”; they are often taking care of others—their lives, their problems—thus, sacrificing themselves and their health in the mode of Jesus Christ’s martyrdom. Mitchem sees the women in her project as engaging their view of themselves with and against views of them by external sources. Their oppression and marginality are a source of creativity.45

Stephanie Mitchem’s post-dissertation scholarship participates in the discourse of spirituality/religiosity and health in important ways with which I will (ultimately) want to reconcile my research agenda (though based on her corpus, this reconciliation will not be completed within this thesis). In African American Folk Healing, she veers from doctrinal analysis to broader yet less clearly distinct methodological tools which she draws from disciplines such as anthropology, psychology, and sociology of religion. Mitchem argues that African American folk healing is “culturally-derived,”46 encompasses a “range of activities and ideas”47, is (human-to-human) “relational,”48 is “intertwined with African American spirituality (which is often a substitute for theological foundations)”49, functions to “renew and balance life”50 and operates in institutional medical encounters, folk healing, and/or socio-political malady because it is a means of resistance not resignation. She asserts that African American folk healing ideals and activities are hybrids of varieties of cross-cultural encounters that meet the

45 Mitchem, “Getting Women off the Cross,” 132.
47 Ibid.
48 Ibid.
49 Ibid, 2.
50 Mitchem, Folk Healing, 3.
needs of individuals and communities. She argues for the maintenance of African American folk healing as a valid cultural form, and more importantly, as more efficacious than doctrinal commitments; for her, its theological contents are embedded and implicit. Mitchem notes that Eric Bailey, a medical anthropologist who studies African American medical experience, may be doing work that is ultimately of benefit to African Americans when he avoids referring to black folk healing as “alternative medicine;” relating African American folk healing to this generic term merely helps the form to fit better within discourse in biomedicine – diminishing its cultural significance.\textsuperscript{51} She understands that it may help to improve medical professionals’ cultural competency related to treating African Americans.\textsuperscript{52} This is another reminder that discourse with biomedicine is not the primary aim of \textit{African American Folk Healing}.

In the introduction to her text, Mitchem identifies a prime example from spirituality/religion and health: the medical establishment’s interpretation of black spirituality that it is fatalistic.\textsuperscript{53} Mitchem recounts a conversation with a medical researcher who, she describes, is designing a program to improve the numbers of African Americans who participate in cancer screening. For the researcher, the success of the study would focus on “the number of black people tested for different forms of cancer.”\textsuperscript{54}

\textsuperscript{51}Mitchem, 146.
\textsuperscript{52}Ibid.
\textsuperscript{53}Ibid, 2. African American cancer fatalism through spirituality is a dominant theme in the medical literature. See also Barbara D. Powe, “Cancer Fatalism—Spiritual Perspectives,” \textit{Journal of Religion and Health}, vol. 36, no. 2 (Summer 1997), 135-144.
\textsuperscript{54}Tests for early detection of cancer sometimes provide the diagnosis at an earlier stage of the disease. There is ongoing debate among the medical community about guidelines related to screening tests. Larger numbers of persons being tested also increases the numbers of persons who will be told that they have cancer when they do not, known as “false positives.” However, significant portions of medical literature show that the death rate among African Americans is higher than their portion of the overall population. See Smedley, et al, \textit{Unequal Treatment; Health, United States}, an annual publication. Some of this disproportionate death is related to diagnosis at a later stage of the disease. Early detection tests could allow for earlier treatment when disease is detected. Groups such as the American Cancer Society educate the general public on information of this sort.
Mitchem writes, “I replied that my interests focused on black Americans’ concepts of health, illness, and healing in light of spirituality in order to better understand health practices;” and that she “presented several examples of the approaches that black people take regarding health care, resulting in …self-directed healing methods.” The white researcher responds that they “often wondered why so many black people were fatalistic when diagnosed with cancer.” Mitchem notes that she intellectually understood how members of the medical community misinterpret the cultural differences in black spirituality as fatalistic, but that “emotionally,” she heard “the word fatalistic as affirmation of racist assumptions about black concepts in healing practices.” That is, that “fatalistic” is the term some members of medical communities use to dismiss the resistive element of an “African American culturally centered response in the face of potentially terminal illness.” To Mitchem, they hear it that way because the African American response they observe equates to “resignation” in Western frameworks—resistance as a culturally centered response never enters their interpretive discourse.

Mitchem’s strategy to deal with this issue of cultural difference is one type of response. Her perspective is that since different healing modalities are efficacious, she chooses to focus on the folk mechanism and its embedded spirituality. Her goal is healing that is holistic, addressing physical and social issues. Later, Mitchem discusses the case of Betty Price, the wife of a “controversial” California evangelistic faith megachurch leader. At first, Mrs. Price rejects chemotherapy and radiation for the disease which at that point is treatable. She chose, instead, faith and the belief that God did not want her to

56 I have used the pronoun “they” here because Mitchem did not identify the gender of the research.
58 Ibid, 3.
59 Mitchem, *Folk Healing*, 134.
accept those treatments “because it kills your good cells and destroys your body.”\textsuperscript{60} But when the tumor began to protrude from her side, she agreed to the treatments believing that God “had offered a new understanding;” treatment would be acceptable because through the treatment, “God [would be] work[ing] through the doctors.”\textsuperscript{61} In this example of faith and healing, Mitchem states that the African American folk healing epistemology is able to function during encounters within institutionalized medicine.

I anticipate that Mitchem’s outline of Betty Price’s story may be replayed in my own research with patients. Still, my interest lies in understanding how this mechanism works within institutional medicine where much health care is provided today. I will speak with patients, some of whom are in the process of making the decision to participate in biomedical treatments that are being studied for their effectiveness. These patients have chosen to participate in potentially risky clinical trials. My questions, then, are how and whether spirituality is operating in those instances as well, especially given a commonly held socio-cultural taboo that warns against medical experimentation based on the history of African Americans and that scientific form. Mrs. Price initially declined any treatment in favor of the expectation of faith healing. Given Mitchem’s retelling of Price’s reassessment, spirituality was operative as resistant even to proven medical science. My discursive strategy differs from Mitchem’s. I acknowledge, for example, with similar emotional trepidation, that Mitchem is entirely correct in her analysis that some in the medical community who are aware of the black-fatalism-in-cancer interpretation are “affirming racist assumptions about black concepts in healing practices; ... [and that it]...implies that African Americans do not have their own culturally centered

\textsuperscript{60}Ibid.  
\textsuperscript{61}Ibid.
responses in place when faced with potentially terminal illness." But I see another, equally important discursive program. I am interested in religious studies being in dialogue with medicine in the areas where the disciplines need to inform one another or where they can locate common ground. In this instance, for example, how, as the African American religious studies expert, might Mitchem’s work help to identify aspects of African American spirituality that might be important to patients to have addressed within the institutional or research setting? How, when the disciplines use different modes of discourse and argumentation, might the discussion move forward—in part because the culture and the science are valid and must operate together on behalf of the ill person?

I agree with Mitchem that a broad range of issues fit under health. Mitchem’s focus is broad because her aim is healing. The bookended projects described above emphasize her interest in the use of that broad definition as the cultural form through which she argues that African American women develop and use their perspective of their spirituality as the basis of their activism. This self-defined spirituality is rooted in marginalization and oppression.

Cheryl Sanders renders another treatment in religion and health in her essay, “Religion and Ethical Decision Making in the African American Community: Bioterrorism and the Black Postal Workers” in the 2007 African American Bioethics. This volume is a follow up compilation to the 1992 African American Perspectives of Biomedical Ethics. In the first volume, Sanders outlined what she thought would need

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62 Mitchem, Folk Healing, 2-3.
to be included in a bioethical system developed from an African American perspective. Near the top of her list is her argument that such a system would be rooted in spirituality. In the later volume, Sanders writes about religious components of the response from African American postal workers when they were threatened with death by inhaling anthrax spores in the mail while working at postal facilities near Washington, D.C. and Trenton, New Jersey. The case comes from anthrax-laced letters sent to two United States Senators after the September 11, 2001 terrorist attacks.

Two workers at the Brentwood postal facility outside Washington, D.C. died from unknowingly having inhaled anthrax spores while processing mail. Rather than accept an offered vaccine as an antidote to the anthrax, Sanders points out that overwhelmingly, 97%, of the postal workers, the majority of whom were African American, declined the vaccine. They preferred to “trust in God” for protection against the possibility that they, too, had inhaled spores. She links folk healing as religiosity to their decisions to reject the prospective treatments. This is similar to Stephanie Mitchem’s view of African American religion and its influence on its adherents during health issues.

In comparison to Sanders’ project, I am interested in the decision making of the three per cent she does not discuss rather than the ninety-seven percent she does. Questions applicable to her project, for example, would inquire as to whether or how religion may have influenced those in the three per cent who decided to take the vaccine for anthrax. We cannot assume anything about their spirituality so this is an area available for study. Most importantly, we cannot assume that the three per cent live in

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some sort of a-religious vacuum. In fact, I would argue, that study of the three percent is appropriate to understand the role religion can play in furthering or hindering African American participation in clinical trials.

Sanders’ projects also do something else. In her analyses of secondary data, she looks at each set of facts through the lens of her professional expertise: theological ethics. This technique opens a place for dialogue in a way that Mitchem never intends. Considering the two language model of the relationship between science/medicine and religion/spirituality, Mitchem allows each language to speak from its own point of reference without translation, but aware that each exists (although she suggests that the medical community is unaware that the black community has its own language). Sanders, on the other hand, suggests that there needs to be dialogue and at pinpointed intersections, she provides specific cases to illustrate the dialogue. Townes, more often than not, is closer to Mitchem in speaking within their shared (academic) disciplinary and cultural community.

Finally, before drawing this section of the literature review to a close, I must also reference Bongmba’s monograph on religion and health. Although he is a scholar of African Religions rather than the African American context, his work is important for the subject matter and methodology he demonstrates as well as for the connections he draws between health solutions that link religion, disease, the institutions of civil society, and public policy. Bongmba’s vision of healing includes a role for the African church in the

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65 I have already provided definitions for spirituality and religion, and explained that they are not synonymous, however, do function in similar ways. In writing science/medicine, I am also not equating them, but acknowledging that their knowledge production processes are similar.

66 For a description of the “two language” model of the relationship between science and religion, see the entry “Science and Religion” in Encyclopedia of Religion. Generally, the model is a non-conflictual relationship between science and religion. In this entry, science and religion refers most often to the physical sciences and religion, I am here using medicine as one form of science.
fight against AIDS and he uses virtue ethics as the methodology for his argument. The African church must take part in seeking solutions –by offering them in service or advocating for them with other sectors of society-- because in the Christian concept of *imago Dei*, all humans are made in the image of God and so all have a relationship with God, and because all humans have a relationship with God, all humans also have a relationship to one another through their common relationship. As one element of this relational experience, Bongmba offers a four-fold involvement between the scientific community and the church to address the AIDS crisis. The four-part plan is: education about HIV/AIDS vaccine testing and drug trials; helping the broader community understand why participation in drug trials are important; the critique of government compliance with trial regulations; and advocating that drug companies make treatments affordable.67

Each of these African Diasporic religious scholars offers ideas which can inform my own work in different ways. Each of them speaks in their primary “language” within religious studies, and may or may not translate to another community, specifically the biomedical community. There are few academics from each of these communities who are “bi-lingual”, but I contend that it is necessary to speak enough of both languages for the paradigm to shift in the other; that religion/spirituality and medicine/health become a mutually informing dialogue. Each discipline has something to say to the other.

**Literature Review: Public Health and Medical Sociology**

Steven Epstein provides a thorough description of the politics of difference to which Townes alludes; for him it is rooted in the way medical research recruitment is

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developed through public policy. His research project, *Inclusion: The Politics of Difference in Medical Research*, was published six years after her volume; it outlines the development of the inclusion requirements since they had been signed into law in 1993.

Epstein’s volume provides the best example of medical sociological literature that is relevant to my project. He describes the politics and social movement activity used by citizens and government officials to include women and racial minorities in medical research. Epstein concludes that many African Americans, women in particular, choose to participate in clinical trials as an altruistic value. If he is correct, one connection to be investigated would be the religious/spiritual aspect of this value. Curiously, Epstein makes little reference to the role of African American religious institutions in the politics of inclusion that he argues exists. This at a time when medical research recruitment efforts for African Americans (and other formerly excluded cultural groups such as Hispanics) increasingly focus on reaching potential subjects through the locations where substantial numbers could be reached—in their churches.

Epstein argues that groups which have employed political power and social movement practices to argue that the young white male has been the ubiquitous human subject oversimplify the sociology of human subjects. Rather, Epstein argues, medical science has had three sets of oppositions with intertwining histories that reflect the design and applicability of the science. In his more complex analysis the three sets of

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68Epstein does mention the role of other African American organizations in the politization of racialized medical recruitment. For example, in the BiDil case, a drug approved for congestive heart failure in African Americans, the Association of Black Cardiologists endorsed medicine based on the incidence of the condition among African Americans. See *Inclusion*, 215. See also the role of the Congressional Black Caucus in including African Americans in the NIH Inclusion Guidelines, *Inclusion*, 54 as well as in the emphasis on health disparities by helping to pass legislation to elevate research on minority health and health disparities from an office to a center in the NIH organizational structure. See *Inclusion*, 79. (Subsequent to Epstein’s publication, the Center has now been elevated to an Institute, the highest level in the NIH structure.) It should be noted that the Congressional Women’s Caucus has played a similar role in achieving regulatory address regarding women’s health issues.
oppositions have been the privileged versus the vulnerable; sameness of subjects versus difference among subjects; and the search for generalizable results versus specificity.\textsuperscript{69}

Epstein’s arguments are best placed in dialogue with Townes’ chapter on women, women’s health, and clinical trials. Albeit for different reasons, they agree that it is an oversimplification to conclude that the white male research subject has historically been viewed as the ideal subject. Townes notes that scientists find data from homogeneous populations easier to analyze.\textsuperscript{70} Townes attempts to rectify the exclusion of women and racial and ethnic minorities through the religious concept of repentance. Epstein argues that the new inclusion has been a policy and political process; he takes no notice of a role from religion or religious players. These scholars’ analyses are consistent within their disciplines. My question is more related to whether and how these two sets of factors -- inclusion on the basis of a religious concept and the political/policy ideal -- may interact in the African American case.

Along this line, I have placed the work of legal educator and bioethicist Patricia A. King within the literature review of medical sociology. One of her primary concerns in the discourse of bioethics has been the inclusion of African Americans through a rigorous examination of public policy and the law. King’s work is important on many levels. She was one of the members of the Commission established to develop standards for human subjects’ protections—the task force that produced The Belmont Report.\textsuperscript{71} From her discipline as an attorney, King has explicated the ways that the principle of justice has

\textsuperscript{69} Epstein, \textit{Inclusion}, 51.
\textsuperscript{70} Townes, 111.
\textsuperscript{71} Childress, et al, eds., vii-x. The \textit{Belmont Report} was written by members of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission was established through Public Law 93-348 in 1974 and completed its work with the \textit{Belmont Report} release in 1978. The function of the Commission has continued through a series of presidentially-appointed commissions and boards.
evolved in the case of population level inclusion in medical research. In her view, the original use of the principle was as a protective measure to reduce the risk of harm caused to certain populations that might be easily accessible. Justice, then, meant that certain classes of prospective subjects, such as African Americans, were being protected by not being recruited for research. However, when HIV/AIDS came to light in the early 1980s – a mere ten years after the general public disclosure of the Tuskegee experiments— the perspective of the principle of justice and its link to persons included in medical research began a dramatic shift. Initial reports in the U.S. press focused on the experience of members of the white male homosexual community; there was a rise in cases of a new, mysterious disease wreaking havoc among this group. Seeking to escape death, they began to demand public research funding that would fight AIDS. King sees this movement as changing the focus of the principle of justice from exclusion of certain, previously-exploited groups to inclusion connected with potential benefits of being included in clinical trials. Justice changed from a distributive model to a compensatory or procedural model; the emphasis is on the achievement of “fair or unbiased…adherence to a set of well-ordered procedures.”

Patricia King’s writings on the evolution of justice (as well as the bioethical principle of beneficence) are an important addition to the discourse on the inclusion of African Americans in clinical trials. She does not link her work to her own religiosity.

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73 Steven Epstein, “The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials” Science, Technology and Human Values 20, no.4 (1995), 408-437. Sociologist Steven Epstein writes of the experience of AIDS advocates gaining credibility with the medical research community by learning the epistemology and language of that field in order to participate in planning and implementation of reforms in the AIDS research enterprise.
Even so, her reformation of the concept of justice based on the progress of medical technology begins to appear similar to Townes’ social ethic of repentance.\textsuperscript{75}

**Psychology of Spirituality/Religion and Health**

Psychologist Kenneth Pargament and Africentric pastoral psychologist Lee Butler provide parameters of literature that will be helpful to the interpretation of the primary data. According to Pargament, coping is the process of sustaining or reorienting one’s identity when it is threatened in some way; it is the activity of seeking significance.\textsuperscript{76} Coping that leads to decision making occurs within a prior orientation.\textsuperscript{77} In other words, decisions are not made \textit{ex nihilio}. Although he doesn’t link it to physical health, for Lee Butler, identity formation among African Americans is salvific activity because it is rooted in religiosity/spirituality.\textsuperscript{78}

So participants in my project who describe their clinical trial decision as influenced by their spirituality/religiosity are making their decision within an orientation that was in place before they arrived at the encounter that called for a decision. The decision resulted from cognitive and emotional elements. Specific activity between these two categories will include the processing of medical information shared from physicians and other providers about the immediate diagnosis and prognosis, reconciling cultural myths and anecdotes, accounting the situation as a health risk/benefit, a coming to terms

\textsuperscript{75}Two other recent works on justice in health care may also be helpful; however, they are not devoted to a reworking of the principle based on particular populations. Rager addresses the inherent tension in the principle of justice when a society hopes to balance holding down costs of health care while and distributing the benefits of access to health care as broadly as possible. Madison Powers and Ruth Faden have recently written about social justice in public health and through some of their examples address matters such as the disparate life expectancy of African American males. Jennifer Prah Ruger, \textit{Health and Social Justice} (New York: Oxford University Press, 2010). Madison Powers and Ruth Faden, \textit{Social Justice: The Moral Foundations of Public Health and Public Policy} (New York: Oxford University Press, 2008).

\textsuperscript{76}Pargament, 90.

\textsuperscript{77}Ibid, 104.

\textsuperscript{78}Lee Butler, Jr., \textit{Liberating Our Dignity, Saving Our Souls}, Danvers, MA: Chalice Press, 2006.
with their mortality, an altruistic gesture on behalf of African Americans, related or not, who are diagnosed with cancer in the future. Data gathered during interviews with participants will allow use of coping theory to code for these as well as other decision making factors that may be expressed.

**Literature Review: Clinical Trial Decision Making**

The three studies described below investigate patients making clinical trial decisions. One, the primary study with which I will engage in the dissertation, investigates spirituality within the clinical trial. Two of the three studies inquire about the decision-making experience of patients invited to phase I trials; these suggest that the patients in those samples view the clinical trial decision as a search for hope for their health—despite their fatal prognosis—often within eighteen months at the outdate. The third study investigates patients in phase III oncology clinical trials.

**Spirituality and Phase I clinical trial decision making**

Daugherty, et al proposed to explore the spirituality of volunteers for phase I oncology clinical trials impacted their care decisions.⁷⁹ They note that there has been some documented evidence that cancer patients report that spirituality is very important to them, and that there appears to be a higher quality of life, and psychological well-being among spiritually rooted cancer patients. They concluded that oncology patients who participated in phase I trials had a slightly higher measured spirituality than the general population of cancer patients; they did not find that these patients possessed less realism about their prognosis. These researchers found that patients were very aware of their prognosis, yet employ their religiosity, in part, to maintain hope with realism. These

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patients found no discrepancy between their decision to participate in this highly experimental measure and their belief in spiritual. But the Daugherty, et al study was limited in that they did not compare spirituality in patients who had declined a phase I trial, nor did they conduct an in-depth review of the relationship between spirituality and the specifics of such an influence in decision making. They left to future researchers to study the role of spirituality, clinical trial decision making, and coping styles and psychosocial resources.

The Daugherty, et al study suggests that the clinical trial decision for cancer patients may be a treatment option, despite the acknowledgement that it is research. This potential interpretation must be taken into account during my own research project. This study is also relevant in that it raises the possibility that hope is a spiritual dimension for these participants. I included questions on the Interview Guide that seek the patients’ knowledge of clinical trials, their understanding of the recruitment discussion, as well as the decision they have made to assent or decline.

*Phase I clinical trial and therapeutic optimism*

Agrawral, Grady, et al conclude that phase I clinical trial patients know that they are choosing to participate in research, not a clinical treatment. The participants in this non-generalizable, five-site study were highly-educated with more than 50% holding a college degree or above, 96% had insurance, had visited an average of two cancer centers, and 88% were white. For these patients, participation gave them a sense of control. On average, these patients had lived with cancer for nearly five years, so they were familiar with diagnostic tests and found comfort in the increased monitoring

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required by the clinical trial. The majority saw information about potential adverse effects, part of the informed consent, as less important information than the potential anticancer effects of the treatment.

The Agrawal, et al study focuses on how patients process the information content aspects of decision making. The authors also identified the “hope” dimension of participants’ decisions. In this case, hope is associated with patients’ expectations that the trial will be effective. These patients are actively engaged in intentional exercise of the options available, of which they are well informed. The authors interpret this decision making as an exercise of agency.

Clinical trial decision making, influencing factors and roles

Wright, Whelan, et al studied clinical trial decision making factors among cancer patients in the Canadian context. These researchers sought to determine the independent factors that influence participation. They first conducted a literature search to compile a comprehensive list of factors which influence patients’ decisions to participate in a randomized clinical trial. They then conducted focus groups with physicians, recruitment coordinators (they refer to this role as clinical research associate (CRA)), and patients. Their final list of factors is categorized into three aspects of the clinical research enterprise: general issues, trial specific factors, and recruitment encounter specific factors. The trial specific factors are immediately relevant to this proposed study; however, the other categories are also important, even if not immediate to the current work.

General issues:
   Socioeconomic issues
   Altruistic motives
   General attitudes regarding research
Decision-making preference

Trial specific:
- Patient’s sense of personal benefit
- Patient’s impression of toxicity
- Patient’s impression of time commitment
- Opinion of family and friends and other supports
- Source of learning of trial availability
- Placebo control

Recruitment encounter-specific:
- Patient’s sense of strength of physician recommendation
- Patient’s sense of strength of CRA’s recommendation
- Impression of recruiter
- Success of information transfer
- Adequate time for decision

Recommendations from Wright, Whelan, et al, focus on the role of the CRA in information sharing and their potential to influence patients in decision making. For the proposed study, the trial specific factors are helpful for reviewing content that may influence decisions in the clinical trial knowledge section of the Interview Guide. This study also provides other process themes to attempt to hear during the proposed interviews. The Wright, Whelan study does not inform the spirituality aspect of the proposed study.

**Literature Review: Decision Making among African Americans Regarding Health**

Finally, I will need to understand literature that describes the experiences of African Americans in health decision making. Nalda Gordon’s dissertation studied decision making among African American women with breast cancer (Stage I through III) – the severity of disease progression codes. Her inquiry was to identify the amount of decision involvement the women wanted to have in their care, and the quality of care outcomes related to various levels of involvement preference. In addition, she compared these data between African American and Hispanic women. She found that the majority
of the African American women preferred a God-shared decision making model as opposed to passive, God-deferring style or a self-directed style of coping. This finding is highly suggestive of a decision and coping process that refers to humans as “co-laborers with God,” often referred to as a “God-human” relational model in a number of African American theologies.\textsuperscript{81}

Gordon’s work is helpful in that she attempted to incorporate cultural differences and spirituality as a dimension of the women’s decision making. It is important to note that the dimension of decision making she investigated was locus of control. Gordon notes that locus of control is a psychological concept that measures a dimension of health decision making. Here, Gordon uses it as a proxy measure of spirituality. Her intent was to measure the amount of control the patient desires with three options: deferred or passive role, shared or collaborative, and self-directed or sole decision making role. God is the dyadic contributor in her construct. In other words, the dimension of spirituality important to Gordon’s analysis was the level of desired decision making partnership with God and the quality of life associated with the congruence with desired and actual involvement. Women with a collaborative involvement with God had the best quality of life outcomes.

Gordon’s findings support previous work about a collaborative decision making preference on the part of African Americans. Similarly, Randi Williams, et al found that the majority of African American men in a prostate cancer study preferred a shared decision making model, however the dyadic partner in that study was the physician; that

project was not a spirituality measure.\textsuperscript{82} Furthermore, this shared decision making model with God mirrors the long argued theological frame of some scholars of African American religion.\textsuperscript{83} Other studies cited in the proposal indicate that control as well as the willingness to relinquish control is only one dimension of spirituality. Gordon’s dissertation does not complete the inquiry sought in the proposed study.

Elizabeth Williams completed her dissertation project in Anthropology on African American breast cancer survivors and their spirituality and the mutual aid they provide to one another as cultural coping mechanisms.\textsuperscript{84} Williams undertakes the subject (African American women’s experience of breast cancer) and methodology (qualitative research through participant-observation and interviews) of her project to dispel the misunderstood and understudied subjects of her work that currently exist in clinical literature. She presents a variety of roles the women take on in survivorship and in thriver-leadership, which she links with similar roles in the Christian Bible. She sees these roles as expressions of spirituality which indicate a motivating influence as well as a resisting or protecting one. Spirituality empowers one woman to move from seeing herself as a second-time victim of breast cancer to a thriving role in which she shares her story of survival in order to motivate other breast cancer patients in their treatment participation—that they not see themselves as living with the inevitability of cancer and the social, financial as well as physical difficulties it can usher into one’s life. Williams appeals to

\textsuperscript{83}Consider, for example, Carroll Watkins Ali, \textit{Survival and Liberation: Pastoral Theology in African American Context} (Atlanta, GA: Chalice Press, 1999).
Black feminist and Womanist works as theoretical interpretive frames for the survivors’ narratives.

Williams also comments on the women’s theological underpinnings. It is important to her to observe that the women do not believe God has caused cancer. Instead, she reads the women’s narratives as constructing God as a “liberator” and/or as a “judge.” In this African American theology (her description), God as liberator removes obstacles even if that obstacle is oneself. God as judge uses the circumstance of the illness to push the women to exercise their agency to rectify their relationship with God, change something in their lives, or to adhere to a principle of the (Christian) faith.

Williams’ dissertation provides helpful methodological considerations, support for my understanding of religion as a social entity through her emphasis on mutual aid, and it has literary value as a way to present an ethnographic project. However, it does not give the insight I seek to uncover regarding clinical trials decisions and how to overcome the history of African Americans and uncertain treatments.

In the next chapter, I take a closer look at the literature and arguments of the primary literature in African American Religions relevant to my dissertation project in order to deconstruct them so that I can ultimately construct a theoretical frame for African American religion and clinical trial decision-making.
Chapter 2
Religion, Black Bodies, and Clinical Trials: Good and Evil, Sacred and Profane

“Evil.”

That’s how one of the black clubwomen I was sitting near summarily described the Tuskegee Syphilis Experiment.85 “Tuskegee” was one of the responses to the question in “Clinical Trials Bingo.” The game moderator, a black female health educator, had asked the women for the reasons why “we” (African Americans) do not participate in clinical trials. The educator had appropriated the popularity of bingo as an entertaining way to share information about various types of clinical trials, their uses, and the potential for their connection to African Americans and health. Remarkably, “Tuskegee” was down the list of responses to the game question.

Hearing the woman’s comment, I looked up. The tone is her comment — a mix of anger and disgust — drew my attention to the speaker. “They just had no regard. Animals get treated better,” she added.

I was also struck by the woman’s use of this particular moral term, “evil.” Her tone and her descriptive term applied a frankness in which she evaluated one of the most infamous episodes in medical research history, and “they,” the people who would conduct clinical research using blacks as petri dishes. That day, in my role as a silent observer, I was unable to ask the woman whether in her choice of a moral term, she

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85 The Tuskegee Experiment is the popular referent for forty-year long medical study in which took place in Macon County, Alabama. The official name of the medical study is “The United States Public Health Service (U.S.PHS) Study of Untreated Syphilis in the Negro Male.” It began in 1932 and was ended in 1972 after it was exposed to the general public through media accounts. Some of the 600 black men who went without treatment for diagnosed cases of syphilis lived near Tuskegee, Alabama where a historically-black university is located. The university continues to provide education in a variety of health services fields.
related “evil” to a religious concept. However, one fact was apparent: among this group of sixty or so women, their responses to the question of the lack of black participation in clinical trials did not generate an immediate and strong link to one of the most well-known episodes of human experimentation in the history of the United States. Forty years after its 1972 public exposure, “Tuskegee” is within the knowledge base and/or memory of these women, but it is further down their list of reasons connected to black under-representation in clinical trials. And to the question of why African Americans do choose to participate in clinical trials, the women included “to help someone else” and “to possibly get access to treatments.”

In his edited history of African American responses to theodicy and moral evil, Anthony Pinn writes: “Behind African American religious institutions and rituals is a concern with divine justice in light of moral evil, as well as with the nature or origin of human suffering.”86 Pinn continues, “Questions concerning the nature of human misery remain intense for Americans of African descent.”87 Pinn also notes that this reality has prompted questions in which the “conversation related to these questions has been marked in several ways, including a sense of urgency, a commitment to the practical consequences of ideas, and the persistence of a theological paradox.” 88 To my mind, the African American experience in the U.S. health care system points to another area where this manner of question bears address as a matter of evil, unmerited human suffering, and ideas for resolution through theoretical and practical research.

87 Ibid.
88 Ibid.
African Americans experience poorer outcomes and a shorter average life expectancy compared to whites with the same diseases/disease processes.\(^8^9\) This aspect of African American suffering has had greater public health attention since the *Task Force report to the Secretary of Health and Human Services* in 1985 and even more intensely since the Institute of Medicine report titled *Unequal Treatment* published in 2003.\(^9^0\)

Nowhere has suffering and evil in the lives of African Americans been felt more profoundly than in their bodies; thus, my intrigue with the woman’s moral assessment that medical research, to her mind, represents “evil” and a threat to black bodies. If, in fact, some African Americans see medical research in humans as “evil,” how might or can African Americans use moral language to assess the possibility of inviting “evil” into their bodies when that evil may also have the potential to relieve the suffering of a medical condition and reduce health disparities across the African American population? Moreover, what does African American religion say to African Americans facing this very dilemma?

**Why Clinical Trials?**

In chapter one of this dissertation, I presented an overview of literature from scholars in African American religious studies who address health and medicine; there is relatively little literature in this subfield of religion and health. That which has been published is relatively recent; however, the broad discourse linking the relationship between religious beliefs, religious practices, medicine and health is thousands of years


old. In this chapter, I move from the general to the particular by exploring an under-investigated component of the relationship between religion and health -- the case of clinical trial participation and decision making. I have chosen to study this interaction within religion and health for a number of reasons. In their broadest sense, my reasons can be visualized in the shape of a triangle. One side would be “religion,” the other side would be “health,” with social processes and social scientific theory and research methods connecting the two. On the health “side” my reasons would be based in considerations of sociocultural aspects of health care as is often academically located in public health research and, to my lay perspective of health policy – a topic relevant to the nation as the din in the political discourse reaches a roar with 78 million members of the Baby Boom generation entering eligibility for Medicare. On the religious studies side, my interest is the continuing development of African American religious studies using health as the field of research because it offers the opportunity to study complex questions. Social processes needed to produce, distribute, and use knowledge(s) connects religion with health.

Within the study of health and populations, clinical trials and human experimentation have been a special (often considered notorious) case within the African American experience. To contemporary patients, clinical trials increasingly have the appearance of being one among patient treatment options especially for serious illnesses such as cancer (just as was so for HIV/AIDS in the early 1990s). Among the portion of

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91 Vivian Nutton, “The Rise of Medicine,” in The Cambridge History of Medicine, ed. by Roy Porter (New York: Cambridge University Press, 2006), 46-70. Here Nutton describes that archaeologists have located evidence of ancient medical texts from Egyptians and Mesopotamians who influenced the Greeks to whom some credit the roots of modern medicine; furthermore, there is evidence of medicine in ancient India and China. Nutton also gives attention to the role of ancient faith systems in healing.

92 Citizens over the age of 65 are automatically enrolled in Medicare, a federal health insurance program.
the research and bioethical community interested in reducing health disparities in racial and ethnic populations, promising yet experimental treatments may offer opportunities for improved health outcomes.

There is a critical mass of public health researchers who believe that reductions in health disparities cannot be achieved without including African American religious communities in these efforts. I believe these communities ought to have a well-reasoned, self-interested response to why they would choose to become involved in or decline opportunities to participate in public health research including clinical trials. From a religious studies perspective, this is especially important as there is sufficient research to indicate that African Americans sometimes participate in clinical studies because it might help someone else. Conducting religious research in the clinical setting and inquiring about a relationship between religion and clinical trials contributes to the development of theory and rationale of the culturally significant aspect of this discourse. Furthermore, for decades now scholars of African American religion have examined social data and theory and restructured and appropriated culturally relevant symbols inputs and tools, respectively, to progress African American views and standing within the U.S. context.\footnote{The appropriation and interpretations of the cultural symbol of Black Power comes to mind. Various religious leaders and religious scholars offered interpretations of the meanings of Black Power. See the “Black Power Statement” by the National Committee of Negro Churchmen published as a full page advertisement in the July 31, 1966 New York Times reprinted in James Cone and Gayraud S. Wilmore. Black Theology: A Documentary History, volume one (Maryknoll, NY: Orbis Press, 1979). Albert Cleage’s volume of published sermons: Albert B. Cleage, Jr. The Black Messiah (Trenton, NJ: Africa World Press, Inc. 1989). Originally published 1968. See also James Cone, Black Power and Black Theology, 20th Anniversary edition (New York: Harper & Row. 1989). Originally published New York: Seabury Press, 1969.}

Finally, I view clinical trials as presenting a unique opportunity to explore what we can learn about how religious systems incorporate new or changing ideas into its values and social processes. Classic theorists did this from an evolutionary philosophical approach
which addresses the universal case. My sociological approach aims at a contextual understanding.

Clinical Trials: A Brief History Lesson

The “United States Public Health Service Study of Untreated Syphilis in the Negro Male,” popularly termed “Tuskegee,” or variant monikers coupling “Tuskegee” with terms such as “experiment” and “syphilis study,” continues to be identified among some African Americans - academics and otherwise – as the seminal episode from the African American experience that continues to influence black thought on issues related to clinical trials. This perspective continues in spite of research that demonstrates that detailed facts of what occurred in the study are often unknown. Furthermore, there is little direct evidence that causally links awareness of the Tuskegee study to African American participation in clinical trials. 94

“Tuskegee” was a forty-year medical study, conducted from 1932-1972 in the Venereal Disease Section of the federal agency we now refer to as the Centers for Disease Control and Prevention. Tuskegee was “hidden in plain sight” given that it was documented in contemporaneous medical journals and, since its exposure in 1972, has been documented in historical accounts and edited collections of essays and archival excerpts. After its exposure, the study was the focus of Congressional hearings and public forums. It has been the subject of creative works, and is one of the foundational cases used to teach bioethics. 95 Bioethicist Vanessa Northington Gamble has written a classic

95 Susan Reverby’s collections provide a broad array of documents including references for medical journal articles from the period of the study as well as post-exposure analysis from involved medical professionals, excerpts from Senatorial hearings, and essays reflecting on the ethics, research design, as well as the philosophy of analytical approaches to the study of Tuskegee (such as issues of
argument which outlines that Tuskegee was not the beginning of the history of medical experimentation on African Americans\(^96\); Harriet Washington has written a monograph highlighting similar research.\(^97\) The case of Tuskegee has earned a prominent place in the public moral imagination relative to the use and abuse of human subjects in medical science.

Historian James H. Jones documents that the study originally began as a community-based effort to treat syphilis in Macon County and other rural locales in Alabama. In the early twentieth century, syphilis, as well as other venereal diseases, was widespread - often having been contracted in the world war zones of Europe.\(^98\) Financing for a feasibility study was provided by the Rosenwald Fund. Rosenwald was known to provide funds in poverty-stricken rural areas of the American South. Primarily, the Fund made contributions to build schools. The syphilis study was to be a public-private foray into a health project within the Fund’s new medical division.\(^99\) When the stock market crash eliminated the ability of Rosenwald to provide funds for charitable projects, the original study was dropped. A few years later, the Public Health Service (USPHS) Venereal Disease Section picked up the study. In its re-design, the study was intended to

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follow patients, without treatment, until the disease ran its course, resulting in the death of each patient, then autopsies could be performed. Throughout the forty years that the study ran, progress reports and intermediate findings were published in academic journals. Specialists in the field had access to “research” being conducted in Macon County. The public learned this federally funded research through news accounts.

Jean Heller, an Associated Press reporter first broke the story on July 25, 1972. It appeared on the front page of the Washington Evening Star with the headline, “Syphilis Patients Died Untreated.” The next day, it appeared on the front page of the New York Times and numerous other papers across the nation. Thus began the public exposure of the forty-year tragedy of shattered lives of the men whose syphilis infections had been allowed to go monitored, but untreated; the 1972 exposure was decades after a cure had been devised. Now, in the early twenty-first century, the largely untold story of the women and offspring connected to these men remains, as does an enduring pall over the name, Tuskegee, the name of the town and its famous Institute known for scientific discovery and training in state-of-the-art medicine which was the pride of the local community. For the next several months, federal health administrators scrambled to justify the reasons for the lengthy study as well as to update Congress and the American public about its status. The study was not officially ended until March 1973 on order from Casper Weinberger, Acting Secretary of Health, Education and Welfare.100

In 1997, U.S. President William Jefferson Clinton issued an official, state-sanctioned apology for the government having funded intentional neglect - under the

\[\text{100 Most sources date the end of the study as November 1972. Jones uses the March 1973 date because that is when Weinberger issued instructions to provide medical care for the study survivors. This had been a point of contention between Dr. Merlin K. Duval, the assistant secretary for health and scientific affairs at Health, Education, and Welfare, and the ad hoc panel charged with investigating the study. In order to close the study, Weinberger had to reopen it and use his authority to direct its closure. See James H. Jones, } \textit{Bad Blood} (New York: Free Press, 1981), 211.\]
guise of clinical research - on its own citizens in Macon County, AL. Despite the efforts of the committee that orchestrated the apology to change the referent of the episode to its official name, the “United States Public Health Service Study of Untreated Syphilis in the Negro Male,” the place name, “Tuskegee,” continues as the name by which this episode is popularly known. At a thirty year remembrance, journalist Alex Chadwick called it “one of America’s most notorious medical studies.” And after forty years, it is possible to say, that for some African Americans, the episode is entirely representative of human experimentation. From today’s vantage point, it is easy to argue the bioethics of the study from its design to the withholding of treatment, to its lack of informed consent, to its targeted recruitment of a vulnerable population – men who largely could not understand and whose lack of treatment allowed for spread of the disease to sexual partners and children. Except for the withholding of treatment, some could argue that much of what occurred at Tuskegee was standard practice in the mistreatment of blacks in its day – including recruiting participants who might not be able to give consent based on some issue of free or full mental capacity. Beyond the academic bioethics community, the ways that activity after Tuskegee’s exposure changed public policy and the ethics of medical research from the late 1970s to the present is rarely discussed.

Congressional hearings led by Senator Edward Kennedy resulted in legislation which established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. It was this Commission that approved ethics principles for medical research and published them as The Belmont Report in 1979. In the past 30 years, these basic principles – respect for persons, beneficence, and justice –

continue to ground the evaluation of ethical practice in medical care and research. Terms such as “vulnerable population” and “informed consent” have a direct link to the tragedy of Tuskegee.

Tuskegee’s legacy also leads me to state that Tuskegee was one of the most effectively executed, publicly-funded, community-based human subjects clinical studies in recent history. I am referring to its effectiveness in reaching communities and tracking patients with whom it is can be difficult to sustain contact and to sustain the routine of following study protocols. Tuskegee provided a template for how researchers can successfully conduct a research study for maximum participation in geographical, cultural, and racial and ethnic communities which are often on the periphery of the scientific community. Its buy-in from community leaders such as racially-concordant physicians, school administrators, and pastors who can provide a gateway continues to be formulaically successful. In as much as Tuskegee was a national scandal, its legacy is the tragedy it left, but less acknowledged are the reforms its exposure helped to usher in.1\textsuperscript{02}

Race, Tuskegee, and African American Religious Studies

Were this dissertation solely a religious studies analysis of Tuskegee, I would write about the ways that recounting the episode suggests a discussion of the sacred and the profane in that Tuskegee’s abuses affronts the connection of human life to the very

1\textsuperscript{02} Outspoken bioethicist Art Caplan has also commented on the legacy of Tuskegee. In one essay, he expresses concern about the discourse of the ethics of dismissing medical findings from Tuskegee because they were obtained through unethical means. He argues that medical science continues to teach about the progression of syphilis including citations that credit some of the original thirteen academic papers published during the course of the forty years of the study. Arthur L. Caplan, “When Evil Intrudes,” in Tuskegee’s Truths: Rethinking the Tuskegee Syphilis Study, Susan M. Reverby, ed. (Chapel Hill: University of North Carolina Press, 2000): 418-423.
image of God.\textsuperscript{103} For the clubwoman at the beginning of this chapter, Tuskegee points to “evil.” For her and for some other African Americans, Tuskegee’s abuses are to be held up as a story which demonstrated the disregard for black and poor bodies. With the acts of the doctors who conducted the experiments and racism as the systemic ill or evil which helped to sustain the abuse, the discourse around Tuskegee fits into the religious category of the profane, simply, the non-sacred – even the demonstration of evil beyond the moral evil perpetrated.

I, however, question the categorization of Tuskegee in the realm of the profane: since the interpretation by some African Americans of its rendering as the ever-present evidence of racism in medicine is at once immutable and unbound by history. I argue that the Tuskegee narrative has achieved a sacred nature – of the form I will explain from Gordon Lynch. As set apart in the African American religious scholarship, black bodies-as-petri-dishes go beyond cultural symbolism to approach religious symbolism. Tuskegee’s symbolism is transferable to all African Americans, not only the original victims. In its recitation, the narrative never moves beyond the perspectives of race from the mid-twentieth century. This ahistorical aspect of the ongoing rendering creates a discursive circle around which the racism central to the narrative encloses the facts which must be included in the recounting. In academic or lay recitation, this pattern may not be transgressed. Accepting this reality of practice, I propose an argument for a Durkheimian-derived analysis of the sacrality of Tuskegee in the way that it is being presented in the work of the primary scholars of African American religion and health.

\textsuperscript{103}Bongmba uses the religious symbol of the image of God as important in the religious response to the African HIV/AIDS pandemic. See Elias K. Bongmba, \textit{Facing a Pandemic}: (Waco, TX: Baylor University Press, 2007).
Scholars in African American religious studies have included the Tuskegee narrative in their work related to religion and health, and they are not alone. Health academics also have asserted that Tuskegee must be invoked in order to progress to encouraging more African Americans to participate in clinical trials. One such health researcher is academic physician Giselle Corbie-Smith. She holds professorial appointments in the Department of Social Medicine and the Department of Medicine at the University of North Carolina School of Medicine located in Chapel Hill. Corbie-Smith has produced a body of work through research, publications, and community engagement that promulgates the argument for the importance of the involvement of African American churches in community-based participatory research including clinical trials advocacy. To this end, one recent turn in her research has included train-the-trainer sessions with congregants in North Carolina who have been identified by their pastors as representatives of church health ministries. Participants in these training sessions learn about Tuskegee, the resultant ethical framework, as well as instructional techniques which they can use to inform their fellow congregants about the language, processes, and (clinical) possibilities available when they give consideration to participating in clinical trials. In another case, the bioethicist who served as the first director of the National Bioethics Center for Research and Health Care (which is located at Tuskegee University) has stated that progress in African American clinical trial participation cannot be achieved without African American churches. To this end, she notes that “Bioethics

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104 With support from the Bioethics Initiative for Equity in Health Care and Research, I was a participant-observer at the Rocky Mount, NC training April 14, 2012.

Sunday,” a day for preaching, teaching, and healing was held at the Tuskegee University Chapel (in connection with the National Bioethics Center).

A distinct pattern in activities from public health researchers and bioethicists emerges when they argue that African American churches must be included in the discourse if improvements are to be made in black participation in clinical trials: their expertise is not the content and functionality of religion and religious communities. They involve churches in large part because they see these institutions as a means of reaching assembled collectives of African Americans who may benefit from the health information connected to clinical trials. This facilitative view of churches is not dissimilar to the way that churches and schools were engaged with these institutions during the design and implementation of Tuskegee, especially in its early stages of seeking support from community leaders and community recruitment sites. I do not make this observation in order to comment about the ethical intentions of public health researchers and bioethicists who discuss and work with African American churches around issues related to clinical trials. Rather, I am pointing out two things: that the engagement of religious institutions as sites for conducting health education and clinical research was also effectively used in the Tuskegee and Macon County region; and that in approaching religious institutions in this way, public health researchers demonstrate that they engage and deploy the Tuskegee narrative differently than religious scholars. In a 2005 lecture at the University of Toronto, Northington Gamble states that in order to make a difference, some who are addressing the issue of African American clinical trial participation and its links to health disparities will be practitioners, others will be theoreticians, still others will be bridges
between practice and theory. If engagement in clinical trials is to be aided by religious structures through meaning or content and social processes, religious scholars can make significant contributions as theoreticians, practitioners, and as bridge builders. The work of Emilie Townes and Stephanie Mitchem provides a starting place for these contributions.

African American Religion and Health Scholarship and the Tuskegee Syphilis Study

Stephanie Y. Mitchem and Emilie M. Townes are arguably the most prominent scholars of African American religion and health. They take very different approaches in the monographs they have contributed to the field. Mitchem sees the U.S. as having failed to provide healing mechanisms for African Americans, whether the ills of the community are bodily diseases or social, economic, and political blight. For her, the remedy lies in African Americans identifying their own culturally-relevant structures of healing which are always relational. Through various religious systems, including hybrid sets, Mitchem notes that African Americans locate their own healing in folk ways of knowing and acting. In *Breaking the Fine Rain of Death*, Townes proposes a social ethics response to the failures of the U.S. health care system to meet the needs of African Americans. She constructs a Womanist ethic of care as a remedy beyond lament and repentance – the religious category she uses to outline the problem.

My entrance into the discourse seeks to engage both of these prolific writers. There are points where I agree with them and other areas where I diverge. I, too, see a social-cultural issue for which there can be, there must be, a religious response. For my own analysis, then, I have taken a key component from both Townes and Mitchem as a

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starting place to which I apply the classical religious theory of Emile Durkheim. Each of these writers includes some aspect of the Tuskegee Syphilis Study.

My interest is in the way that the story of this study continues to have life in the African American experience. The story of this horrendous episode is sustained by its roots in race, power, and abuse. In academic discourse, then, we continue to discuss the narrative largely through the lens of race. The story has cultural power to keep some African Americans from acting on their health and medical knowledge because of the rampant (and justified) distrust of the medical establishment. In the religion and health discourse among African American scholars of religion, “Tuskegee” is the central narrative; it is totalizing and response to it affects the will of the collective. Tuskegee has become our set apart story – the sacred narrative in religion and health.

I assert another view of the sacredness of the Tuskegee narrative. A religious studies analysis that motivates the collective to a proactive rather than reactive response honors the lives of the men who died because of Tuskegee; the social theory of religion in Emile Durkheim’s *The Elementary Forms of Religious Life* helps to interpret, ground, and construct such a response. And I suggest that this classic works with not instead of Womanist thought, the intellectual frame to which both of the primary scholars in African American religion and health demonstrate commitment. Using *Elementary Forms*, provides space for discourse around the social functions of embodiment and epistemology, two areas to which Womanist thought can and does make significant contribution to religious studies, generally, and can make even more significant contribution to religion and health, in particular.
Womanist religious scholars Townes and Mitchem both engage the Tuskegee narrative. Literature in health research suggests shifting attitudes, with some African Americans expressing a willingness to participate in clinical trials. To be responsive to what I believe is an emerging trend, I want to remove the narrative as an active, presumed cultural barrier for African Americans who may still be wary of its historical place yet need to consider participation in a clinical trial. A changing attitudinal landscape rooted in social, cultural, and historical norms and events does not operate like electric power supplying a light switch, with collective attitudes being one thing in one moment and their meaning and effect turned off in the next moment. Attitudes are more like a smoke-filled room; when the smoke clears, its odors - meaning symbols - linger in the air and often leave a hint on whatever the smoke touched. The power of or meaning within Tuskegee may be retained by any individual while not remaining for the entirety of the collective. Townes and Mitchem treat the narrative as though the smoke is still in the room; I see the smoke clearing with the need to engage its meaning, and I do so through the rhetoric of sacred symbolism.

The Durkheimian analysis I propose accomplishes a number of goals. It offers the opportunity for additional ways that the episode can be deployed in the field of religion and health within African American religious studies; it expands the epistemological and sociology of knowledge values available through sacred-as-social theory - in the current study and for the general case (of African American religion and health); and it provides a way to engage both Townes and Mitchem without diminishing the Womanist strain of


110 The use of the term “rhetoric” here can be attributed to Jeffrey C. Alexander in The Meanings of Social Life: A Cultural Sociology (New York: Oxford University, 2003). I will provide additional detail about this source below.
their broad research agenda. A Durkheimian analysis has been made especially realizable since the establishment of a ritual-like annual commemorative event, held on the Tuskegee University campus, to mark the occasion of the 1997 official U.S. apology.

Men and women whose fathers, uncles, and cousins were Tuskegee study participants are among the invitees to the annual commemoration. During the 2012 Commemoration, there was a time for family members to reflect together on the past and lingering effects of the study. The commemoration has various moments of solemnity including visitation to “holy” sites such as a memorial established by Fred Gray, the attorney who filed a class action suit against the U.S government and the responsible agencies on behalf of the study participants in 1973, as well as the Shiloh Missionary Baptist Church and the restored Rosenwald School next to the church in Notasulga, Alabama. Local residents report that Shiloh is the site where the largest number of men was recruited for the study, and the school grounds were where “treatments” were scheduled. As a ritual analysis, the Commemoration event follows the form of Durkheim’s “formula” in which the community (society) adheres because it sees in, and expresses itself through social practice.

Various activities within the two-day ritual commemoration remind attendees that the study was forty years of deliberate harm through the refusal to treat the men for a

111 Mitchem does not advance the Womanist aspect of her work in African American Folk Healing; however, she features black women in her examples of folk healing and spirituality. She grounds her dissertation, “Getting of the Cross: African American Women, Health and Salvation,” in the Womanist approach.

112 With travel support from the Bioethics Initiative for Equity in Health Care and Research, I attended the Fifteenth Annual Commemoration in April 2012. Statement of support: The project described was supported by Award Number RC2MD004764 from the National Center on Minority Health and Health Disparities. The content is solely the responsibility of the author and does not necessarily represent the official views of the National Center on Minority Health and Health Disparities or the National Institutes of Health. (The National Center on Minority Health and Health Disparities is now a National Institute.)

113 To date, I have not been able to confirm that Shiloh is the site of the largest numbers of recruits. It is, however, well documented that treatments were not provided to the participants.
diagnosed disease; intentional neglect was committed against the victims. The presence of family members is an embodied reminder of those originally harmed. Too, the commemoration brings other invitees into community with the families who bear the psychical scars of knowing that their loved ones were victims of their own government. Everyone in attendance shares in the lingering pain - which some family members describe as physical.\textsuperscript{114} These and various other activities during the Commemoration mimic Durkheim’s cognitive and emotional effect in ritual. The suffering is renewed in the living memory of the attendees, and they are drawn into the experience of suffering of the men and their surviving family members. The embodied recitation elicits the collective emotion connected to this horrendous episode from African American history. Durkheim’s effervescence appears in this twenty-first century analysis.

In their works to address African American religion and health, Emilie Townes and Stephanie Mitchem both include the Tuskegee narrative. Because Mitchem’s primary interest is folk healing, she devotes a brief three pages in her chapter about institutionalized medicine.\textsuperscript{115} The narrative is included because, for her, healing for African Americans includes a spiritual dimension regardless of one’s faith system. Mitchem’s broader reason for the story’s deployment is to bring focus to the role of some of the African Americans who participated in the experiment as health professionals. She

\textsuperscript{114}During the time of public reflection, some of the children of men who had been included in the study described incidents of annual skin shedding. They expressed this concern publicly as a means of informing attendees that they wondered whether these symptoms could be lingering effects from the Experiment. Participant observation April 25, 2012. In his history of the study, James Jones draws attention to a 1973 internal memorandum between staffers at the Centers for Disease Control discussing the cost of care for women and children who might have lingering effects from congenital syphilis. See Jones, 254-5.

credits them with intending to improve the health of the local black public.\footnote{Ibid, 49.} She notes that in their movement out of slavery to Emancipation, some African Americans wanted to exercise full citizenship and social participation in the life of the United States. To them, entering a health profession was among the ways that they might be able to achieve this self-perception. Such aspiration created a set of “complex relationships” of which the Tuskegee study was one.\footnote{Ibid, 48.} She then goes on to identify some of the black health care professionals who took part in the study in which “several hundred black men with syphilis…were used as guinea pigs to collect data on the long-term effects of untreated syphilis.”\footnote{Mitchem, \textit{African American Folk Healing}, 48.} Mitchem’s brief account of the study highlights the abuse and the harms that can be imposed through institutional medicine, of which human experimentation is a part. She wishes to observe the ways that race created a complicated set of issues to be navigated by professionals and patients, and that these complications contribute to the reasons that folk healing continues among African Americans - beyond the reach of institutionalized medicine. She even adds that some contemporary physicians choose to retain their belief in folk medicine in spite of their medical school training – a suggestion that should predispose them to the employment of various forms of institutionalized medicine.\footnote{Ibid, 52.}

Townes devotes an entire chapter to the Tuskegee narrative. Her goal in her monograph is to call to account the social ethical failure of the religious community in not demanding that the U.S. health care system be genuinely accessible to all. Townes’ greater number of pages gives her more space to outline additional parameters and
complications of Tuskegee. In her recounting, she includes the early twentieth century health status and health care context in which syphilis came to be studied in Macon County as well as the theo-ethical implications of the abuse which warrant the social activity of lament that she emphasizes as the religious ordering category throughout her book. In the opening of this chapter, Townes notes that she is presenting Tuskegee as a means of demonstrating “the cultural production of Black health.”

Before she enters the contextual section of the chapter, Townes quotes W.E.B. DuBois when he stated that “being a problem is a strange experience.” Townes is setting the tone for the racial (and class) analysis that will be central throughout her chapter on Tuskegee. Townes returns to the subject of race in her chapter titled, “And All the Colored Folks is Cursed” about the HIV/AIDS crisis in the African American community. In reporting the perspective of the husband-and-wife team who are two of the nation’s most well-known health disparities researchers, Townes refers to an observation from Stephen B. Thomas and Sandra Quinn who believe that public health professionals err when they “[fail] to comprehensively discuss the study… [This failure] contributes to [the use of Tuskegee] as a source of misinformation and helps to maintain a barrier between the Black community and health care service providers.” Townes firmly believes that “(a)lthough the Tuskegee Study was immoral, the PHS [Public Health Service] developed a model for its implementation that was culturally sensitive (to a degree), politically astute, and collaborative. It is a serious miscalculation to think that a study that was

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122 Ibid, 127.
ended nearly thirty years ago\textsuperscript{123} (after running for forty years) has no enduring impact on the perceptions and beliefs of African Americans.\textsuperscript{124}

In highlighting the way that race is central to discussions about Tuskegee, I am in no way, suggesting that the racial dimension of this American nightmare is inaccurate or unimportant. I am observing the way that it drives academic discourse related to African Americans and health care. In the discourse, Tuskegee is not only about African American participation in clinical trials; Tuskegee becomes a totalizing, cultural narrative that explains why African Americans distrust institutionalized medicine and all of its related parts, including human experimentation. As one traumatic episode in African American history, Tuskegee becomes singularly defining in much the same way that Victor Anderson describes the limitations of ontological blackness.\textsuperscript{125} In this case, the narrative is a proxy that “connotes categorical, essentialist, and representational languages depicting black life and experience.”\textsuperscript{126} To be fair, Townes and Mitchem do point to the complicated nature of race and race relations during that period in American history. But in the end, in their reading, the Tuskegee narrative encapsulates how and why African Americans distrust the medical system. The race elements of Tuskegee continue to be held up in its tragic value, vividly pegged to the evil of racist scientists, a racist health care system, and a racist government unwilling to end a study designed to

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\footnote{123}{It was thirty years past the public exposure at the time of Townes’ publication.}
\footnote{124}{Ibid, 126.}
\footnote{126}{Ibid, 11. My concern is less the reification of race than the possibility of a “pathologization” of race through disease. This concern rises from the literature on separating disproportional disease and death, comparing across racial and ethnic groups, from race-causal links, as associated with genetics, for example. An excellent resource is: Kevin Fitzgerald and Charmaine Royal, “Race, Genetics, and Ethics,” in \textit{African American Bioethics}, Lawrence Prograis, Jr. and Edmund Pellegrino, eds. (Washington, D.C.: Georgetown Press, 2007): 137-152. The essay outlines how race, genetics, and ethical questions have been raised from the approval of BiDil, a heart disease medication approved for use among African Americans whose incidence and death from heart failure is greater than their white counterparts.}
\end{footnotes}
watch black men die – however long it took. As the defining episode of African American health, Tuskegee is founded in and driven by racism, and this embedded evil is imposed from outside. For me, race does matter in the Tuskegee narrative, but for the present day, the racial lens is not the only feature of the study that is problematic. I disagree with scholars of African American religion and health when it is held up for the values in this totalizing effect.

There is also a social component to both Townes’ and Mitchem’s reading of religion and health, and for this point, I also want to include Sanders’ essays. For Townes and Sanders, this component is made evident in practices of the collective. Sanders recommends that shifting African American attitudes on the acceptance of advanced technologies (in her case organ transplant) belongs as a part of worship ritual. Through sermons pastors could teach the theology of bodily resurrection so that congregants would be less concerned about making kidney donations where they believe that bodily resurrection requires an intact body. Townes’ lament and repent is a communal calling. Together we (Americans) should lament that everyone does not have access to adequate health care then repent of it together by locating a solution within community asset health care development. Finally, Mitchem sees African American folk healing through relational activity and ideas. Mitchem uses examples of singular women using hybrid spiritualities in their healing activities, but they are always interconnected to others. For Mitchem the relational is required, and she is flexible as to how many might make up the gathered. All of these scholars see the social in their approaches to spirituality/religion and health. Through the social component of their scholarship, I also see a connection to Durkheim’s thesis that “religion is eminently social.”
The totalizing race component of the narrative is where I diverge from my scholarly predecessors. Deploying a Durkheimian theoretical framework, the requirement to include the Tuskegee syphilis study narrative adheres the collective, African Americans, but it does not do so as a ritual of evil or profanity. Rather, I see its totalizing effect as possessing a sacred quality sustained as would be a piacular rite – an exercise in communal mourning.\textsuperscript{127} Townes’ communal lament comes closest to straightforward identification with this collective functionality. The narrative must be included in the discourse in religion and health in the African American context, and its race elements must be given prime focus above other issues related to black health. Failure to acknowledge the narrative or to place race as the prime focus offends the community because race is how the community defines.\textsuperscript{128,129} This is where use of public health and bioethical literature helps to provide shape for the physical or material racialized body beyond the discursive racialized body in African American religion and health scholarship.\textsuperscript{130} I assert that the scholarly invocation of this narrative highlights the reality of racism and, in doing so, establishes a set apart brand of sacredness rather than a

\textsuperscript{127}I wish to thank Stephen C. Finley for his engagement with me as I was thinking through this refiguring concept.

\textsuperscript{128}Emile Durkheim, \textit{The Elementary Forms of Religious Life} (New York: The Free Press, 1995), 393-4, 400-403.

\textsuperscript{129}As a matter of personal intellectual integrity, I admit that I struggled greatly with whether I needed to include anything about Tuskegee in this dissertation. My preference, as I identified in my research proposal, was to locate a way to give a brief history only. I wanted to handle the narrative in this way, not as a matter of being dismissive of the importance of the episode, but as a way to be able to give the most page space to solutions for the future of African Americans and clinical trials, especially given the ways in which this topic appears to be growing in public health research literature. In the end, this quote from Durkheim’s \textit{Forms} as well as an unexpected emotional experience I had giving a paper on religion, embodiment, and health within ten days of leaving the Tuskegee commemoration resulted in my accepting that the Tuskegee narrative needed to be included: “When the individual feels firmly attached to the society to which he belongs, he feels morally bound to share in its grief and its joy.” Durkheim, 403.

\textsuperscript{130}Public health and bioethics literature sustains race, but the physical effects are \textit{embodied}. For example, the Institutes of Medicines’ expansive study of health care in the US demonstrates that the idea of race and race discrimination includes effects such as failure to offer black pain medication or offering less pain medicine than whites. As stated in the text, Townes comes closest to speaking to the issues of the physical not just discursive body. See Institutes of Medicine, \textit{Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare} (Washington, D.C.: National Academies Press, 2003).
superficial profane nature of the Tuskegee narrative. The invocation reinforces righteous indignation and communal outrage as appropriate, categorical responses within the African American experience. Furthermore, anyone writing about African American religion and health should be prepared to include this totalizing narrative in their own work. Unconsciously, assigning the narrative to the profane places it in the world of taboo;\textsuperscript{131} ideas associated with the narrative fall within a narrow range of interpretation and anything otherwise should be avoided. But I have re-visioned the profane classification of the narrative to the sacred. With sacred qualities, its set apart nature takes on an immutable quality. It gains a sense of humanity relatable to the \textit{imago Dei}. In its retelling within African American religion and health the race element of the Tuskegee narrative becomes fixed – in time and in space.\textsuperscript{132} Furthermore, the ritualized deployment of the narrative falls under Durkheim’s scheme of reinforcing, positive rites. In the piacular form, these rites generate a particular “sadness which expressed, may happen to be truly felt. But generally there is no relationship between the feelings felt and the actions done by those who take part in the rite (or to those of a particular individual.)”\textsuperscript{133} Durkheim continues, “Mourning is not the natural response of a private sensibility hurt by a cruel loss. It is an obligation imposed by the group. One laments not simply because one is sad but because one is obligated to lament. It is a ritual façade that must be adopted out of respect for custom…”\textsuperscript{134} The required deployment of the Tuskegee narrative to explain black broader racial distrust in the health care system fails to acknowledge the places where nuances may have resonance in individuals’ experiences. In accordance

\textsuperscript{131}Durkheim, \textit{The Elementary Forms of Religious Life}, 304.
\textsuperscript{132}Durkheim, \textit{The Elementary Forms of Religious Life}, 14.
\textsuperscript{133}Ibid, 400.
\textsuperscript{134}Ibid, 400-401.
with tradition, every new research project in African American religion and health must contain a reference to Tuskegee in order to give the narrative (and its victims) the reverence expected.

My concern is that as clinical trials are increasingly offered as hope within a patient’s treatment continuum, the sacred ritualization of Tuskegee’s race discourse takes the focus away from the future discussion of clinical trials participation as opportunity for consideration which may offer the bodily experience of healing. But using the Durkheimian lens to see the narrative as sacred rather than profane opens the subfield of African American religion and health to a discussion about the rational and experiential aspects of Durkheim’s social theory of religion – something which will be very useful in later pages of this chapter. “We need to divide the sacred from the profane if we are to pursue the good and protect ourselves from evil.”135 Furthermore, this view offers the complexity that Thomas and Quinn note need to be added to the Tuskegee account.

An implicit social theory is embedded in the field of religion and health in my reading the different ways that Stephanie Mitchem and Emilie Townes explore the field. Specifically, in this implicitness is the aspect of the Durkheimian framework in which religion functions as a means of adhering members of society (African American communities) to the group and to one another -- largely as a cultural form which sustains a cohesive identity. Of the two scholars, Mitchem is clearest in this presentation. For her, healing is central to any form of illness, somatic or social; it is “relational” and has “spiritual dimensions.”136 The identity function harkens back to the origins of independent African American religious experience founded in the hush arbors during

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enslavement – that embodied history. Albert Raboteau’s seminal work in *Slave Religion* provides a widely accepted account of the beginnings of what we now have expanded into the academic field of African American religions. Raboteau’s history shows the melding of enslaved peoples from various groups in Africa and how they constructed something new based on their shared experience in enslavement. In her volume, *African American Folk Healing*, Stephanie Mitchem picks up Raboteau’s thesis when she writes that “ideas from the African continent traveled to the United States with black people.” She continues, “Even without a one-to-one material correspondence, cultural patterns and concepts could be shared as enslaved people found commonalities.” Then Mitchem goes further. She observes an African American epistemology that flows from Africanisms. The African “epistemological frameworks…insured that cultural retentions became crucial factors in survival.” I will return to the importance of Mitchem’s use of “epistemological framework” later. For now, it is merely important to observe that Mitchem’s views on healing for African American bodies are rooted in a long-standing social and spiritual dimension, and in this, at the very least; it implies an acceptance of Durkheimian theory that “religion is eminently social.” The sociality in African American religion (and health) offers the community a sense of the retained past as well as a means of survival.

Along this line, the work of Gordon Lynch presents a fresh way to bridge Durkheim’s imperfect yet classical theory of religion as a mechanism of social cohesiveness which I believe will be helpful as a hypothetical element in my application

140 Ibid.
regarding clinical trials and religion. Lynch has two goals in his analysis of a “social theory of the sacred” that he grounds in Durkheim. He wants to avoid the essentializing limitations which can occur in functionalist approaches of religion and to distinguish between “religion” and the “sacred.” To achieve this, he focuses on a reconceptualization of three key aspects of the sacred in Durkheim’s Elementary Forms: the cognitive-symbolic, affective, and ritual. Working with these three elements provides the opportunity to examine the ways that notions of the sacred contain characteristics that are rational, non-rational or emotional, and, finally, practices or performances.

Lynch begins his monograph, *The Sacred in the Modern World*, by recalling the 7/7 (July 7, 2005) transit bombings in London which resulted in the deaths of 53 people. He notes the ways in which there is a sense of the sacred within the incident – from the purview of the religiously-motivated suicide bomber on a double-decker bus to the same sense of those on subway trains who, motivated by their appreciation for the sacrality of human life, provided comfort to fellow passengers who had been complete strangers only moments before. In order to address his goal to move past potential limitations in a functionalist analysis of religion, Lynch points to the restrictiveness he finds in ontological theories of religion, which, he claims, were so prevalent in the twentieth century. He finds them limiting because they assume that there is a universal, embodied experience in which humans seek religion or the sacred. (He will later

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141 One of the noteworthy imperfections of Durkheim’s theory is its grounding in evolutionary perspective of societies. It provides a problem for modern societies which retain elements of culture that appear to be from prior epochs of human developments. It begs the question as to whether those societies are modern, ‘primitive,’ or whether there are other ways in which they must be categorized. In application, this is especially troublesome in my own uses of race and culture as factors that can influence social processes of health care as well as the history of “race science.”


144 Lynch, 12.
distinguish between the two.) To Lynch, the expectation of this universal experience is reductionist and essentializing, and it overlooks cultural boundaries and historically connected dimensions of religious notions. At least two of the major thinkers in African American religious scholarship assume this very notion— that there is a universal experience of seeking religion among this racial group. Mitchem, as I pointed out above, has stated that healing, in the African American folk tradition, has a spiritual dimension. She does not attribute this spirituality to a specific religious system. In fact, she asserts that this spirituality has a quality of hybridity. Cheryl Sanders, the pastor and theological ethicist who has also given some attention to bioethical issues, has argued that if there is such a thing as an African American perspective on bioethics, it must also have a spiritual connection.

Next, Lynch provides additional insight into why he wants to move beyond the term “religion” or “religious” to the use of his preferred terminology, “sacred.” In this case, very simply, Lynch believes that “religion” has become a term with too much meaning that may not be intended. The term is “loaded”; that is, the term is no longer “neutral.” Furthermore, he asserts, the term is too closely associated with the (Western) European exercise of the study of an object; a rational and remote notion removed from the realities of the lives that are expressed in expressions of spirituality.

Lynch deploys the work of several scholars to reinterpret Durkheim. He credits one, Jeffrey Alexander, with devising the idea of a cultural sociological approach which

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145 Lynch, 2.
Lynch then extends to the study of the sacred. Alexander first distinguishes between sociology of culture and cultural sociology. Alexander draws his ideas from science studies in which the culture of development of thought “matters”; this is separate from the development of facts from processes of “pure” objectivity. Instead the particular culture determines the thought which gets developed. Alexander will argue that the “rhetorics” which we present as rationality are “cultural structures.” “They [cultural structures] are deeply constraining but also enabling at the same time. The problem is that we don’t understand them. This is the task of a cultural sociology.” What we don’t understand is how these cultural structures impact us. Alexander continues: “Cultural sociology makes collective emotions and ideas central to its methods and theories precisely because it is such subjective and internal feelings that so often seem to rule the world. Socially constructed subjectivity forms the will of collectivities; shapes the rules of organizations; defines the moral substance of law; and provides the meaning and motivations…” (emphasis added – to highlight the meaning as well as the motivations to act). For Alexander what is most important is the when and how of the voluntary rather than compulsory assent to cultural structures. Looking at the symbol of Tuskegee through a cultural sociological approach, we have more leeway to interpret its sacredness (for which I have argued) apart from its profanity as well as a broader array of aspects of the narrative that we may choose to retain. We can raise the abuse and the suffering because human lives are sacred. In doing so, the race critique can remain a point of analysis in the narrative – one among many. No; suffering from syphilis ought not to have been allowed to occur, especially after the 1940s when penicillin had become available. Suffering can

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151 Alexander, 5.
take the central place of the sacred symbol as it is extended to black health disparities in the twenty-first century. Ending suffering becomes the obvious point of effort in this expanded use of the narrative; it is the only option available if life truly is sacred -- and alluding back to Pinn – that which is grounded in the practical that is so closely linked to African descended religious thought.\textsuperscript{152} Instead of its centrality being interpreted as the causal link to African American in-action, it can be re-deployed to motivate action that meets the community’s future goals. The community can ground a subjective collective experience and use another of its own cultural structures to create new responses – not just protective ones.

Lynch’s application of Alexander’s cultural sociological approach produces notions of sacrality:

- The sacred is socially constructed and subjective to the collective
- It produces normative claims out of the collective’s realities
- The constructed sacred forms are historically contingent
- Sacred forms are expressed through symbols, thought/discourse, emotions and actions
- Sacred forms are experienced in and reproduced in the body
- The sacred is a distinction from the profane and from the mundane\textsuperscript{153}

In Lynch’s extension of Alexander, the sacred is much more comprehensive than merely the separation from the profane. Lynch focuses on how the sacred is communicated, to whom it is communicated, and how this communication is experienced. It is also important to note that he accepts Durkheim’s notion that the sacred is constructed by particular collectives and that it is historically-bound.

Using this view of the sacred allows us to take another look at Tuskegee beyond the profanity of race as a construct that supports the misuse of power. In short, the racism

\textsuperscript{152}Pinn, \textit{Moral Evil and Redemptive Suffering}, 5.
of Tuskegee was real. By design, the study included only black men in Macon County\textsuperscript{154} when syphilis was a public health concern throughout the local population, and in fact, across the country.\textsuperscript{155} It is a reality from the history of the study that the men who went untreated were not told that they were not being treated, and that the sole reason for not treating them was to observe the course of the destruction to their bodies in an autopsy. Conventional wisdom holds that contemporary African Americans who did not participate in the experiment, and have no connection to it except as an act of racism, still connect to Tuskegee as a factor in declining to participate in clinical trials.\textsuperscript{156}

Through Lynch’s reimagined Durkheimian theory, Tuskegee’s sacrality moves beyond the ritual commemoration to other aspects of the abuse which could be considered separate from the profane and from the mundane. The meanings gleaned from Tuskegee and the manner in which it was exposed and the communicative structures of its exposure bleed well past the episode and the annual commemoration. The entire episode becomes a cultural symbol which evokes the normative reality and practice that African Americans do not choose to participate in human experimentation. As Lynch has modified Alexander, “[the] cultural sociological approach understands sacrality as a particular form of cultural signification in which symbols, objects, sentiments, and

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\item \textsuperscript{154} Professional and folk scholars are only now beginning to research the impact of the syphilis on the sexual partners and offspring of the men in the study. There is local, undocumented speculation that some women and children connected to the men in the study may have been treated for syphilis by Public Health Service providers. I have not examined this research as a part of this dissertation; that is work for another project.
\item \textsuperscript{155} Insert Citation from John Parascandola in \textit{Sex, Sin, and Science: The History of Syphilis in America} (Westport, CT: Praeger, 2008), ##.
\item \textsuperscript{156} Katz, Green, et al, challenge this. Their findings indicate that African Americans appear willing to participate in medical research. See Ralph V. Katz, B. Lee Green, Nancy R. Kressin, et al. “Willingness of Minorities to Participate in Biomedical Studies: Confirmatory Findings from a Follow-Up Study Using the Tuskegee Legacy Project Questionnaire.” \textit{Journal of the National Medical Association} vol. no. (September) 2007: 1052-1060
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practices are experienced as expressions of a normative, absolute reality."\textsuperscript{157} The reality of Tuskegee, even without the personal experience or association, bears resemblance to the cultural signification of disregard for black bodies. According to Gordon Lynch, “An ontological approach asks what sacred forms emerge out of a fundamental experience of the sacred. A cultural approach asks what specific kinds of experience (embodied ways of feeling, thinking, and acting) are bound up with historically contingent and socially constructed forms of the sacred.”\textsuperscript{158}

In the case of Tuskegee, then, to reexamine its profanity and to place it within sacrality is to disturb the effect that this horrendous episode continues to place within the discourse, and ultimately upon the bodies of African Americans. Questioning whether Tuskegee continues to affect decision making and black participation in clinical trials offends the intelligibility of members of African American communities because everyone “knows” that the government gave syphilis to those men – even though this is not supported by current and continuing research in public health, much of it, notably, by African American researchers whose goal is the same as that of African American scholars of religion – to end disproportionate suffering of ill health and death in African American communities. Nor does contemporary research support that African Americans decline to participate in clinical trials because of lingering concerns about Tuskegee.\textsuperscript{159} In fact, studies demonstrate that the actual facts of the Tuskegee Experiment are often misstated.\textsuperscript{160} In the classical, ontological approach to the examination of Tuskegee, it is

\textsuperscript{157}Lynch, \textit{The Sacred in the Modern World}, 15.
\textsuperscript{158}Ibid.
\textsuperscript{159}I will address the role of Tuskegee for the patients in my primary data.
\textsuperscript{160}One such helpful study is a literature review of studies which review current awareness and knowledge about Tuskegee. See Jan M. McCallum, et al, “Awareness and Knowledge of the U.S. Public Health Service Syphilis Study at Tuskegee: Implications for Biomedical Research” \textit{Journal of Health Care for the Poor and Underserved} no. 17, vol. 4, (November 2006): 716-733.
not sacred because “sacred” implies “good.” It is the other side of the binary – evil. It is not possible to suggest that Tuskegee is sacred and that it can both be held up as such because of it is deplorable and examined for making agential use of its deplorable abuse. Rather, it contains a historicity that might not be revered by African Americans for whom it is not a part of their living memory. The study of Tuskegee continues in a variety of disciplines; for my work, it is most notable in the multidisciplinary and interdisciplinary work of bioethics and as a historical event. The question is whether the sacrality of Tuskegee gives it a divine and immutable quality rested in the binary of good-versus-evil. This view of the sacred relates back to the aspects of the Durkheimian paradigm covered through implication in African American religious studies: Durkheim’s insistence that the sacred is that which is separated from the profane. Lynch offers an alternative way to consider the sacred. By deploying Lynch, the Tuskegee-as-sacred can move beyond its untouchable status. It is not only the blackness of the bodies abused at Tuskegee that matters, but the way in which we can learn from Tuskegee’s “sacred” qualities that make it a case to study as we seek to incorporate clinical trials into their broader potential for progressive treatments that may help to reduce health disparities among African Americans and to refocus African American religious studies on the ways in which the sacred is also a regenerative reality. Furthermore, in Lynch’s refashioning, “sacred” items are more than symbols that come directly out of the belief structures tied to faith systems. Rather, sacred items can be part of the socially derived, cultural cognitions which can be taken into account in related realities. Sacrality, thus formed, honors experience which is foundational to both Womanists and to Durkheim. For the present
project, then, the sacrality of Tuskegee and all of its meanings can be examined for its relationship to the thinking and ‘knowing’ of contemporary patients.\textsuperscript{161}

In this chapter, I have offered an alternative way to interpret the Tuskegee narrative as it has been deployment in African American religion and health while using a theoretical approach that retains a connection to Durkheimian roots as important to the role of religion among African Americans. Gordon Lynch’s sacred rhetoric is a means of developing the Tuskegee narrative beyond a seemingly implicit yet cultural conceptualization of race as its central impulse moving into the twenty-first century. In this case, the race element remains important. However, as the scholarly study of African American religion and institutionalized medicine continues to mature, other aspects of the relationship between (primarily) institutionalized religion and institutional medicine are also important to develop and explore; namely, the social processes that operate within each institution, and that present an opportunity for bridge-building and overlap for greater understanding for patients. For the purposes of the current study, an alternative Tuskegee narrative will be important in the event that some patients present the narrative in any form during their patient interviews. Even if not, I have retained this alternative narrative because it continues to be presented in the African American religion and health scholarship as well as an inconclusive discourse among public health researchers. Social, economic, and educational diversity among African Americans making health decisions suggests that alternative narratives that sustain the cultural importance of the narrative to some African Americans should be contingently retained as an aspect of cultural

\textsuperscript{161}It should be noted that this formation applies beyond African Americans. Present research studies show low participation rates in cancer clinical trials by blacks and whites. Approximately five per cent (5\%) of whites who are eligible to participate in a cancer clinical trial choose to do so; the number for blacks has been reported at 25-50\% less. See Vivek H. Murthy, Harlan M. Krumholz, Cary P. Gross, “Participation in Cancer Trials: Race-Sex-, and Age-Based Disparities. \textit{JAMA} vol. 291, no. 22 (June 9, 2004): 2720-2726.
competence in medicine. Social, economic, and educational diversity are also central to ways and “practices” of knowing that guide decision making; therefore, I turn to sociologies of knowledge in the next chapter.
Chapter 3

“I Don’t Care How Much You Know, Until I Know How Much You Care”: Religion, African Americans, and the Sociology of (Medical) Knowledge

In this chapter, I lay out theoretical parameters for a key component of decision making: knowledge. In the past thirty years, there has been a shift in the patient-physician relationship from a culture of paternalism to one in which patients are significantly more empowered to make decisions using the information provided to them. The older, paternalistic perspective focused on when and whether physicians should disclose certain information about diagnosis and prognosis to patients.162 During the shift, physicians learned that they underestimated that many patients wanted considerable information, much more than physicians realized.163 In the last chapter, I identified Stephanie Mitchem and Emilie Townes as the primary scholars in African American religion on whose work in religion and health I will focus. Both scholars intellectually self-identify as using Womanist approaches although they choose to analyze different aspects of the complex field of African American religion and health. Besides the deployment of the Tuskegee narrative discussed in the previous chapter, they share an epistemological reference with social grounding. This reference presents the opportunity for me to introduce my own perspective: although the semi-structured patient interviews are broad, the focus is on understanding the link between social processes and the use and development of knowledge and information. Before establishing a hypothesis for the data that might be

163 Ibid.
anticipated from patient interviews – grounded theory\textsuperscript{164} -- I have researched the social processes that will support decision making and the themes that may arise. This chapter focuses on the parameters of the social processes of knowledge. If African American religion is “eminently social,” I should be able to identify how this is true. There should be an intelligibility or knowledge exchange. “Men [sic] owe to religion not only the content of their knowledge…but also the form in which that knowledge is elaborated.”\textsuperscript{165} There should be evidence that patients pursue, gain, use and interpret information about their prostate cancer diagnosis and about clinical trials through their doctors as well as through social processes that include their social networks. Furthermore, the Durkheimian perspective makes room for the processing from reason and emotion, and although Durkheim argues that the collective experience of rites is the mechanism of transmission, the Alexander-Lynch adaptations provide the means to amend the rites requirement to culturally subjective symbols. This chapter outlines how I should recognize those processes and networks.

A Brief Introduction to “Social Knowledge” and “Sociology of Knowledge”

In Medical Power and Social Knowledge Bryan S. Turner’s aim was to contribute a theoretical framework to a then-emerging medical sociology. His title refers to “social knowledge” because in his view, very simply, “knowledge”, especially about what it means to be sick, is socially produced.\textsuperscript{166} “Sociology of knowledge” is not a phrase in common use beyond the vocabulary of specialists in sociology and philosophy although the process, as I will describe it, is commonly recognized. E. Doyle McCarthy defines the


\textsuperscript{165}Anne Warfield Rawls, Epistemology and Practice: Durkheim’s The Elementary Forms of Religious Life (Cambridge, UK: Cambridge University Press, 2004), 48.

term as a subfield of sociology associated with the origins of “knowledge, ideas, theories, and mentalities.” To him, understanding, what he refers to as the “ideational realm,” is important as a means of observing how “particular social and political forces” impact how certain groups arise or interact with specified contexts and institutions. These concepts are important in the current study in the sense of being usable both as a noun and as a verb. “Social knowledge” and “sociology of knowledge” suggest that there is a logic, so to speak, to what is known and to how “it” comes to be known. As noted above, there are some differences in these terms; however, some literature uses these terms nearly interchangeably. Unless otherwise stated, I will do the same, although, for the remainder of this section, I focus primarily on sociology of knowledge as different forms of knowledge and the ways that these different forms are dispersed in society.

**Introduction to Sociology of Knowledge**

In their analysis of the beginnings of the sociology of knowledge, Peter Berger and Thomas Luckmann credit Max Scheler and Karl Mannheim with pioneering the investigation of the sociology of knowledge as a means of studying sociology. Mannheim’s *Ideology and Utopia*, provides the intellectual opening to engage in discourse around the notion that persons from various strata of society may interpret and engage knowledge differently and have access to different forms of knowledge. In the twenty-first century, we may take for granted that people view the world differently based on their position in life. In fact, in this information age with widespread access to the Internet (especially in the developed world), we may be lulled into the belief that the

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168 Ibid, 2953-60.
distribution of information and ideas is universal and democratic, and that the ability to interpret data to which we have access is equally democratic. However, in 1932 Germany, during the early days of Nazism as an emerging socio-political reality, it was a novelty to think that knowledge processes could be influenced by social stratification. In the main, in writing about ideology and ideological development, Mannheim was writing about ideas and to whom ideas are accessible. Two structural arguments from Scheler and Mannheim are helpful for my own project: knowledge distribution and evaluation as a social process.

According to Berger and Luckmann, Scheler emphasizes human knowledge as a given in society and as a priori to individual experience. The a priori condition also provides a frame to bring “order of meaning.” This order, although it is relative to a particular socio-historical situation, appears to the individual as the natural way of looking at the world. In other words, the world seems and is as it should be based on one’s experiences of it and that experience, and one’s acceptance of that experience as normal or nature, is based on one’s location within society. Applied to my project, given the history of abuse perpetrated against black bodies, medical experimentation of any form would be expected to be steeped in distrust causing avoidance of participation. This finding would be expected from the upcoming patient interviews. It remains to be seen whether the patients in this project will know the previous socio-historical situation (e.g., Tuskegee as a culturally relevant symbol) or the previous clinical trial history. In addition, Mannheim expected that the examination of knowledge and knowledge

\footnote{Berger and Luckmann, 8.}  
\footnote{Ibid.}  
\footnote{Ibid.}  
\footnote{See Harriet Washington, Vanessa Northington Gamble, and other scholars of race and medical history. The work of both of these scholars was discussed in chapter one.}
production in the natural sciences would also apply to the human sciences. Previous to him, Durkheim thought similarly (although Durkheim did not contain the social stratification element). I link the social processes of sociology of knowledge in the sciences with social processes of knowledge in religious studies and religious practices as a particular case in the human sciences.

Berger and Luckmann’s comparative analysis of Scheler and Mannheim provide an additional aspect for the structural development of arguments to use the concept of the sociology of knowledge in this project. They question the wisdom of Mannheim’s focus on elites who develop and use knowledge. They broaden the use of knowledge to include humanity beyond theoretical thinkers. Theory is a small part of everyday life.\(^{174}\) They conclude that for sociology of knowledge to be complete, it must include all forms of knowledge.\(^{175}\) “The theoretical formulations of reality, whether they be scientific or philosophical or even mythological, do not exhaust what is ‘real’ for the members of a society. Since this is so, the sociology of knowledge must first of all concern itself with what people ‘know’ as ‘reality’ in their everyday, non- or pre-theoretical lives.”\(^{176}\) To Berger and Luckmann, only commonsense meets this broadly distributed criterion.\(^{177}\) As my project involves current patients, I expect to evaluate data from the realities of non-elites as cancer patients. These patients would be operating in the commonsense rather than theoretical knowledge space.

Berger continues his arguments about social knowledge in *The Sacred Canopy*. There, he applies the theoretical structures developed by Luckmann and himself to the

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\(^{175}\) Ibid.

\(^{176}\) Berger and Luckmann, 15.

\(^{177}\) Ibid, 15.
case of religion. He argues that the overall purpose of religious knowledge is to bring meaning and order to one’s experiences. The primary use taken from *The Social Construction of Reality* and *The Sacred Canopy* relate to their presentation of the process of the relationship between an individual’s experience and the social structure in which it exists. As noted above, society exists before the individual’s experience. In *Elementary Forms*, Durkheim alludes to another dimension of the *a priori* concept. A problem or an experience that doesn’t fit into the prearranged social order is a situation of marginalization, but, according to Berger, religion does not leave the marginalized situation as an outlier or as some sort of fluke. Rather, religion suggests that the marginalized, unencountered experience or problem has a place within the already ordered world. Religion “legitimatizes” the reality of a previously un-experienced event. The legitimization simply means that the society (or institution) has sanctioned the “knowledge.” This suggests that in religion there are set categories with limited or no capacity for expansion. Newly encountered issues must be slotted into an existing knowledge/idea category. Based on Berger’s view, the knowledge use process is something of a closed loop with nothing truly new entering or leaving a cycle. This would appear to pose a significant hurdle for the present study if the clinical trial is presented as something “new” – even though it is knowledge distribution and gathering rather than production. As low as is the rate of African American participation in cancer

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180 Again, for Durkheim, these were the categories Aristotle also identified for understanding humanity and its world. Durkheim, *Elementary Forms*, 8.
clinical trials (reported as between 1 and 3%)\textsuperscript{183}, it is reasonable to anticipate that the trial
decision may be an unencountered experience for the men. So if Berger’s concept of \textit{a priori} meaning ordering holds for patients in this study who indicate that religion
influences their decision, will they legitimize their decision to participate or to decline
participation so that their religious beliefs can be sustained? Berger’s goal and
Luckmann’s goal is to observe that there “is an intimate relationship between religion and
social solidarity.”\textsuperscript{184} Presumably, individuals who have been socialized or taught the
ordered system “know” when their thought or activity is within the realm of the
predetermined social order. Will they sustain that religion and social solidarity
connection when their lives are at risk? How will they prioritize their sense of
institutional primacy if there is a conflict?

Knowledge Production is Collective Activity

Berger and Luckmann help to establish that there is a “logic” to the group
development, dissemination, and deployment of knowledge.\textsuperscript{185} Furthermore, they
emphasize that there are different categories of knowledge, theoretical and commonsense,
being two categories in their scheme. Besides Berger’s and Luckmann’s categories, there
are other schemas for identifying types or varieties of knowledge. One may refer, for
example, to “spheres of knowledge” such as religion and science relative to the current
discussion. Ian Barbour has written one of the classic texts that explores the questions
investigated by and the relationship between religion and science as two spheres of

\textsuperscript{183}Murthy, et al.
\textsuperscript{184}Berger, \textit{Sacred Canopy}, 51.
\textsuperscript{185}Berger and Luckmann, 14-15; Berger, 19-20.
knowledge. In the religion-science knowledge discourse, religious knowledge can refer to cosmological or the ordering system of the universe, including sets of explanations about the existence of and relationship between humans and the divine creator or creative force of the universe. Scientific knowledge also explores questions which address issues such as the composition, origin, and the material order of the universe. Although some thinkers have argued that the realms of religious and scientific knowledge engage in a conflictual relationship, others have noted that these realms may operate in a complementary fashion. In spite of religion and science being in different realms or spheres, when we think of both of them as categories of knowledge, we can extend Berger and Luckmann’s arguments to suggest that, as knowledge, these worlds can have commonalities in the way that they operate within their respective schema and the way in which they operate in society. One way of thinking about how knowledge schema work is to recall the cognitive and affective components introduced in the previous chapter with the re-visioning of the Tuskegee narrative. These operative features, I assert, allow for overlapping knowledge realms.

There are various processes within knowledge production; three such processes are the exploration, development, and dissemination or distribution. Science in Action is a study in the social construction of scientific knowledge. The author, Bruno Latour, gives an account of the use of rhetoric to drive science while it is in the making. Before science becomes fact (and even afterward), its potential truth is subject to questioning by specialists in the field as well as observers who study what Latour refers to as “science,

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187 Barbour, 77-106.
technology, and society.”  

He notes that historians, sociologists, philosophers, analysts, journalists, and concerned citizens are among the observers. When the science has not been settled and facts are in dispute, the rhetoric of knowledge production fuels the controversy at-hand.

It is necessary to fetch further resources coming from other places and times. People start using texts, files, documents, articles to force others to transform what was at first an opinion into a fact. If the discussion continues then the contenders in an oral dispute become the readers of technical texts or reports. The more they dissent, the more the literature that is read will become scientific and technical…You (do not) quit rhetoric for the quieter realm of pure reason. It means that rhetoric has become heated enough or is still active that many more resources have to be brought in to keep the debates going.

Latour notes that the rhetorical process begins to point to trusted authorities or “friends” and then to additional texts and literature. Purity of reason and content argumentation get swept up with locating additional sources resting as much on notoriety of those sources for the authority they have gained through fame and professional accomplishments as well as through the numbers of persons who agree with the new line of thinking. In the early twenty-first century, we have seen this rhetorical process at work - in reverse – to deconstruct what was once accepted scientific knowledge. The discourse on climate change and global warming became contentious when scientists whose investigative credibility was questionable began to be cited as arguments for why climate change was not settled or not certain as it previously had been accepted. This discourse was sometimes led by political conservatives who wanted to be able to destabilize the

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189 Latour, 16.


framework of (scientific) knowledge production in order to be able to make additional claims about the scientific community more broadly, where members of that community are viewed as opponents of creationism. My primary aim here is to establish that there are social processes embedded in knowledge production. This is consistent with Berger and Luckmann in sociology and sociology of knowledge; with Berger in a sociological theory of religion, as well as with Durkheim whose theory of religion was used earlier in this chapter. Furthermore, as medical science-in-the-making, from design to execution and the publishing of findings - clinical trials, also involve a social process which contains the same operations as other forms of knowledge production. Following Latour’s rhetorical description lay persons can also be commentators regarding the natural sciences as well as medical science. It may be that when lay persons comment, they are doing so as a matter of opinion rather than fact, but the accessibility of information via the Internet may make it difficult for subsequent readers of these opinions to distinguish fact from opinion especially when it is supported by religious authority.

Here, the notion of science-in-action is important for two reasons.\(^\text{192}\) For one, scholarship in African American religion and health has inadequately interrogated the social construction of scientific knowledge as a social process within epistemology.\(^\text{193}\) As in the rest of religious studies the epistemic relationship (or specifically, the epistemic difference) between religion and science is grounded in the content relationship between the two -- the differing truth claims debated beginning in the Enlightenment. These

\(^{192}\)This concept fits under the sociological field of science studies, thus pointing to another stream of discourse into which to continue my research.

\(^{193}\)I am saying that there has been inadequate investigation in the sense that there is little to connect the concept to African American religion. Emilie Townes touches on the subject in *The Cultural Production of Evil* by stating that for her experience is important, and that the experiences black women have are vastly distinguished from those of white men.
arguments focus on the content of scientific knowledge and its process of producing replicable evidentiary facts as relates to the broad concept of discovery. This is part of the general discourse in the discipline of religious studies; it is the discussion of revealed versus reasoned knowledge. These are important foci which include that the replicability requirement in evidentiary knowledge is methodological, not merely a matter of content. In other words, knowledge produced is able to be reproduced by someone else following the same methodology. This cannot be said of revealed knowledge. And in the humanities people are different so they and their responses are not entirely replicable.

However, the question of evidence has permeated into an evaluative requirement for many forms of knowledge production in the modern era. The reproductive requirement of (evidentiary) knowledge is intended to raise and defend the quality of its content. This is not to suggest that evidentiary knowledge is either greater than or less than experiential knowledge. The use of systematic, qualitative research methods such as semi-structured interviews can raise the level of experiential knowledge to the replicative qualities across a sufficient sample akin to what may be thought of as evidentiary knowledge in “hard sciences.” My point is to establish that there are ways in which religion and science can be considered to have similar means of development, distribution, and acceptance or prehension processes, and that both are valid knowledge structures on which people make decisions about their lives. This also leaves intellectual space for the sociology of knowledge to be operable across the spectrum of religious belief systems and expressions. One person who aligns with knowledge as produced in

\[194\] Barbour, 77.
the scientific community may value “faith” in evidentiary knowledge because for that person evidentiary knowledge supersedes superstition. For the religionist, “faith” in evidentiary knowledge can be evaluated on a range of values including that which is “manmade” versus that which is divinely created. A sociology of knowledge argument validates each knowledge production frame as information used in the decision making process, and allows either frames or realms of knowledge to stand of their own accord.

The effectiveness of sociology of knowledge is related to its distribution, prehension, and use beyond its producer. Peter Burke refers to these issues as “knowledge practices;” in these, humans gather, analyze, disseminate, and employ knowledges. The distribution of medical knowledge during, medical care, for example, is an inherently social process as it is with religious knowledge. It is often shared in person-to-person encounters. Both medical knowledge and religious knowledge recognize content experts or specialists and the weighing of an individual’s value set in its prehension alongside the acknowledgment of this informational expertise. The distribution of medical knowledge can be very formal; it is through teaching and training, journals, and publications as well as in office visits or other medical system encounters. The formalized nature of medical knowledge can inhibit its widespread distribution in ways that could help patients make decisions. Most patients do not have expertise in the body systems which have gone awry in some way such that they experience illness. They are “expert” only in any symptoms they are experiencing. Patients are dependent upon the pedagogical ability of the physician and supporting healthcare staff to communicate

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196 M.G. Myriam Hunink and Paul P. Glasziou, *Decision Making in Health and Medicine: Integrating Evidence and Values* (Cambridge, UK: Cambridge University Press, 2001), 18-19. Here, the authors are discussing that information sets and values help to identify determinants of decisions in medical settings.
specialized medical information in a way that helps the patient to make pertinent
decisions to be considered along with personal values. Thus, deciding between possible
options which may restore a patient’s health, or at least improve it from its new ill
“norm”, requires at least three presuppositions: medical information explained at a
comprehension level germane to the individual; an adequate level of trust in the person or
the information being presented to me,\textsuperscript{197} and an emotional state to process the
information and enter the relationship (transactional or long term) of trust. The entire
situation wrests in an environment of risk and uncertainty, and this may be doubly so for
many African Americans. Evidence from the landmark study by the Institute of Medicine
shows that African Americans are believed to be less intelligent.\textsuperscript{198} This impacts the
quality of information some physicians share with African Americans, on average, as
well as the amount of time and quality of discussion between physicians and African
American patients.\textsuperscript{199}

However, medical knowledge – no knowledge – is shared only in these formal
methods from content experts. More recently, the experience of illness is being shared

\textsuperscript{197}LaVera Crawley, “African American Participation in Clinical Trials: Situating Trust and
Trustworthiness” \textit{Journal of the National Medical Association} no. 93, vol. 11 (Supplement, November
2001):14S-17S.

\textsuperscript{198}“(In) a study based on actual clinical encounters, van Ryn and Burke (2000) found that doctors
rated black patients as less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to
fail to comply with medical advice, more likely to lack social support, and less likely to participate in
cardiac rehabilitation than white patients, even after patients’ income, education, and personality
characteristics were taken into account. These findings suggest that while the relationship between race and
ethnicity and treatment decisions is complex and may also be influenced by gender, providers’ perceptions
and attitudes toward patients are influenced by patient race or ethnicity, often in subtle ways.” Institute of
Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care,
\textit{Unequal Treatment}, 11.

\textsuperscript{199}Terri Laws and Janice A. Chilton, “Ethics, Cultural Competence, and the Changing ‘Face of
America’” \textit{Pastoral Psychology} vol. 62, no. 2 (April 1, 2013):175-188. See Lisa A. Cooper, Debra L.
Roter, Rachel L. Johnson, Daniel E. Ford, et al, “Patient-Centered Communication, Ratings of Care, and
among persons through Internet websites and social media platforms. In fact, social networks have been previously used among friends and family members to gain and to share information. Contemporary social networks sometimes get significant attention because the electronic technologies through which information is now distributed facilitate the distribution of knowledge while making it appear that the electronic distribution is substantively different than the past. As we saw from Latour’s rhetoric, trusted sources quickly become the focus of whether data is accepted as knowledge that will, in turn, be deployed. Whether consciously understood or not, all knowledge has cognitive and affective aspects of their assent and deployment. Seen as a social process, knowledge through religion becomes a form against which medical information, bodily science and practice, gets evaluated and can influence an individual or a social group’s response to it. “Knowledge, as an element of power relations, generates not merely coercive, distorting and repressive consequences, as many traditional conceptions of power would imply, but has productive and enabling features that allow individuals and groups to organize resistance, avoidance and opposition.”

The question remains: How does African American religious experience, content, or institutions “organize resistance, avoidance and opposition” to medical (scientific) knowledge? Do these aspects of African American life engage with medicine as an institution of knowledge? Twentieth century French philosopher and religious commentator, Michel Foucault, made additional observations about the relationship between knowledge and power.

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200 See websites such as those maintained by the Centers for Disease Control and Prevention, WebMD established with the assistance of former Surgeon General of the United States, C. Everett Coop, and Mayo Clinic online maintained by the Mayo Clinic a multi-specialty, multi-site physician practice/medical institution.

Knowledge, Power and Bodies

Michel Foucault argues that as medical examination moved from the patient’s bedside into the clinic (teaching hospital), as a cultural and discursive form, its result was the production of speech and the production of knowledge. In other words, as institutionalized medicine emerged and developed, it moved from patients’ description of symptoms to patient observation to the ultimately invasive mode of seeking knowledge, the totalizing gaze, achieved most notably through the autopsy. In this exposure, the examiner literally opens the patient to moral judgment. In *Birth of the Clinic* the way to life is through death. The pathological examination, the autopsy, is the act that provides the ultimate knowledge of the body. For Foucault, the meaning of the pathological examination lies in the power of the medical gaze to compel discourse. In the autopsy, as in the clinical examining room, the body generates speech even involuntarily. In Foucault’s reading of the history of medicine, the language generated by the gaze also points toward religious symbolism in the form of confession. These ideas, briefly described here, are found in the previously mentioned *Birth of the Clinic* and in Foucault’s *History of Sexuality, Volume I*. These works point to directions that scholars have extended his specific assertions about discourse, power and bodies. They also afford a broad platform to develop a discourse about the social components of medicine as experienced from the underside, that patient or subject’s perspective. In a similar fashion,

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203 Ibid.


Talcott Parsons’ contributed the notion of a social world of illness when he describes a psycho-sociological analysis of the “sick role,” and argues that illness occurs within a set of social relations—expectations sanctioned and delimited by those around the sick person. The milieu of medical institutions and the interactions of its various agents provide a place for studies of various perspectives from within the humanities and social sciences.

In *The Body and Social Theory*, Chris Shilling uses the body as an organizing category within sociology. He examines Foucault’s basic argument about the body and the discourse of knowledge and observes that in the past when sociologists studied processes such as family dynamics or prejudice, researchers were writing about social processes that involved humans yet the bodies in those social processes were concealed. Shilling interprets the previous sociological disciplinary efforts as largely “concerned implicitly with the movement, location, care and education of bodies.” (Emphasis added). In spite of their hiddenness in the study of social processes, he observes, bodies “matter.” To this idea, he highlights scholarship that distinguishes between the socially constructed body and the natural body, and makes an attempt to bring them together.

Shilling credits Bryan Turner with also seeking to bridge the socially constructed body with the naturalistic body. “[Bryan] Turner wants to combine a view of the body as

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206 Talcott Parsons, “Illness and the Role of the Physician: A Sociological Perspective” in *American Journal of Orthopsychiatry: A Journal of Human Behavior* vol.21, no.3 (July 1951): 452-460. Although the deviance characterization Parsons assigned to the sick role is quite debatable, the establishment of social responsibility and attention to the role that illness plays on the part of the person who is ill and on the part of those around her is my primary point.


208 Ibid, 18.

209 Ibid.
a biological organism and as ‘lived experience’, which contributes towards social relations, with an analysis of the body as a system of representation.”

Shilling references Turner in his 1984 *Body and Society: Explorations in Social Theory*. Bringing the body into the center of sociological studies opens intellectual space for Turner’s later work, *Medical Power and Social Knowledge* first published in 1987. In the latter publication, Turner’s objective is to identify organizing categories in medical sociology. He observes that one approach to the study of illness in anthropology was comparative, for example in the comparative cause of disease (etiology). Turner also extended Foucault’s arguments about the power in the medical gaze. He argues that the source of power in medicine is knowledge itself. After reviewing the approaches of previous scholars, for his organizing category, Turner settled on the study of bodies, socially constructed and in their lived experience in the processes of medical encounter. I keep all of these basic considerations in mind as I move forward into the study of clinical trials as a related process in medicine and the study of it as concerns African Americans and religious experience. I want to emphasize Turner’s point that the source of power in medicine is the knowledge itself. This point cannot be underestimated given the history of African Americans, the medical establishment, and the mistrust that separates the two.

John Hoberman argues that the power that physicians possess comes through their medical encounters with African Americans and the cultural authority physicians are given rarely investigates or challenges in any way their views even when those views

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210 Ibid, 89.
211 Turner, *Medical Power and Social Knowledge*.
212 Ibid.
produce medical racism.\footnote{John Hoberman, \textit{Black and Blue: The Origins of Consequences of Medical Racism} (Berkeley, CA: University of California Press, 2012).} In this sense natural black bodies are used to support socially constructed black bodies that are less intelligent, difficult to manage – medically and otherwise – and have been willful in its attempts to escape (white) supervision for more 150 years (since Emancipation).\footnote{Ibid, 20.} So these same socially constructed, naturalistic bodies use their own social constructions, knowledges included, to sustain their natural bodies.

I have addressed what knowledge is, how it is constructed, and different types. I have also highlighted that social theory has developed such that it no longer treats bodies in the discursive, but in the physical as well. Now I want to return to how black bodies, religion, and knowledge processes interact.

Black Bodies, Society, and Medical Knowledge: For Whose Benefit?

For a large number of African Americans, religion and religious communities anchor social knowledge by serving as a location for its distribution. This distribution channel does not connect only persons who have direct encounters within these communities; as a network hub, the knowledge shared there can also spread out through persons who indirectly are connected to the hub.

Medical research is scientific knowledge-in-production which comes into being through the scientific method of inquiry, but which gains its cache of factualism, in part, through social construction by members of the specialist or expert community.\footnote{Latour, \textit{Science in Action}, 27-31.} The idea of the social construction of scientific knowledge is relatively new.\footnote{Stehr and Meja, 2.} Through this process of production and adoption, medical science inquiries become prospective medical knowledge (and practice), when members of the public agree to participate as

\footnote{Ibid, 20.}
human subjects. The prospective knowledge gets “distributed” through academic channels through journals and conference presentations. These are expert channels of knowledge distribution which generally are not accessible to persons outside the field. Given what social scientists and public health researchers have learned from studying African American health and health disparities, understanding both of these forms of social knowledge – religious and scientific -- and how they work together has the potential to offer another tool to make inroads in reducing the disparate health status of African Americans\textsuperscript{217} as well as for African American religion to learn something about itself, namely its process of adaptability. This project can contribute theoretically and methodologically to applications in public health; my ultimate interest here is to identify how African American religion functions in the face of medical science where medical science, in this case, represents the concept of innovation.

Foucault’s contributions aptly identify the relationship between power relations and knowledge, and Turner extends that relationship to medical knowledge and the material body rather than discursive body within the social realm; both are helpful to the current study. However, it must also be said that Foucault has been rightly critiqued for the one sided way he views power. In his philosophical model from Birth of the Clinic, only medicine holds power. Bringing back an updated view of scientific knowledge from Stehr and Meja noted above, knowledge can also be productive as a resistant force.\textsuperscript{218}

Seeing various forms of knowledge as 1) productive and 2) as socially constructed,

\textsuperscript{217}Christopher G. Ellison and Robert A. Hummer, et al, Religion, Families, and Health: Population-Based Research in the United States. Christopher G. Ellison and Robert A. Hummer, eds. (New Brunswick, NJ: Rutgers University Press, 2010), 321-348. In their summation, the authors note that there has been significant growth in the field of religion and health, but that the research has left “unexplored” connections between these religion and health among racial and ethnic minority communications. Ellison, Hummer, et al. 348.

\textsuperscript{218}Stehr and Meja, Society and Knowledge, 13.
affords the opportunity to understand how some patients, encountering knowledge across these two spheres, might consider them to have equal standing. For patients for whom this is true, they find both spheres of knowledge to be relevant mechanisms of knowing and evaluating in order to make decisions about the circumstances which arise in their lives. I am not implying that scientific knowledge and religious knowledge are the same. However, I am saying that for some patients I expect to encounter in this study, religion and science may have equivalent significance as factors that they use to guide their lives.

“Research on the ‘manufacture’ of natural-scientific knowledge has led to a reassessment of traditional assumptions about the unique rationality of scientific knowledge. Seen through the ‘strong program’ of the sociology of knowledge, scientific knowledge and everyday knowledge are in fact surprisingly similar in certain respects.” Stehr and Meja are also instructive in noting the difference between knowing and the content of knowledge. And it should be reiterated, that “the sociology of knowledge investigates the interconnections between categories of thought, knowledge claims and social reality.”

Where scholars of African American religion have made observations about knowledge and knowledge production with regard to the field of health and medicine, the focus has largely been to note the differing structures of religion and medical science. Here, again, both Townes and Mitchem, whose work is central to any study of African American religion and health, have contributed perspective to this discourse. In *African American Folk Healing*, Mitchem asserts that African American epistemology is directly

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219 Stehr and Meja, 3.
220 Stehr and Meja,
221 Stehr and Meja, 2.
connected to its African retentions. Townes takes up epistemology in *Womanist Ethics and the Cultural Production of Evil*. There she argues that experience, not mere reasoned abstractions, are vital to developing a well-functioning epistemology which produces public policy that works for diverse populations. For both scholars, the segregation and exclusion from locating solutions for society are ultimately grounded in racism (and sexism and other ‘isms’). I do not wish to argue this point; racism remains a deep matter of social divide in the United States. In fact, I philosophically agree. Mitchem’s work is descriptive at that point - working from within culturally constructed knowledge structures, as is Townes’s assertion - where the term experience may be extended to history - as in the historical context in which African Americans are making new individualized decisions on an on-going basis. Furthermore, a recent monograph provides greater credence to Mitchem’s and Townes’s claims as well as to my own focus on the social mechanisms that support the charge of racism.

By examining physicians’ rhetorical content, Hoberman has described how medical racism is developed and promulgated from one generation of doctors to the next. Through physicians’ oral tradition, Hoberman observes that there is the formal “bedside” discussion between teaching physicians and training doctors, such as residents and medical students; then there is the learning “evil twin,” the hallway conversations that occur out of the earshot of the patient. Physicians’ perspectives on race are no different than that of the general populace. In fact, Hoberman asserts, “It is probable that many

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225 Ibid.
doctors, like police officers, are exposed to more than their fair share of extreme and unattractive behaviors of the troubled and the indigent, a disproportionate number of whom may be black.²²⁷ The legal authority (powers) embedded, masked and supported in sociocultural norms skewed by notions of race and advanced to both police and physicians are reasons why on-going critique and address at the institutional level remains important including the cultural symbols of religion. The potential for disproportionate exposure to social ills is facilitated by the fact that a significant amount of medical education occurs in teaching hospitals which are often located in the urban centers of our nation in the process of giving emergency care and treating the indigent. However, as the Institute of Medicine study noted, what Hoberman refers to as medical racism occurs without respect to African Americans’ economic class standing and insurance coverage. Earlier I noted that Linda Barnes, a medical anthropologist teaching in a medical school has observed that what physicians formally learn about religion is most likely learned in an undergraduate religion course. Attention to the spiritual lives of patients, bolstered by health care institutional accreditation requirements, is part of the sociocultural and regulatory framework that has increased the number of medical schools that teach modules related to spirituality to more than 100.²²⁸ I have located no data on the number or percentage of American students who receive any type of formal education related to race. However, sociologist Ann Morning conducted a study about the content of college-level race education. Her findings suggest that race continues to be thought of as an essentialist rather than socially construct based on U.S. institutions including

²²⁷Ibid.
²²⁸For additional information and guidance on accreditation review for critical care environments see http://www.jointcommission.org/mobile/standards_information/jcfaqdetails.aspx?StandardsFAQId=290&S tandardsFAQChapterId=29 <accessed 6 March 2015 > This link describes various approaches to the conduct of spiritual assessment among patients. See also Bonnie Booth bibliographic reference.
education (Morning surveyed high school biology text books from the last sixty years), the U.S. Census form requesting that respondents report their race, and race self-reporting during medical encounters.\textsuperscript{229} Knowledge about race and spirituality can impact patients’ care, and the U.S. physician workforce is not socially concordant to the population.

Social concordance matters. For African American patients, one study found that social concordance could result in an additional two minutes of dialogue with their treating physician. In a fifteen minute visit, two minutes presents the opportunity for a substantive exchange between doctor and patient that can help to unearth additional medical issues and solutions.

“‘Religion as eminently social’ thought, feelings, and actions”

My hypothesis is straightforward: in accordance with the functional Durkheimian thesis in \textit{Elementary Forms}, African American patients who identify religion as an influencing factor will prioritize their decision making with that which they identify as sacred, but only as it also aligns with their experience of sociology of knowledge. In other words, if African American religion has established a pattern of knowledge that links to sacrality, patients will be willing to prioritize their decision making with this pattern. However, where no pattern has been laid, patients will formulate a separated social alignment that links to the knowledge pattern that they consider to be available, supportive, and concrete.\textsuperscript{230} Although this hypothesis is straightforward, identifying which patients will follow this hypothesized pathway does not produce a predictive model. It is not possible to determine which aspects of a particular patient’s experience he will indicate as meeting his view of sacrality. It is important to note that this


\textsuperscript{230} Pinn, \textit{Moral Evil}, 5.
hypothesis makes no presumptive claim to a connection between knowledge and specific health behaviors. Rather, this hypothesis suggests that there may be a link between what one holds to be sacred, what one holds to be knowledge, and that social ties influence an individual’s choice to accept both.

Among African Americans, religion has often been viewed as a cultural asset that has provided a sense of identity, and has offered a stable and countering alternative to the social, political and bodily hostility and violence aimed at blacks since their arrival in the New World. Yet, for some scholars of African American religion, such adherence has also contained problematic markers, and they have attempted to reform troubling aspects of the tradition’s valuing of social adherence. In her dissertation project, Stephanie Mitchem told black women they needed to reconsider the doctrine of salvation, “get off the cross,” and take care of their health. Delores Williams also located a problem in traditional Christianity’s salvation in that, for her, it reinforced gender roles that sublimated black women to self-sacrificing decisions that followed the pattern of the crucifixion of Christ. Instead, black women should look to Jesus’ life and ministry to emulate his pattern of transforming one’s relationship with oneself and with others to create a life in which sin is conquered by the refusal “to allow evil forces to defile the balanced relation between the material and the spiritual, between life and death, between power and the exertion of it.”

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religion such as Kenneth Pargament state that African Americans turn to religion as a coping mechanism where they may have fewer resources than other Americans. Against all of these interpretations, I acknowledge the challenge put forth by sociologists Christopher Ellison and Robert Hummer who have documented that religion appears to provide African Americans a sense of health better than objective measures would warrant, but that little is known about how this relationship might function.

Emilie Townes offers perspective on why there might not be a functional explanation. In *Breaking the Fine Rain of Death*, Townes theorizes that a negative, Cartesian dualism is the theological foundation that accounts for the disconnect between mind and body with implications for religion and health. This thought can be supported as plausible since the largest percentage of African Americans identifies with Christianity, specifically, Protestantism, as their faith system of choice. In this framework, development of the spirit is deemed superior to the acquiescence of the desires of the material body. She goes on to remind her reader that everything humans do is mediated in the body, and that this fracturing spirit from body is not commensurate with the various episodes of incarnated experience in the birth, life, and death of Jesus Christ. Furthermore, she observes that many Christian rituals involve the reenactment of these stories in Jesus’ life as a means of connecting believers to Jesus and to ritual practices such as baptism, communion, and foot washing. Finally, the

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235 Townes, 172-3.
238 Ibid, 172.
239 Ibid, 173.
scriptural passage that Townes uses to ground this section of her constructive chapter, Hebrews 10:19 – 11:3, enjoins believers to continue in their faith and warns against the failure to gather together so that they may encourage one another in love and good deeds and in the tenets of the faith. Townes’ overall goal is to establish a Womanist way of expressing care for those who are marginalized in or fall outside the U.S. health care system. In the above outline, I also see an implied model for the analytical approach I propose.

I anticipate that the split or rupture will not be with belief. As I have already noted from Berger and Durkheim, the knowledge community is a relatively closed loop with new experiences being located within familiar categories. In order to consider innovations where religion cannot process them, religious practitioners will face a crisis (experienced with different degrees of measure) which he will choose to align with a different community of knowledge – even if temporarily – to make his decision to participate in a clinical trial.

The concept of a breaking away or a redirection can be a part of the social reality in religious experience. In much the same way that Foucault understood irruption or discontinuity in discourses on history, I understand a disruption in the course of one’s religious biography or conceptualizations, when faced with a never before experienced life episode, to have the potential to signal toward new formations in religious life.241

Contravention of Primary Mode of Sociology of Knowledge

241 As a reminder, this concept is being explored for its meanings related to religion as a cultural form in African American communities. Although, my language appears to be referring to the religious life of an individual, in the constructive chapter, I will discuss the impact on the cultural form, African American religion.
My hypothesis is that when confronted with the need to make a decision related to their long-term health and life, the African Americans patients in this study who acknowledge the influence of religiosity/spirituality in making their decision regarding clinical trial participation first will need to perceive a need for some sort of break with the social conventions of the religious bond. The break induces the exploration of knowledge from a realm or relationship outside the usual knowledge distribution channel (in religiosity). When they make this break, even if on a subconscious or temporary basis, the patient will make their decision outside the socially coherent bond of religiosity. At a later time, the patient may then reintegrate with the “eminently social” religious bond.

“Outside” can be interpreted in any number of practical ways. Outside the social bond could mean making the decision without the counsel of persons outside oneself or oneself and the physician who is conveying relevant information. Outside could mean making the decision without sharing the details with persons who may have been one’s spiritual confidante to this point. Outside could also mean suspending particular aspects of orthodox beliefs which may have been a part of one’s core religious beliefs until the experience or instance of this particular life issue. These patients end up with a new form of the social in religion, potentially an expanded socio-religious bond.

I hypothesize that because it is an embodied process, the patients will be fully conscious of the confrontation. They may not, however, be able to consciously articulate the break that they make so I will need to listen intently for verbal cues during their interviews. Each patient will have a sense of his body in time and space, and a sense of directional push or pull or movement which directs agency. In the decision making process, the patients move toward consent or denial for trial participation and away from
the break. I am not attempting to construct a predictive model, but I expect that patients who go through the full process described above are more likely to consent to a clinical trial. They are willing to risk a break although it may mean isolation; this is their expression of religiosity/spirituality. In this moment, this expression of faith is not necessarily linked to a divine Being, but to the struggle in the movement toward whatever is to come next in the sense of agency.

The notion of a break or rupture is important because it diverges with the anticipated social coherence functions of African American religion which I have argued are implicit in African American religious scholarship. When I speak of a “rupture,” I am thinking very broadly of a concept closely related to Michel Foucault’s discontinuity. In his concept, Foucault was looking for a way to enter discourse about “history of subject matter” as in history of science, history of ideas, or the history of philosophy. He wants to investigate “beneath the continuities of thought, beneath the solid homogeneous manifestations of a single mind or of a collective mentality.” He wants to undertake this venture because to Foucault, the method of historians seems to “prefer…to reveal the stable, almost indestructible system of checks and balances, the irreversible processes, the constant readjustments, the underlying tendencies that gather force, and are then suddenly reversed after centuries of continuity.” By using investigative models which analyze the long history, historians become the experts who must also interpret this long view when they select the events which get included or discarded as moving toward the political pattern that eventually emerges. But Foucault recognizes the value of discontinuity, and, he believes, so do contemporary historians. Discontinuities “become

242 Foucault, The Archaeology of Knowledge, 2.
243 Ibid, 4.
244 Ibid.
the work itself.” They can provide a “working concept” that eventually “validates” a new analysis.

Discontinuities can lead to “transformations that serve as new foundations.”

Foucault outlines several types of ruptures or discontinuities. Two types of discontinuities are suggested in the present investigation; one has already been introduced. The first type is the displacement and transformation of concepts. In this type of discontinuity, the history of a concept has become self-validating rather than in continuous refinement. I have reinterpreted the Tuskegee narrative in light of this type of discontinuity. As observed earlier, the narrative sometimes has been deployed as a totalizing and causal proxy for the distrust in which African Americans hold institutionalized medicine.

Scholarly literature in public health and in African American religious studies is beginning to review the deployment of the narrative. I have argued to transform its concept from its evil or profane pronouncement to acknowledging it as a sacred narrative with which its continued deployment needs a living rather than mourning relationship. The next type of discontinuity that will be helpful here is the epistemological act and/or threshold. This type of interruption acknowledges that a “suspension of the accumulation of knowledge” can allow for the search for new ways to rationalize history and potentially locate “new effects” from this effort. Using these concepts, I am looking for these discontinuities in African American religious scholarship in connection with the history and future of African American participation in clinical trials as a marker of religion and health.

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245 Ibid, 9
246 Ibid, 9
247 Ibid, 5.
248 Ibid, 4.
250 Ibid.
Moving Through Life: Time, Space, and Risk Assessment and Aversion

In constructing my thoughts about these discontinuities and breaks, I have identified three aspects of human experience that I expect will be germane to the idea of a social break and religiously influenced decision making: time, space, and uncertainty or risk; I will follow how any or all of these elements can be influenced by religious connections. The interaction of these three as elements of embodied social knowledge may occur subconsciously, but this study is not an individualized, psychological approach to the question explored. Rather, mine is a social-cultural examination; that is, I am interested in the same dimensions of life where religious experience and medical experience are constructed for meaningful examination or reflection. To be sure, other theorists have investigated only one or two of these dimensions – time, space, and risk – within one work. For me, it is the interaction of these three that shapes the religious experience in the medical setting.

In this project, I introduce time below, then fully address time and risk where they naturally enter the text. Black bodies are the contested “space” of human experimentation as well as their entry in the clinical encounter for medical research. I have already given an overview of the problematic history of the treatment of African Americans with emphasis on the ways that black bodies have been abused with specifically troublesome concern because the mistreatment was within clinical settings where persons would expect help if not respect.

Time

The element of time as an ordering or as an analytical category in religion rests on long and varied arguments. For example, historian of religion Mircea Eliade produced
what has become a classic in the field of religious studies, *The Sacred and the Profane*. For Eliade, time as an analytical category of sacrality rests in ritual and myth. Time (and space) is a means of determining that which is sacred from the ordinary or the non-sacred. African American philosopher of religion Eddie Glaude, Jr., has considered time in black and womanist theology as an orientation to the past, as history, serving the function of identity formation. To Glaude, history has been misappropriated in that it produces a fixed identity that is inadequate to consider the present no less the future. In essence, time has stopped (as it relates to identity formation for African Americans). If I accept Glaude’s critique, this use of time would not be useful for my hypothesized model because there is little movement toward something new or reconsideration of the old. This is Glaude’s central complaint; that the emphasis on history to ground racial identity does not inherently allow for trying something new and thus stifles the political activity of a generation whose lived experience is too recent to be a part of some of the hallowed days of African Americans’ civic achievement. In other religious analysis, time has been related to history in another way. Religious traditions sometimes mark the march of time across the cosmos. In Christianity, this includes the chronological march from creation to eschatology. For Eliade, time as an analytical category in religious construction is delimited in the symbolic; for Glaude, history as identity marker threatens to make time a symbolic feature of life. The connecting fiber is being. Eliade describes it best when he discusses the separation of the sacred from the profane: they are two modes

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252 Ibid, 68.
of being. Furthermore, Eliade’s arguments emphasize the content of the religious rather than the social processes of religions as is the emphasis here, and so is unlikely to inform the current research project. Glaude’s project, however, might; since he is concerned about the function of black and womanist theology.

Overall, however, I reiterate that my project seeks to identify when the patients may feel the need to make a break with the social functions of black religion.

Conclusion

My reading of scholarship in African American religion and health suggests deference to the aspect of the Durkheimian theory that “religion is eminently social.” Notably, we see this paradigm at work in the deployment of the Tuskegee syphilis study narrative by scholars Stephanie Mitchem and Emilie Townes. Their use of the narrative and its emphasis on race demonstrates that the “social” aspect that is “eminent” is racial identification. I have argued for reverential treatment of the narrative; however, I have argued for an expansion of the functional and theoretical categories that can be used from Durkheim. I have introduced the concept of irruption as the social process of an expanded category. It is a rupture or discontinuity that may challenge that adherence to the social group is mostly grounded in the racial identity functionality – a key function of African American religions. The themes that begin to emerge from their interviews will then be used to devise a pattern for a grounded theory based on this notion of a rupture from the social adherence theory implied in the literature from the primary scholars of religion and health who write from within African American religious studies. I prefer to emphasize the knowledge production aspect of Durkheim’s theory should be reconsidered as the point of emphasis. This consideration supports my movement of the narrative from the

255Eliade, 14.
profanity of the evil of racism to the sacrality of the reverence for the narrative while also seeking a way to use it such that it motivates new generations whose experience of racism may not be the same as those of African Americans from the mid-twentieth century.

In this chapter, I have posited that knowledge and epistemology are socially constructed – in religion and in health/medical science. While these two realms of knowledge have different specific mechanisms for affirmation and confirmation, they function similarly. The next chapter provides the opportunity to test which of the hypotheses in this sociology of knowledge framework remains as I examine patients’ illness and decision narratives.
Chapter 4

“That’s My Story and I’m Sticking to It”: Illness Narratives of African American Men, Their Spirituality, and Prostate Cancer

The first time I attended the annual meeting of the American Society of Bioethics and the Humanities (ASBH) I glanced at the schedule and rushed off to a session titled, “Witness and Response.”256 Perhaps, in my haste to choose the next session to attend, then reach the correct room on time, I subconsciously misread the title through a “Black Church” frame. Within the frame of that milieu, I errantly translated the meaning I expected to be transmitted during the session. Perhaps I thought the title would somehow address black church cultural expressions such as “call-and-response”258 or “witnessing-and-testifying.”259 As I listened to the presentations and responses from members of the audience, I felt that I had accidentally entered a private support group meeting or some sort of group confession. Most of the attendees identified as physicians and other health

257Here, I am referring to cultural practice within that institutional context. The term “Black Church” is used colloquially and in religious scholarship to denote African American Protestantism. C. Eric Lincoln and Lawrence H. Mamiya gave it a formal definition in their widely used text, The Black Church in the African American Experience. Seven historically black Christian denominations also led by African Americans comprise their definition. They estimate that more than eighty percent of African Americans were worshipping in these denominations at the time of publication. C. Eric Lincoln and Lawrence H. Mamiya, The Black Church in the African American Experience (Durham, NC: Duke University Press, 1990), 1.
258“Call and response” is a common speaker and audience interaction among African American congregations. The speaker makes a proclamation to which the audience responds with a pithy corresponding, often in unison. For example, from the pulpit, the preacher may loudly yell part of a Bible verse or familiar phrase, and the audience responds by completing the phrase.
259“Rooted in accounts of slaves and ex-slaves after conversion experiences, testimonies in African American religion are verbal affirmations of belief and narratives of divine interaction with ordinary life. ‘In testimony, people speak truthfully about what they have experienced and seen, offering it to the community for edification of all,’ theologian Thomas Hoyt writes. ‘In testimony, a believer describes what God has done in her life, in words both biblical and personal, and the hands of her friends clap in affirmation. Her individual speech thus becomes part of an affirmation that is shared.’” See Rosetta E. Ross, Witnessing & Testifying: Black Women, Religion, and Civil Rights (Minneapolis: Augsburg Fortress, 2003), 13.
care professionals who were acknowledging to each other the ways that they used writing as a mechanism for self-healing. Panelists as well as members of the overflow audience described how they write – sometimes as full-length novels - to release their feelings and concerns about emotionally-taxing patient cases or problematic ethical dilemmas and injustices they have seen as providers in the clinical setting. The ASBH session that I “accidentally” attended resurfaced as significant to the ethnographic portion of this research experience: it suggested a humanistic form I could employ to report the data and findings I had collected from patient interviews. The written narrative form exhibited in the “Witness and Response” session, coupled with the differing uses of the historical Tuskegee episode, including its metaphorical, cultural narration about the black experience in health care, suggest that narrative is also a helpful form through which to better understand how African Americans engage their spirituality within the disparate complex cultural institutions represented in African American religion and the U.S. health care and medical research enterprise. Narrative form has been instrumental in the distribution of African American history and culture.

In this chapter, then, I examine the illness narrative or narrative journey each patient presents in a qualitative interview in order to discover patterns of concerns including religious thought and spirituality. The patients in this study were accrued through referrals from a low-risk observational, highly monitored, behavioral clinical study at an academic medical and research cancer center. I compare this patterned narrative to the overarching narratives about African American religion and health by scholars of African American religion and by scholars writing about African American spirituality and religiosity in public health. Although each patient was interviewed using
a script, their responses vary. Even so, as I present the patient narratives and the scholarly narratives, I highlight themes related to topics in chapters 1-3 of this volume: deployment of the Tuskegee narrative; the social processes of sociology of knowledge/social knowledge; and the primary theme that emerges from the patient interviews: risk.

The History and Value of (Illness) Narrative as a Cultural Form

Ann Jurecic is a scholar of English and literature who has connected her biography with her scholarship; her husband has been diagnosed with cancer multiple times, and has experienced surgical and chemotherapeutic treatment for these bouts. During his episodes with cancer, Jurecic reflected on the suffering she saw among other cancer patients. She converted those reflections into a research project on the history and uses of narrative as a literary form; she argues for their use during and about illness.

In, *Illness as Narrative*, Jurecic traces the twentieth century history and content of what has come to be referred to as the “illness narrative.” She begins by observing the scant contemporaneous literature – from journalistic accounts to personal narratives related to the 1918-19 influenza pandemic that may have killed as much as five per cent of the world’s population, possibly as many as 100 million people. She juxtaposes this lack of literary illness accounts to the work of literary scholar, Susan Sontag, who so famously wrote about the ways that uses of the language of illness, specifically, tuberculosis and cancer, has been crafted to generate commentary about problematic social contagion such as in the phrase a “cancer of (something undesired)” as well as for the metaphoric description of emotions. Sontag argues against the use of illness as metaphor.

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261 Ibid, 8.
search for adequate metaphors. But the modern disease metaphors are all cheap shots. The people who have the real disease are...hardly helped by hearing their disease’s name constantly being dropped as the epitome of evil.”

Representations of illness as source material for literary analysis tell only part of the story.

Continuing with Jurecic’s history of the form, the HIV/AIDS epidemic of the late twentieth century sealed the use of story to discuss illness itself, not just as a representation of something else. She speculates that initially, this may have been because the epidemic hit the arts community so voraciously, and writing has long been a tool of expression for members of the arts communities. But through the HIV/AIDS crisis of the 1980s, writing also became “a weapon in a cultural battle against homophobia, the disdain of the medical establishment, and the indifference of the government. Activists and people with HIV/AIDS wrote letters, editorials, pamphlets, and manifestos, as well as plays and screenplays, poems, stories, essays, and memoirs. They got the word out.”

Activists took the slogan: “Silence = Death.” Writing helped to redirect the narrative that concluded that these early victims of a little understood illness did not warrant attention in terms of research resources and social impetus to act on their behalf. In the age of the then mysterious death sentence which came to be known as AIDS, the illness narrative took on a multitude of uses. It was at once educational about the experience of illness and political device. In the same spirit that late twentieth century illness narratives shed light on the lives of men living and dying with HIV/AIDS during its earliest days, this chapter provides African American men a unique opportunity to begin to share their own illness narratives.

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263 Jurecic, 9.
264 Ibid.
The African American experience narrative has been an important expressive form used both orally, in writing, and in song. Accounts of their lives in enslavement and beyond have been instrumental in later generations gaining first-hand understanding of the misery and agency of their day-to-day existence, thoughts, feelings and religious life. Harriet Jacobs’s fictionalized account of her trials seeking freedom from sexual threats as well as freedom from enslavement for herself and her children is one example demonstrating this sort of valuable understanding. The narrative demonstrates her sense of her will in the face of slavery as an institution in which she was deemed to have no legal power. Jacobs understood that her audience, Northern women abolitionists, might be persuaded to greater empathy by learning the facts of Southern enslaved women. Others’ narratives about African Americans often shaped a pathologized view of black life. The emergence of self-narrated accounts has been important to gaining a more balanced view of blacks’ experiences.

African American scholarship across academic disciplines, including religious studies, has showcased research that has countered unproductive, limited and incorrect narratives about African Americans. Likewise, the illness narrative offered by each patient in my study provides primary data to begin to compile a broader, collective narrative from men with prostate cancer about their experience in the intersection of

265 Harriet Jacobs’s *Incidents in the Life of a Slave Girl* provides a documented accounted of the slave and free experience of one enslaved female. Frederick Douglass also wrote an account of episodes of his life in enslavement as well as his thoughts about the hypocrisy of U.S. ideals. Both accounts offer insights into the moral life of their writers as well as a sense of the religious and race morality of their time. See Harriet Jacobs, *Incidents in the Life of a Slave Girl*. A Norton Critical Edition. (New York: W.W. Norton, 2000) and *Narrative of the Life of Frederick Douglass: An American Slave, Written by Himself* (Boston: Bedford/St. Martin’s, 2003).

266 See Peter Paris’s discussion of traditional and vindicationist styles of academic scholarship. Scholars in other disciplines have made similar arguments categorizing scholarship about African diasporic life and history. I have selected Paris because of his training from within religious studies; my discipline. Peter J. Paris, *The Spirituality of African Peoples: The Search for a Common Moral Discourse* (Minneapolis: Augsburg Fortress, 1995), 17.
religion and medical science related to their cancer diagnosis. There is little published research about black men’s spirituality and even less about black men’s spirituality and health.\textsuperscript{267} There is, however, a body of published research describing prostate cancer screening efforts with African American men through churches as sites for recruitment about this attitudinal and behavioral research.\textsuperscript{268} In addition to data from the qualitative interviews about clinical trial participation, I have included observations about African American men and spirituality made during cancer clinic visits at a local county hospital that largely served underserved and indigent patients including county prisoners. Training and faculty oncologists from the facility where I conducted my primary research provided medical care to patients at the county hospital.

The collective narrative about the influence of religion on African American men’s decision making about prostate cancer clinical trial decision making will be compiled from the contents of individual patients’ stories. This collective narrative will be compared to two key narratives about African American religion and health – one in African American religion and health scholarship from religious studies and the other from health research on African American spirituality.

In chapter 2, I described the Tuskegee Syphilis Study as the key unifying narrative in African American religion and health scholarship produced by scholars of African American religions. I observed that it was flawed for the current moment in

\textsuperscript{267}Interestingly, women scholars of African American religion have written about matters of health. This actually flows with sociological data that women are intimately involved as decision makers about health related to children, women, and men.

\textsuperscript{268}See “Church Programs Motivate Black Men to Get Prostate Cancer Screening” - See more at: http://www.cancernetwork.com/articles/church-programs-motivate-black-men-get-prostate-cancer-screening#sthash.bUyOfpKt.dpuf; http://www.cancernetwork.com/articles/church-programs-motivate-black-men-get-prostate-cancer-screening and Baqar A. Husaini, Michelle C. Reece, Janice S. Emerson, Samuel Scales, Pamela C. Hull, Robert S. Levine, “A Church-Based Program on Prostate Cancer Screening for African American Men: Reducing Health Disparities” \textit{Ethnicity and Disease} Volume 18 (Spring 2008), S2-179-S2-184.
history. My interdisciplinary reading of spirituality/religion and health literature in the African American context suggests that a new interpretive paradigm is in order in African American religious studies. The new paradigm should take into account public health research on African Americans’ willingness to participate in clinical trials – given the opportunity. I suggested using Durkheimian-derived cultural sociological theory to sacralize the Tuskegee narrative. In this reinterpretation, the solemnity of Tuskegee’s cultural value would be retained as would the broadened narrative that acknowledges that public exposure of the horrid tale wrought against black bodies also facilitated modern bioethics standards including respect for persons and justice that are still in use today.

The other key narrative - from health research on African American spirituality – concludes that African American spirituality grounds a fatalistic perspective that inhibits patients’ agency in addressing health behaviors related to cancer. As part of my bioethics training fellowship, I was required to attend a four-hour training that is elective for staff of the cancer hospital who want to learn about spirituality and health views among diverse groups. The trainer developed the curriculum for the course. In his research he found a substantial amount of literature describing African American spirituality during cancer as being “fatalistic,” so this broad framing was how he described African American spirituality in his summary chart to facilitate trainees’ learning. After the training, I researched the literature on black spirituality and cancer as the other key narrative I would need to listen for during patient interviews in my project. In that follow up work I became familiar with Barbara Powe as a primary researcher widely published in this field.
In her earliest research, Barbara Powe’s aim is to learn more about the interconnections between African American spirituality, fatalism, and African American’s failure to participate in cancer screening tests.\textsuperscript{269} In her definition, Powe describes fatalism as the belief that any action taken will not change the outcome of their cancer so taking screening tests is futile.\textsuperscript{270} Health research demonstrates that early detection and treatment can be helpful in improving health outcomes.\textsuperscript{271} Therefore, it would be important to look for this category of interpreted lack of agency among the patients in my interviews both to observe the socially constructed factors in the literature that supply this prominent narrative about African American patients, and to understand whether and how such a perspective among medical providers may impact medical providers’ decisions to present a spectrum of treatment options to African American patients. In addition to literature on this latter point, during clinic visits, I was able to observe physician-to-physician discussions about patient cases and to shadow physicians as they discussed treatment plans with patients and/or with patients and their family members/support partners. These visits augmented what I read in the literature; I was able to see sample cases that demonstrated interpretations from the literature. A few of those cases stood out as representative of the social mechanisms which limit the decisions African Americans can make about their treatment options. Stated differently, there is evidence in the broad health research literature that African Americans do not always have options presented to them or that their requests for certain types of treatments may


\textsuperscript{270}Powe and Johnson, ibid.

\textsuperscript{271}Studies note that screening may not reduce cancer risk, but may detect cancer earlier thus sometimes improving the treatments that are available. Charles Putman, “Screening and Early Detection,” http://imaging.cancer.gov/programsandresources/reportsandpublications/reportsandpresentations/imagingsciencessubgroup/earlydetection <accessed 23 April 2015>
not be honored because they may be deemed unnecessary. In cases where African American patients do not have access to the full range of known treatments – for any number of reasons - it may well be that spirituality becomes a mechanism for coping as has been suggested by psychology of religion and coping specialist Kenneth Pargament.\textsuperscript{272} In his view, religion may be the only resource some African Americans have, given that they may have fewer material resources to call upon during illness, and that it takes both to address issues of illness.\textsuperscript{273} While observing in the clinical settings to which I had access, I witnessed that both the lack of material and social resources and the presumption of a non-agency stance on the part of African American patients can impact the treatment options made available. I will present these examples later in this chapter. First, I will present my methodology for the research. Next, I will discuss my findings related to the two major narratives mentioned above from African American religious studies regarding the Tuskegee narrative and from health research on African American spirituality in health regarding fatalism. Then I will present other data of interest. Finally, I will discuss the major finding that will ground my social theory of African American religion and health.

Background, Research Environment and Methodology

\textbf{Background and Study Procedure}

This project was proposed as grounded theory research using concepts and methods from Strauss and Corbin’s second edition on the \textit{Basis of Qualitative Research}. My plan was to collect primary data for this study using a semi-structured interview guide. That is, an interview script that asked each patient roughly the same questions in

\textsuperscript{272}Pargament, 145.
\textsuperscript{273}Ibid.
the same order while remaining flexible for differences in patients’ understanding and use of language and manner of responding to questions designed to illicit more than ‘yes’ or ‘no’ answers. A copy of the Interview Guide has been included in the Appendix.

By the time my research proposal was approved, I had been awarded a bioethics training and research fellowship at a Houston hospital. An internal partnership at the hospital between a public health researcher in health disparities and the clinical ethics department provided an opportunity for me to gain access to potential clinical research partners as well as to have support for the research for expenses such as patient incentives and transcription services. The internal partnership had won a grant from the National Center for Minority Health and Health Disparities.274 Their grant was funded to investigate underrepresentation of racial and ethnic minorities in clinical trial participation with their research inquiry to investigate moral components of the participation of racial and ethnic minorities. The fellowship provided access to patients who I could interview, but it also presented challenges.

The first challenge was to develop a second research proposal that met the set of rigorous standards in the clinical setting. I needed the second proposal to match the language, format, and procedures of the public health research discipline and my research sponsor within the hospital. I had already completed a research approval process through the Office of Sponsored Research at Rice University. The dual process meant that I was engaged in the two-language world of the two-knowledge worlds described in chapter 3. The hospital’s approval process was complex and required several months to complete. The research approval process included submitting the written proposal for review to a

274Within the 2010 Affordable Care Act, the Center was designated to become the twenty-seventh institute of the National Institutes of Health. www.nimhd.nih.gov/about/nimhdHistory.html <accessed 2 January 2015>
behavioral research subcommittee of the Institutional Review Board and appearing for oral testimony. The Rice proposal was approved through an exempt, expedited review of its Institutional Review Board. Its exempt status indicated that there was little risk for the human subjects who might consent to participate in my study because the patients would not be identifiable once the data became public; furthermore, an alternative review procedure other than the full committee of the Institutional Review Board would be acceptable to examine the research project to ensure that it protects human subjects and their rights.\textsuperscript{275} Patients would be referred to me from clinical studies at the hospital where they had been recruited and enrolled; I would recruit patients from those studies.\textsuperscript{276}

The next challenge was to locate an internal clinical partner. I was paired with a member of the faculty who would act as a collaborator; he is a professor and urological surgeon with whom the program director of the training and research program and principal investigator had a professional relationship. As my faculty collaborator, Dr. Curtis Pettaway provided me the opportunity to shadow with him during clinic visits with patients. Physician shadowing is a frequently used pedagogical opportunity in the clinical setting for both enrolled and prospective students. I also shadowed with clinicians who saw patients in what is referred to as a multidisciplinary clinic. There, patients are seen by specialists who offer the various treatment options: radiological and surgical. These combined experiences provided me broad understanding about the treatment options for prostate cancer patients. I was skeptical of working with men; I was unsure of their numbers in the patient population and I expected that they would be less communicative

\footnotesize{\textsuperscript{275}“Human Subject Regulations Decision Charts http://www.hhs.gov/ohrp/policy/checklists/decisioncharts.html#c2 <accessed 22 October 2014>}

\footnotesize{\textsuperscript{276}The study was approved under protocol 2011-0430 at the University of Texas MD Anderson Cancer Center.}
about spirituality and potentially hesitant to discuss urologic cancer and urologic function with me as a female researcher. To gain context on these concerns I met with a data manager in the health disparities department who searched the institution’s data to try to determine whether there would be sufficient patients to attempt to populate my study as it had been proposed and approved by my dissertation committee. Although the preliminary raw numbers were sufficient the timing of patient visits and dispersion of the enrollment in clinical trials proved otherwise.

Locating a sufficient sample of participants for this study proved to be exceedingly challenging. Seven men completed the full interview. One additional patient provided information based on the initial information session provided by the recruiter from his clinical trial. He wanted to participate, but declined to complete the informed consent procedure. I will discuss him further later in this chapter. Neither my proposed project patient accrual goal to collect data from 20-30 participants nor the program statistician’s estimate of 15-20 patients that would be sufficient to identify repeating themes in patient responses were met. Seeking to accrue more participants to the study, I amended the Rice-approved protocol in order to cast a broader net through outreach to men’s organizations in the Houston area. These efforts, as is often true for community-based research outside established connections, did not yield additional participants. The overall accrual rate was disappointing, but the project did generate the broad areas of responses I wanted to capture. I was able to conduct a project which opens the door for more research. Further qualitative projects involving similar questions should be fronted.

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277 Protocol 11-008E Bongmba Rice University. Multiple outreach attempts to local contacts for: Kappa Alpha Psi Fraternity, Alpha Phi Alpha Fraternity; Tex Us Too, a prostate cancer education, support, and advocacy organization; a prostate cancer organization especially for African American men; Prince Hall Masons; 100 Black Men of Houston; Sisters Network, a cancer support network especially for African American women.
by a relationship development period with the community involved, and can even focus
on the structural barriers that inhibit black participation in behavioral research.

Regardless of the accrual issue, my goal was to interview patients active in the
decision making process – real time decision making, if you will; this, too, proved to be
procedurally challenging. A clinical partner who was willing to routinely refer patients
emerged approximately five months after the protocol was approved by the hospital
Institutional Review Board. This partnership signaled promise as a complementary
research project. The investigator was working on a multi-year study which had begun
five years before, and should have had a sufficient flow to populate my own study
through the referral process. The researcher’s data coordinator would initially screen
patients who appeared to meet the eligibility criteria for my study. She would then
contact me by telephone, pager, or email as she identified patients who were African
American, over eighteen years of age, had a diagnosis of prostate cancer, and had
consented to participate in the clinical study she coordinated. She would identify the
referable patients as she recruited them for the primary clinical trial. She would then
introduce the idea of participating in my behavioral study. If the patient seemed willing,
the coordinator would contact me, and I would have the opportunity to conduct a
recruitment discussion with the patient. When the process reached my recruitment
discussion, most patients responded by agreeing to sign the written consent.

I learned nuances of this process through experience. For example, in one
instance, I had completed the recruitment discussion, and the patient signed the written
consent. Just as the patient signed the document, he was notified that the doctor was
ready to see him because a number of patients had cancelled that day – moving up the
appointment time of the patient with whom I had been discussing recruitment. I returned
to the waiting room in order to be able to interview the patient after his clinical
appointment - the reason for his visit to Houston. The visit lasted more than 90 minutes,
during which time I remained in the waiting room while the patient’s brother spoke with
me about a variety of subjects. Included in our conversation was information that would
prove helpful in providing context about issues in the region such as about health
insurance and the economic engine that the petrochemical industry provides for
employment in the local region. When the patient completed the office visit, he was
given orders for a radiographic imaging procedure. Given the amount of time the
imaging would take, the patient stated that he would need to begin his travels to return to
his home city after the visit to radiology. He indicated his skepticism to participate in the
study to which he had consented; I was never successful in completing an interview with
this patient, who, during the recruitment and consent discussion, conveyed hesitance
about participating.

I learned from each contact: the average length of time for an interview, to
attempt to determine where the patient was in a typical appointment timeline, how a
spouse or companion wanted to interact (usually not) during the recruitment and
interviewing process. As I learned patterns of clinic flow and patient mindset, I was
able to incorporate this information into the unwritten procedural nuances which were
most likely to contribute to successful conditions for the interview. In the case of the

278 The conversation with this patient’s brother provided an excellent introduction to local men’s
sense of economic interests and opportunities. It was through this lengthy conversation that I learned
verifiable information about the regional petrochemical industry which has provided opportunities for
middle class incomes to high school graduates. This context helped me to understand discussions about
health insurance and insurance access during interviews with later patients.

279 The sponsoring faculty/principal investigator had provided me with guidance that patients’
appointment companions might want to remain involved and to attempt interview the patient privately to
reduce potential influence of the companion.
patient from whom I had obtained written consent before his clinical visit began, I submitted a change to the protocol. The change was intended to facilitate visit processes. For example, the change would allow me to be able to speak with patients via telephone to provide recruitment information and to gauge patient interest and willingness to participate on his next visit as well as to answer questions or concerns that would help the patient consider whether to participate or to conduct or continue an interview.

I also established interview processes based on what I learned during clinic shadowing. Many of the patients I saw during the clinic shadow visits had come for a confirmatory diagnosis of prostate cancer or to identify next treatment options for other male reproductive system cancers. In other words, they had received an initial diagnosis from a physician, generally a urologist in their home communities, and made an appointment at Big Cancer\textsuperscript{280} for a second opinion – either at the recommendation of the first physician or at the patient’s request. The design of the examining rooms at the main hospital maintained patients’ privacy (and dignity) such that during physical examinations I and a friend or relative who had come to support the patient could listen in on the interaction from behind privacy curtains. During my shadow visits I was introduced as a student-observer, and wore a hospital-issued picture identification badge whenever I visited clinical areas where patient would be present. At this teaching and research center, patients were accustomed to the presentation of various types of learners, and verbally or non-verbally consented to my remaining in the room during the visit; none voiced opposition.

I began interviews after the protocol approvals and after completing observational visits. Generally, patients demonstrated a congenial willingness to participate in the study.

\textsuperscript{280}Pseudonym for the academic and research facility where I spoke with this patient.
and share their stories. The opportunity to speak privately about these private matters such as medical matters, religious beliefs, and sexuality seemed to influence some of the men to share.

The Environment

I met the men in this study through referrals from a member of a staff working on a research study about the use of “active surveillance” as a means of treating prostate cancer.281 All except one travels from outside Houston to access the medical experts at Big Cancer. Consistently, the facility has been ranked by other cancer doctors, oncologists, as the first or second rated cancer research and treatment center in the country – many specialists rate it at that level as a world center. The facility is located in Houston, Texas and is part of the Texas Medical Center (TMC). The TMC lies approximately seven miles from downtown Houston; it is an expanse of 1300 acres. There are 54 member institutions of which Rice University is one, having established its affiliate institutional status in 2004. Across all of the institutions in the Medical Center, there are approximately 106,000 employees, 18,000 of which work at Big Cancer.282 Houston is a global oil and energy sector center; as such, persons in need of the expertise of its specialists arrive from their homes around the globe.

The Active Surveillance Study, from which the men I recruited for my project, is an open study which means the researcher is continuing to enroll patients. It is listed on the clinicaltrials.gov website. The website is usable by lay persons and was established to provide information to patients seeking clinical trials for which they may be eligible. The site also provides a level of transparency to government funded research. Researchers can

281 The Active Surveillance protocol information is located on the clinicaltrials.gov website. See ClinicalTrials.gov identifier: NCT00490763.
list their trials as a matter of disclosure; at Big Cancer, this listing can be selected by researchers once their study procedure or protocol has been approved by the appropriate Institutional Review Board. The institutional review board is a policy derived committee of other researchers and administrators tasked with reviewing study designs to determine that they will be safe for patients who assent to participation. At Big Cancer, research oversight is administered by one of five Institutional Review Boards. These committees usually include community representation, an ethicist, and pastoral care or social worker; the goal is for these members to act in the role of advocates who will consider protocol details and effects from the perspective of potential patients and their families. Other members’ role would be to protect the integrity of the scientific process, and the legal and risk concerns of the institution.

Tools such as clinicaltrials.gov are intended to allow patients to participate in their disease management with or without the direct aid of a referring physician. (This is important to note as patients with whom I spoke mentioned their efforts to educate themselves once they had been informed of their initial cancer diagnosis.) Often, patient participation in a clinical trial requires that the patient’s physician be aware of networks of specialists currently conducting clinical research related to the patient’s diagnosis. Although researchers who list their studies on clinicaltrials.gov still have to agree to consider patients for inclusion, the site can give patients a sense of the democratic availability of information related to their disease. Much in the same way that pharmaceutical firms began direct advertising to the general public in the late twentieth century, clinicaltrials.gov provides a sort of “advertising” for publicly funded clinical

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research - and just as the pharmaceutical ads suggest, patients must “talk to their provider” about the recommended “product.” In this case, the patient would need to talk with his physician about whether participation in a particular clinical trial might be deemed feasible – notwithstanding whether the patient might be referred for recruitment and entry consideration into the trial. The U.S. government also uses the Internet to educate the citizenry about other health issues.

According to the National Cancer Institute, prostate cancer is often a slow-growing cancer. Some patients with the disease may be told that they may die of old age before they die from the cancer. Even so, patients do die from prostate cancer; the rate of death among African American men is two to three times higher than that of white males. Its initial symptoms may show up, among other indicators, as an increased frequency in the urge to urinate. An early empirical marker may be measured by a rising prostate specific antigen test also known as the PSA, a test used to monitor the size of the prostate. In the past, preventative health guidelines suggested that patients begin prostate screening by age 50. Curtis Pettaway, who has conducted extensive research on the incidence of prostate cancer and the need for preventative care in this population, has suggested that African American men begin to get screening as early as 40 or 45. If patients have not had preventative prostate screens, they may be alerted to potential problems because the gland has enlarged, causing the need to urinate more frequently than usual. Various men in my sample mentioned that their physicians noted enlarged

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285 Patient interviews. See Walter’s recollection.
prostates during routine checkups or that they had demonstrated symptoms such as frequent urination and that their partners had suggested a doctor’s visit to seek a cause.

By the time the men I met were being recruited to the Active Surveillance study, an enlarged prostate and elevated PSA were already evidenced.\textsuperscript{287} A digital rectal examination involves the physician reaching through the anus to palpate the gland in order to learn the degree to which it responds with a “spongy” feel and to get a general sense as to whether its size is within normal range. An enlarged prostate may prompt the physician to order a biopsy. In this procedure, a small portion (typically anywhere from 3-10 pieces) of the prostate is snipped from the whole and tested for the presence of cancerous cells and their severity if they are present. (An ultrasound is also typically done in order to get a sense of texture and size; this is considered more reliable than the physical check) When the biopsy is positive, there may be a number of options from which the patient can decide: to do nothing; various forms of radiation in order to shrink the enlarged gland; and/or surgery to remove the enlarged prostate. The biopsy determines the presence of cancer cells as well as the severity (or evaluated stage of the presence). All of the patients in this study have been through the above cycle at least twice – with their local physician, a general practitioner or urologist, and with a Big Cancer urologist who specializes in the treatment of various cancers of the urinary and male reproductive systems. One such urologist designed and conducts the Active Surveillance Study.

In one sense, the Active Surveillance Study is the option to “do nothing” with the hope that the cancer is sufficiently slow growing that it will not harm the patient to

\textsuperscript{287}NCI, Prostate-Specific Antigen (PSA) Test. http://www.cancer.gov/cancertopics/types/prostate/psa-fact-sheet
participate in the multi-year, guided monitoring, including diet and semi-annual examinations. The recruitment discussion describes the study eligibility, participation requirements, and the consent process including that the patient could leave the study at any time, and that they would provide their consent by signing a document which will be kept with their patient records.\footnote{This is the same process I completed with the patients when I recruited them to participate in this research project.} During the consent process, patients learn the details of the study and are informed that they may decide to exit the study at any time. Once patients consent to participation, they meet with a dietician who discusses their eating habits and dietary expectations during the trial; they also complete a lengthy dietary questionnaire.

The men in my study were referred from the Active Surveillance Study described above. The intent of my study design was to ask patients to share the narrative of their diagnosis up to the time of our interview. In addition to asking the men about their spiritual biography, I asked each of them to provide a brief story of how they learned about their illness and whether or not that news impacted their spirituality in any way. My goal for recruiting patients was to be able to interview them while they were in decision mode. When I was writing the protocol, I anticipated that I would be able to capture prospective recruits during a period before they consented to the clinical trial. In practice, this design procedure was not feasible for a number of reasons. All except one of the patients had traveled into Houston for their clinic visits. The visits were often hours-long affairs in which patients encountered a number of possible touch points with clinical and ancillary staff, including visits to a laboratory where blood samples were taken and sent for examination, travel to another part of the vast medical complex when x
rays were ordered, and possibly a visit to the procedure suite where a (or another) biopsy was performed. For new enrollees, clinic visits were for the second opinion - to obtain a diagnosis confirming the presence of cancer. If the patient met eligibility for the Active Surveillance study, the examining physician might describe the study to them and ask whether they would be willing listen to the recruitment conversation. Finally, if the patient was African American, they met my study criteria, so the recruiter for the Active Surveillance study would ask them whether they would be willing to listen to my recruitment discussion. Each interview began with patients confirming that they met the study criteria for race and age; the clinical staff who referred the patient would have already confirmed each patient’s diagnostic eligibility. In these confirmatory questions, I wanted to ensure that the men were African American since Houston also has a sizeable black African diasporic population. I had taken care in the writing of the protocol to make this distinction given that religion, religious beliefs and practices are formed within particular cultural contexts. As I learned various types of details, I submitted modifications for approval by the behavioral research subcommittee of the clinical institutional review board.

One of the helpful modifications came as a result of meeting with in-house researcher, Robert Volk, whose focus area is decision-making – including that of patients. A portion of his research has included work regarding decision making among the Active Surveillance patient population. Volk informed me that in this population, patients’ decisions extend the moment that they sign the consent document - one of the gains of research ethics which can be linked to informed consent established within the bioethical principle of respect for persons codified in the 1979 published *Belmont*
In Volk’s experience, patients in the Active Surveillance study continued to consider their decision to participate for as long as eighteen months after giving written consent. In fact, in the consent document for my own non-invasive study, language informs prospective participants that as volunteers, they may enter and leave a research study at will. These modifications did not solve every problem with increasing the recruitment pool; however, the process taught me further how important it is to remain very close to ways to develop quality data.

Now that I have provided an overview of the data collection process, in the next section I present data that will help to shape my later arguments about what should be the focus of African American religion and health, highlighting clinical trial decision making.

Data

The data collected for this project was gathered during semi-structured interviews. Most of the interviews were conducted in person or after meeting the patient on-site. In some cases, interviews were begun in person, but needed to be completed via telephone; only one interview was conducted entirely via telephone. In this section, I first present an overview of the cohort, then findings around the two major narratives identified earlier: the Tuskegee narrative in African American religion and health, and fatalism from health research on African American spirituality in health regarding fatalism. Then I will

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289 The Belmont Report is also available on line at: http://archive.hhs.gov/ohrp/humansubjects/guidance/belmont.htm
290 At MD Anderson, consent documents are edited for research protocols by member of the consent editorial staff. Researchers provide study details for a template and editors review the language and documentation to the IRB that the consent meets the necessary requirements. “Your participation in this research study is strictly voluntary. You may choose not to take part in this study without any penalty or loss of benefits to which you are otherwise entitled. You may also withdraw from participation in this study at any time without any penalty or loss of benefits.” “Informed Consent” version 03 for 2011-0430 approved 08/08/2011.
present other data of interest. Finally, I introduce the data related to the major theme that developed: religion, risk, and research.

Characteristics of the Sample of the Study Participants

Here, I feature characteristics of the study participants as a cohort. These characteristics are important as factors that often influence affirmative clinical trial decisions, including education and insurance status. The men in this study weigh a complex set of issues related to deciding whether to participate in the Active Surveillance clinical trial. They are considering their bodies, their overall health, sexuality, relationships with the women who share their lives, children and grandchildren, the doctors who advise them, their own sense of agency, and about the relationship between their religiosity, science, and their processing of information from these two spheres of knowledge. Most of them identify as men with an active spiritual life that includes practices such as regular worship attendance, prayer, Bible reading, congregational involvement, and television ministry viewing. Their spirituality is not isolated in this complex web of considerations.

The men in this study ranged in age from 53-71. They were all married at the time of our interview, the majority to their first and only wife for an average of nearly 30 years. Between them they had an average of nearly 4 children. The level of education achieved among this group ranged from a high school diploma to a juris doctorate, with some college to a bachelor’s degree being most common. In fact, one of the older men in the sample had earned his bachelor’s degree in 1964 when just more than 5 percent of

\[\text{Charles was not married. He declined to consent as a study participant, so I have not included him as a study participant with a recorded interview. However, I have included aspects of his narrative as recorded from my field note.}\]
African Americans had earned a four-year college degree. All of the men could be described as having reached middle class – even the high school graduate and the two men who completed two years of college. The men with less education were able to join the middle class and were currently employed or retired from occupations which paid relatively high salaries. Earlier, I described that petrochemical manufacturing in the region allowed some of the men in the study to earn a substantial living. For example, Howard, a high school graduate, worked in the lucrative petrochemical manufacturing industry and was planning his retirement in the following year even though he was only 53 at the time of our interview. Each of the men in my study had given initial consent to participate in the clinical study from which I recruited them for my research.

The above demographic characteristics of the men in my study mirror those of patients who participated in an empirical bioethics research study conducted by Manish Agrawal, Christine Grady, et al. In each study, factors such as higher than average (American) education, income, and health insurance provided patients the opportunities to be recruited for clinical studies. As the Agrawal, Grady, et al study points out, the popular notion of clinical trial patients is one of vulnerability, including less education, less income, and potentially no insurance. This is certainly the legacy belief about the Tuskegee participants, and it is generally, but not universally accurate.

\(^{292}\)National Center for Education Statistics, “Percentage of persons 25 to 29 years old with selected levels of educational attainment, by race/ethnicity and sex: Selected years, 1920 through 2013” http://nces.ed.gov/programs/digest/d13/tables/dt13_104.20.asp <accessed 26 October 2014>

\(^{293}\)I am saying initial consent because during my interview with him, Xavier disclosed that he did not intend to continue with the clinical trial, but he had not informed the clinical study coordinator that he did not plan to return for his next scheduled monitoring visit.


\(^{295}\)Ibid.

\(^{296}\)Although the documentation is unreliable, Tuskegee Syphilis Study subject, Charles Pollard, is believed to have been a college graduate.
Eighty-eight per cent (88%) of the patients in the Agrawal, Grady, et al study were white; 96% had health insurance; and 51% had earned at least a college degree. Comparatively, 72% of the general U.S. population identifies as “white,” 35% of Americans have earned a bachelor’s degree, and 84% are estimated to have some form of health insurance coverage. And African Americans make up 13% of the population, 20% have earned a college degree or more and average earnings are $32,000. The men in my research study have a profile much more like the Agrawal, Grady, et al., decision making study than the men I encountered at the public health center oncology clinic. This suggests that clinical trial decision making is connected to access to clinical trials in order to be able to make such a decision. Access to clinical trials is a complex, systemic process governed by scientific study design (patients’ ability to meet the study protocol), medical diagnoses, patient health status, physician referral networks, insurance coverage and non-covered costs. These are factors and parameters beyond patients’ actual decision making, but they are important factors that point to structural issues that affect black participation in diagnosis related trials.

Besides these access facilitating characteristics, the men in my study all profess a relationship in the life of a religious (Christian) community. They report worship attendance rates from once to twice per month to two to three times per week. The majority of the patients report that they attend worship services weekly. Involvement from a number of the respondents includes spiritual leadership or high visibility in the affiliated congregation. One of them was a Methodist ministerial candidate at the time that we talked; another worked as a hospice chaplain and was a former pastor; a third had

\[\text{U.S. health insurance coverage estimates:}\]
just been named a deacon, and another served as a musician accompanying the church choir on guitar. All-in-all, based on the sociological measure of church attendance, as a group, the patients in this study would be considered highly-involved religiously.

Now that we have a picture of the religiosity of the participant sample, I will review the first key narrative – the impact of the Tuskegee narrative – taken from prominent scholars of African American religions.

Respondents’ Attentiveness to African American Religion and the Tuskegee Narrative

As identified in chapter 2, current prominent scholars in African American religion and health have pointed to the importance of the Tuskegee Syphilis Study as a key narrative relevant to the field of African Americans and health; they have each included the narrative in their religious responses to problems marked by the Tuskegee Study. In that earlier chapter, I argued that contemporary healthcare delivery supports an alternative interpretation of the Tuskegee narrative from the totalizing essentialism offered by Townes and Mitchem. I constructed the alternative to the narrative so that the cultural symbolism could be retained more fully, especially for African Americans who remain concerned about the meaning of Tuskegee as a metaphor for black treatment in the healthcare system – beyond its historical episode as an egregiously unethical medical research study.

In my study cohort, none of the patients independently raised the issue of Tuskegee or its effects, such as in the language of not wanting to become a “guinea pig.” For Howard, the idea of a clinical trial was new; he was especially unaware that there were non-pharmaceutical trials. I tried any number of ways to elicit a response about
Tuskegee; Avery’s interview best depicts the futility of these efforts to have patients in my study link their decision to Tuskegee. At first, I attempted to garner some sense of a connection to Tuskegee, by asking in more obtuse ways. For example, I asked whether any historical episodes came to mind as he was making his decision. In the end, I Avery outright referenced “Tuskegee” to which Avery provided responses noting that it is “located in the state of Alabama, the university that bears the name, that it is the home of one of the most popular rhythm and blues music groups of the 1970s (the Commodores).” He did not make any links to the widely researched sociocultural symbol of black health in the twentieth century examined in both public health research and black religious studies.

Although Avery’s representative response did not bear any link to Tuskegee, I will not go so far as to suggest that no linkages remain between African Americans and the metaphoric value of Tuskegee. A study by Hamilton, Aliyu, Lyons, et al, for example, supports nuances in contemporary African Americans’ responses to Tuskegee. They found that younger participants in their qualitative study on African Americans’ attitudes, schizophrenia, and medical research (mean age 21) were largely unfamiliar with the Tuskegee Syphilis Study, but that older participants (mean age 63) had immediate recall of the event. Prostate cancer diagnoses typically manifest at a later stage of life so it would have seemed that the men in my sample (mean age also 63) might have been expected to have attitudes more like the older participants in the Hamilton, Aliyu, Lyons, et al study on this topic. However, I was unable to coax any knowledge of Tuskegee from

298 Patient interview.
300 Ibid.
the patients in my study. It may be a factor that the Hamilton, Aliyu, Lyons, et al study was conducted in Alabama, proximally nearer to Tuskegee. So in addition to the older age of their participants, geography, that is, proximity, could have influenced their recall. (It should be noted that religiosity did influence their attitudes related to causes and intervention for the medical condition at hand, schizophrenia.)\textsuperscript{301} In addition, fear of becoming a “guinea pig” emerges in attitudinal studies about clinical trial participation by whites and blacks.\textsuperscript{302} Recall that rates of clinical trial participation is low among whites and blacks – only reaching about 5% in whites, and one-third to one-half of that rate among blacks.\textsuperscript{303} But I do conclude that “on the ground” where patients are making decisions that will impact their health care options, they are not considering Tuskegee during such active decision making. Published empirical studies measuring lingering Tuskegee effects are attitudinal studies not active care studies. Grounded in sociological methods, rather than the historical event, my study contributes a new premise for the study of African American religion and health: to query whether a new trend is emerging. To this new premise then, I have presented an alternative narrative, the cultural sociological interpretation of the Tuskegee narrative as a form of sacred rhetoric. As sacred rhetoric, the alternate interpretation affords a greater opportunity to encompass the nuance in the emerging trend.

Next, I will address how participants in my study give attention to the key narrative about African Americans and health from the field of public health research. This narrative identifies religious/spiritual influence as supporting African American

\textsuperscript{301}Ibid.
\textsuperscript{302}Murthy, et al.
\textsuperscript{303}Ibid.
fatalism - the attitude that African Americans do not believe that their actions can affect their health related to cancer.

Religiously-Influenced Fatalism and African American Men with Prostate Cancer

In the research environment observations of this chapter, I noted that in publications, a fatalistic attitude is widely ascribed to African Americans and it is connected to an African American religious sensibility. In the next chapter, I will describe the dangerous care implications of this expectation among physicians. Here, I will discuss how fatalism appears among the members of my research sample.

Evaluating fatalism among this group of interviewees requires review of their attitudes and behaviors, their words and their actions. In their narratives, the patients in this study value their sense of agency. This is demonstrated in their reports about the circumstances under which they made their decision to participate in the Active Surveillance. They indicate that their religion is a source of stability, helping them to hold steady in the decision they have made to participate in the clinical trial to which they have consented. But they want to be very clear that their decision has been made based on the science presented to them by clinician-scientists. The first finding concurs with other research that concludes that African Americans resource religion as a coping mechanism. However, the second finding on religion and medical science is a distinct area for future research within African American practical theology. The following accounts from the field research will help to illustrate these findings.

Walter made an immediate decision upon hearing about the opportunity to participate in the Active Surveillance clinical trial. At the urging of one of his daughters
who works in Houston as a nurse, Walter had scheduled an appointment at Big Cancer. He was alone the day he visited there for the first visit. Like the other patients in this study, the urologist Walter initially saw recommended surgery. Compared to the surgical option, Walter preferred the “watch-and-wait” option in Active Surveillance. Even so, he was somewhat troubled about being able to continue in the close monitoring that the study protocol provides. For one, Walter was concerned that he might soon lose his insurance coverage; he was a political appointee and his political sponsor was running for re-election.

Howard also had concerns about the continuing availability of health insurance; he wants to retire soon. Like, Walter, Howard also uses his faith as a source of support for the decision that he has made about participating in the Active Surveillance study. He had the most comprehensive sense of agency; in other words, it operates on multiple levels. Howard’s sense of agency began with his use of insurance benefits. “Men don’t go to doctors,” he said. “Some don’t have insurance. Men have the mentality that ‘I’m all right.’ I don’t see the need to go,” Howard continued. He thinks that with the opportunity (offered by insurance), more would men would go to routine doctors’ visits. He admits, “That’s how I learned to go. Take advantage of your benefits.” Unlike Walter, Howard did not decide to participate in the trial alone: “If it’s going to involve both of us, I prefer to include (named his wife).” Finally, Howard’s sense of agency is also related to the drive to have sufficient information. He used the model I had expected to hear more of the men describe based on the social theory of religion that I read in the works of Mitchem and Townes. Howard said, “The more you know, the more knowledgeable your

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304 The patient’s nurse-daughter also told him to use grape seed oil as a form of complementary medicine.
decision will be. I ask God to guide me to make the right decision. I would like to make an educated decision rather than go with the flow: what the doctor says.” His information gathering ran the gamut from the doctors’ recommendation to books to asking a number of the deacons at the church he attends. He wanted to know their experiences and to compare them against what he was learning from the other sources. “The deacons said, ‘Get it out.’ (Have the surgery.) I asked, ‘Did they experience pain? Blood in the stool? Did it affect their livelihood with their wives (sexual function)?’” Howard was aggressive in asking about the physiological, personal, and social aspects of his prospects. Unlike the expectations of the fatalism conceptualization, for Howard, his sense of religiosity helps him to assert his sense of agency in a number of ways: seeking information from other members of his religious community, taking advantage of his insurance benefits to locate additional options, and to sustain him in his decision to participate in the clinical trial and to hope that it continues to be the right treatment option for him – and for his life with his wife of more than thirty years. Howard had grown up Baptist; church attendance was mandatory until he was about fifteen years old. As an adult, Howard went to church off- and-on. He and his wife decided to return to Christianity about eight years ago. For them, it was “show time” – time for us to show God some time.” Howard continued, “We started talking about how God has been good to us so we decided to give some time (to God).”

It is difficult to determine whether Howard’s or Walter’s decisions to participate in the Active Surveillance clinical trial are motivated by its relatively low risk and the fact that it is substantially less invasive than other options presented to them. Even if these confounding factors partially explain their decisions, they still provide hints into
how African American religion is functioning psychically and socially, and that this intra- and interpersonal processing provides alternative interpretations to the widely accepted notion of fatalism in public health literature about African American spirituality and religiosity during cancer.

Now that I have identified ways that the attitudes and behaviors of this sample of research participants compare to the key narratives of African American religion and health from the perspective of scholars of African American religion in the form of the Tuskegee narrative, and the fatalism narrative in public health research, I will move on to other key findings from my study that will help me to construct what I see as missing from the scholarship on African Americans and health, with an emphasis on developing an African American religious perspective on clinical trials and experimental treatment. The first of these is how this study informs African Americans’ attitudes about the relationship between religion and scientific information.

The Relationship between Religiosity, Science, and Patients’ Processing of Information from These Two Realms of Knowledge

Religious sensibility meets medical science in the cancer diagnosis that the patients in this study are facing. This intersection may emerge during any serious disease. This calls then for a practical response that assists patients to make decisions that leave them satisfied with the choices they are able to make and/or to retain or restore a sense of personal wholeness during a situation they are unable to control. For the men in this study divine omniscience and omnipotence are at-stake.\(^{305}\) Their sense of God’s

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knowledge and power will be retained. Asked directly about how the intersection of religion and science operates in their current circumstance, these men stated that their decision to participate in the clinical trial had been driven by the medical science that had been presented to them. However, acknowledging the potential threat from cancer to their lives and lifestyles, their religious sensibilities incorporate the experience of the diagnosis and they begin to process a hierarchical and dialogical relationship between these knowledge worlds. God masters science and allows its advances. This statement differs from a religiously motivated explanation for illness; rather it expresses a willingness to sustain openness to both science and religion. This is not unlike Berger’s assertion, discussed in chapter two, that religion offers a legitimating power that helps to bring order and integrates “marginal situations” including “disease and acute emotional disturbance” and helps to make sense of these psychologically (and potentially physical) events. It is as if in their verbalizing their decision to participate in the trial their words begin to sound contradictory to the traditions of their religious beliefs. As such, nearly as quickly as the words leave their mouths, they reconstruct their thoughts about this relationship from different spheres of knowledge so that what they say better fits the traditional hierarchy of knowledge that privileges religion (as faith). Representative commentary from Walter, Bill, and Avery demonstrate this thought evolution.

Walter relished the opportunity to talk about his views related to religion and science in light of a question considering clinical trials as a form of medical science. Religion had played a “prominent part” of his childhood; growing up, he was the only child of a Baptist minister. Walter expressed strong opinions about the difference

307 Ibid, 43.
between religiosity and spirituality, and that “some religious people have these orthodox beliefs that don’t really tie in to what the spirit of God has taught us through his word.” In spite of his preference for this distinguishing term to distance himself from these sorts of “religious people” (Walter prefers the referent term “spiritual”), his view of the relationship between religion and science is very similar to that of the men in the study who affirm their deep sense of connection to the institutional church.

I feel like God is over everything. If God wants it to happen, it’s going to happen. Because of or in spite of, it’s going to happen. I feel like God has the best interest of man at heart. I also believe that science has, more or less, the best interest of man at heart because they keep improving things and coming up with new inventions or solutions to illnesses, etc. I think God is intertwined into all of that because if God didn’t mean it to be, it wouldn’t be.308

When Walter thinks about religion and science, he takes a positivist view. He believes that regardless of how scientific thought and work begin, in the end it all works for humankind, consistent with “divine intervention.”309

Bill, too, viewed his upbringing as very involved in church life; his mother was very religious and required it of her children. He described himself as having a “healthy skepticism of men of the cloth” - shaped, in part, by his having had many male relatives who became Baptist ministers.

Beginning in young adulthood, Bill expressed his religiosity as a sense of being able to rationally consider questions of faith as a way of attaining “deeper meaning.” In fact, he came to his current faith commitment in Catholicism, in part, because he wanted additional opportunities to exercise the thought-life of his religiosity, unlike in the Baptist churches in which he was involved earlier. He did not think that some of the rhetoric coming from the Baptist pulpits he frequented provided the depth he sought. Bill was

308 Patient interview.
309 Ibid.
introduced to Catholicism when he became engaged to a woman who was an adherent in the faith. He needed to convert so their marriage would be recognized by the Roman Catholic Church. His catechism lessons took place one-on-one with a priest rather than in a classroom with others. For Bill, these hours with the priest discussing the tenets of the faith were a unique, in-depth opportunity to question and to learn. He and the woman did not marry, but he continued in Catholicism. An attorney and former federal justice system appointee, Bill prides himself on the rational approach he takes to religious beliefs.

Bill also took a rational approach to locating options for his low grade cancer. His understanding of the science as detailed by the doctor led him to decide that Active Surveillance would be sufficient treatment, preferable to more intensive options including surgery. According to him, “Other than generalized prayer, as in ‘God helps me to make good decisions,’” religion did not support his decision. Similar to Walter, Bill connects his belief about the relationship between religion and science to a sense of spirituality. For him, science will eventually “swallow religion” – the institution that is the source of much violent human conflict. Spirituality will remain. To Bill, spirituality has a “realness” that religion cannot match; spirituality allows for an expansiveness that can accept work with science.

Avery’s story provides the final illustration of this decision and the pattern of the relationship between religion and science; he, too, finds religion “confining.” Avery, already a previous cancer survivor, expressed the strongest feelings about the relationship

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310 Bill also acknowledged that his social-professional connections could provide him access to another renowned cancer treatment center. He chose the center where we interviewed because it was hundreds of miles closer to his home.  
311 Patient interview.
between religion and science. His views too, are explainable as a knowledge problem, and his views come closest to describing the classic explanation of the relationship between these as two spheres of knowledge. He used science to make his decision, but he sees science as having certain limitations.

Science is science, and spirituality is spirituality. Spirituality can overlap into science, if you want it to. Science can take you as far as they can go, and once that’s over, they can’t take you any farther. They can take you…It has its place, and it’s very good… in its place. But when spirituality kicks in, and if a person is feeding into that spirituality, it can take you, I won’t say it can override science, it can add a dimension to the person that science can’t.

Not only is Avery seeing a divide between the capacities of science and religion, he is suggesting the natural/spirit split that Townes observes as the “traditional Christian theological formulation,” the “body-spirit fracture” that keeps some Christians from acknowledging the embodied experience of spirituality including Christ’s incarnation.\textsuperscript{312} Avery and the other men appear to sustain the traditional view, but decline to allow it to keep them either from decision making or from assertively pursuing treatment options that support them in sustaining their embodiment to their desire. Only time will tell, medically, whether they made the correct decision in light of their cancer potentially becoming more aggressive.

Walter’s, Bill’s and Avery’s perspectives on the relationship between science and religion suggest that their spirituality adds an affective dimension to their cognitive decision to participate in a clinical trial. We see the types of language that these African American men employ to see themselves as having expanded religiosity by naming it spirituality. Furthermore, it is affective in the sense that it sustains for them a sense of themselves, sustains aspects of their self-determined identity. This cognitive and affective

\textsuperscript{312}Townes, \textit{Breaking the Fine Rain of Death}, 172-3.
combination is consistent with African Americans’ general approach to aggressive treatments in end of life care.\textsuperscript{313} It demonstrates that while many African Americans value their spirituality these beliefs do not negate a healthy respect for medical science in spite of the well-documented racism in medicine. African American mistrust of medical systems and medical personnel is based on racism – perpetuated by humans – not upon an issue with science itself. Although views expressed by the men in my sample are qualitative and descriptive and of insufficient size to be generalizable to all African Americans, they indicate a cultural phenomenon – distinct from the access issues that drive these men’s ability to participate in the trial because they have sufficient insurance that includes one of the top cancer centers in the nation and likely the world. The cultural phenomenon provides further support for the development of an alternative reading of the Tuskegee narrative data for scholars and members of the general African American public who continue to sense a cultural purpose for sustaining and meaning in the narrative. For this reason, I have proposed a meaningful, culturally significant sacred rhetorical understanding. Based on my research, the Tuskegee narrative may continue to have cultural meaning for African Americans aware of it, but it no longer has widespread effect for individuals’ decision making during illness such as the members of this cohort.

So, Now What?

I began this chapter noting the usefulness of illness narratives from the perspective of a literary scholar for whom understanding of narrative form was both biography and humanistic coping. Written and oral illness narratives from patients and/or

care givers - professional and lay - provide clues to the inner world of persons living through illness. Arthur Kleinman provides perspective on the content and purposes of illness narrative. He is a physician whose ethnographic work about chronic illness and pain helped to spawn the academic, interdisciplinary study of health and medicine when he wrote the now classic, *Illness Narratives: Suffering, Healing, and the Human Condition*. Kleinman’s work also helps to explain the relationship between the decision, action based on the evaluation of risk, the patients in this study have made and the religio-cultural narratives that discursively surround them, such as the Tuskegee narrative in the academic study of black religion and health, – whether or not particular narratives appear in individual illness narratives – as they do not here.

Risks associated with the treatment options provided to them have been a guiding factor in their decision to participate in the clinical trial that was presented as one of those options. Kleinman writes that “laymen,” among them, patients, tend to “reinterpret” the risk (and probability) statements that doctors and scientists present into “qualitative, absolute, personalized (non-random) terms.” When patients and other non-scientists do this, they are attempting to answer the question, “Why me?,” which Kleinman refers to as the “bafflement” question. In Kleinman’s view, this is a “misinterpretation” in that it violates the scientific development and use of risk. The use of risk and statistical data in discussions with patients is intended to present information from research on the probability of development of a disease, its course of progression, probability of success with a particular treatment etc.; it is not intended to explain or predict the experience of a particular patient. In this sense, Kleinman’s observation that this is a common

layperson’s misunderstanding of “risk” stands in my research. However, I do not read these patients as misunderstanding the facts or the scientific process. It could be that in the twenty-five years since Kleinman’s book was published, patients have better knowledge of the process of risk. The patients I interviewed heard about the various risks and side effects of their treatment options and used their ability to research alternatives and excellent health care system access to seek treatment at one of the top, if not the top, cancer center in the country. Furthermore, they had the additional resources, such as the ability to schedule themselves away from work and/or the ability to travel to Houston to take full advantage of these resources.

Rather than misunderstanding the technicalities of the term risk and its role in diagnoses and treatments medical research, these patients’ descriptions reflect the issue of therapeutic optimism, the bioethical concept that patients enter research in the hope that it will provide the treatment outcome that they are seeking. In addition, these patients have incorporated their sense of spirituality by making faith statements, even when they are sometimes laced with doubt. Howard acknowledges that he prayed for good news while he was in the waiting room during his appointment to learn the results from his second opinion. He recalled that the doctor said it (the first opinion) “must have been a mistake;” the result showed only a “low grade” cancer. He says he thought, “He (God) heard my prayers.” He shared the news with his pastor who announced to the congregation that “Big Cancer couldn’t find any cancer,’ and everyone cheered.” The details of Howard’s recollection conflict Kleinman’s assertion. Howard and the other patients are not seeking the answer to medicine’s question: “What can be done?” Instead, they have blurred the lines between medicine’s question and their own agency to ask,
“What does this mean to my faith?” and “What can I do (to help medicine do what it can do)? Howard and his experiential companions are seeking to know something in the existential realm, and the existential is agential, thus challenging notions of black cancer fatalism. Cancer, illness, especially one that is life threatening can generate both questions. I disagree with Kleinman that these questions are so cleanly separated one from the other. Without any sense of confusion, the patients in this study were comfortable acknowledging both sets of questions, and they accommodate both into their sense of spirituality. Kleinman saw this relationship in this way: “Suffering is not easily put aside by biomedical science; it remains central to the experience of illness, a core tension in clinical care.” For the men in this study – and informed patients more broadly - access to both biomedical science and spirituality for their prospective suffering is a core sense of hope, not a core tension.

With this hope function operable, the standout data from this study has been these patients’ engagement with another of Kleinman’s observations: risk. The theme of risk arose without prompting. For example, when I asked Howard about his impression regarding clinical trials before he assented to one (the Active Surveillance study) he responded that he “thought a clinical trial was an experimental drug or something.” During the informed consent process, he learned that there could be risk in over treatment of low grade cancer. Howard noted that he was therefore attentive to what in the language of bioethics would be termed his autonomous option to end his participation in the study “if anything goes wrong.” Howard admitted he was continuously revisiting his

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315 Kleinman, 30.
316 A high grade cancer is one which is more susceptible to spreading to other areas of the body. National Cancer Institute at the National Institutes of Health. “Prostate-Specific Antigen (PSA) Test” http://www.cancer.gov/cancertopics/factsheet/detection/PSA.
decision to remain in the study, including when we spoke. His decision to move ahead
with surgery is related, in part, to his concern as to whether he will have health insurance.
Although Howard is only 52, he is planning to retire soon, and doesn’t want the cancer to
be considered a pre-existing condition when he moves to a new health insurance plan.
Howard (as was true of other respondents) undertook the risk of the study because during
the consent process they were informed that they could end their participation at any
time.

Conclusion

In short, spirituality indirectly influenced these African American men’s decisions to
participate in the Active Surveillance clinical trial. The Tuskegee syphilis study is not a
consideration for them historically or as metaphorical narrative. These men are focused
on the practical matter of making the best decision they can with the information
available, and employing their spirituality as reinforcement for the emotional, and where
in community, social support for their decisions. Each of the men in this study learned
that he had prostate cancer during routine recommended preventative medical care paid
for through health insurance. Between them, they have gained the information they need
for decision making through medical opinions, research via the Internet, and talking with
other men who have had the experience, including men in their religious community of
affiliation. Through it all, they remain hopeful that they are making the correct decision
for themselves and their family. They steady themselves in their hopefulness through
their faith and by knowing that the risk that they have undertaken can be reversed if they
decide that they want to take another course of action.
Chapter 5

The Anatomy of African American Religion, Medical Research, and Risk

In this chapter, I construct a sociological model of risk and risk-taking as it relates to African American Religions. I do this by engaging the emergent theme from patient interviews with the primary writers in African American Religion and health and with sociological theories of risk. First, I fully explore risk as the central theme that emerged from the interviews collected to generate primary data for this dissertation research and that connects spiritual faith and scientific understanding - the two interrelated knowledge worlds that ground the health care decisions of the men in the present study. In the last chapter, I noted that the men in my study accept the risk to participate in a clinical trial related to their cancer diagnosis. They reach their decisions to participate in a clinical trial by seeking out information about prostate cancer and treatment options. They consider participation in the Active Surveillance research study as one among various treatment options posed to them. They state that knowledge of the scientific content of the risk involved was a key factor in their decision among the options, and their language indicates that they employ their faith as a means of providing themselves assurance regarding their decisions. Using the language of bioethics, it is implied that they have weighed risks and benefits and have determined to move forward seeing the potential for the trial as providing the opportunity for more benefits than burdens, more beneficial than risky. Besides holding religious faith and life as a value to them personally, several of the
men make statements indicative of a sense of altruism – a well-documented factor in attitude studies of African American willingness to participate in clinical trials.\textsuperscript{317}

I link the use of faith as a moral component of risk perception and acceptability using the work of Mary Douglas and Aaron Wildavsky. In her 1985 analysis of risk perception and acceptability, Mary Douglas noted that little attention had been given to the moral components of the sociological risk discourse. In religion and health literature, the concept of risk has been linked with behaviors that threaten excellent health, such as smoking and substance abuse. For example, using Durkheimian theory, Julie Ford and Charles Kadushin compared doctrinal beliefs with moral community involvement as factors among religiously identified persons who avoided the risk of alcohol dependency.\textsuperscript{318} They concluded that for blacks, higher levels of social integration with a moral community (which they measured as church attendance) accounted for the majority of avoidance of risky behaviors whereas for whites, a doctrinal objection to the use of alcohol was more of a contributor to avoidance of this type of risk.\textsuperscript{319} Their study suggests risks as dangers, behaviors to be avoided. But risk taking may also yield benefits. Consider, for example, investments as risk taking - risking the investment of one dollar (or some larger sum) in order to earn the benefit of additional dollars over and above the original dollar – the gain of economic benefits. Of course, the original investment sum could also be lost. Similarly, in medical research, risks may produce dangerous outcomes, but may also offer distinctly beneficial ones; clinical trial

\textsuperscript{317}Steven Epstein also documents altruism as a factor influencing African American decisions to participate in clinical trials. See Steven Epstein, \textit{Inclusion: The Politics of Difference in Medical Research} (Chicago: University of Chicago, 2007).


\textsuperscript{319}Ibid.
participation ascertains the difference. My study seeks a further distinction: to develop discourse that shows the use of religion linked to risk when the concept of risk acceptance and risk taking is weighed against the potential for benefit related to physical health where a harmful diagnosis has been identified. In my study, then, religion linked to risk as benefit is connected not only to individual and/or social benefits, but to the affective and cognitive structures within African American Religions.

To move toward such a theoretical understanding of risk, I first reiterate the context of the emergence of the theme then provide an overview of the sociological theorists who have shaped the discourse by providing various models that present an opportunity to explore the topic from a social scientific perspective for its usefulness when coupled with religion. I then explore implications of these connections for African American religious scholarship more broadly.

Risk: Emergence of the Theme

Having approached my dissertation research as a grounded theory project, the term “risk” emerged as an unsolicited, recurring theme in the data. In retrospect, this makes sense as the language and reality of “risks and benefits” looms large in the milieu of clinical trials. Within the principles and practices of modern standards of the ethical conduct of research with human subjects, disclosure of the risks and benefits of clinical research are an essential condition of a normative ability for patient-participants to make autonomous decisions. Beyond an egregious research design, a serious ethical failure of the health professionals involved in the Tuskegee Syphilis Study was that their refusal to disclose that they were conducting a research project and the risks involved with that

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research deprived the research subjects afflicted with syphilis (as well as members of the
control group who did not have an active case of syphilis) of the ability to make informed
decisions about their participation.\textsuperscript{321} More important to my longer-term research agenda,
the emergence of the risk theme fits one of my aims -- to learn how African American
religious content and perspectives expands by incorporating ideas and experiences related
to social and cultural innovations. Engagement with literature as well as primary research
in religion and health related to African Americans provides such an opportunity. There
is a small body of literature in religion and health that focuses on African Americans.\textsuperscript{322}

Much of this literature has been produced by health researchers and sociologists. A
careful reading of the literature review conducted by Ellison, Hummer, Burdette and
Benjamins concerning the connections between religion and mortality, mental health, and
physical health point to a mixed picture.\textsuperscript{323} On the one hand, religious involvement and
religious practices can help African Americans promote health through diverse activities,
from participation in preventative health measures to the avoidance of risky habits such
as smoking and alcohol abuse, and even higher use of seat belts.\textsuperscript{324} On the other hand, the
healthiness of some of the mechanisms of religious involvement that may result in
favorable health outcomes is debatable. For example, religious teaching can influence
these behaviors through the promotion of guilt feelings, fear of divine retribution, and
conformity to specific norms based on wanting to avoid social sanctions such as

\textsuperscript{321}The design of the study was to deny care to the men with syphilis so that autopsies could be
performed on their bodies. See Jones, \textit{Bad Blood}; Reverby, ed., \textit{Tuskegee Truths}.
\textsuperscript{322}Christopher G. Ellison, Robert A. Hummer, Amy M. Burdette, and Maureen R. Benjamins.
“Race, Religious Involvement, and Health: The Case of African Americans” in \textit{Religion, Families, and
Health: Population-Based Religion in the Unites States}. Christopher G. Ellison and Robert A. Hummer,
\textsuperscript{323}Ibid, 325-339.
\textsuperscript{324}Ibid, 324-5.
ostracism.\textsuperscript{325} It may not be possible to identify predictive values related to religion and health, but it appears possible to develop messaging that promotes behaviors that will be constructive in the case of health. Moreover, and perhaps long-term for my research agenda, understanding the content and mechanisms of the links between African American religious experience and behavior could contribute to motivating individuals and collectives in various progressive activities. This deeper understanding might suggest conditions under which risk might be accepted, such as among the majority of patients in this study. Other ways to think about this concept may be described using wording through various schema relevant to the discussion: rather than risk acceptance, risk might function as a (socially) protective, (individually) existentially conservative force, or, as a risk avoidance mechanism. This understanding contributes nuance to discourse in the psychology of religion that has identified religion as influencing coping among African Americans (as well as the elderly, the less educated, widowed persons, persons of low income and women) at a comparatively higher rate than that of whites, (persons with more education, higher income, men, etc.).\textsuperscript{326} Pargament also speculates religion is often an accessible resource among these groups – more accessible than other types of resources such as adequate health care or monetary stores.\textsuperscript{327} Stated differently, risk as a category of analysis can explore how religion among African Americans, at the individual or collective level, accepts and incorporates or grows to include some aspects of cultural phenomenon and repels or excludes others. Christian ethicist Cheryl Sanders has written that in 2001 97% of black postal workers exposed to potential anthrax

\textsuperscript{325}Ibid, 324.  
\textsuperscript{327}Ibid.
poisoning refused a U.S. government antidote due to historical mistrust combined with their trust in God’s capacity to protect them against the same substance that killed two fellow workers.\textsuperscript{328} The workers were unwilling to risk an untrustworthy government over a trustworthy divine figure. Even if coping accounts for the decision of the 97\%, there are lessons to be learned from the 152 of the 5,100 postal workers who chose to accept the anthrax vaccine since coping practices can differ so widely.\textsuperscript{329,330}

Jens O. Zinn sees the conceptualization of risk as “interdisciplinary” and “heterogeneous,” and “tied to the possibility that the future can be altered – or at least perceived as such by human activities.”\textsuperscript{331} Zinn’s assessment of the field allows for various approaches to the study of risk. Just as I began my research project within sociological conceptualizations of religion, I begin my investigation of the heterogeneous models of risk likewise.

Sociological risk literature offers the opportunity to expand African American religious scholarship by enhancing the exploration of the cognitive and affective conditions of collective agency within particular types of embodied circumstances. It provides another lens through which to interpret time/space activity outside a historically contingent anticipation. For these theorists, risk is a “universal”\textsuperscript{332} category of

\begin{itemize}
\item \textsuperscript{329} Ibid.
\item \textsuperscript{330} Pargament includes a list of twelve coping methods located in the literature: cognitive restructuring, problem solving, tension reduction, social skills, self-disclosure, structuring, seeking information, stress monitoring, assertiveness, avoidance/withdrawal, suppression/denial, and self-medication. Pargament, 107.
\item \textsuperscript{332} The term universal relative to the study of risk in sociology is taken from Niklas Luhmann. See Luhmann, \textit{Risk: A Sociological Theory} (Berlin: Walter de Gruyter, 1993), ix-x.
\end{itemize}
modernity. Some of this literature also confirms a related term, uncertainty, which is connected to the conceptualization I wanted to explore in a theoretical understanding and interpretation of this theme from the patient data, and want to explore in African American religion broadly.

Anthony Pinn has critiqued the notion of certainty that African American religion purports to offer. In response, he has constructed a black humanist theology that declines to include the certainty that life does not offer. Pinn’s proposal is consistent with his on-going, well-defined project to expand the examination of African American non-theistic expression as one among the diverse expressions of culturally based spirituality. Even as I can agree with Pinn that the ultimate goal will be to protect the stability of God, my agenda is to expound upon ways in which African American religious sensibility influences responses relative to issues of certainty and uncertainty. I work from where the majority of adherents are – in Protestant denominations. I grant that there is a significant range of individual responses to these issues and that the pattern of response from a large number of adherents may unconsciously restate mainstream beliefs of Protestantism. But in practice many adherents do make choices that do not appear in

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333 Rather than identify them here, I will expound upon how each of several sociological risk theories in the next several pages.
337 Pinn has developed this argument across several of his works. For example, in Moral Evil and Redemptive Suffering: A History of Theodicy in African-American Religious Thought, he compiles black moral thought on the subject of suffering. The introduction to the volume includes the observation that “…several forms of theodicy have emerged during the course of African American religious history. A small percentage of African-Americans argued for atheism or humanism because of moral evil.” See p. 7. See also Pinn, Varieties of African American Religious Experience, (Minneapolis: Fortress Press, 1998), 154-185.
strict alignment with the stated beliefs of their faith. My addition to this discourse is that I observe how adherents meet uncertainty as a challenge to their faith with considerations of the risk involved. For example, Mary Douglas and Aaron Wildavsky recurrently use the term “uncertainty” as they develop the background for their arguments about a cultural approach to risk.\textsuperscript{339} Given the emergence of this theme, I wanted to examine it more closely to consider what it means to this cohort of patients. As active cancer patients and as lay persons, the men in this study focus on the potential outcomes of risk, and in this case, uncalculatable risk or risk-taking, for them. Risk involves the possibility of dying from the prostate cancer with which they have been diagnosed. They are concerned about risk as a sense of their vulnerability in submitting to various treatment options – of which one is the clinical trial. Risk also refers to their doubts, and that they may experience detrimental effects on their quality of life – whether or not a treatment rids their bodies of cancer. The decisions they make about treatment, or non-treatment in their study, affect all of these potential outcomes. Beyond the individual responses of the members of this study cohort, I also wanted to understand the meaning of risk and risk-taking in relationship to faith and religious scholarship. For this, I use selected aspects of what this active patient population can provide to the expansion of the risk discourse and African American religious scholarship. I use these sources in order to understand, describe, and interpret how risk is incorporated into the scholarship and praxis of African American religion, with Christianity being the focus here, and how risk may be a proxy for my interests in innovation and uncertainty since these seem to me natural discussion

points for terms such as “faith” especially as linked to religious “belief.”

I wanted to know if and how faith as African American religious expression engages the idea of risk as a generative act. What, if anything, does African American religious studies promote about risk? And is there an obligation on the part of African American religious studies (and African American religion) as a cultural “system” to give and or continuously expand the capacity for self-determining or liberative activity? Finally, what, if anything, can we use from the risk discourse about black embodiment for the engagement of religion and health? To identify a level of risk-taking connected to faith, suggests something about both the relationship among these men and the divine that they worship as well as their sense of agency related to their illness. Both of these areas extend current research and thought in health literature that studies attributions of fatalism and locus of control among African Americans.

Sociological Risk Discourse

At least since the 1980s, sociologists and other social scientists have been writing about and theorizing risk as an analytical category. How each of them constructs their theory of “risk” varies; however, each theorist views risk as a form of danger or threat. For many of these early sociological risk theorists, the danger they wanted to address focused on the destructive threats to humanity from environmental concerns, industrial accidents, nuclear power and nuclear armament and the social implications that might be drawn from the potential for disaster should any of their concerns come to fruition – as

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340 Here I am referring to one branch of the disciplinary juxtaposition of religion as oppositional to science. This can be seen in the language of religion such as in the term “belief” against that of the language of science, such as in the term, “proof.” Or in the parlance of Ian Barbour (and centuries of other thinkers) the epistemological approach of revelation versus reason. See Ian G. Barbour, Religion and Science: Historical and Contemporary Issues (San Francisco: HarperSanFrancisco, 1990), 6-7 and 24-25.
some of them had in the late 1970s and 1980s. In this section, I introduce key elements from several prominent early sociological risk theorists. I present these theories in order to demonstrate the issues associated with analyzing risk-talk among patients in the current study as well as how the academic risk discourse might converge with African American Religions, especially as relates to religion and health. Ulrich Beck, Anthony Giddens, Niklas Luhmann, Mary Douglas, and Aaron Wildavsky, working as solo authors and as various groupings of collaborators, produced some of the earliest and enduring social theories of risk. Besides considerations of the equal-opportunity dangers of their day, another dimension of portions of this literature was developed to provide an analytical lens through which to examine and critique the role and impact of knowledge, especially of a scientific nature. In one form or another, these theorists share their interest in exploring risk as a category for analyzing the relationship between the individual and society since the Enlightenment – the age referred to as modernity. The sociological risk discourse provides a range of associated terms that I introduce here, and explain below, along with the theorist who uses the term in his or her work. Terms and concepts of interest will include “ontological security,” “tradition,” “reflexive,” “institution,” and

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342 During my research I noted that a canon of sorts had developed in the sociological theories of risk. David Garland offers a helpful essay that outlines the array of ways that risk has been studied across practical and academic disciplines. See David Garland, “The Rise of Risk” in Risk and Morality. Richard V. Ericson and Aaron Doyle, eds. (Toronto: University of Toronto Press, 2003): 48-83. Deborah Lupton has offered an excellent analysis of the sociological field of risk then applies risk as an analytical category for other social issues. Her volume is most helpful to the reader who is familiar with the primary texts she is referencing. See Deborah Lupton, Risk (London: Routledge, 1999).

343 I am using the risk-talk here in anticipation of placing it future discourse with the theology and religious studies as “God-talk.” Anthony Pinn, for example, uses the term to refer to theology.
“governmentality.” Given some of the analysis that has endured from these early theorists, it is also worth noting that these scholars were constructing their risk theories as contemporary concepts were unfolding - concepts such as globalization and post-modernity, as they are discussed in the humanities today.\textsuperscript{344} For example, in the “risk society,” Beck identifies the polar and divergent ways that sociologists were beginning to perceive post-modernity with some thinkers seeing postmodernity as the response to hegemonic scientism while others were concerned about its suggestion of individualization and relativism rather than deference to social institutions such as the family.\textsuperscript{345} Broadly, the parameters of the sociological concept of risk include: who identifies risks (as danger), who calculates the extent of risk, who is at risk and from what are they at risk; through what media (e.g., forums, knowledge distribution channels) are these risks communicated; who has power to distribute knowledge about risk; and who interprets risk to experts outside a particular risk application and, most importantly, to lay persons. In the following pages, I provide a brief summary of the theories and theorists who have outlined these parameters.

Ulrich Beck’s primary concern is to develop a thick description of the risk society, and its impact on social relations. His immediate application is the destruction of the global environment and the manner in which these harms are enmeshed within social behavior, trans-national political responses, and knowledge rhetoric.\textsuperscript{346} Each of these requires a bit of unpacking before I discuss them for their application to my problem at-

\textsuperscript{344} As an example, I am thinking here of the term postmodern – now frequently thought of in short hand for a meaning such as relativistic. However, this short-hand was one of many ways in which the term was being used.


\textsuperscript{346} Ibid.
hand. Beck approaches his explanation largely through analogy to the nineteenth century and twentieth century industrial age. To him, life is materially focused during the industrial age. Risk was often analyzed as class-based with individuals unable to provide for themselves materially. Poverty and hunger, which went along with class, were likely to be life-long. Social processes during the industrial age focused on problems of materiality – producing it, gaining it, and avoiding scarcity. By contrast, in the late twentieth century when Beck was writing his theory of modernity, there are potential risks even in wealthy societies, and it is the very threat of harms and one’s inability to autonomously avoid these threats that make for a risk society. In the risk society, harms such as nuclear threat and air pollution are distributed “universally.” “[Risks] are ‘piggy-back products’ which are inhaled or ingested with other things. They are the stowaways of normal consumption. They travel on the wind and in the water. They can be in anything and everything, and along with the absolute necessities of life – air to breath, food, clothing, home furnishings…” They have an “equalizing effect.” This is not to say that class is non-existent in the risk society; rather, it can be (and often is) cumulative. The types of widespread risks of the risk society “seem to strengthen, not to abolish, the class society.” Still, widespread vulnerability to risks that cannot be contained by one’s nation-state is not equivalent to “risk position.” “In risk positions…unlike class positions, quality of life and the production of knowledge are

347 Beck, Risk Society, 52.  
348 Beck, 19.  
349 Ibid, 52.  
350 Ibid. In the early twentieth-first century, some might update Beck’s concerns with the term “climate change.”  
351 Ibid, 40-41.  
352 Ibid, 36.  
354 Ibid, 35.
locked together.” Beck suggests that there is also a way in which the risk society is also the information society. Access to information does not protect one from risks, but may allow an individual in the risk society to participate in ways to structure knowledge, which, in turn, provides access to its benefits including both tangible profits (for example, from investing in firms that can take advantage of laissez-faire industrial control regulations) or even the distribution of knowledge, such as through mass media. The capacity to structure knowledge alludes to Beck’s assertion that in turn, this capacity affects a new “antagonistic” relationship between those who “produce risk definitions and those who consume them,” those who “are afflicted by risks and those who profit from them.” Under the industrial society, “need” holds together the interests of the masses; in the risk society, anxiety is the social glue. Whereas avoiding material lack or scarcity was a significant goal in the industrial age, in the risk society anxiety can point to a lack of action: “preventing the worst; self-limitation is the goal which emerges.” But the threat or danger does not have to be concrete; the mere possibility of a threat is sufficient to ground the anxiety of the risk society. Succinctly, for Beck, “risk may be defined as a systematic way of dealing with hazards and insecurities induced and introduced by modernization itself.” So does this cohort of patients or any pattern of experience or thought identified in African American religious scholarship demonstrate a systematic way of dealing with hazards and insecurities related to modernity such that participants achieve benefits, material or otherwise, when it comes to health?

355Ibid, 55.
356Ibid, 46.
357Ibid.
358Ibid.
359Ibid, 49.
360Ibid.
361Ibid, 52.
If one accepts Beck’s premise that the post-industrial age has given way and that the next epoch of modernity is the risk society and its sociological effects, this conceptualization provides a means of interpreting one aspect of my cohort’s analysis of risk. Most of the patients quite consciously acknowledged their capacity to end their participation in the clinical study at any time that they might change their mind and for any reason. They understood this as part of the process of having been duly informed of the risks and benefits, and as indicative of their rights as (research) subjects. As I have stated elsewhere in this dissertation, informed consent and autonomous decision making are key provisions of bioethics. Informed consent and autonomous decision making were key aspects of the ills of the foundational Tuskegee case. The men in that study were not informed that they were part of a study, much less that the ultimate intent of the study was to deceptively give the impression that they were receiving treatment for their diagnosed syphilis. The bioethical secular process also points out the divergence in their use of knowledge separated from a direct sense of religiosity, even for the most self-identified religiously grounded men in my sample. These men are not encumbered by their choice, rather they feel empowered by the information they have and feel aware of the risk even though, as is true of their treating physicians and the clinician-researchers, they are unable to determine the future turns that their prostate cancer might take. They are depending on probability statistics (that the cancer will not rapidly grow), and the use of technology in routine monitoring to keep them informed as to whether a change of course will be needed in order to remain as healthy as possible. But for Walter, Howard, and Avery this is also where religiosity makes its parallel connection.

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Beauchamp and Childress, 101-110, 120-125.
Walter clearly describes his view of the linked process between his decision to participate in the trial based on probabilities, the routine clinical monitoring built into the study design, and his religious sensibilities. When he is tempted to stop communication with God about his decision (to participate in the clinical trial), he turns to God to sustain him in his decision based on the science. Howard, the most active knowledge seeker through his religious-social network, used his faith to sustain his decision and the image of himself that he wanted to retain – something he did not feel he would be able to do as effectively if he changed his mind and chose the surgical option. It should be acknowledged that it may be that all of the men may be attempting to avoid the most invasive option – surgery. Their faith becomes important to them as they are uncertain as to what treatment decision is most risky. Here is also where I return to one more aspect of Beck’s conceptualization of risk. Those who have most access to participation in modern knowledge structures are the most afflicted \(^{364}\) and, further, in the risk society, sociological activity is a move from social organizations and institutions toward individualization.\(^{365}\)

How was this borne out in my research cohort? Before entering the project, I anticipated that study participants’ behavior would follow Howard’s pattern of seeking answers from within the social group – in his case, his religious community. While this was his initial effort, he soon reverted to the pattern of the other men by looking for information on his own. The effect of his religious community pointed to the avoidance of the risk of the trial (although risks were also associated with the surgery that most of his religious community “consultants” underwent. Instead, Howard as well as Bill and


\(^{365}\)Ibid, 87.
Walter, struck out on their own to get the best answers they could to their questions – akin to Beck’s argument for both individualization and knowledge production through inquiries. In this way, according to Beck’s notion of the afflicted, consciousness of risk spreads most to those who are among the best educated, and who have sought to inform themselves.

A few more of Beck’s arguments are applicable in the current study. For one, as has been noted, the men in this study have achieved a level of education (and income) above that of the majority of African Americans. Educational achievement may be a proxy for a higher level of participation in the information society. Approximately, 20 per cent of African Americans have earned a bachelor’s degree. Comparatively, all but one of these men have earned a bachelor’s degree, and six of the eight participants in this study have earned a four-year college degree or more, with half of the six having been educated beyond the four-year degree. As I noted above, this high degree of educational achievement across this (small) sample mirrors that of participants in the Agrawal, Grady, et al study of which slightly more than one-half of those patients had earned a college degree or more education (compared to 75% of the men in my sample.)

I have already detailed that a number of the men (or their respective partners) sought to educate themselves in order to weigh the risks of the Active Surveillance study and the various treatment options. It is the consciousness of their decision, the inability to

366 Beck, Risk Society,
367 Ibid, 53.
368 Ibid, 46.
be able to predict whether they have made the correct decision, held in place by their faith that emerges as the relationship between faith and risk for the men in this study. The men use their faith to stabilize their decision rather than that their decision is a direct outflow of faith or of religious sensibility; science and faith work together, albeit indirectly. Charles makes this clear when he responds that his faith “indirectly” influenced his decision making about participating in the trial. Harold sees a closer relationship between his faith and the medical science about which he is making decisions: “I think it’s all about science as far as the doctors and medication. I pray that God directs the doctors as far as what is good for me. You can take all the medicine you want, but healing comes from God. The end result depends on what God has in store for you.” This two-sphere knowledge processing approach with (medical) science and religion governing different spheres of life and truth was common among the men, none of whom had a science background, as was their hierarchical ranking of the divine above science. And in the interview with Walter, he said he would describe his spirituality as related to his diagnosis and his participation in the trial by saying that “God is in control. Point blank;” adding, “I am and I try to adhere to the word of God. And when I do, things work out fine. If I stray, the Lord has to (makes thumping noise). I say, “Excuse me, Lord,” and get back on track.” Walter goes on, “It’s kind of like, okay, God has got this under control, and then my paranoia comes in and starts flowing away from God. But that doesn’t last long because you pull it back in. God is still in control. It’s going to be all right.”

372 Patient 001 interview transcript.
373 Ibid.
I’ll mention one more prospective connection to Beck’s theory of risk that could emerge from the primary data or previous African American religious scholarship related to healing and health. Beck speculates that in the *risk society* one would expect a new type of socio-cultural or political arrangement to form – one based on the “commonalities” borne through risks. For Beck, the socio-cultural arrangement based on commonalities could form new social movements; the political arrangements could be citizens’ groups. For this aspect of Beck’s sociological approach to risk to bear out, the evidence should surface in the examination of my categories of source material listed above. Appealing to Mitchem, she sees “African American folk healing…embedded in black religious life, art, social activism, and marital relationships.” She also sees this healing “(operating) in black communities as both individual and communal practice, with attitudes ranging from revulsion to reverence.” Within her description, social activism would be the aspect of Mitchem’s healing definition where the commonalities could emerge. Allowing for only the broadest efforts at inclusiveness from Mitchem’s examples one could conclude consistency with Beck’s sociological theory of risk that commonalities would produce new political movements. Specifically, Mitchem states that “folk healing reflects black cultural changes born of the civil rights, feminist, and Black Power movements.”

Mitchem’s text largely focuses on various expressions of physiological and emotional healing. However, in one chapter, she highlights the socio-political work of seeking reparations and reconciliation based on past systemic abuses against African

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375 Ibid.
377 Ibid.
Americans.\textsuperscript{379} She features the work of the National Coalition of Blacks for Reparations in America as a contemporary example, but she notes that the call for reparations for black enslavement and post-Emancipation disenfranchisement are not new.\textsuperscript{380} So, in this sense, it is questionable as to whether this social activism fits Giddens’ perspective of the new forms which he suggests will emerge in modernity’s \textit{risk society}. For this, black activism would be pushing for expansions rooted in the black epistemologies that Mitchem highlights throughout her text on healing. These expansions would locate a collective response to accepting a threat or interpreting one’s epistemology in a way that expands the collective. Mitchem comes closest to this in the Betty Price story. Price’s original plan to do nothing while waiting for God’s healing results in a tumor that began to protrude from her side. Eventually, Price expands her theology and articulates a belief that God is able to operate through the surgeon whose cures she previously declined. But as Mitchem outlines the story, Price’s view is as an individual rather than collective activity. No new collective, political activity forms from her expanded theological perspective.

With that, I turn to Townes to look for the new socio-political movement that Beck anticipates as a result of response to the \textit{risk society}. In her social ethical approach, Emilie Townes’ perspective argues for a communal address, first in a lament through socially engaged identification of the problems associated with health care, then in repentance by creating culturally derived, community based solutions. On the surface, it would seem that Townes’ construction in collectively turning from failure to take responsibility for providing care to all would fit Beck’s aims. However, upon closer look,

\textsuperscript{379} Ibid, 110.
Townes’ social engagement is not the new political organization that Beck suggests will be the outcome of new-found commonalities laid bare through circumstances of risk. She has connected her lament to the attitude of hope and she has rooted her construct on the turn from despair in Jürgen Moltmann’s *Theology of Hope.*

In hope, Townes conceives the edges of risk theories; but risk taking goes a step beyond the attitudinal shift where she stops. The evidence of Townes’s approach toward risk lies in the final pages of *Breaking the Fine Rain.* There she says that “hope is far more than optimism” and that “it moves beyond images and constructions of fatedness.” Furthermore, “hope is based on possibilities and promises. Ultimately…God’s promises to us.” Her strongest language is the call to eschew “the rhetoric of victimization,” and in a poem she has penned to end the book, she references Tuskegee and that “doing love and justice” through faith means not accepting structures such as  “inadequate clinical trials…unaffordable health care, [and] unattainable [health] insurance.” Townes wants hope to become more than attitudinal. Yet in her urging, she metaphorically walks up to the line of risk and the engagement of risk theory. Now, nearly a decade and one-half after her monograph was published, the field of African American religion and health needs to go to the next step and appropriate an activity based risk acceptance and risk taking perspective as a question of faith as well as a matter of academic religious inquiry, even while continuing to seek health justice via full access to the benefits of America’s healthcare system. It also evokes embracing the reality that some of the notions of black resistance or hindrance to full engagement in the

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381 Townes, 182.
382 Townes, 183.
383 Ibid.
384 Ibid.
385 Townes, 184.
medical treatment and research enterprise have been sociological and that this history
does not need to dictate the future. In other words, acknowledge the history; look back -
for the lesson, not for the recurrence of the incident. This may, in part, explain why the
past, represented in the historical Tuskegee narrative, is not an utterance in the responses
of these men. Its narrative and meaning can remain even as its lived experience fades
with each successive generation of African Americans who may choose to enter clinical
trials, absorbing the consequences of their agency. These men are not looking to the past;
they are looking to the future. Culture is dynamic, as is the ever-moving cycle of life and
death.

The next sociological risk theorist, Anthony Giddens, offers an extension of the
concept of time related to risk. In his text Modernity and Self-Identity, Anthony Giddens
discusses modernity as a post-traditional, globalized risk culture in which experts and lay
persons intentionally act to organize and reorganize their lives around risks they
encounter or potentially may encounter. 386 In composing his theory of modernity and the
existential issues relevant to it, Giddens explicates parameters such as the sociology of
knowledge, risk, time (and space) orientation, and the role of institutions in the interplay
of these concepts with individual persons. 387 In modernity, as opposed to pre-modernity,
lay persons can access expert knowledge.

Acting to one’s benefit in modernity is often a matter of adequately responding to
sets of counterfactual knowledge produced by “experts” who are acquainted with
substantial amounts of specialized knowledge. 388 In pre-modern cultures, knowledge

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held by experts was esoteric - available to and through only a few. Furthermore, low literacy meant that shared expert knowledge was spread through symbol systems and activities (think rituals and ceremonies). In contemporary, modern societies, expert knowledge is much more accessible, and is accessed via various types of technologies. Giddens acknowledges that differences such as ethnicity, gender, and class are factors of inequality that produce “differential access to forms of self-actualisation and empowerment.” Giddens does not investigate these various technological phenomena that impact these differentiating factors nor does he apply his theory to these factors. I will not address it here; however, I do wish to note that technologies and these and other differentiating factors, including stigma, impact the role and function of spirituality, religion, and religious community.

Giddens begins with the basic unit of society, the individual human, then builds up to his sociological theory; he does this because he thinks that it is in institutions where the use of knowledge is “regularized” or regulated – in this case best understood as the process of identifying and deploying analytical categories relevant to one’s life. (At this point, it is irrelevant whether the categories are internally or externally controlled.) He starts by employing select psychological language and theory to explain the construction of the self with regard to ontological security. Early in life most humans gain a sense of trust through their relationships with care givers. This sense of trust figures prominently in the ability to sustain a sense of ontological security. Trust, Giddens argues, acts as

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389 Ibid.
390 Ibid.
391 Ibid.
392 Ibid, 6.
393 Ibid.
394 I will say more about this in the conclusion to this dissertation.
395 Ibid, 3.
“emotional inoculation against existential anxieties – a protection against future threats and dangers which allow the individual to sustain hope and courage in the face of whatever debilitating circumstances she or he might later confront. Basic trust is a screening-off device in relation to risks and dangers in the surrounding settings of action and interaction.”

Giddens’ aim is to develop a theory of modernity and risk is a central component thereof. To work toward describing one’s orientation to risk, Giddens begins by explaining that the development of such an orientation is shaped culturally and socially adds to one’s sense of trust. Trust is learned in each person’s earliest relationships with care givers, and can also be thought of as the opposite of a sense of abandonment or loss. The self forms within this framework of trust and contributes to one’s “ontological security.” To be ontologically secure is to live in a sort of “taken-for-granted state.” A taken-for-granted state is facilitated by “bracketing” existential aspects of life including “big questions” such as time, space, continuity, and identity.

For Giddens, part of being human is to be in a near constant state of knowing what one is doing and why one is taking part in a particular activity. Giddens’ initial psychological framing is grounded in the trust relationships humans learn early in life. “As a general phenomenon, anxiety derives from the capacity – and, indeed, necessity – for the individual to think ahead, to anticipate future possibilities counterfactually in relation to present action.” This need to have a sense of the future runs counter to the very act of

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396 Giddens, Modernity and Self-Identity, 39-40.
397 Ibid, 46. For these theories, Giddens points to thinkers such as Erik Erickson, D.W. Winnicott, and Wittgenstein
398 Giddens, 3.
399 Ibid, 37.
400 Ibid.
401 Giddens, Modernity and Self-Identity, 35.
402 Giddens, Modernity and Self-Identity, 46.
403 Giddens, 47-8.
making a decision about one’s health care including a clinical trial; there is an inherent
degree of anxiety. How one might be oriented to deal with such anxiety points us to
Giddens’s next step. There he concentrates on institutions and how they impact each
person or the ‘self’ in society; the institutional focus makes his examination sociological
not psychological. Similar to Beck’s argument that risk in modern society impacts the
individual’s relationship with traditional institutions, Giddens’ argument speculates that
traditional institutional arrangements, such as marriage and the engagement of the
individual with social or institutional arrangements, are changed in the risk society.

Despite Giddens’s acknowledgement that his theory of modernity may be
impacted by various factors of social stratification, aspects of his work are helpful for
analysis with the primary data sample. For example, in terms of expert knowledge and
technology perspective about the access of information, a number of the patients
highlighted their efforts using the Internet to research their symptoms and prospective
treatment facilities. In spite of their diligent efforts to access expert knowledge, these
men understand and accept that it is not possible to perfectly assess risk. Effectually, they
are operating in what Giddens describes as modernity as well as remnants of pre-
modernity cultures’ use of esoteric expert knowledge. Giddens’s broad frames listed
above confirm my assessment that time orientation is a part of the equation of risk-taking.
These are the same frames of importance to my work in this project as well as in the
semiotics and cultural and social processes that go along with them. In my own study, I
have focused on the expanse of the decision making activities associated with the patients
having received a cancer diagnosis. Decision-making is also the focus of the sociological
risk theory of Niklas Luhmann.

404 Giddens, Modernity and the Self, 1.
For Luhmann’s conceptualization, a key element of risk lies in communication structures which he identifies as decisions and within the process of decision making about risk acceptability and selection. The decision to act or the failure to make a decision is a decision. Luhmann’s focus on communication structures is his effort to revise the published risk theory of the time. As he understands it, the risk theory is too focused on the individual. For him, deciding about risk taking is not merely a psychological act; rather decisions occur within the confines of one’s socialization. “Cultural anthropologists, social anthropologists, and political scientists point out – and rightly – that the evaluation of risk and the willingness to accept risk are not only psychological problems, but above all social problems. In this regard, one behaves as the pertinent group expects one to or - either in conformity with or in breach of prevailing opinion – in terms of one’s socialization.” As a general sociocultural category, decisions made in the present, determine the future. Luhmann is speaking largely of societal dangers rather than individuals’ decisional challenges, and health outcomes literature suggests sociological applicability. Public health researchers often conduct studies and examine health behavior data according to stratification such as race and education. Stratification of various groups within the total population can point to problems and opportunities to develop strategies to resolve differences in health

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406 Ibid, 5. In Luhmann’s reference here, he identifies various sociological risk theorists including Beck, to whom I am already made reference, and to Mary Douglas and Aaron Wildavsky whose work follows this introduction to Luhmann’s goals with his risk theory.
408 Ibid, 3.
409 Ibid.
410 Luhmann, x.
outcomes among various groups. For Luhmann, to decline to make a decision is, by default, an act or decision that can produce exposure to dangers. He notes, “Refusing to assume risks or demanding their rejection have become dangerous behaviour (sic). The reaction is a refusal to calculate whenever one feels that risky behaviour could lead to disaster.” Here Luhmann is referring especially to decision makers whose failures to decide and act protectively endangers the general public. He also provides a note that the communication structures that he is referencing include the selectivity of mass media. This reading of sociological effects of risk suggests that, in large part, it is the responsibility of persons within the group to identify and effectively develop a campaign that raises consciousness of particular issues, then to strategize and to take action regarding the issue. Luhmann’s conceptual contribution continues as a subset of time analysis. He notes that the de facto decision to decline to act carries with it the cost or effects from the danger(s), and it can be viewed in social terms.

Applied to the study at-hand, the failure of African American religion to “decide” on an affirmative frontal approach to serious illness – often a motivator in clinical trial participation – or a few, simplified organizing principles for an approach makes the form less influential than its perceived pervasiveness in African American culture would predict and less. A portion of the health literature attributes religious beliefs to patients

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411 The National Center for Health Statistics annually publishes *Health, United States*. This volume available from the Centers for Disease Control and Prevention measures death statistics (mortality) and illness (morbidity) as well as health resource use and health workforce make up. Depending on the category of measure, statistics are tracked by age, race and ethnicity disease groups. Category examples include life expectancy, infant mortality, new cases of HIV/AIDS diagnosis, number of types of persons who die from heart disease-related illnesses. The most recent report presents data for 2012, and contains a focus on emergency room use and care.

412 Luhmann, x.

413 Luhmann, x. See footnote 5.

declining to make decisions – including deferring the decision to God – or delaying decisions about cancer treatment until there are detrimental health effects. As has been stated previously, according to patients in my sample who registered commentary on the subject, religion plays an indirect role in these their decision making related to the trial. This is a nuanced distinction from public health literature. These men’s religious beliefs sustain them in the decisions they have made - given the science. Only two of the men even make statements assenting to the development of science as a God-driven or God-made activity. My broader question is then answered as to whether the religious form I have been studying accepts innovation; effectually, it does not. Black religion as configured by these participants does not expand in the face of medical technology, medical possibility. Religion stands in parallel to, but apart from science. Genomic scientific innovator and confirmed Christian, John Carpten, acknowledges a similar pattern in his epistemological frame.

Carpten counts Francis Collins, current head of the National Institutes of Health as one of his mentors. I met him during a minority health disparities conference in the primary ethnographic site. During his presentation, he made reference to “church” several times. Curious about the inclusion of the term and references to his family life in his presentation, I asked Dr. Carpten during the lunch break that followed about his

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415Mitchem’s Betty Price reference is an example as is Powe’s fatalism, and there are other examples. Various studies in public health identify the concept of locus of control as a situation in which patients do not perceive that their decisions about their health are completely their own. For example, Nalda Z. Gordon’s dissertation in public health and clinical psychology suggests that African American female breast cancer patients whose lives are less inclusive of whites and white norms - acculturated is her term - appear to be more likely to depend on God for a health decision. Gordon attributes this to lack of trust in whites. See Nalda Z. Gordon, “Cultural Differences in Medical Decision Making in Women with Stage I, II, and III Breast Cancer,” Loma Linda University, 2002.

416John Carpten, Health Disparities Symposium, June 21-26, 2010, Houston, TX.

417John D. Carpten, “Genomics-Guided Therapeutic Options for Oncology: Is it Feasible?” June 22, 2010 at 8th Annual Disparities in Health in America Workshop: Celebrating Scholar Entrepreneurs Working Toward Social Justice, MD Anderson Cancer Center, Houston, TX.
religious beliefs, and how he reconciles them with his quest for cancer-relevant genomic discoveries. “I believe Jesus Christ is the Son of God; anything after that is fair game.” Carpten found satisfaction in his ability to use his scientific knowledge to help to provide genomic diagnostic tools and potentially cures. His work was all the more salient to him as he described one woman’s case during his presentation. He had not had a sense of dilemma about the relationship between religion and science in part because a number of his mentors, including Collins, had been Christian believers. Carpten’s parallel perspective on religion relative to science is grounded in Christian doctrine, but most notably, his is an institutionally-connected belief. Institutional connections to risk are the focus of the next theory.

For Mary Douglas and Aaron Wildavsky risk perception, acceptance, selection and the individual undertaking these processes are nested within the same social-cultural system. Furthermore, there is an ideal consensual relationship between knowledge and risk-taking. “Risk should be seen as a joint product of knowledge about the future and consent about the most desired prospects.”

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418 John Carpten quote; informal interview, June 2010. At that point, a brief discussion ensued between Carpten and another genomic scholar, Charmaine Royal, about the fact that his mentors in the field had also been Christian believers so he had not felt any sense of pressure to relinquish religious beliefs during his genomics training. As I prepared my final manuscript, I contacted Dr. Carpten to whether he would expound upon his statement; he did not respond.

419 In The Language of God, Francis Collins recounts his early life as a child growing up in a non-religious home where intellectual curiosity was fostered. His curiosity ultimately led to his journey seeking answers to questions in the religious realm and to his becoming a Christian. The title is taken from President Bill Clinton’s announcement of the discovery of the genetic sequence as the “formula” for life; with Craig Venter, Collins co-led the team that broke the code. Collins also describes how his understanding of science enhances his belief in God. Francis S. Collins, The Language of God: A Scientist Presents Evidence for Belief (New York: Simon & Schuster, 2006).


421 Ibid, 6.

422 Ibid, 5.
opportunity.\textsuperscript{423} Theirs is a cultural approach that sustains a close intellectual tie to Douglas’ cultural approach to ‘purity and danger.’\textsuperscript{424} Risk is a human process, socially, culturally, and politically constructed.\textsuperscript{425} They, too, are interested in environmental dangers, but also technological advancement. In the latter, Douglas and Wildavsky sometimes construct their arguments around examples from medicine. I will return to expound upon this sociological risk theory.

The final frame for risk is very different from the others; it comes from Niels Henrik Gregersen who published an article in which he argues for an application using risk discourse within Christianity. I am most interested in the time orientation, but this model establishes a religious argument for risk through a theological analysis.

Gregersen examined the most popular sociological models of risk in order to explore a Trinitarian “theology of risk” in which the focus is on the loss proposition of the divine Christ on the cross.\textsuperscript{426} He observes that the first potential is to answer whether the scriptural God presents as risk averse or as risk taker as interpreted by theologians. He finds that there are scholars on both sides of the divide, so he briefly presents both “schools” of thought.\textsuperscript{427} Of thinkers who perceive a risk averse divine, they argue that God has no knowledge gaps, no patience for sinners, does no negotiate and or change God’s plans.\textsuperscript{428} A risk-taking God is “creating a world endowed with freedom”\textsuperscript{429} as a by-

\textsuperscript{423}Ibid, 6.
\textsuperscript{425}See Douglas’ and Wildavsky’s summary of these arguments in their conclusion in \textit{Risk and Culture}, 186-198.
\textsuperscript{427}Scholars who have published on this subject are minimal so to state that there are schools of thought on the risk presentation of the supreme deity is merely a means of speaking shorthand in order to describe the distinctions.
\textsuperscript{428}Gregersen, 369.
product of God’s love. Gregersen questions the biblical stories used to develop these conclusions. For example, he notes that God negotiates with Abraham to exempt Sodom and Gomorrah from destruction due to the weightiness of sin conducted there; God knows all about the sin and allows Abraham to bargain down the number of righteous men needed to save Sodom. There is also the opportunity to interpret God as endorsing risk taking through the New Testament parable of the talents. In that biblical story, three servants are put to the test of what to do with the talent their master has given them. The servant who has increased the value of the master’s talent is rewarded with the un-risked talent of the unsuccessful servant.\textsuperscript{430} In spite of the above biblical accounts, Gregersen cites Niklas Luhmann as failing to see traditional teaching endorsing risk taking in premodern Christianity, and that, although there might be gains, risks are to be avoided.\textsuperscript{431} When Gregersen constructs his theology of risk taking for modernity, he concludes that believers cannot lose when taking risk or losing to risk taken; when Christ died on the cross and was resurrected, the divine reconciled the God-self to humanity and humanity’s suffering.

Gregersen shares my own contention that the time element in risk is oriented to the future; he connects the time feature to the relationships between Christian hope, expectation and risk. Hope lies within trust and is never neutral; when humans hope, they anticipate only something good.\textsuperscript{432} Hope is not able to be calculated, and is related to time as an extension of symbols or aspects of extensions of the present.\textsuperscript{433} A response to the contingencies or uncertainties of risk in the form of expectation suggests a calculable

\textsuperscript{429}Ibid.
\textsuperscript{431}Gregersen, 367.
\textsuperscript{432}Gregersen, 360.
\textsuperscript{433}Ibid.
consideration that is an extension of the past and the present. A weather prediction, for example, is a calculation that concludes an expected outcome. Expectation uses reason, and a longer time line; it builds on the past and present to anticipate the future.

Whether through hope or expectation, in Gregersen’s view, and this is helpful to support my argument, both attitudes “blend [the] tenses to seek the signs of the future in the present.” Again, risk, is focused on a future state.

Sociological Risk Theory and the Current Research Project

The language of risk – as danger or loss and the burden of these experiences - and an alternate evaluation or calculated possibility identified as benefits or gains, looms large in the milieu of clinical trials. Ethically, as a part of the informed consent process, federally funded researchers must disclose to potential participants who they are recruiting that they are entering a clinical study, and that they are being recruited as a human subject within the study. Participants in clinical research are to be informed that the research they are considering is not intended to provide them, personally, with clinical benefits, and that if any benefits accrue to them, it will have not been the expressed intent of the administered treatment or drug. These disclosures and the patient-subjects’ understanding of them and assent thereto, contribute to the ability for subjects to exercise their autonomy.

In the field of bioethics, informed consent originally resided within the principle of respect for persons as documented in the

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434 Ibid.
435 Ibid.
436 Ibid.
Belmont Report.\textsuperscript{440} Renee Fox and Judith Swazey connect the Congressionally-mandated investigation into the Tuskegee syphilis study as a central episode in the development of this particular principle.\textsuperscript{441} But even when they have been duly informed that they are entering medical research, some patients retain the mistaken belief that the trial is treatment in the phenomenon known as therapeutic misconception; these patients mistakenly believe that researchers who are doctors are also there to provide treatment specific to their medical condition.\textsuperscript{442} Still other patients believe that although a particular research protocol is not intended as a clinical treatment, it likely will help them, but not help other patients in the phenomenon of therapeutic optimism.\textsuperscript{443} I have observed neither therapeutic misconception nor therapeutic optimism in the beliefs of the patients in the current study. However, there is a fine line to be delineated since patients are responding to the clinical trial option as though it is one among several treatments.

Given that the patients in this study indicated that they saw an indirect relationship to a connection between religion and their clinical trial decision, it is a fair question to ask whether this is a null response finding, inconclusive finding, and whether there is other relevance to this research. The theme of risk that emerged during the interviews provides an opportunity to examine the scope of the influence of black religion within a particular type of experience. One valid interpretation of the primary data is to conclude that for some of the black male patients in this study, the scope of religion is narrow – relevant only to aspects of life that are explicitly spiritual. An equally


\textsuperscript{441}Renee Fox and Judith Swazey, \textit{Observing Bioethics} (New York: Oxford University Press, 2008), 46.


\textsuperscript{443}Beauchamp and Childress, 134.
val interpretation is that the study shows an opportunity to expand the scope of the content of black religion in several ways.

First, in religious experience research, some scholars explore questions such as how faith interacts with individuals’ behaviors (regardless of academic discipline). Sociologists, for example, have studied the question of how religion plays a role in assisting youth to refrain from what might be deemed risky behaviors such as taking and abusing illicit drugs and alcohol. Of particular interest, for me, is to understand the risk and religion branch of query as a way that risk offers an opportunity to explore questions of what aspects of religious belief and/or practice generate or influence decisions and activity during conditions of uncertainty in African American life and religions. Specifically, when religion influences progressive activity, how does it do this? What are the factors in religion that inhibit or promote social activism? Is it only the social, political, or economic situation?

As noted earlier in this chapter, Pinn, for one, has challenged the way that black religion appears to assert a certainty about the human experience of being in the world in the face of suffering. His concern is that this position of certainty leaves far too little theological capacity for human agency, doubt and contingency. Furthermore, he suggests, this [leads to the] “tendency in black religious studies to think of the most important element of knowledge as grounded in faith, based in metaphysical and transcendent claims.” He sees the opportunity to struggle beyond the historically rooted rituals of reference as the emergence from a crisis of subjectivity to form a more

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446 Ibid, 172.
complex subjectivity, and follows William James’ theoretical foundation along with work from black religious scholars, Edward and Anne Streaty Wimberly. Pinn’s theoretical evidence is based on the individual’s crisis of identity. Illness, however, is a social situation. Not in the same definitions of Talcott Parsons’ “role of the sick”, but in that wholeness and wellness requires measures of social dependence. So while there are certain subjectivities required, healing takes place with a view toward the future (even if one sees healing as restoration, bodily and otherwise, as does the World Health Organization) that can only be met with the assistance of others – for better or for worse – with no guarantees for the outcome.

Other scholars of the field have focused on the resistance aspect of black religion (and black culture, more broadly) to offer social sustenance in the wake of the constant possibility of danger or terror in one form or another: social, bodily, psychological, and/or economic. Hans Baer and Merrill Singer, for example, contend that the locus of black religious resistance is based on threats to economic survival and that black religion generates a number of adaptive responses that the scholars categorize. Debra King Walker goes even further in the social phenomenon and coined the phrase blackpain to argue that in the U.S., black bodies serve as the symbolic repository for the national expression of pain through violent acts as well as through violence as entertainment, such as through news and movie images. In Walker’s language, “black bodies are a normalized representation of suffering...material representations of pain.”

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447 Ibid, 183.
449 Debra King Walker *African Americans and the Culture of Pain* (Charlottesville, VA: University of Virginia Press, 2008.): 15.
American” in a nation where “true ‘Americans’ are constructed as virtually pain-free individuals who live in economic prosperity and political authority while helping others move beyond the painful realities of unfortunate circumstances.” Black bodies at risk of danger are symbolic in that they are more likely to be displayed in de-humanized images. Black pain is material, whether caused by violence perpetrated by whites or by other African Americans, and it occurs within the justice system, medical practices, and other societal institutions. The circumstances behind these two representative examples of scholarship related to the black sociocultural experience suggest a relationship between personal and collective responses to the power struggles exacted against persons of African descent and the role of their spirituality as a motivating impetus driving their responses. In the case of African American religious scholarship, this response has broadly been referred to as resistance. Often resistance appears as a force against economic, social, political, and cultural forces of colonialism and white supremacy. In this mode, resistance is justifiably reactive, yet not inherently generative; as attitude and action, resistance is focused on survival rather than thriving. Resistance as future possibility for black life is the re-imagination of the problem of risk, risk analysis, and risk taking.

I am arguing for risk as an analytical category that challenges the resistance trope within black religion and culture to focus on its generative nature in addition to its opposition mode. It is not only the self that needs complexities; so too, do the strategies to promote one’s own will in the world – in response to or as a previously unimagined

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450 Ibid, 49.
451 Ibid.
452 Ibid, 9. “The constant ‘truth’ about interpretations of black pain in America is that black people disappear while their bodies are constantly renewed as memorials to suffering and as tools for lessons benefiting systems of American acculturation.”
453 Ibid, 153.
future. The opposition strand of resistance focuses on the harms of the uncertainties of daily life and threatens to reduce this important cultural trope to one that is largely intended to be protective. Offered uncritically, the resistance trope suggests that black religion operates primarily as a mechanism that shields black bodies from the violence perpetrated against them in any number of forms making it conservative, preserving attitude and activity. In other words, when African American religions, in their academic and praxis forms, are focused on the dangers of life’s uncertainties with resistance as the response to these dangers, religion may be seen as grounded in risk avoidance. Here, we are reminded that Luhmann has argued that the decision to refuse to decide to take risk is itself a decision.454

The examples above serve to introduce resistance and to demonstrate the interplay between risk and resistance. Momentarily, I will return to the relationship between risk and resistance and their connection to religion. First, I will summarize the data in order to discuss the implications of risk for African American religion.

In my primary data, review of the theme of risk begins with the illness journey each man told about the moment of initial diagnosis that he might have prostate cancer; risk follows the trajectory of Giddens’s description of risk as danger. At initial diagnosis, nearly universally across the cohort, study participants requested a second opinion. In the contemporary health care delivery system, this may not seem an important observation. However, non-elderly African Americans are more likely to lack health insurance than non-Hispanic whites; one in five African Americans does not have health insurance.455

454Luhmann, 11, 13.
So the capacity to obtain an initial diagnosis – during a routine preventive care exam, much less a second opinion, is not a right among patients; it remains a privilege unavailable to an estimated seven million, nearly twenty per cent of African Americans. At this writing it is unclear how many more African Americans will gain comprehensive health insurance with the enactment of the Affordable Care Act. Comprehensive health insurance, as prescribed by coverage requirements, includes access to preventive care. In contrast, some insured persons have insurance coverage only for catastrophic illness such as would be required for costly injuries and illnesses as might be treated during surgery or hospitalization. This noted, except for Absalom, each of these men stated that he initiated his quest to get a second opinion to confirm the prospective cancer diagnosis. Absalom sought one as well, but he stated that his original physician suggested the idea to him. Absalom presented his demeanor as considerably less assertive than that of other men in the study. The men in this study (or members of their social support network) had sufficient mental capacity, health education, agential fortitude, and health insurance – all necessary resources – to obtain another opinion which would allow them additional options to evaluate the risk they would undertake.

Their request for a second opinion, search for a specialist and for prostate cancer health

affordable-care-act/ <accessed 19 January 2014>. It should be added that the refusal of several states to expand Medicaid, a key piece of the Affordable Care Act greatly impacts people of color because although they work or there is a full-time worker in the household, they tend to be clustered in lower wage work that either does not extend employer-sponsored insurance, pays relatively low wages making them income-eligible for Medicaid – if it would have been expanded by their states. “Health Coverage by Race and Ethnicity: The Potential Impact of the Affordable Care Act”, http://kaiserfamilyfoundation.files.wordpress.com/2013/04/8423.pdf <accessed 20 January 2014>. See also http://kff.org/disparities-policy/fact-sheet/health-coverage-for-the-black-population-today-and-under-the-affordable-care-act/. The observation of the ‘non-elderly’ demographic is important because Americans who are older than 65 are automatically eligible for government sponsored health insurance through Medicare. Furthermore, the average age of the men in this cohort is less than 65.


457Catastrophic coverage often comes with lower monthly premiums, and higher deductibles (directly paid by the patient or insurance subscriber before insurance begins paying), and often greater limitations when care is needed.
information is the first exercise of their agency, sometimes unconsciously linked to their faith.

The term “risk” appears to have entered the patients’ lexicon during the informed consent process when the risks and benefits of the clinical trial were presented to them during study recruitment. As a result, they understood that they could end the trial at any time, and viewed this option as a benefit. They were also well informed about the various treatment options because those options had previously been described to them in their research, in their contacts with other men, or by another physician. They wanted the most successful, least invasive opportunity available that would help them to sustain the quality of their life. Avery and Howard spoke in terms that most integrated their faith with the scientific information that was shared with them for their decision making. None of the men connected their participation to the Tuskegee experiment.

In my understanding of their comments, the patients mean risk as danger and that their meaning for what is at stake or at risk falls into one of two categories – although these lines could be blurred for any particular individual. The two categories are danger to quality of life or danger of allowing the cancer to lead to death, so for the latter group of men, it is their very mortality that is at risk. The (clearest) indicator for the first group is their discussion of interest in sustaining the portion of their identity that is linked to sexual function. For the latter group, it is their focus on their spiritual life and the corresponding possibility of their death.

The meaning of risk for patients in the quality of life group is recognizable because their perspective appears similar to that of non-study, observed patients who I

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458 A nurse practitioner I spoke with from the multi-specialty clinic thought this was short-sighted and that the men were overly focused on their sexual function.
saw during outpatient clinic visits.\textsuperscript{459} Howard’s narrative is representative of this line of thought. Certainly, his desire is to live, but he makes it clear that being able to remain “natural” with his wife, is important in the risks he is willing to take. I suspect that Howard’s youth (then 52) relative to other patients in the study may account for some of his focus. Howard’s view of himself and his life can be best described as “holistic;” he includes her in every step of his decision making. They indicate close relationships with each other and to their abundant family including siblings and their only child and grandchildren who all live nearby. All of these relationships are central to his way of life.

The perspective of the men whose thoughts center on their mortality group is best represented by Avery. He made the point that he was pursuing an improved and integrated spiritual life before the prostate cancer diagnosis. Recall that this was Avery’s second bout with a cancer diagnosis; the first was approximately thirteen years before when he survived living with lymphoma. For all of the men, their faith works to help them accept the risk associated with the clinical trial presented to them. Since all of the men report a high degree of involvement in institutional religion, I turn next to religion and how it currently constructs an entry in the risk discourse.

Risk, Resistance, and African American Religions

Resistance is a foundational trope in African American religious scholarship. I use the term “trope” in the sense that it is a recurring theme in the field used to demonstrate a functional element within African American religious sensibility and experience. The black religious studies canon is filled with constructions of resistance-as-opposition.

Drawing on source material such as the history of black enslavement, Jim Crow, and

\textsuperscript{459}Ethnographic note.
continuously evolving forms of racialized segregation and violence, strategies of survival come in the form of theologies, creative projects, and various cultural expressions in between. Resistance operates in a defensive mode to stave off various degrees and forms of inferiority foisted upon individual and collective black bodies and the individual and collective consciousness of African Americans. For example, in his history of Islam among Africans in the New World, Richard Brent Turner observes that African slaves who practiced Islam were often seen as particularly resistant, sometimes through violent means, to their institutionalized confinement.  

Womanist Delores Williams takes note of the “doctrine of resistance” passed along from a former slave by the woman’s mother who had lived in slavery. “A strong resistance posture” continued beyond slavery as a means of survival. C. Eric Lincoln and Lawrence H. Mamiya see this same survival spirit especially when black congregations operate in the priestly mode of the priestly/prophetic dialectic. Although most black churches, at times, swing between either end of the dialectic, some churches spend more time and activity focused on the private/internal, existential-spiritual mode of being human and religious than the freedom seeking, public mode of being black and American. M. Shawn Copeland brings together resistance, existence, and the black body in *Enfleshing Freedom*. It is instructive that Copeland’s theological anthropology was influenced by her own embodied

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461Delores S. Williams, *Sisters in the Wilderness: The Challenge of Womanist God-Talk* (Maryknoll, NY: Orbis Books, 1993), 138. In the passage, Williams does not claim that the “doctrine” is religiously-based; rather it is doctrine in the sense of teaching skills connected to persistence and survival. Williams, 137-138.

462Ibid.

463Ibid.

experiences of illness and three major surgeries within four years.⁴⁶⁵ Her observations about resistance and black bodies come with a warning argued by Victor Anderson that it is a mistake to limit black experience to black resistance and black suffering; to do so “truncates” black humanity as a subject.⁴⁶⁶ To move beyond this truncation, it is important to state that African American religious scholarship has also seen resistance as having a productive role. The default form of resistance suggests an avoidant risk orientation in favor of self-preservation.⁴⁶⁷ But black religious studies also interprets black religion as a cultural form that is dynamic and creative - creative to adapt itself to social, political, economic and other threats, and to contribute to the resilience of African-descended people through, not from, trials. Such dynamism can only be activated by taking risks, by seeing beyond risk as danger to the benefits that may be gained by encountering the danger in risk. And can risk point to both content and function of black religion that demonstrates its most helpful regenerative powers without falling victim to a scientific (or technological) positivism?

Womanist sociologist of religion, Cheryl Townsend Gilkes deploys Minna Caulfield’s concept of the “culture of resistance” to spotlight the activist work of African American women in their communities of concern, including women such as Nannie Helen Burroughs, who led training efforts of women and girls in early twentieth century National Baptist Convention.⁴⁶⁸ For Townsend Gilkes, the resistance trope has a life-

⁴⁶⁸ “Minna Caulfield’s concept of a ‘culture of resistance’ captures one of several dimensions of life in oppressed communities. In addition to combatting the damage imposed on their communities, oppressed people often try to develop and instill values that differ drastically from those communicated by
generative, agential mode that motivates ethical formation and community activism; it is not merely defensive. Delores Williams’s observes black women’s civil rights era resistance efforts as “bold,” driving them to “organize” in spite of the men who were credited with leading the movement toward freedom.\footnote{Williams, 138.} A third use of the term resistance appears in sociologically-based health behavior literature relative to religiosity offering a resistive effect for teen-aged African Americans’ use of drugs and the delay of first sexual activity.\footnote{One such study has been authored by Jill W. Sinha, Ram A. Cnaan, and Richard W. Gelles, “Adolescent Risk Behaviors and Religion: Findings from a National Study,” \textit{Journal of Adolescence} vol. 30, no. 2 (April 2007): 231-249.} In the resistance/resistive mode, subjectivity is blurred between the protective/defensive and the generative/active effect. And I would argue that as a sociocultural mechanism, these modes of resistance have been coded into bodies assigned to the black race. In religious studies, these distinctions are often assumed according to the description of the activity that follows the use of the term. But in the field of religion and health, as it has been developed by cancer researchers, the name of resistance is fatalism and its mode is hesitance and inaction – anything but generative and active.

Powe and the Fatalism Research Agenda

In cancer research, fatalism is believed to be a widespread attitude among African Americans with regard to their ability to affect their own health outcomes.\footnote{Monica D. Franklin, David G. Schlundt and Kenneth A. Wallston, “Development and Validation of a Religious Health Fatalism Measure for the African-American Faith Community” \textit{Journal of Health Psychology} vol. 13, no.3 (2008) 324–325.} Broadly,
fatalism is the belief that patients will fail to act to stave off disease given a biological or genetic predisposition for diseases such as various types of cancer.\textsuperscript{472}

One of the leading researchers in fatalism among African Americans is Barbara Powe. In the past twenty years, Powe, a nursing and health communications researcher, has been the lead or a contributing author on more than thirty journal articles built on the premise of African American cancer fatalism.\textsuperscript{473} In Powe’s definition, fatalism “represents the categorical surrender of the human spirit to the external forces of life that destroy human personality, potential, hope, and life.”\textsuperscript{474} “Fatalism is one of the principal fruits of the nihilistic philosophy.”\textsuperscript{475} In her framework, patients who project a fatalistic attitude are believed to have a sense of hopelessness that inhibits taking action such as getting medical tests (e.g., mammograms, prostate-specific antigen (PSA), digital rectal exams) that help physicians screen for the presence of cancer. Once diagnosed with cancer, fatalistic attitudes are a factor in African Americans delaying treatment. Ultimately, both types of actions could be lifesaving. Powe has observed the coexistence of cancer fatalism and a deep sense of spirituality. The widespread acceptance of fatalism among African Americans and the length and breadth of her body of research on the topic provides an opportunity for discourse with African American religious scholarship and the perspectives of patients in my study – all of whom have been diagnosed with cancer. I engage Powe’s fatalism research alongside the notion of

\textsuperscript{472}Ibid.
\textsuperscript{473}A broad, non-scholarly search of Google Scholar yielded 32 articles on this topic. At this writing, Powe is director of underserved populations research at the American Cancer Society headquartered in Atlanta, GA. http://www.cancer.org/research/researchprograms/funding/barbara-d-powe-phd-rn <accessed 7 December 2013>
resistance in African American religious scholarship and the experiences of the patients I interviewed.

Within her body of cancer research, Powe has a conceptual interpretive framework that employs religious studies scholarship to explain one way to understand the presence of fatalism and African Americans’ religious sensibilities; later she developed an itemized scale that seeks to measure fatalism. The interpretive framework was developed in collaboration with colleague Alonzo Johnson, then a member of the religious studies faculty of the University of South Carolina, when they both were members of the faculty at that institution.476 They coauthored an article on the philosophical origins that provide context for African American fatalism; it is theoretically grounded in Cornel West’s notion of nihilism as they see it developed across two of his works: Race Matters and Prophesy Deliverance!: An Afro-American Revolutionary Christianity.477 Powe’s early research also challenged a strand of scholarly explanation for the causes of African Americans’ later entry into cancer treatment. Powe and Johnson disagreed with previous research by Freeman who had concluded that African Americans entered treatment later primarily because African Americans often lived in poverty; Powe and Johnson concluded that poverty was not the sole factor.478 Rather, in their view, poverty was one of several factors that included “oppressive forces

such as the long history of slavery, segregation, discrimination, substandard health care, and the subsequent” fatalism. In the ensuing years, Powe’s continuing concerns about African Americans’ fatalism led her to develop an inventory to measure the phenomenon. During the course of her two decades of research, Powe also studied additional factors that may influence delayed screening or treatment such as educational achievement, income, age, and health knowledge about cancer. Understanding the factors that contribute to lack of cancer screening and treatment delays could, in turn, prevent the higher rates of death among African Americans whose diagnoses tend to be identified at later stages of cancer wherein fewer treatments are available for its elimination or cure.

As opposed to her earlier hypotheses, Powe’s perspective on how African American religious sensibilities influence fatalism appears to be becoming more nuanced than her original findings already described here. Similar to other health researchers, Powe has learned that religiosity and spirituality can be an important source of coping and hope. Despite her evolving interpretive lens, Powe’s lengthy publication record has established a legacy of the notion of African American fatalism as well as behavior or attitudes descriptive of the phenomenon that is now available to be taught, formally and informally, to new generations of health providers. (In fact, I was taught about the link between African American spirituality and cancer fatalism in a required workshop during

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my bioethics training and research fellowship in a cancer facility.) Furthermore, Powe’s own research published a decade after her original article with Johnson demonstrates that physicians’ beliefs that African Americans hold a fatalistic view toward cancer can influence the treatment options their physicians present to them – even when the patients’ fatalistic attitudes are less prominent than that of their physician. In short, the effects of fatalism in patients, and/or the prevalence of physicians’ belief in African American cancer fatalism can have concrete, limiting implications in the choices that African American patients are able to make.

It is important to add that although Mitchem does not explain her views in this detail, she hones in on the racism in cancer fatalism. I am including this level of detail as a reminder about the social impacts of information and knowledge structures discussed in chapter three. Powe’s physician study demonstrates that it is not what physicians there knew about African Americans’ cancer fatalism, it was what they believed (affect) about African American fatalism that influenced them to limit the treatment options presented to patients. More detailed understanding about links between African American spirituality, physician retraining, and even restructuring of religious symbols (such as redemptive suffering) are all needed as tools. The behaviors behind the racism within this

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482 I first learned about the concept of African American patients’ fatalism during a staff course on cross-cultural perspectives on spirituality and health during my bioethics training and research fellowship. The instructor presented fatalism as a defining characteristic of African Americans’ spiritual attitudes during health crises. I asked the instructor about this concept after the class; he stated that this characteristic perspective of African Americans was located in multiple sources. I subsequently began my search on use of the term. In *African American Folk Healing*, Stephanie Y. Mitchem notes that a researcher suggested the term to her about African Americans’ attitudes when diagnosed with cancer. See *African American Folk Healing* (New York: New York University Press, 2007), 2-3. The course was open to any hospital staff, but was one of the training requirements for participants in the fellowship.

researched scenario can be changed as a result of the incremental, structural change in the knowledge and information.

Powe’s Fatalism Index is a fifteen item inventory the researcher uses to ask patients direct questions about fatalistic attitudes. Representative questions include: “I believe if someone has cancer, it was meant to be,” and “I believe if someone has cancer, it is already too late to do anything about it.” A “yes” response renders a point; the index scores accumulated responses from 0 – 15. A higher score indicates a higher fatalistic attitude.\(^4\)\(^8\)\(^4\) Even though her interpretive understandings are becoming more complex from some of her earliest publications, I find Powe’s speculative work to be a helpful starting point through which to consider risk and spirituality among the current study patients.

Two aspects of Powe’s work make it a good choice for engagement with my research project; the fatalism concept presents a challenge as well as an opportunity to African American religious scholarship and its engagement with issues related to health, health care, and health care decision making. Powe’s fatalism challenges African American religious scholarship to demonstrate that its content is agentially motivating, or at a minimum how it could become so. Alternatively, this scholarship must concede its inability to do so, and that its purpose and functionality is limited to issues such as cultural identity development.\(^4\)\(^8\)\(^5\) The opportunity is in the content or function of African American religious scholarship meeting that challenge in order to enter participation in the religion and health discourse by demonstrating to behavioral scientists that their


\(^{485}\)A helpful black religious studies identity development text is Lee Butler’s *Liberating Our Dignity, Saving Our Souls* (St. Louis: Chalice Press, 2006).
interpretations may be faulty. For example, Powe, failed to understand nuances associated with the potential that religious perspective can, in the words of Emile Durkheim, operate ambiguously. Religious perspective or orientation can point to positive affirmations of religious belief as well as away from positive affirmation – in the same stroke of content or ritual. Furthermore, she doesn’t appear to understand ways to work with African Americans’ religious content rather than to interpret its influence in cancer as influencing a non-normative, failure to support health behavioral agency. Alternatively, the men in my study, for example, verbalize phraseology similar to that in Powe’s Fatalism Index, yet a number of them have been quite aggressive in seeking information for their health benefit – even if their initial response had been one of momentary agential faltering as they pondered the possibility of their death from cancer upon first hearing the diagnosis. Bill, Howard, Avery, and Walter took a very aggressive stance with their cancer while also holding their spiritual practices intact. Daniel described his wife “more aggressive;” she supported him by seeking various treatment options. My study sample is too small to be generalizable, however if the high percentage and level of aggressive knowledge seeking activity was sustained across a much larger pool of respondents, it would present a serious challenge and rethinking to Powe’s fatalism hypothesis. All in all, besides the hypothetical logic of my last statement that can be investigated with a larger pool of study participants, the topic of fatalism brings to bear the opportunity to discuss risk and faith as an existential experience ripe for investigation with uses for various branches of religious scholarship including theology.

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486 Durkheim citation from *Forms*. In particular, Durkheim is referring to ritual values.
488 Durkheim citation.
pastoral care, sociology of religion, psychology of religion, anthropology of religion, and biblical hermeneutics. A number of the men in this study noted that their immediate reaction to hearing the news was concern about their death. An immediate concern about death is different from Powe’s concept of agential hopelessness along with the expectation of death about which the patient would be unable to affect in any way. Powe’s backdrop of African American fatalism is juxtaposed to other research in religion and health that locate a sense of hopefulness from scholarship in African American religion and helpfulness from religion in scholarship from medical sociology. In fact, later researchers are beginning to challenge the conflicting findings from Powe’s long publication record linking fatalism and African American religiosity. These later researchers believe, as do I, that Powe’s work may be incorrect or at a minimum, is insufficiently nuanced to be so important in cancer researcher and African American spirituality.

Franklin, et al, investigate the African American religion and health fatalism link for a number of reasons. These authors wanted to devise a tool to measure fatalism beyond the disease specific cancer index developed by Powe. They wanted to examine the fatalism phenomenon with attention to African American church members and to be able to compare fatalistic attitudes with church members’ stated health behaviors. This team conducted focus groups and key informant interviews to develop an initial list of questions which they pared down to the final 25-item questionnaire. Throughout their process, they noted three factors that comprise the construct of fatalism: “Divine

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Provision, Destined Plan, and Helpless Inevitability.\textsuperscript{490} The newer measuring tool, the Religious Fatalism Health Questionnaire (RFHQ) focuses on understanding the social constructs and uses of fatalism rather than fatalism in individuals.

As can be seen, Franklin, Schlundt, and Wallston are not attempting to reform the definition of fatalism, per se, but understanding the construct provides details that allow it to be useful for re-construction using tools in the disciplines in religious studies. Religiously connected fatalism as a paradigm in health attitudes among African Americans continues to be researched as a potential way to understand barriers that contribute to disproportionately poorer health outcomes in these populations with attention to how these attitudes hinder preventive health activity.\textsuperscript{491} But the often negative conclusions about the widespread effects of fatalism appear incomplete given the data as suggested from my study participants – each diagnosed with cancer, each expressing a degree of (Christian) faith and practice, and each having been willing to consider participating not only in the screening that brought early detection of the presence of disease, but also in the clinical trial in which they each enrolled. Furthermore, black religion – as historically recorded in religious scholarship – from its very birth has incorporated a social valuing (compared to primacy of the individual) delivered through religion and religious structure.

African American religious scholarship and much of public health literature interpret the assistive value of African American religion in health. The substantial


\textsuperscript{491}Ibid.
amount of literature in cancer fatalism takes the opposite view. In African American religious studies, besides the social valuing, the assistive value of religion lies in resistance, whether the protective mode for survival or the agential mode for freedom. But how could African American religious studies explain the type of overcoming of fatalism demonstrated by the men in this study? They report what amounts to the benefit of religion without either modes of the resistance trope. They gain agency in the worlds that live between religious faith and knowledge, scientific knowledge, and personal agency. Franklin, et al and Powe’s research analyze health beliefs holding religious beliefs as a constant. I am investigating religious influences within health decision making; my focus is the structure of the religious beliefs involved rather than the health beliefs influenced by religion. It may be a subtle nuance. The nature of this interdisciplinary problem appears in this nuance. Powe and Franklin, et al are interested in how health behaviors are influenced by religious fatalism. I am holding the clinical trial decision constant (as participating or not participating) and allowing the structures within the culturally derived religious agency (positive or negative) to emerge relative to that decision. If there is a driver behind religious agency, what could it be?

Comparing the decisions of these men to the historical construct of African American religion, one primary factor stands out: the trope of resistance. The men in this study do not reveal any sense of linking the trope of resistance to their health decision. They are focused on their will to live and the quality of that life in spite of their diagnosis. The most obvious link would be to the Tuskegee narrative. It also did not emerge in this study. Even with additional research into the concept of fatalism beginning to challenge this paradigm that may influence care providers’ treatment.

492 As does much of the end of life literature.
recommendations, risk, the theme that emerges from my primary research, has not been explored for its relationship to religiosity, health, and African Americans.

As stated earlier, the resistance trope is grounded in the historical experience of Africans needing to oppose the activity and discourse that captured and enslaved them and wrapped up justification for these in theologized and scientized arguments that asserted that Africans were being enslaved to bring them Christianity and that European colonizers were not mistreating their brothers and sisters because Africans were not of the human species. Scholars of African American religion assert that there remains a need for resistance as a historically grounded construction. Earlier in this chapter, I referenced Cheryl Sanders’ essay about African American postal workers’ response to exposure to anthrax. She links the refusal of the government provided antidote for anthrax by the overwhelming majority of African American postal workers from the Brentwood facility in 2001 to their “resistant attitudes” rooted in African American folk religion and health practices; the workers “trusted God for healing and protection” more than they were willing to trust medicine. Furthermore, these government workers declined to allow the U.S. government to use them as “guinea pigs” in line with the history of “racial discrimination in American medical practice which brings a persistent threat to bear upon the health and well-being of African Americans.”

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496 Ibid.
frame of the United States (as well as the global black experience) continues to demonstrate that blacks are often despised, degraded, and discriminated against at the individual, institutional, and policy level and that these experiences occur in these strata of health care.\footnote{Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care is a landmark study published by the Institute of Medicine, one of the National Academies; it provides health information to policy makers. The beginning sentences of Unequal Treatment begin thusly: “Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients. Consistent with the charge, the study committee focused part of its analysis on the clinical encounter itself, and found evidence that stereotyping, biases, and uncertainty on the part of healthcare providers can all contribute to unequal treatment.”} Similar readings of the black experience in health care continue in the present even if the particulars of contemporary episodes occur in constantly changing forms. My aim has been to note the manner in which the trope of resistance-as-opposition is culturally derived and can be an influential inhibitor impacting patients’ decision making in the clinical setting, broadly, with greater effect in the experimental clinical setting.

As described above, the roots of black religious expression counter the dominant culture in the United States. In the language of bioethics, one could say that African Americans would be seeking to exercise negative rights – the “right to be free from some intervention by others,”\footnote{Tom L. Beauchamp and James F. Childress, Principles of Biomedical Ethics, Seventh Edition (New York: Oxford University Press, 2013), 370.} such as…a right to forgo a treatment.\footnote{Ibid.} However, in order to construct a theory of religion and risk, we would need to demonstrate that religion could influence not just various forms of resistance, but also decisions and acts of commission or progressive (decision-making). As noted in the beginning of this chapter, high percentages of African Americans have an orientation resourcing religion for a coping mechanism. While resorting to comfort or “tension reduction” through religion is one
mode of coping, “cognitive restructuring, problem solving, …seeking information...[and] assertiveness” are other modes. So the answer is “yes,” African American religion can also influence forms of coping that are active, including cognitive components.

Resistance can be negative and positive; in other words, agential.

Durkheim would not be surprised that religion could influence positively or negatively; this is his notion of the “ambiguous” response. He would only argue that the mechanism for the influence would be located in ritual, a social “device,” so to speak. And as it happens, each of the men featured in my study assert that they regularly attend church worship services or participate in religion reinforcing ritual practices. The combined analysis of African American religious scholarship and religious experience within the stories of the men in my study show the ambiguous nature of religion to influence patients’ decisions and actions.

On African American Religion, Risk Acceptance, and Health

Based on the sociological risk models described earlier and their engagement with the study participants’ decision making and African American religious scholarship, there is enough justification and background to develop components of a sociological risk approach to African American religion and health decision making. The construct should: 1) acknowledge the need to balance sociologies of knowledge; 2) acknowledge that fatalism may be present for some African Americans, but is not a universally presenting response; and 3) address the effects of anti-black racism without race necessarily being explicitly central to the structure of the construct. In this section, I outline my approach to this construct. First, I summarize the facts from this project that point to the framework that comprises the foundation for the constructive approach.

In order to sustain their quality of life in the face of prostate cancer, the men in this study decide to risk participation in a clinical trial. They do so in part because they know that through the informed consent process they may choose to opt out of the trial at any point and for any reason. The Tuskegee Syphilis Study, during which there was incomplete disclosure, is one of several paradigmatic cases that help to develop the standards, principles, and practices of modern bioethics. The informed consent process does not end with the disclosure that the men in my research project are choosing to enroll in a medical research project – something the men associated with Tuskegee were never told. In the present case, the informed consent process continues with the participants’ understanding that they have made a reversible decision to participate in medical research, and their care is not dependent on their decision to participate in the clinical trial. So ongoing, these patients, who are also research participants, are evaluating the risks and benefits of their decision, which to them, looks like one of several treatment options.

The men I interviewed attribute their spirituality as indirectly impacting their decisions. They are fully conscious of their faith journey as intentional, embodied, religious thought in action and of their embodied experience of cancer as an active “contagion.” There is no blind faith fueling fatalism as it is sometimes referenced in health research investigating topics related to black spirituality/religiosity. This project explicates the religious sensibilities of this group of African American men for their

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501 Informed consent in clinical care and medical research represents a disclosure document, but it is also an ongoing process of disclosure in the relationship between care givers and patients even when the patients are research participants.

502 The informed consent document language for studies conducted at this research facility. The process includes that treatment will be provided regardless of whether patients enroll in the clinical trial and the name and telephone number of who to contact should the patient believe they have been placed in harm’s way.
concordance with scientific processes. The men’s religious beliefs facilitate their capacity to choose to utilize the scientific knowledge they begin to seek out at diagnosis and continue to welcome during the recruitment process for this diagnosis-relevant clinical trial. Their engagement in this way challenges the widespread notion that African Americans exhibit cancer fatalism – the failure to act in the face of a cancer diagnosis.\textsuperscript{503}

Not all African Americans demonstrate fatalism with difficult diagnoses; this study and continuing research into ways to empirically construct fatalism through indices contribute to better understanding of this phenomenon. Even so, the concept of fatalism in African American decision making should be addressed in a construct of risk because the experience in medicine has real effects as the condition of individual patients can worsen when they delay a course of action.\textsuperscript{504}

In spite of differences in the approaches to sociological risk theories, their authors agree that risk is inherently a future-oriented proposition. With risk the time orientation in the structure of African American Religions shifts from its cultural grounding (past) and its coping function (present). Two interrelated elements within African American Religions present challenges to constructing a theory of risk for application in health: 1) the construct of African American Religion is grounded in history and historical reference, the role of the trans-Atlantic slave trade and black enslavement, in particular, with its beginning in the deprivation of cultural and humanity, and; 2) the collective experience of color based race and racism facilitated by social, economic, legal, and political systems and manifestations within their particular moment in history. Both of these challenges are situated within time, one of the ubiquitous categories of human

\textsuperscript{503} Citation from effect of delay of treatment among breast cancer patients

\textsuperscript{504} Citation from Powe physicians’ perceptions and treatment options study.
understanding identified by Durkheim.\textsuperscript{505} Again, the time orientation in risk is future, not past or present. Given that humans can guess at, but not foresee the future, how shall a cultural form shift its embedded time orientation?

For patients facing a medical decision of any sort, especially one in which an experimental treatment is an option, they are confronting a present problem while their focus is on a future outcome. Recall that Giddens sees the “voluntary embrace” of certain risks as part of life planning and as the “colonizing of the future.”\textsuperscript{506} Time is implied within the stories of the men in this study; it is inherent in their life planning and thinking of the future including their relationships with their wives, children, grandchildren and other family members. Across the sample, the past, such as in the history of the Tuskegee experiments is not a factor in their decision making. This finding is consistent with attitudinal research about the willingness of African Americans to participate in clinical trials. For example, a study by Odulana, Kim, Green, et al concludes that African Americans report that they are willing to participate in clinical trials should they be presented the opportunity.\textsuperscript{507} The current study was unique in that it is not about attitudes should the opportunity to participate in research be presented to them; rather, that the opportunity has been presented to them and the overwhelming majority of these patients decided to participate in the clinical experiment. It should be noted that that the literature indicates various structural barriers that leave African Americans with less opportunity to

\textsuperscript{505}Durkheim, 8.

\textsuperscript{506}Giddens, Modernity and Self-Identity, 125. How might a people whose past is riddled with the colonization of her homelands and civilizations as well as the bodies of her people respond to the concept of colonization as acceptable activity that is not inherently de-humanizing?

\textsuperscript{507}Adebawale Odulana, Mimi Kim, Melissa Green, et al., “Participating in Research: Attitudes within the African American Church” Journal of Religion and Health vol. 53, no. 2 (April 2014): 373-381. Published on line August 11, 2012.
participate in clinical trials. The focus on a future state is a precondition of the modality all patients are seeking when they select healing, whether it is within the folk tradition, clinical high technologies, or an experimental form. In African American religious studies specifically related to health, the primary thinkers are not focused on time as a specifically named and required category.

In the stories she collected, Stephanie Mitchem locates both the history and experience aspects of African American spirituality in folk healing modalities. For her, in the twenty-first century, African American healing modalities are a “continuation of past practices” “hybridized by education, class, gender, and contact with Africans through the Diaspora.” Although she uses the term “past,” the focus of her work is “practices,” not the means by which the human categorical concept of time is embedded. Within Mitchem’s framework, the use of these modalities does not necessarily preclude the use of modern technologies.

Using Mitchem’s formulation of healing, from my study, Walter’s interview is a good example. He uses both the folk healing grape seed oil that his hospital-employed, registered nurse daughter suggested to him and the clinical trial offered at one of the world’s most renowned academic cancer centers. Mitchem’s intent to highlight cultural products is clear, and it is an important aspect of the African American religion and health discourse. Yet I entertain concerns and questions about how the creativity that she

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508 Yvonne Harris, Phillip. B. Gorelick, P. Samuels, and I. Bempong, “Why African Americans May Not Be Participating in Clinical Trials” Journal of the National Medical Association vol. 88, no. 10 (October 1996): 630-34. The barriers cited in this study include: economic barriers, mistrust, general lack of information or awareness about clinical trials, and communication issues. In my primary data, the lack of awareness about clinical trials also emerged as a repeated comment.

509 Mitchem, African American Folk Healing, 2-3. The term “modalities” refers to methods and approaches. In this case, the opposite modality would be Western biomedicine.

510 Mitchem, 99.

511 Ibid.
sees in African American spirituality can also expand by addressing the conceptualization and concerns of risk and risk taking. The purpose of her text is to focus on spirituality as a cultural product that offers healing; the various folk modalities are arrived at through a black epistemology closely connected to spirituality. My focus is the broad structure and the processes that shape concepts of health and risk taking in the black religious experience in order to gain healing with risk as an inherently future-oriented endeavor.

As important as both the folk and technological modalities are, so too is Walter’s inclusion of time which he expresses in experiential and relational terms – his and those of relevant others. Factored into his risk calculation was his observation that he learned that his uncle lived with prostate cancer for twenty years after initial diagnosis. This suggests his desire to live at least equally as long with his cancer as did his uncle. Applied to risk, he wants his decision to accept the risks associated with participating in the trial to result in a lengthy life regardless of the cancer. Time and experience span his responses; his spirituality, focused on his healthful future, binds them all together.

In Townes’s message to the collective, she focuses more on the time-and-experience problem as a category of meaningful experience than of time. She makes an urgent appeal for hope to be active and much more than a languishing despair focused on past victimization including Tuskegee. Townes supports her delineation of hope drawing on the work of Jürgen Moltmann’s theology of hope. She leaves room for hope to be interpreted as a religious category – “when it is grounded in the divine.” Townes describes hope as source of power to “overcome skepticism and doubt.” Hope enables a press onward when we feel like giving up. It enables us to draw strength from the future.

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512 Townes, 182-184.
513 Townes, 180.
514 Townes, 180.
to live in a discouraging present." It leaves behind the “sinful” “rhetoric of victimization” that can arise despite the very difficult circumstances some African Americans face. In other words, hope is a coping mechanism that attempts to bring a desired outcome into the present out of an amorphous future. Townes’s delineation of hope barely infers it as a time category; rather, it understands hope as relief from a present anxiety. She even includes the thought that in hope with God, “we are led into a life of risk.” Moving a step closer to unearthing a theoretical outlook on risk in African American Religions, we can view Walter’s process of his spirituality holding together past, present, and future and his personal and social relationships and experiences through Durkheim’s discussion of a priorism.

In Durkheim’s discussion of a priorism, he reflects on previous religious scholarship on the subject. He observes that some argue that human categories are a precondition, a priori, to individuals’ experiences, and that scholars before him make and inductive argument that individuals’ experiences develop the categories of the human condition. Durkheim asserts that these are arguments shift between reason and experience and have gone back and forth “for centuries” because they are more or less equivalent; both are based on the individual. For him the emphasis on the individual is what places them in error. To Durkheim, “religious representations are collective representations that express collective realities….” Furthermore, “collective representations are the product of an immense cooperation that extends not only through space but also through time; to make them, a multitude of different minds have

515 Townes, 180.
516 Townes, 182.
517 Townes, 180.
518 Durkheim, 12-13.
519 Durkheim, 13.
520 Durkheim, 9.
associated, intermixed, and combined their ideas and feelings; long generations have accumulated their experience and knowledge. All concepts that have meaning have a classification system and a social component. For example, time can be divided because there is an agreed upon, accepted means of measuring it. And religion, a concept that provides meaning, also has a social component. For Durkheim, a single individual’s experience cannot devise a category of the human condition; “religion is imminently social.” The same is true for risk as part of the modern human experience; it, too, is a social construct that asks what dangers might one be willing to consider in the face of illness and what role does socially supported religious sensibilities play in accepting risk?

Having worked through the varieties of sociological risk theories, no one of these models is adequate so I use elements from the various theories I have previously highlighted. I propose to construct a framework built on a basic idea from one of Durkheim’s theoretical successors, interjecting points from the other theorists. The base idea comes from Mary Douglas and her co-author political scientist Aaron Wildavsky for their arguments about the social construction of risk acceptance.

Douglas’s and Wildavsky’s model contains substantive elements from the criteria identified above. Again, those elements are: 1) acknowledge the need to balance sociologies of knowledge; 2) acknowledge that fatalism may be present for some African Americans, but is not a universally presenting response; and 3) address the effects of anti-black racism without race necessarily being explicitly central to the structure of the construct. Douglas’s and Wildavsky’s model takes into account sociologies of

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521 Ibid, 15.
522 Durkheim, 13.
523 This theoretical assertion can be developed to critique that a single social group’s expressions also may neither be identified as universal nor as sui generis. The latter will present a challenge to long-standing African American religious scholarship that its expressions are sui generis rather than solely cultural expressions. The former will challenge Western concepts within the study of religion as object.
knowledge, and in doing so, addresses the problem of fatalism by mitigating a significant factor, knowledge gaps, and that it must have cognitive and affective aspects. Noticeably absent is the component of the construction that addresses the effects of anti-black racism without necessarily being explicitly race-based; for that I will use a moral construct argument from Cornel West that I will introduce after describing the aspects of the construct built on the Douglas and Wildavsky theoretical approach.

Douglas and Wildavsky argue that individuals’ evaluation of risk is socially formed; the institutions in which persons engage shape their perspectives of risk acceptance and determine which risks are worth taking.\(^{524}\) This cognitive processing is consistent with Durkheim’s a priorism. Individuals enter a personal experience already socially formed, thus predisposed to process the experience through the learned lens. The person entering that social system must make decisions about accepting the risk of the new situation while comparing the risk (taken or declined) to the ideals of the social organization. They must determine whether to assent, reject, or reform those ideals. Douglas and Wildavsky describe a cultural theory of risk perception by observing that cultural biases are embedded in institutional structures. “In risk perception, humans act less as individuals and more as social beings who have internalized social pressures and delegated their decision making processes to institutions.”\(^{525}\) Risk perception is the background that exists prior to risk selection or risk acceptance.\(^{526}\)

In my reading of the patient interview data, the “institution” here is the congregation with which the men report a regular relationship, but it is also a narrow


\(^{525}\)Ibid, 80.

band of theologies and religious practices that the men have learned are acceptable to
express within the confines of their institutional religious beliefs, that is, the risk
perception that has been unconsciously communicated about how to respond to the
various doctors’ suggestions. (Recall that each patient saw at least one doctor before the
trial was suggested to them, and some of the men had seen two or more physicians: a
primary care physician and a first urologist before seeing the urological cancer
specialist.) So each patient is choosing not just treatment, but also between the attitudinal
and knowledge confines of their religious institutions’ approaches to illness (agency and
theology). Each of the patients retains a degree of connection to a Christian congregation,
and report that they attend worship services at least twice per month. They verbalize
when they distinguish their interpretation of what is acceptable for themselves from that
which seems to fall outside the range of teachings offered in the churches they attend.
This is not to suggest that they do not hold their beliefs sincerely; however, what suffers
is the whole sharing of information with the religious community. They verbalize to
members of their religious communities that which falls within the narrowly acceptable
band; the good news of the lack of cancer progression is shared; the participation as
clinical trial is not.

Walter, for example, attends church regularly and grew up the son of a Baptist
minister; he identifies as “spiritual” rather than religious. Walter questions how some
believers incorporate the knowledge they claim from their faith: "Some religious people
have these orthodox beliefs which don’t really tie in to what the spirit of God has taught
us through his word. As a matter of fact, some religious people do things outright
different from what God has asked us to do in his commandments or in his way of
doing." From his perspective, his spirituality allows him a range of understandings beyond orthodoxy even while he retains his relationship with the institutional church, and this broadened belief is useful as he faces cancer and a clinical trial. During our interview, Walter demonstrated that his spirituality provides him the capacity to articulate the knowledge-world merger between religion and science because God is involved in scientific innovation:

A lot of these inventions and creations could not be done, I believe, without the spirit of God being involved. I feel like God is over everything. If God wants it to happen, it’s going to happen. Because of or in spite of, it’s going to happen. I feel like God has the best interest of man at heart. I also believe that science has, more or less, the best interest of man at heart because they keep improving things and coming up with new inventions or solutions to illnesses, etc. I think God is intertwined into all of that because if God didn’t mean it to be, it wouldn’t be. So I think that a religious belief and a scientific belief can work together and does work together.

For Walter, because God has created science, his participation in experimental medical science is consistent with his spirituality. Walter is able to balance religious beliefs with a faith in (medical) science. He believes he is stretching the narrowness of the theological orthodoxy of his social world to expand his agency to include his decision, and, in his mind, he can do so because his spirituality is more than religiosity. Although Walter sees his spirituality as progressive – in part because he is thinking about science – his views are consistent with views in African American religious studies about the creator deity’s continuous involvement in history. Too, this finding is consistent with one of the few studies that researches patient spirituality with an active cancer diagnosis and their views of clinical trials; those patients have a terminal prognosis. The study is aptly titled
“Trusting God and Medicine.”

However, it should also be noted that Walter limits his conversation with his pastor to issues that they can share. For example, the pastor, like Walter has diabetes; they discuss information they have learned about the experience of living with the disease. Walter’s manner of parsing information with his pastor calls into question research that suggests the extent of the pastoral relationship in decision making. Douglas’s and Wildavsky’s basic frame is focused on institutional inculcation of social values that guide the moral choices that are embedded within risk perception and risk acceptance.

Since my research project concludes that risk should be an analytical category in religion and health in the African American context, my sociological approach to risk will need a conceptual mechanism to include race in addition to the modifications to the classical sociological risk theory on which it is constructed. In chapter two, I noted that race remains important in taking a stance and that increased African American participation in clinical trials may be one approach to reducing health inequities including higher death rates for blacks where whites have the same diseases. I also noted, however, that current uses of race and clinical trials in African American religious scholarship reference the Tuskegee syphilis study, and that this reference has become metaphorical for black participation in health care even beyond clinical trials. I offered an interpretation that allows for its continued use where necessary. But the alternative culturally-symbolic appropriation of Tuskegee into a religious framework is only a stop-

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528 The study by Odulana, Kim, Green and suggest an important role on the part of the pastor in shaping attitudinal willingness to participate in medical research, but again, this is attitudinal rather than an actual decision based on the option having been presented. This type of study could, however, provide additional clues to support arguments for risk perception (but not risk selection or acceptance).
gap, culturally formed measure. Ongoing, Tuskegee is problematic when extended well beyond the historical event (as it is in African American religion and health - unbound from its time). To fail to follow the procedural effects of Tuskegee overlooks the contemporaneous unfolding narrative that ultimately contributed to the rights-protective conceptualization of the respect for persons and justice standards included in The Belmont Report.529

Placing race at the forefront underestimates opportunity that allows black experiences of religion and health to be indicative of the human experience of these cultural phenomena – meaning that health and health care are culturally formed. There are times when the empathic appeal to one’s humanity ought to be a sufficient category of analysis. That said I fully understand that the failure or refusal by society to make this acknowledgement of black humanity is what upholds race as an ongoing category for analysis of social and cultural phenomena. But as I said earlier, to leave race at the center gives it a fixed quality that belies the morphing that the category and the mechanisms of social processing of that category have done over time and that neither of these has been able to overtake the human will to live and to thrive. The human drive to live fully is greater than the racism that seeks to thwart life encased by racial categories. In much the same way, one of the ways that Durkheim has remained one of the classical theorists of sociology and the sociology of religion has been through the universal applicability - the time element that I discussed above being one of these. So all of this summarized, the construct needs a way to include the importance of race without race being the center of

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529 Tuskegee is one of the several foundational or paradigmatic cases taught in the development of the modern U.S. bioethics. See Albert Jonsen, Birth of Bioethics.
the race-impacted framework I want to bring into the African American religion and risk theory.

In my theoretical construction, race does not have to be an explicit focus because race and effects such as racism are embedded and become evident. However, for the effects to become evident does require the collection of race data in order for it to be available as an analytical category when reviewing for various social effects and correlations. Similarly, in taking a socio-cultural approach to risk, Douglas and Wildavsky are also focused on the effects of risk. They write: “A cultural theory of risk perception (contains) the distribution of power in relation to the pattern of risks;” otherwise it would be “trivial.”

I choose to make race relevant as an issue within power struggle, but not the central lens, in part, because of the dynamics and functionality of race and its effects. I acknowledge that racial categories are socially constructed.

Additionally, racial categories are reinforced by a number of societal processes – legal, political, and economic; they, too, can be dynamic. Evidence for this is found in the dynamic descriptions of race categories used by the United States Census Bureau.

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<https://www.census.gov/history/www/through_the_decades/index_of_questions/1930_1.html> accessed

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530 Douglas and Wildavsky, Risk and Culture, 8.
532 Ann Morning’s research race will be helpful to my continuing development of race as an important, but not necessarily the only lens. She, too, takes a sociology of knowledge approach to identify the ways in which the idea of race is held by scientists, social and biological, and that their knowledge about race is disseminated to the general public in the United States through formally through educational institutions such as high-schools and colleges, as well as through other institutions including the census, the criminal justice system and the medical establishment. In the latter, each time a patient is asked his/her race during a medical encounter, it reinforces the thought that race must somehow be linked to the medical process of diagnosis and healing. Why else would the medical expert ask for such information? See Ann Morning, The Nature of Race: How Scientists Think and Teach about Human Difference (Berkeley: University of California, 2011), 3.
533 In one example, the 1930 census dropped the racial classification, “Mulatto.” Persons who had various mixtures of black, white, and what we now term as “Native American,” were identified by a schedule of factors; with most falling into the “Black” category. Persons of other racial mixtures might ultimately be identified by the race of the father which usually meant that the person was not identified as “White.” “Mexican” was also a racial category for that census.
Over the history of the Census, race categories have been added, deleted, contracted and expanded. Although race as a category shifts, the effects of racism, the underlying cultural cache that it holds, and its social impacts have remained continuous.\(^5\) To address my construction in this manner, I turn to Cornel West. His moral framework fits the goal to acknowledge the role of race without race being the central lens.

In Race Matters, philosopher Cornel West provides an opportunity to discuss race as important and ever-present. But, he asserts, additional conceptual processes – based on moral standards – are needed to highlight how to analyze and use race without succumbing to sociocultural, political entrapments that can come with centering on the changeable category of race.\(^5\) The focus should be on the pernicious effects of the power mechanisms that are a result of anti-black racism. In an excellent example, West focuses on the Clarence Thomas-Anita Hill confrontation of the early 1990s. Thomas had been nominated by President George H.W. Bush to replace the retiring Thurgood Marshall as the next lone black man on the Supreme Court. While Thomas is a black man, he is also a staunch conservative whose record indicated that he would likely work to roll back gains that were won by African Americans during the civil rights movement of the 1950s and 1960s and through subsequent affirmative action policies.\(^5\)

Black leaders where entrapped into focusing on race when they demanded that a black male be...

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\(^5\) Part of this record had been his tenure as head of the Equal Opportunity Employment Commission. In contemporaneous news reporting some had an expectation that Thomas could be expected to be questioned about that record. See, for example, Douglas Frantz, “Thomas Seems Sure to Face Criticism on EEOC Policies” Los Angeles Times July 03, 1991, http://articles.latimes.com/1991-07-03/news/mn-1550_1_clarence-thomas <accessed 8 March 2015>
nominated to replace the black male who was retiring. West then argues that had black leaders focused on moral reasoning they could have argued for a black progressive agenda that addressed issues that confront black communities, and they could do so without having to ignore race. Instead black leaders ended up publicly supporting a nominee whose (minimal) legal scholarship and judicial agenda opposed the very agenda that black leaders would want to support. (Not to mention, as West notes, that the leaders’ support for this particular black man followed a pattern of seeking black political gains by diminishing the concerns of a particular black woman).

In another example, as I was writing these pages, an Ebola crisis was unfolding as the incurable infectious disease was spreading across multiple countries in western Africa. Race took center stage when news accounts reported that experimental drugs that had found success in animal testing were in development in the global West. As the numbers of dead black Africans continued to accumulate, among some African Americans, including medical historian and medical ethicist Harriet Washington\footnote{Harriet A. Washington, “Make More Ebola Drugs and Give it to Africans” cnn.com August 6, 2014. http://www.cnn.com/2014/08/06/opinion/washington-ebola-zmapp-drug-africa/index.html?iref=allsearch <accessed 8 August 2014> Harriet A. Washington is also the author of Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present.}, the ethics debate about the experimental drugs focused on why the first-in-humans doses were used to treat two white Americans rather than any of the Africans living in the countries where the feverous infection was moving across nation-state borders.\footnote{In the end, Washington settles on distributive justice as the rationale for why Africans should have had access to the extremely limited supply of the potentially effective drug, ZMapp. Washington acknowledges that the actual effectiveness of was unknown, but that those risks could have been explained to any African to whom the drug would have been offered. Washington, “Make More Ebola Drugs and Give it to Africans,” Ibid.} In my analysis of this ongoing, quickly developing news, race combined with concepts in bioethics. Some who were engaged in the cultural conversation in social media wanted
the experimental drug, ZMapp, used to save the lives of Africans although ZMapp was untested in humans. Drugs that have not been tested in humans are inherently risky; it is unknown what will occur - which is why they must be tested in human volunteers before widespread approval and distribution in entire populations – even when the populations are extremely ill. Furthermore, the history of research ethics first-use in persons of color has been problematic. For example, in the 1950s, women of color were among the first, ready-volunteers for testing the birth control pill; these women of color included participants in Haiti, Puerto Rico, Mexico City, Ceylon, Japan, and Hong Kong. In Puerto Rico, as many as 17 per cent of the women experienced nausea, headaches, and dizziness – so much so that one of the on-site researchers wanted to stop the trial because the effects were too unpredictable for the effects desired – simply avoiding pregnancy. In the 2014 Ebola crisis, in my own analysis, another line of reasoning in the moral discourse of bioethics was at least as important as the race issue ensuing among some in the general public: the distribution of scarce resources. In this case, distributing the scarce supply of this experimental drug could be reasoned as an attempt to save the lives of doctors and health providers with knowledge of how to stop the epidemic by providing care to additional potential patients. In fact, in the ensuing weeks, a news report emerged that the first person considered for the drug was one of the leading hemorrhagic fever specialists from Sierra Leone who trained other indigenous African doctors. From first accounts, the decision was made against giving him the drug. According to members of his family, they were not approached for informed consent, thus neither the doctor,

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540 Ibid.
541 Andrew Pollack, “Opting Against Ebola Drug for Ill African Doctor” nytimes.com August 12, 2014. The account remains troubling on ethical grounds. It appears that Dr. Khan’s autonomy was violated.
Dr. Sheik Umar Khan, nor his family were given the opportunity to decide to accept the risks involved or the opportunity to potentially survive the disease; rather other people on the health care team made the decision for him. Race colors and overshadows other key ethical issues, such as the scarce resource of an experimental drug never used in humans, including the scarce resource of too few doctors to serve a population with a spreading contagion, not to mention the ethics of the process that allows drug companies to determine the appropriateness of compassionate use distribution.542

By no means am I suggesting that bioethics as a field is not without problems as a pluralistic moral framework; according to H. Tristram Engelhardt, bioethics is based on secular rationale for this reason.543 Furthermore, Catherine Myser penned a provocative essay, charging that even as a reasoning system, bioethics is embedded with cultural whiteness through ideals such as individualism and the over-valuing of autonomy at the expense of values such as empathy, caring, and altruism.544 The emergence of feminist bioethics and the countering, relational autonomy, suggests that there are like-minded thinkers who understand that bioethics suffers from the same challenges of normativity as other social process based disciplines. The process of human denigration and the assignment of hierarchical powers make race an element in moral argument rather than

542 Beauchamp and Childress, 209.
543 H. Tristram Engelhardt famously argues that with the plurality of canonical and secular moral systems, it would be impossible to discover and establish a singular ethical system so he proposes a ‘content-less secular ethics.’ Content differences present difficulty for making ethical decisions in a broad-based society. Based on secular reason, not merely a procedural ethic; secular ethics can identify right conduct. H. Tristram Engelhardt, Jr., The Foundation of Bioethics, second edition. New York: Oxford University Press, 1996.
the category itself. Race is intertwined in the ethical issues of the emerging Ebola crisis and in bioethics as a field; it is imperfect as the basis of a moral framework.

In my choosing to adopt West’s call for a moral framework, I need to draw a link between this moral reasoning and religion. For many African Americans, attitudinal morality is grounded in institutionalized religion. West’s construct does present a challenge in that he asserts that weakened black institutions, including the church, present the conditions for an increased threat of black nihilism. But the institutional connection to religion was especially prevalent in this cohort of black men, and West’s assertion is not mutually exclusive to a cultural connection to attitudinal morality as religion. According to Portraits of American Life Study data, persons who attend church appear to be influenced by its teachings as relates to their sense of morality. Added to that, some sociologists of religion empirically measure religiosity through the observable (even if self-reported behavior of) church attendance, and a higher percentage of African Americans claim a level of religiosity than do whites. (It may appear that I am using religiosity and spirituality interchangeably here. Spirituality is more difficult to observe; it is often an internalized process, measurable as self-reported behaviors and feelings. Behavioral scientists have developed indices for use in healthcare, including specialized instruments for use with cancer patients that measure spiritual well-being – acknowledging the intensity of concerns that patients may have with a serious illness.

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545 I note as the source data from the Portrait of American Life Study and a white paper that I co-authored with W. Duncan Wadsworth and Michael O. Emerson: “Making Babies: Religion and Moral Diversity in Views on Abortion and Human Engineering”, June 2013. I will continue to pursue the link between African American morality and religion as I further develop my research agenda in religion and health.


Aside from spiritual well-being during illness, religiosity and spirituality are interconnected for many African Americans.) Here, I am simply connecting religiosity/spirituality with moral codes among many African Americans. As the PALS data suggests, this religiosity, cultural or empirical, influences the moral sensibilities that African Americans gain from institutional religion. This is true even while a growing threat of nihilism is at hand which West links to declines in institutional influences.\(^5\) A declining societal institutional relevance is not mutually exclusive to the effects for persons who are deeply involved within religious institutions. In one example, Steven Epstein has documented that altruism is one of the reasons African Americans give for participating in medical research.\(^5\) Research from Neal Krause suggests that religious involvement promotes feelings beyond attitudes, specifically, to act with altruism, and that this act as an outgrowth of religious orientation is linked to one’s relationship with a particular religious congregation.\(^5\) Altruistic expressions were among the reasons presented by the participants in my research. Altruism is an affect with agential consequences within religion and health research, and this affect is a key motivator among African Americans.

Next I want to connect the cognitive component of religion and risk.

For Douglas and Wildavsky, “risk should be seen as a joint product of knowledge about the future and consent about the most desired prospects.”\(^5\) In accepting the risk of the clinical trial in which they have consented to participate, the men in my study are

\(^5\)My PALS white paper.
\(^5\)Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago: University of Chicago Press, 2007), 190. Epstein cautions about various appeals to responsibility or duty to racial and social group allegiance as a mechanism to induce research participation.
joining knowledge from the medical sciences presented to them with their consent for their desired future quality of life. They were dissatisfied with the standard alternatives presented to them and driven to seek something else; this drive ultimately helped them to locate the clinical trial. It would be conjecture to place this experience of their knowledge search in science or religion; they do not explicitly state. But it was consistently clear that when they are doubtful about the consent they have given, they allow their religiosity – in the context of their faith beliefs and/or in the relationships of their faith community – to bolster their confidence in their decision. They decline to give up their social relationship within the institutional religious realm where they identify various forms of social support. At least two processes are functioning here that are important to their risk acceptance and risk-taking: 1) they are using two systems of knowledge, and 2) they are benefitting from the spiritual support from their church embeddedness. Avery was the last interviewee in this project, but the first to disclose that the clinical trial design also included the opportunity to participate in a prostate cancer support group. He attended a requested introductory session, but did not choose to participate in the group. He said he did not feel the need to participate, believing that he had ample reinforcing support from his religious resources including televised religious programming and Bible study. This omission by the majority of the men suggests that the supports built into the clinical trial were unimportant or less important to them than the supports they specified including prayer, especially with family members, and church attendance. Since the trial appears

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similar to a treatment option, the social network is providing support by affirming the
good news of medical progress such as a reduction in the detection of cancer cells.

Cognitively, the men are exercising both/and reasoning. They do not approach
their decision as strict either/or reasoning. When asked, they say that they have made
their decision based on the science; however, as the question lingers in their thinking they
amend their responses to incorporate spirituality: God is in medical science. More
specifically, God is above medical science. They give the appearance that they know
this is what they are supposed to say.

Their responses give voice to the Krause research, but also challenge it. Some of
the men share with no one that they have received a cancer diagnosis; no one except their
spouse. In these cases, they are not attempting to use their church embeddedness to
bolster them in their difficult experience, nor are they seeking support in their decision to
take part in the clinical trial. The Krause research helps to explain why the men might
choose to participate in the trial as assistive to someone else, but is not useful for their
choosing the trial for themselves. For that, the risk acceptance and risk taking model is
central.

Before I close this discussion of the elements of the sociological risk theory for
African American religion and health, I offer a brief commentary.

The state of full access to health care options continues to be precarious for
African Americans, Hispanic Americans, and all persons without financial, insurance,
and knowledge resources or flexible employment. Even with the passage of the

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553 Theophas Smith, Conjouring Culture: Biblical Formation of Black America (Oxford: Oxford
University Press, 1994). Theophas Smith writes about this sort of both/and capacity in African American
religious culture; it stands apart from a “oppositional binary” located in traditional Western thought. It
should be noted that Smith’s religious concern centers on Christianity.
Affordable Care Act, the American health safety net continues to rely on emergency care and does not routinely provide full access to health care for a number of reasons which are beyond the scope of this dissertation. Although the Supreme Court has established the constitutionality of the law, litigation will continue about various aspects of it that may restrict coverage and patients’ decisional options. Just the number of states that have declined to expand Medicaid has left nearly five million citizens without access because their income is not low enough to qualify for Medicaid within existing thresholds yet is too low to afford even subsidized health insurance premiums.\(^{554}\) This intentional lack of access due to denial through politics falls among moral issues that I will continue to develop as a part of this research trajectory; it is a question within systemic justice framed through categories in African American religion and health.

To conclude this chapter, then, I will summarize the components of the theory of risk applicable to African American religion and health:

Townes and Mitchem work from very different frames in religion and health, but based on how they have constructed the issues in religion and health noted here, Durkheim’s approach to religion, as “eminently social,” allows both to fit within a theoretical framing that makes comparison feasible; racial identity, marked through the Tuskegee narrative is their key organizing category to shape their solutions. Extending this Durkheimian “system” the Tuskegee narrative that each scholar uses can be reimagined. Furthermore, when thinking of risk, a sociological approach can be located here as well. But here, the construction possibilities are much broader. Still, based on the

\(^{554}\)“A Closer Look at the Impact of State Decisions Not to Expand Medicaid on Coverage for Uninsured Adults” Henry J. Kaiser Family Foundation, April 24, 2014
manner in which the primary data unfolds, the model would be based on Douglas and Wildavsky’s institutional focus as the primary source of influence on risk perception, risk acceptance, and risk taking. Within the data, it happens that each of the participants is embedded, with relatively high levels of congregational involvement, to demonstrate a band of cognitive and affective influence that warrants interpreting institutionalized religion as key in the shaping of their notions of risk. However, other factors such as access to excellent health insurance, what appears to be middle class financial resources, informational resources including family members with substantial educational achievement, as well as their own much better than average educational achievement, and, finally, vital social supports outside their congregations all work to extend their capacity to accept risk such that they are participating in the Active Surveillance trial – a clinical study seeking the most effective treatment for prostate cancer – from which they were referred to me. A sociological risk model emerging from this case of African American Religion and health is based on a moral standard of a self-defined best quality of life in the foreseeable future which is grounded in the relationships and activities that each man enjoys as well as their sense of the ability to act to shape their lives as they envision themselves. For the majority, their agential identity is connected to their very ability to act for their benefit, and they share a sense of willingness to go to great lengths to exercise this capacity in all of its dimensions, intellectual, chief among them; where they cannot affect their own outcome, they believe their God will remain with them until they can try no more themselves.
Conclusion

“Writing a New Chapter”:
An Emerging Narrative in African American Religious Views of Clinical Trials

By investigating religious aspects of the decision making of prostate cancer patients considering participation in a clinical trial related to their diagnosis, this dissertation project has posed new questions of two key social and cultural conventions or narratives within the academic study of African American religion and health. Within their respective academic disciplines in African American religion and in health research discourse, both contested narratives have been constructed as barriers that block pathways to better health for African Americans, thus sustaining health disparities.

The first narrative is from scholars of African American religion who have published on topics related to health. Stephanie Mitchem and Emilie Townes both contend that the Tuskegee Syphilis Study, which ended in 1972, is a narrative that shapes African Americans’ mistrust of the US health care system beyond the medical research that is at the center of the history of Tuskegee. African American distrust of the medical system is well-documented, and that history is much older than Tuskegee’s race-based patient selection study designed to withhold treatment, while never disclosing that it was a research project. My study suggests these further questions of the continued use of this history: What is the productive wisdom and function of deploying the Tuskegee narrative as a means of recounting its substantial harms?; What can African American religious scholarship gain by including the additional ways that the Tuskegee story unfolded such that it has contributed to modern bioethical processes?; and How might a fuller understanding of the results of the Tuskegee history point to a twenty-first century
spiritual consciousness that motivates personal and collective activity related to issues of African American health that reduce health disparities and inequities? For the patients in active treatment in this study, the history of Tuskegee is unimportant; the narrative did not emerge among their concerns. They were focused on making their future lives as meaningful as they had been in the recent past. This is not unlike other patients with an active, serious condition; some patients are motivated to participate in medical research when they believe it may improve their condition. Culture is dynamic, and must remain serviceable to people who hold it to be valuable. Culture can, and culture does change—even if slowly so. Religion, then, as a cultural expression, can also change. Changes—and in this case, additions to the topics, symbols, and practices of religion can further assist patients facing clinical trial decisions today and tomorrow where they want their religion to remain fully serviceable to them so they may remain transparent to their religious communities. Patients are willing and do enter clinical trials when they sense their full agency is available; that is, that full disclosure through the informed consent process helps them to understand that it is their prerogative to exit a clinical trial at any time for any reason and that this decision will be honored. In the meantime, they will use their sense of religiosity and spirituality to sustain them in their decision to risk participation.

This project also poses new questions for a second narrative - this one in public health research about African American spirituality: that religion influences African American health fatalism, particularly with regard to cancer screening and diagnosis. Patients in this study held in tension that their ultimate outcome was in the hands of the God in whom they believe while they searched for sufficient information to make the
decision that would best support their vision of their quality of life. All of the men were able to enter the trial because they had participated in routine health screening that prompted additional testing which, in turn, detected cancer while it was a manageable diagnosis. In spite of the African American fatalism theory, the results here demonstrate that patients with adequate resources are able to both sustain a reverence for their religious sensibilities and simultaneously fully participate in the range of health care available to them. There was less evidence in the indigent care setting at the public hospital; though the cases were few, they suggested a greater potential for both cost-based systemic withholding of options, and patients who made cultural, including religious, decisions to not participate in certain health measures. But even there, patients verbalized a clear rational and affective sense of self-determined agency.

In spite of more than twenty years of policies intended to improve their participation, African Americans continue to be underrepresented in publicly funded medical research. During the past decades of these policies, sufficient research has been conducted to demonstrate that under the right circumstances, African Americans are willing and do participate in medical research. Factors of the “right” circumstances include referral access, adequate insurance benefits or financial resources, sufficient information, and a lifestyle that allows participants to meet the requirements study protocols. These are largely structural barriers, some related to study design and institutional placement, controllable by researchers and the institutions in which their investigations occur. Academic medical centers (affiliated with medical schools where employed physicians may also hold faculty appointments) are often urban, public
hospitals where the next generation of doctors is trained.\textsuperscript{555} Teaching hospitals often provide care to poor and indigent, which in urban areas, also means patients are disproportionately patients of color.\textsuperscript{556} As noted earlier, the profile of the patients in my study are not typical of African American patients. Although they were served at an academic medical center that is also an urban teaching hospital, it is not a safety net hospital where indigent patients are routinely served. The public hospital where I observed more restricted options offered to patients sometimes based on social factors is a safety net facility; there were no current research studies to test my hypothesis which in turn did not provide patients the opportunity to decline or accept the risks associated with participation in a clinical trial.

And this is more the point.

I have not attempted to absolve, or to resolve, the structural impediments to participation that have arisen as an unintended consequence of this research. My focus has been on religion as a sociocultural aspect of African American participation in clinical trials. This does not mean that African American Religious Studies does not have additional critiques to offer. One of the aims of the program announcement of the original grant that provided funding support for portions of this research was: “to develop and use non-traditional methods to build trust in the health care system to increase racial and ethnic participation in clinical trials.” My project was accepted in large part because it offered an opportunity to examine religion as a “non-traditional” means of investigating concerns about African American under-representation.


\textsuperscript{556}Ibid.
Although this project is not generalizable, the challenges it presents to current narratives suggests sufficient evidence to support that a new narrative is emerging that will support additional research and constructive opportunities. Patients for whom religion is important may be facing clinical decisions with less support than they might desire from their religious communities since there was evidence that patients in this study restricted portions of their sharing to perspectives that fit within the theological norms of the community, either because religion was ill-equipped to provide answers or because some religious leaders actions suggest that they prefer sharing moments of victory during the men’s medical struggles. This project has described aspects of the structural framework available to be developed in African American religious communities and African American spirituality broadly. Increasingly, medical research has the appearance of clinical treatments and, in fact, sometimes research does provide treatment, as is the case in this study where researchers are seeking the most effective among any number of treatments. At present, when patients are participating in trials they may not be sharing that information with members of their faith communities. This lack of sharing unnecessarily thwarts the “eminently social” by inhibiting the best evidence of the goodwill that religion brings to patients who are embedded in religious communities. African Americans are willing to accept risks associated with participating in the clinical trials. African American religious studies can offer these culturally based adjustments; I have offered two: a modified perspective on the Tuskegee narrative and a sociological perspective of risk. I assert that cognitive and affective thought and symbolism as a matter of justice will be instrumental in shaping greater participation.

557 The same is true for Phase III drug trials.
Issues of justice have been the ebb-and-flow of calls for public policies which advance improved social, political, educational, legal, and economic conditions for African Americans. Such justice seeking often has found cultural grounding and support for its achievement through the original independent African American institution - African American religion. In fact, as mentioned earlier, public exposure of the Tuskegee Syphilis Study, referenced several times in this dissertation, along with several other egregious cases of medical experimentation in mid-twentieth century, gave impetus to the adoption of the policy and bioethical framework in use today. The bioethical principle of justice is also coming under increased scholarly examination aided by new theories of justice from outside the field. I have offered arguments that there is a shifting paradigm with regard to African Americans and clinical trials. Here, I close by calling for the development of the justice principle for the primary purpose of articulating the concepts and practices so that they focus on religion and health with an eye toward reducing health disparities. African American religion has a long history of invoking justice as a divine promise and a divinely rendered right.

\[\text{Footnotes:}\]
\[558\text{Here I again appeal to Albert Raboteau’s seminal history on slave religion, the “invisible institution” rather than to independent black churches and denominations. See Albert J. Raboteau, } \textit{Slave Religion: The “Invisible Institution” in the Antebellum South} \textit{ (New York: Oxford University Press, 2004). Originally published 1978.}\]
Epilogue

As I was writing my final pages, two fronts emerged to provide additional evidence that point to the urgency of new justice work for African American religious institutions and for continued work in African American religious scholarship in health, including new questions for my research trajectory in the intersection of religion, health, and public policy: the “right-to-try movement” and the 2014 Ebola crisis.

The right-to-try movement includes model legislation intended to give terminally ill patients the impression that they have a right to request experimental drugs from pharmaceutical firms developing such drugs. At this writing, right to try legislation has become the law in five states during 2014. Implied in their well-crafted name is that patients have a “right to try” what may be a miracle drug that saves their lives. But these laws do nothing to reform the processes that provide general access to monitored clinical trials for drugs in development. Rather, these laws hinder potentially safer developmental drug distribution practices, and are intended to by-pass Food and Drug Administration drug approval processes that can take several years to complete. Reforms that provide quicker access to drugs with potential for cures yet sustain patient safety are warranted, but there are sufficient examples of drugs found to be unsafe in after-market studies that these reforms must occur in systematically safe mechanisms. From the view of right-to-try proponents, the potential for a cure rather than safety is the focus. I

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561 Goldwater Institute, “‘Right to Try Model Legislation.” http://goldwaterinstitute.org/sites/default/files/RIGHT%20TO%20TRY%20MODEL%20LEGISLATION%20%282%29_1.pdf <accessed 23 November 2014>

562 Phase four clinical trials are studies of approved drugs prescribed to patients by their physicians. These types of studies continue to monitor the safety of drugs after they have been in use by actual patients.
do not advocate for either/or thinking on such matters. Patients with precarious medical conditions are vulnerable; compassion calls for safety as well as hope for their existential dilemma. The Ebola crisis presented a similar predicament.

The West African Ebola crisis brought calls from throughout the African diaspora for access to experimental drugs being developed by pharmaceutical firms in the Western Hemisphere. These drugs first came to the attention of many African Americans when they saw news footage of two white Christian medical missionaries being repatriated to the U.S. in order to get medical care that included the experimental drugs. In spite of the fact that none of these drugs had ever been tested in humans, some African diasporic commentary (in the general public) focused on the mounting deaths of west Africans who were not getting access to these drugs. Several news outlets reported on the first patient, an American doctor who contracted the disease while working in an Ebola treatment facility in Liberia; his employer, Samaritan’s Purse, asked the U.S. government to put them in touch with Mapp Biopharmaceuticals in order to make a direct request for the drug that might save the doctor’s life. It remains inconclusive that the experimental drug was instrumental in the initial improvement and eventual survival of the doctor. Yet some African Americans expressed skepticism when the supply of the experimental drug, ZMapp, was said to have been exhausted. Skeptics suspected that the experimental drug was being withheld when it was needed to attempt to save the life of Liberian Thomas Eric Duncan, who was diagnosed with Ebola while visiting Dallas, Texas. The social-political narrative of race-based distrust of the U.S. healthcare emerged quickly after Mr. Duncan’s death, and was reported to be the belief of members of his family. Besides an initial misdiagnosis that caused a delay in identifying Duncan as having contracted the
deadly virus, no other experimental treatment was offered to him until approximately two days before his death when he was already on kidney dialysis due to organ failure. This general public discussion did not take the Tuskegee narrative into account or any other narratives from the African diasporic history with experimental treatments. Rather the focus was on access to potentially life-saving drugs. And this has been my argument – that African Americans appear to be ready to accept risks involved with experimental drugs – the threat to life with the simultaneous development of more and more drugs and experimental treatments changes the old narrative. The Ebola crisis, including Thomas Eric Duncan’s death from the disease on American soil, evoked the African American justice sentiment. However, for every Ebola episode, there are tens of thousands of African Americans dying of non-infectious diseases such as heart disease and cancer each year. Where are the demands for access to clinical trials for experimental drugs that treat these conditions?

There are many tasks needed to improve underrepresentation of African Americans in clinical trials, and just as many to be addressed by scholars of African American Religions. Religious studies can acknowledge the shifting cultural paradigm of African American willingness to participate by offering arguments to the students they train in colleges, seminaries, and graduate programs, who, in turn, become the next generation of praxis leaders and thinkers examining the field and developing the models that encourage believers in how they may engage both their spirituality and their reason to take the risks associated with medical research participation. And current collectives can begin today in engaging in justice work that demands clinical trial access that matches the public dollars they help to provide. The sole African American institution
with sufficient reach to create such a clamor is the collective voice of African American religion with the diversity of its internal perspectives of health care professionals, patients, class differences, degrees of religiosity, and faith commitments.
Appendix A: Semi-Structured Interview Script

[This document is a reproduction of the script used in the semi-structured patient interviews. It was a part of the protocol submitted and approved by the hospital’s behavioral research Institutional Review Board.]

T. Laws, Interview Guide/Script

“Religiosity/Spirituality, and Clinical Trial Decision Making: Religious/Spiritual Influences on African American Adult Male Participation in Decision-Making for Phase III Clinical Trials”

I’ve asked to speak with you because I understand that you are in the process of making a decision about participating in a clinical trial. I am researching how religion might affect these sorts of decisions. This research is the reason for this interview. I will ask about your religious upbringing; whether religion is a part of your life; and how these may make an impact on the decision you are making about the clinical trial. Some of the questions can be answered with short answers; others will need more thought.

I. Establishing rapport

1. Please tell me a little about yourself.

Do you identify yourself as black or African American?

Where were you born?

Where did you grow up?

Where do you live now? How long have you lived there?

Are you married? [Or have a long-term partner?]

Now I’d like to move to some of the more personal aspects of our conversation. Tell me a little about the role religion plays in your life.
II. Religiosity/spirituality history and current life

2. Was religion a part of your life as a child? In what way?

3. Do you consider yourself religious or spiritual at this point in your life?

4. Do you identify with a particular faith or spiritual beliefs? (such as Christianity, Islam, etc.)

5. Does your faith include a belief in God?

I also have a few short questions about your religious/spiritual beliefs and practices.

6. Do you attend church?

7. How often?

8. Are there other practices that help you in your religion/spirituality? (Bible reading, prayer times, personal-home altar, carry a rosary)

III. Illness

9. At some point, you learned about your illness, would you share with me what happened?

I’d like to know whether religion/spirituality has come up during your illness.

IV. Illness and Spirituality

10. How did being diagnosed with cancer influence you religiously/spiritually? (For example, did you begin to attend church more? Begin to pray/pray more? Take walks in the park? Etc.

Things that help you feel closer to God or your sense of spirituality.)

11. How would you compare your spirituality before and after diagnosis?

12. Since you have been diagnosed, have you spoken to a faith leader such as a pastor or imam about your illness? Someone you would consider your spiritual leader.
13. What about a friend or someone else you consider a spiritual partner?

Now I’d like to switch to clinical trials and the clinical trial recruitment process.

V. Clinical Trial Knowledge

14. Would you use two or three words to describe your impression about participating in a clinical trial--before you were heard about the study you are deciding about?

15. Has your impression about what it means to participate in a clinical trial changed in any way?

VI. Clinical Trial Communication, Recommendation, and Recruitment Process

16. Please tell me about how you came to be recruited to a trial. Start with how you came to be treated at MD Anderson.

17. Was anyone with you when you first learned about the trial?

18. Did any historical events come to mind when you first heard about the trial?

19. Did you have any emotions about participating in a clinical trial?

Now I’d like to talk about how you plan to make your decision.

VII. Decision-making

A. Decision making preference:

20. Did you make your decision alone?

21. Did someone help you make your decision?

22. When you were making up your mind, did you talk with anyone you trust about religious/spiritual concerns?

23. What was your decision?

24. What influenced your decision?

B. Religion and science – African American perspective
Some people think there is a conflict between religion and science. In this case, the clinical trial is the science.

25. Do you see any relationship between your religious beliefs and your decision related to the clinical trial as science?

26. Can you think of a time when you might have heard about this conflict between religion and science in a way that might have influenced your decision?

27. Do you think your religion/spirituality was related to your decision to participate in the clinical trial in any way?

VIII. Closing

28. Is there anything about your religion/spirituality that helps you as you are dealing with your illness?

29. Is there anything else you would like to add about your religious beliefs, spiritual practices, or your decision-making about participating in a clinical trial?

IX. Could we end with a few more questions about yourself and your life?

30. Would you share your age/age range? (Age comparisons)

31. What is the highest level of education you have achieved? (Socioeconomic status)

32. What kind of work do/did you do?

33. If interviewee has a spouse/partner: What is the highest level of education he/she has achieved? (Socioeconomic status, household)

34. Do you have children? How many? And what are their ages?

Thank you for sharing your story.
Appendix B: Community Organization Recruitment Flyer

RELIGION AND HEALTH

Seeking 25 African American men to participate in a research study in religion and health.

You’re eligible if:
You are a U.S. born African American man over 18.

Have been diagnosed with prostate cancer.

Have considered a clinical trial related to prostate cancer, preferably within the last eighteen months.

What will you do?
Participate in an interview about your decision related to the clinical trial.

Receive a gift card for your participation

African Americans participate in cancer clinical trials 25% - 50% less often than whites. Yet clinical trials can offer innovative treatment options. This study asks: Does religion influence whether African Americans decide to enter clinical trials?

Want details?
Email: terri.laws@rice.edu
Call: 404.625.7185
About the researcher: http://pinn.rice.edu/african-american-religion/current-students/

Snapshot of recruitment flier used to seek additional subjects from male-membered community groups.
Appendix C: Fellowship Program Announcement

Bioethics Initiative for Equity in Health Care and Research

CALL FOR APPLICANTS

The overarching goal of the Bioethics Initiative for Equity in Health Care and Research is to develop a diverse, multidisciplinary workforce capable of the translation of research findings into evidence-based policies and practices for improving health care and research equity among racial and ethnic populations in Texas, and in keeping with the overall mission of The University of Texas M. D. Anderson Cancer Center, the nation and the world. This tract is designed to become a long-standing program of M. D. Anderson’s Section for Integrated Ethics in Cancer Care.

The project aims to:

- To develop the Bioethics Initiative for Equity in Health Care and Research, a program dedicated to the training of individuals from historically racial or ethnic minorities in bioethics to address the under-representation of minorities in clinical trials.
- To increase the number of and to advance women and historically underrepresented ethnic and racial individuals to the bioethics academic enterprise.
- To develop and use non-traditional methods to build trust in the health care system to increase racial and ethnic participation in clinical trials.
- The project is a joint effort between researchers in The University of Texas M.D. Anderson’s Center for Research on Minority Health, the nation’s only congressionally mandated center for the study of Health Disparities.

Fellowship Selection Criteria:

- Training in a discipline compatible with basic, clinical, behavioral research, or health care ethics.
- Potential contribution to the diversity of the Bioethics Initiative for Equity in Health Care and Research tract.
- Completion of a degree compatible with the goals of the Bioethics Initiative for Equity in Health Care and Research from an accredited institution. (Doctorate preferred. Master’s level training and professional experience will be considered.)
- Fit with the research program of Bioethics Initiative for Equity in Health Care and Research Tract.
- Previous clinical and/or clinical research experience (abstracts, publications, awards).
- Express interest in a career in multidisciplinary clinical research or Health Care Ethics.
- Interest in studying health differences and disparities or health in historically underserved populations.

Fellowship Site:

The University of Texas M. D. Anderson Cancer Center in Houston, TX, with rotations at various institutions throughout the Texas Medical Center.

Application Deadline:

Applicants must submit their application online no later than today, December 4, 2009.

Applications for the Bioethics Initiative Fellowship are accepted through M. D. Anderson Cancer Center’s DISCOVER System. Access to this system requires a password that is generated when the applicant creates an account on the DISCOVER System.

To request creation of an account, please contact Yvonne M. Bailey-Haller at 713-792-8776 or yhaller@mdanderson.org. A Curriculum Vitae (CV) or resume is required.

The University of Texas M. D. Anderson Cancer Center is an equal opportunity employer and does not discriminate on the basis of race, color, national origin, gender, sexual orientation, age, religion, disability or veteran status, except where such distinction is required by law. All positions at The University of Texas M. D. Anderson Cancer Center are security sensitive and subject to a criminal history record check.

For more information, please contact:

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Bibliography


Brandon, Dwayne T., Lydia A. Isaac, and Thomas LaVeist, “The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Difference in Mistrust in Medical Care?” *Journal of the National Medical Association* vol. 97, no.7 (July 2005): 951-956.


Carpten, John D. “Genomics-Guided Therapeutic Options for Oncology: Is it Feasible?” June 22, 2010. 8th Annual Disparities in Health in America Workshop: Celebrating Scholar Entrepreneurs Working Toward Social Justice, MD Anderson Cancer Center, Houston, TX.


Henderson, Gail E., Larry R. Churchill, Arlene M. Davis, Michele M Easter, Christine Grady, Steven Joffe, Nancy Kass, Nancy M. P King, Charles W Lidz, Franklin G Miller, Daniel K Nelson, Jeffrey Peppercorn, Barbra Bluestone


Lewis, Rhonda and L. Bruce Green, “Assessing the Health Attitudes, Beliefs, and Behaviors of African Americans,” *Journal of Community Health* 25, no.3 (2000), 211-224.


National Cancer Institute at the National Institutes of Health. “Prostate-Specific Antigen (PSA) Test” http://www.cancer.gov/cancertopics/factsheet/detection/PSA


University of Texas Medical Branch, http://www.utmb.edu/imh/BSHScriteria.pdf.
University of Texas Medical Branch, Graduate Program, Required Courses, http://www.utmb.edu/imh/GraduateProgram/gp.asp?show=Course-Req.


