FROM THE CONGREGATIONAL HEALTH NETWORK TO THE HEALING TREE: A NEW MODEL FOR PROVIDING COLLABORATIVE AND EQUITABLE CARE FOR PATIENTS AND FAMILIES MANAGING SICKLE CELL DISEASE

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ABSTRACT

FROM THE CONGREGATIONAL HEALTH NETWORK TO THE HEALING TREE: A NEW MODEL FOR PROVIDING COLLABORATIVE AND EQUITABLE CARE FOR PATIENTS AND FAMILIES MANAGING SICKLE CELL DISEASE

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This project focuses on bridging the gap between treatment and care for children and families managing Sickle Cell Disease (SCD) by applying spiritual and religious resources as health care assets.

This work follows the Participatory Action Research process where patients and the principal investigator use qualitative research methods to co-create a program in a regional children's hospital. By applying the FICA (Faith, Importance, Community, Address) validated tool for spiritual assessment and supplementing this tool with four questions designed to assess the difficulties experienced in the sickle cell journey, faith communities were engaged to meet the needs that would ease the difficulties that were identified. This work is based on the Congregational Health Network (CHN) first implemented by Rev. Dr. Gary Gunderson and colleagues at the Methodist LeBonheur Health System in Memphis Tennessee. This project is distinct from Gunderson's because it is the first implementation to focus on pediatric patients managing sickle cell disease.

121 patients and family members managing SCD were interviewed. 10 primary needs were identified: increasing SCD awareness; increasing SCD literacy; prescribed diet support; medically tailored groceries; transition mentoring into adult care; emergency

transportation to the hospital; access to prescribed vitamins; appointment transportation to and from the clinic; childcare during extensive hospitalization including bone marrow transplant and emergency financial support.

3000 volunteer hours were invested by the author to secure 10 partners who joined the Congregational Health Network pilot which launched on April 17, 2023. The scope of this dissertation is to describe the inspiration for and the process of establishing this pilot; to trace the development of structural racism with particular emphasis on the delivery of healthcare to the Black and indigenous populations; to address the theological issues surrounding the treatment of blood disorders that appear to be focused on a single race; to measure utilization and efficacy through the pilot implementation phase; to propose a path forward to institutionalize the CHN and to offer a model, the Healing Tree, for the provision of more equitable healthcare. Measurement of specific health outcome data will begin in the second year of the project using baseline data secured from all participants. These activities will require a separate Institutional Review Board application and will be reported in future papers and/or publications.

DEDICATION

The project and paper are dedicated to the day when skin color has no bearing whatsoever on how we love and care for each other. “Now faith is the assurance of things hoped for, the conviction of things not seen.” Hebrews 11:1 NRSV

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ACKNOWLEDGEMENTS

Thank you, first, to my family, who believed this work was worthwhile and that I could make a difference.

Rev. Dr. Gary Gunderson and Dr. Teresa Cutts built the first Congregational Health Network. I am grateful for and privileged to attempt to continue their work.

To my hospital mentors: Dr. Elissa Miller, Dr. Robin Miller, Dr. Stephanie Guarino. Dr. Cathy Haut, Dr. Mindy Dickerman, Dr. Chuck Bean, Dr. Erin Coyne, Dr. Jennifer Hwang, all the dedicated and loving members of the SCD clinic Staff, the office of pastoral care, and the hospital foundation.

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CHAPTER ONE

INTRODUCTION: A QUESTION BECOMES A CALLING

"[We] seem to forget that there is a *cause* for every ailment, and that it may be in [our] power to remove it." Rebecca Lee Crumpler, First Black Female Doctor in America, 1883[1]

"So, faith, by itself, if it has no works, is dead." James 2:17, NRSV

It was a bright fall morning in 2021 when I was called to 17-year-old Brandon's bedside at a regional children's hospital in the Northeast United States where I served as a chaplain on the palliative care team. Brandon had been hospitalized for 12 days with intractable pain due to a vaso-occlusive crisis (VOC), the result of Sickle Cell Disease (SCD). SCD is a chronic disease caused by a genetic blood disorder that impacts 1 in 365 Black people worldwide. White people are affected at a fraction of this rate. Most patients managing SCD are people of color because the genetic trait evolved as a protective response to malaria which is prevalent in sub-Saharan Africa. [2] SCD also

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[1] Rebecca Lee Crumpler, *A Book of Medical Discourse in Two Parts* (Boston: Cashman, Keaton, 1883), 4. Emphasis original.

[2] Charis Taylor, "Why African Americans Are Affected More by Sickle Cell Anemia and Multiple Myeloma," *There Goes My Hero*, no.6 (June 17, 2021): 1, https://theregoesmyhero.org/author/ctaylor. Accessed November 3, 2022.

affects people from South and Central America, the Caribbean, Saudi Arabia, the Mediterranean and India.

Before entering his room, I was briefed by the treatment team gathered in the hallway for morning rounds. Every available pain medicine prescribed for Brandon brought no relief. We could still hear his screams through the door as he threatened harm to himself and others. Then I heard these words; I knew Brandon could hear them as well. “Drug-seeking? Behavioral health concerns? Difficulty adhering to his treatment plan. Non-compliant and over-reacting. Remember when we referred Mallory to a behavioral health center? That seemed to help.” I was asked by the psychiatry fellow to research facilities that might be helpful to Brandon. 12 telephone inquiries later I still had no answer for the team or for Brandon.

When I saw Brandon, he asked me a question that no practitioner could answer, “Pastor Pat, why has God cursed me?” As we unpacked the question and I heard his story, I discovered the challenges this young man faced as a high school honor student, helping his single parent raise his two brothers while also holding down a job at a local lumber yard. When he felt the onset of another VOC, he knew he had to get to the hospital quickly, but he had no car, and his usual sources of help were all busy. He was delayed in getting to the emergency department, missing the optimal window for receiving the pain medication that would quell the VOC. *Brandon did not need a behavioral health facility; he needed a ride*.

Throughout my life I have asked God for an answer to a problem, a challenge, or a prayer. I have learned that I never receive an answer; but there is almost always a question that prompts me to act in some way. The question written on my heart at that moment was: “Pat, will you let this stand?” I interpreted “this” as the structural racism that perpetuates healthcare inequity and the suffering of our Black, Indigenous, people of color (BIPOC) who are our patients and our fellow human beings. I had to respond in some way to that holy query. This project is my answer to that question.

Health Treatment or Healthcare?

PEW research data indicates that BIPOC persons “are more likely than Americans at large to believe in God, attend religious services, say religion is ‘very important’ in their lives and affiliate with a religion.” [3] The majority of the BIPOC patients I meet, including Brandon, have a strong faith in God, but not in the healthcare system. They struggle to gain access to the treatment they need as the socio-economic drivers of health (SDOH) still present significant barriers. “Socio-economic (drivers) of health are defined as the circumstances in which people are born, live, work and age which are recognized as having a powerful role in shaping disease risk and outcomes and contribute more to population health than healthcare services.” [4] When our BIPOC patients finally get to the doctor, often sad news awaits them: an unanticipated diagnosis, sometimes accompanied by a scolding as to why they did not get to the hospital more promptly or why they did not comply with an earlier treatment plan. Our well-intentioned providers do not always

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[3] Jeremy Weber and Morgan Lee, “The Black Church, Explained by Pew’s Biggest Survey of African Americans,” *Christianity Today,* (February 16, 2021): 2, https://www.christianitytoday.com/news/2021/february/black-church-african-american-christians-pew-survey. Accessed November 2, 2022.

[4] Kim Hanh Nguyen, Anupama G. Cemballi, et. al., “Applying a sociological framework to chronic disease management: implications for social informatics interventions in safety-net healthcare settings,” *JAMIA Open* 5, no.1 (April 2022): 3, doi:10.1093/jamiaopen/ooac014.

consider the fact that so much of the healthcare that the BIPOC population needs is provided by their families and communities. They come to the hospital for treatment which is transactional (read that “billable”) and includes a meeting with a provider, an evaluation, perhaps some tests, a prescription, and a plan for follow-up. But the treatment team at the hospital cannot provide the care they need to manage SCD in the real world and to live well day-to-day. This day-to-day care is relational and includes making the arrangements for transportation, gathering the money, or finding sources for the recommended healthy diet and over the counter medicines, or finding a volunteer to check on a hospitalized patient so a parent can continue to work during their child’s hospitalization. Medical care and health care are not synonymous. Our BIPOC population suffers from a dearth of both. After observing these conditions for years, my concern became a calling after the encounter with Brandon. If ever there was a diagnosis that encompassed the faith, health, and equity challenges that interdisciplinary teams face together, sickle cell disease is the perfect storm.

Bridging the Gap

One week later I was in Dr. Kenneth Ngwa’s Faith, Health, and Social Equity class. He introduced a book authored by Rev. Dr. Gary Gunderson and Joe Cochrane entitled *Religion and the Health of the Public*. In this book Gunderson described a model, called a Congregational Health Network (CHN) for leveraging faith communities as partners with the Methodist LeBonheur Health System in Memphis, TN, to provide care to chronically ill patients. I called Gunderson and spoke with his spouse and research partner, Dr. Teresa Cutts. She explained that in the Memphis Model one or more of the network congregations could provide transportation and after care for Brandon and kids like him. Although the CHN was implemented for adult patients with diabetes, renal and congestive heart failure, there was no reason that it might not be adapted for pediatric SCD patients.

Providers Also Need Help

Healthcare providers, relying on scientific understanding, have developed expertise as ‘specialists’ who diagnose diseases and prescribe treatment. Billable hours, publishing goals and teaching responsibilities limit the time that providers have available to meet with patients. Social workers and chaplains have been enlisted to provide more help. It remains that most of the care and support needed by chronically ill people to live their lives is provided outside of the hospital or clinic. It is difficult for providers and patients to be in a relationship with one another, to understand our shared challenges and to trust each other. Racism further divides us. Add to this mix the reality that BIPOC people in America are more likely than white people to use religion and spirituality as coping resources when facing health challenges[5] and the stage is set for clinicians to be cast as the bearers of unwelcome news borne by science, while God, through faith, is the source of good news. A CHN can be a bridge joining clinicians and faith communities, who come together as bearers of good news. This good news is more accessible, equitable and responsive healthcare, starting with our families managing SCD.

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[5] Latiena F. Williams and Lakeshia Cousin, “A Charge to Keep I Have: Black Pastors’ Perceptions of Their Influence on Health Behaviors and Outcomes in Their Churches and Communities,” *Journal of Religion and Health* 60, no. 2 (2021): 1070.

“In God we trust; everyone else brings data.” [6]

The words attributed to Deming ring true in the clinic. This project is my calling, but it has no standing in the clinic without data to support it. One of the first steps in this process was inviting Dr. Teresa Cutts to present the patient outcome data from the Memphis Model to the hospital staff during grand rounds on October 12, 2022. I followed this with the submission of my research design to the hospital Institutional Review Board (IRB). My proposal was approved in November 2022 as a Quality Improvement Project. I began my work by interviewing 57 families living with SCD consisting of 62 patients and 59 parents and siblings. My goal was to understand if these families had a faith and a connection to a faith community; the role of that faith/connection, if any, in their medical decision-making; and to elicit any unmet healthcare needs as they worked to comply with their SCD treatment plan. In the second part of my work, I leveraged the faith community connections mentioned by these patients to build a pilot CHN. Each faith community I contacted was asked to respond to at least one unmet healthcare need articulated by the patients and families during our interviews. Once the pilot CHN was up and running, I recorded patient utilization of services provided by our faith and community partners. The goal was to provide services to 30 (10%) of our patients. The research questions, methodology and project outline follow.

The Research Questions

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[6] Attributed to W. Edwards Deming, management consultant and founder of the discipline of Total Quality Management.

(1) What percentage, based on sampling, of the sickle cell patients and families we serve, profess a faith and a connection to a faith community strong enough to impact their healthcare decisions? Examples of this connection include a family who consults their pastor before making the decision to fill a prescription or who enlists a prayer circle for a fasting ritual designed to cleanse the blood or refuses a bone marrow or blood donation because it irrevocably changes the body that God gave them. The validated 4-question FICA tool (Faith, Importance, Community and Address in the treatment plan) was used for this spiritual assessment. [7]

(2) What percentage of our sickle cell patients and families have unmet care needs? I used a semi-structured interview consisting of four additional questions to ascertain unmet needs. These questions were reviewed for face validity by the pediatric hematologist who served as the Director of the SCD clinic.

A copy of the patient interview guide is provided in Appendix 2.

(3) What unmet patient care needs can be addressed through a Congregational Health Network? I evaluated this in cooperation with patients and the 10 community and congregation partners who joined the CHN pilot.

The Research Methodology

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[7] The acronym FICA can help structure questions in taking a spiritual history. F=faith, belief, meaning; I= importance and influence, C= community, A= how to address one’s faith in care plan. Adapted with permission from Christina M. Puchalski and A.L. Romer, “Taking a Spiritual History Allows Clinicians to Understand Patients More Fully,” *Journal of Palliative Medicine,* 3, no. 1 (2000):130.

The five-part Participatory Action Research (PAR) **methodology** detailed by Mark Chapman outlines five research goals which have been a gift in organizing my work. [8] My attempt to engage the PAR model and address each of these goals follows.

The **first** goal is to comprehend the situation, which is to understand the role that faith plays or does not play in our patients' sickle cell journey. Advanced Practice Registered Nurses gave patients and their families a brief overview of this project and asked if they would be willing to speak with me to answer eight questions; 4 FICA questions and 4 related to sickle cell disease. If they agreed to a conversation, I met with them in person, documenting their willingness to participate in my transcript form. A parent was always present with a patient under the age of eighteen. If a patient was over the age of seven, I tried to engage them directly; if they were under seven my discussion was often with their parent(s). I completed each response form by hand (provided in Appendix 2) noting the 8 responses verbatim as they were received. I did not use a recording device. I found that patients and families appreciated this approach, which nurtured mutual trust. It was a conversation with a pastor rather than an investigation by a researcher. I noted specific additional comments on the response form during the conversation, with permission. I then scanned each response sheet into a password protected file that is maintained on a secure server in the hospital.[9]

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[8] Mark D. Chapman, "Action Research Ethics for DMin Students," *Journal of Christian Ministry* 7 (2018): 4, https://journalofchristianministry.org/article/view/18250.

[9] My Clinical Pastoral Education (CPE) courses use a verbatim method where the pastor recalls and transcribes the conversation with the patient after the encounter. After receiving the responses to the 8 interview questions, I sometimes made some personal notes about the encounter within 15 minutes of the actual interview. These notes, often called fair notes, can decrease data collection time while still providing detailed and relevant information. These notes helped me see the larger context of my work and were valuable in organizing this paper. See Zelee Hill, et.al., "Are Verbatim Transcripts Necessary in Applied Qualitative Research: Experience from Two Community-Based Intervention Trials in Ghana," *Emerging Themes in Epidemiology* 19, no. 5 (2022): 1, doi:1186/S/12982-022-00115-W.

The **second** goal is to identify what issues most require attention; these are the unmet care needs of our patients and families. When our patients come to the clinic, they usually receive the results of bloodwork, prescriptions, a list of recommended over-the-counter drugs, and a diet plan. These interventions are examples of treatment. BUT what if there are no funds for medicine either prescribed or over-the counter? What if there is no money for food? What if there is no available transportation home or back to the hospital? These are examples of unmet care needs. Once I compiled a list of unmet needs, I sent that list to all patient participants for review, comment, and validation in a letter mailed on December 10, 2022. Five families responded via email to that letter with expressions of gratitude and encouragement. No negative responses were received.

The **third** goal is to develop a constructive response. A constructive response to these unmet needs was provided and tested through the implementation of the pilot Congregational Health Network.

The **fourth** goal is to implement a plan. The FICA tool assesses connections to a faith community. If the patient identified with a community of faith and gave me permission to visit that community, I attended worship at the next available opportunity. I introduced myself to the pastor, deacon, or imam to request a follow-up appointment to explain the CHN pilot in more detail. I revealed NO patient information. From these visits I developed a list of faith communities interested in participating in the pilot. Multiple meetings followed with various stakeholders and committees in each organization to fully understand the CHN and to discern the specific role of each collaborator. Concurrently, I raised $30,000 (from family and former parishioners) to fund Opportunity Grants designed to offset any costs a collaborator might incur in joining the CHN and to encourage the development of a healthcare project specific to their community. A written covenant was made between the clinic and the congregation confirming what each party would provide to support the other.

Assessing the outcome is the **fifth** step. It took more than five years for Gunderson and Cutts to produce detailed outcome data for the Memphis Model. The CHN pilot aims to demonstrate that the network can respond to unmet patient needs, documenting sufficient value for the hospital to make a long-term commitment to utilize and expand the CHN. I measured the frequency of use of network resources by patient families and assessed the impact of this support. After confirming the covenant partners, a bi-monthly resource sheet was given to each clinic patient detailing the available services and contact information for each congregation. This sheet includes a QR code to the Red Cap system which patients can upload through their phone each time they access a congregation resource so that utilization is tracked. Collaborators are evaluating their experience with bi-monthly meetings with the author.

This paper unfolds according to the following outline.

I. Introduction: A Question Becomes a Calling

This chapter presented the encounter that inspired this project, the research questions, design, and methodology.

II. Will You Let This Stand?

Both the Memphis Model and the pilot CHN seek to demonstrate that social drivers of health create barriers to equitable healthcare; that removing these barriers is a matter of justice; that a CHN is a viable model for breaking down these barriers, thereby beginning the process of weakening structural racism in a specific hospital context. This section will offer a definition of structural racism and trace its development in healthcare in the United States. The impact of structural racism in the treatment and care of SCD patients will receive particular emphasis.

III. My Sorrow is in My Blood

This chapter will explore the theology of blood in the Bible and the relationship between blood, blessing, curse, and purity. This discussion will be informed by scholars who draw comparisons between the Old Testament (life sustaining) and New Testament (purity vs. impurity) understandings of the function and power of blood. Atonement through sacrifice and the Eucharist will also be addressed. Passages of particular interest are Genesis 4:10-11, Leviticus 17:10-11, John 6:53-56 and Acts 17:26-28. I will also provide a response to Brandon's question, "Pastor Pat, why has God cursed me?"

IV. What Clinicians Don't Know: The Potential for Spiritual Care to Improve Patient Outcomes through the Congregational Health Network

This section will discuss the value of spiritual care in the clinic, especially for BIPOC patients, the healthcare outcomes resulting from the Memphis Model and other models of congregation involvement in public health.

V. A Way Out of No Way: Building the CHN Pilot This section will answer the research questions posed at the beginning of this project (applying mixed quantitative and qualitative data thematic analysis) and detail the experience of building the pilot CHN which was launched on April 17, 2023.

VI. **A Vision of an Equitable Healthcare System: The Healing Tree** This section will explore the impact, key learnings, strengths, weaknesses, and opportunities for further research from the CHN pilot. I also offer a model for more equitable healthcare that promotes healing, especially for patients managing chronic disease which can be applied beyond the SCD community.

VII. **Good Trouble** This section presents the challenges to institutionalization of the CHN within the hospital system and points to the task of re-structuring the pilot to expand its scope of service to patients.

Appendix 1 is a Primer on Sickle Cell Disease offering a current understanding of the etiology, symptoms, and available treatment for SCD. This section has been reviewed by two clinicians.

Appendix 2 contains the supporting documentation for this effort including the research interview guide.

Appendix 3 is the patient menu of the specific CHN services that were made available at the pilot launch on April 17, 2023.

Appendix 4 provides specific details on the process of collaborator engagement.

Appendix 5 is the description of the Health Navigator position. This is the job the author has been doing in building the CHN pilot. Two years of funding for this position (totaling $180,000 or $90,000 per year) must be obtained for the hospital to include this job in their permanent roster, an essential step in transitioning the CHN from pilot to program. Grant writing to fund this position is underway.

The annotated bibliography is the last section.

CHAPTER TWO

WILL YOU LET THIS STAND?

The life expectancy of African Americans is as much as six years less than that of whites. Black people are dying, not of exotic, incurable, poorly understood illnesses nor of any genetic diseases that target only them, but from common ailments that are more often prevented and treated among whites than among Black people.[1] "Medical experts of every persuasion agree that African Americans share the most deplorable health profile in the nation, by far, one that resembles that of Third World countries." [2]

"This is America, you just a Black man in this world, just a barcode, a big dawg, kenneled in the back yard, ain't life to a dog. This is America." Childish Gambino, 2018 [3]

"Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane." [4] For justice to prevail, injustice must be seen. But white people, including me, have remained stubbornly blind. The knowledge, credentials, skills, and extensive training in cultural humility that American clinicians and psychosocial providers bring to their work fuels the notion that we have transcended racism in our healthcare system. This is not true. Bias lives on. It is evident in the health outcomes of BIPOC patients and the behavior of white practitioners. Such behavior is thoughtless and often claimed to be unintentional. White people of privilege rarely notice it. But our BIPOC patients LIVE

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[1] Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Anchor Books, Random House, 2006), 3.

[2] Ibid., 20.

[3] Childish Gambino and Ludwig Goransson, *This is America* (Nashville, TN: RCA Records, 2018).

[4] Ibid., 3, spoken by Dr. Martin Luther King in Montgomery Alabama in 1965.

IT. There is a long history of structural racism in the provision of healthcare in the United States. I define structural racism as, "a system, *codified into American law*, which assigns value and power based on race, thereby *enforcing* discriminatory practices and policies that perpetuate inequity." [5] My goal in this chapter is to trace the journey that has brought us to this shameful reality and to open our eyes to the ways in which our behaviors, behaviors that are encoded in our relationships, maintain structural racism in healthcare. We begin with a summary of the present differences in health outcomes between BIPOC and white people in America.

The Fear Factor

On June 14, 2022, The JAMA (Journal of the American Medical Association) Network Open published the results of a cross-sectional analysis of 29 surveys conducted in the United States between 1963 and 2019 to assess the trends in Black-White disparities in healthcare. Just under 600,000 respondents participated in these surveys.[6] The analysis confirms that Black people in the US experience a greater burden of ill health suggesting that care is distributed inversely to need. Black individuals are more frequently hospitalized for conditions that are usually treated in a doctor's office. Black persons with hypertension are less likely to have their blood pressure controlled. Black

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[5] Julia E. LaMotte, PhD, Gerald D. Hills, MD, Khajae Henry, MSW, LSW, Seethal A. Jacob, MD, MS, "Understanding the roots of mistrust in medicine: Learning from the example of sickle cell disease," *Journal of Hospital Medicine* 17, no. 6 (2022): 495. My amendments to this definition are italicized. I believe these amendments are necessary because they emphasize an important characteristic of structural racism in that it is codified into law and policy.

[6] Samuel L. Dickman, MD, Adam Gaffney, MD, et.al., "Trends in Healthcare use Among Black and White Persons in the US, 1963-2019," *JAMA Network Open* 5, no. 6 (2022): 1, e2217383.doi:10.1001/jamanetworkopen.2022.17383, 1, accessed 11/23/2022.

people underutilize knee replacements, optimal surgery for lung and laryngeal cancers, mental health and substance abuse treatment, neurological care for complex conditions, and prenatal and postpartum care. A much greater percentage of Black than white people in the US are uninsured and more Black adults report skipping needed care because of costs.[7] The conclusion to this analysis follows.

> "Psychosocial factors, such as differences in cultural norms and Black patients' beliefs that they may be unwelcome, will face bias, or cannot trust the health care system may reduce their care-seeking and healthcare use. Some medical practitioners' implicit racial bias may cause them to make fewer needed referrals to specialists. Finally, the paucity of Black medical practitioners may also discourage Black patients from complying with recommendations for follow-up visits, testing and other care."[8]

The authors suggest that the current situation can be improved by taking these actions: training more Black healthcare professionals, increasing investments in health facilities serving Black patients, and implementing universal health coverage that eliminates cost barriers. The authors acknowledge that the Affordable Care Act (2010) has made health insurance available to many Americans, but it is not universal health coverage.[9]

Alyson Capp adds to the body of health inequity evidence through her 2021 study of racial disparity in infant mortality. "In the US Black infants die at twice the rate of their

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[7] Ibid., 6-7.

[8] Ibid., 8.

[9] The ACA, 42 U.S.C. 18116, Pub. L. 111-149, title I section 1101, March 23, 2010, extended health insurance to 35M Americans since its passage on March 23, 2010. Presently 27M Americans remain uninsured. These citizens are BIPOC, non-elderly adults in families where at least one person is working full-time, but not for an employer that provides health insurance. The ACA also prohibits discrimination based on race, color, national origin, age, disability, pregnancy, sexual orientation, and gender identity in covered health programs including insurance. Fact Sheet: March 18, 2022, Celebrating the ACA, US Department of Health, and Human Services. hhs.gov/about/news/2022/03/18/fact-sheet-celebrating-affordable-care-act.html., accessed December 14, 2022.

White counterparts. Black mothers identify violence and stress as the predominant barriers to healthy pregnancies and birth outcomes." [10]

These circumstances exist, in part, because of the long history of medical mistreatment of Black Americans, so profound, that medical ethicist Harriet Washington has coined a novel word for a diagnosis specific to the BIPOC community: *iatrophobia*. The term originates from *iatro,* the Greek for healer, and *phobia*, the Greek for fear. Black *iatrophobia* is the fear of medicine.[11] Those who suffer from *iatrophobia* are much less likely to seek healthcare and therefore less likely to obtain any benefits from it. These fears are legitimate, and evidence based. White people know little about the history of medical mistreatment to the BIPOC community. We think of the Tuskegee Syphilis study and the misuse of Henrietta Lacks' cells as the most egregious examples. There is so much more to consider. *Iatrophobia* is rooted in our history and plagues us even now. Slavery is the mother of *iatrophobia* and the sin from which we may never heal.

Slavery and the So-Called "Inferiority' Gene

The White Lion was the first slave ship to land in the Colonies from Africa. It arrived in Jamestown, VA in August 1619.[12] There is no accurate count of the number of people that were on board. But one thing is certain. If any of the captives suffered with an

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[10] Alyson Isaksson Capp, "They Make You Feel Less of a Human Being: Understanding and Responding to Milwaukee's Racial Disparity in Infant Mortality," *Maternal and Child Health Journal* 26, no.4 (November 2021): 736 and 739.

[11] Washington, *Medical Apartheid*, 2.

[12] The last recorded arrival of a slave ship in American was the Clotilda which made port in Mobile, Alabama on July 9, 1860. Over 388,000 slaves were shipped to America between 1619 and 1860. For more information see Henry Louis Gates, Jr., "100 Amazing Facts About the Negro: How Many Slaves Landed in the U.S.?." *The African Americans Many Rivers to Cross,* PBS, (2013), 1.

illness or got sick on the ship, treatment was immediate and severe. The crew simply threw them overboard. There was no reason to expect better care once on dry land.

Enslaved persons were chattel property, essential to the maintenance of an economic system built on the premise that no one needs to pay for their labor. The value of an enslaved human being was based on one's ability to work wherever the owner deemed necessary as long and as hard as life and breath would allow. Should one become ill, the owner decided to call a doctor or not. The deciding factor was always whether the enslaved person might continue to work; the slaveowners wanted to protect their investments. There was no consideration of preventative medicine, rest, proper housing, clothing, or nutrition. "As far back as the 1600s Black/African Americans were traumatized and abused by the medical profession. During slavery Black bodies were volunteered by slave owners for physicians' experimental treatments, paraded in surgical theaters, and stolen from graveyards for dissection.[13] A relative or friend familiar with traditional herbal and natural healing arts was the primary source of treatment. This experience lives in the memories of BIPOC patients at the root of their assumption that as far as healthcare goes, they must solve their problems on their own. [14] Most enslaved persons never met a doctor in their lifetime.

As the abolitionist movement gained momentum, it became important for the advocates of slavery and slave owners to find a justification, other than the color of one's

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[13] Nicole Rockich-Wilson, et. al., "All Patients are Not Treated as Equal: Extending Medicine's Social Contract to Black/African American Communities," *Teaching and Learning in Medicine* 34, no. 3 (2022), 239.

[14] This assumption was evident to me in clinic interviews. For example, all SCD patients that I interviewed assumed that they must have a sibling bone marrow donor if they chose and were eligible for a bone marrow transplant, the only cure for SCD. This is not true. A sibling match is more likely to be a higher percentage, but it is entirely possible to secure a viable match that is not a blood relative.

skin, to continue to oppress BIPOC people. Scientists were keen to respond to the challenge. French intellectual George-Louis Leclerc, Swedish naturalist Carl von Linne, and American physicians Samuel George Morton, Josiah Clark Nott, Louis Agassiz, George Robins Gliddon, and Samuel Cartwright advanced the theory that skin color indicated an entirely distinct species of persons with different origins as well as distinct characteristics for Black people and whites.[15] Those who advocated this theory were polygenists. They asserted that Black people were physically inferior, biological liars, malingerers, hypersexual and indolent. Cartwright discovered and devised a list of imaginary Black diseases such as 'Hebetude Drapetomania" which is chronic laziness that results in the mishandling of the owner's property.[16] Nott and Gliddin published "Types of Mankind" which claims that Blacks' physical and mental differences prove their inferiority.[17] Enslaved persons were seen as scarcely more than beasts of burden. Beasts were used and abused in any way by their owners, not limited to the use of their bodies as fodder for science.[18]

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[15] Washington, *Medical Apartheid,* 34.

[16] Ibid., 36.

[17] Ibid., 37.

[18] One despicable example of Black body abuse is the work of James Marion Sims, MD of Alabama. Sims is a hero in the history of medicine for developing the surgical procedure that repairs vesicovaginal fistula, a tearing of the vagina, bladder and rectum which occurs far too often in unassisted childbirth. Sims purchased eleven enslaved women, free of the condition, and performed surgical experiments on them, without consent, anesthesia, or anti-biotics for four years to perfect his technique. The women held each other down during repeated procedures. Eventually, Sims administered morphine to ease the women's' pain. This gave him another advantage. By addicting his patients to morphine, they remained submissive. "In 1852 Sims' published his paper on vesicovaginal fistula repair in the American Journal of the Medical Sciences. It made his national reputation as the father of modern gynecology." See Washington, *Medical Apartheid*, p.66.

Dead Black bodies also proved useful in medical training. In December 1882 Dr. William Forbes, chief anatomist of Jefferson Hospital in Philadelphia was charged for paying two so-called 'resurrection men' $8.00 each for 150 bodies a year. When asked how he acquired the bodies, Dr. Forbes was careful to note under oath that he practiced a strict "don't' ask don't tell policy." The two Black resurrection men identified their source as the Lebanon Cemetery in Philadelphia, the Black burial ground. They each received a 10-year prison term. Dr. Forbes was acquitted.[18] Please remember that these bodies were exhumed and dissected

Following the Emancipation Proclamation and the Civil War, many hospitals and physicians refused to supply medical treatment to Black patients until Congress intervened with the passage of the Freedman's Bureau Acts of 1865 and 1866. President Andrew Johnson vetoed this legislation three times. Overrides occurred on two occasions, but the legislation expired in 1868 and with it the hope of establishing any equitable standards of care during Reconstruction. The Dred Scott decision (Dred Scott v. Sandford, 60 U.S. 393(1856)), decided before Reconstruction, denied the legality of Black citizenship in America thus severely limiting opportunities for legal redress of inequities. Attempts were made to codify equitable treatment into law. This was and continues to be a one-step forward, two-steps back process. Whatever legislation promotes equity and manages to become law, is often weakened in the judicial system.[19]

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without the knowledge of or consent from the patient, before death, or next of kin after interment. See Washington, *Medical Apartheid*, p. 133.

[19] The following examples of this assertion are illustrative. In September of 1787 Article 1 Section 2 Clauses 3-8 of the US Constitution formed the 3/5 compromise indicating that "slaves are referred to as such persons or person held to service in labor. 3/5 of each states' enslaved population is added to the free population" to determine the number of representatives to which each state was entitled in Congress. It is difficult to see this provision as anything but a re-definition of an enslaved person's value as 3/5 of a person. In 1857 the Supreme Court ruled in Dred Scott vs. Sandford that African Americans are not entitled to US citizenship even if they are born in the US. In 1863 slaves were freed in the US according to the Emancipation Proclamation. In the same year General William T. Sherman collaborated with Black clergy in Savannah, GA to give farmland and an Army surplus mule to formerly enslaved families. 400,000 acres were cultivated before President Andrew Johnson rescinded the order in the Fall of 1865 and demanded that the freedmen vacate their farms. On December 6, 1865, the 13th amendment to the US Constitution ended slavery in the US EXCEPT as punishment for a crime. The 1866 Civil Rights Act declared that all persons born in the US are entitled to equal protection of the law. On July 9, 1868, the 14th amendment to the Constitution rescinded the Dred Scott decision and established the principle of one man one vote. On February 5, 1870, the 15th amendment explicitly gave Black men the right to vote. The Civil Rights Act of 1875 outlawed discrimination in juries, schools, transportation, and public accommodation. In 1883 the Supreme Court declared this same legislation unconstitutional in the Civil Rights Cases (109 U.S. 3, S. Ct 18,27 L. Ed 835 (1883). The Supreme Court case of Plessy v. Ferguson (163 U.S. 537, (1896) established the principle of 'separate but equal' in the provision of public services. In 1920 white women were given the right to vote. In 1945 President Harry S Truman advanced a proposal to provide pre-paid medical insurance for all Americans. A horrified Congress seized on one part of Truman's proposal to build new hospitals in the US. During the post WWII period 40% of the counties in the US had no hospital. The Hill-Burton Act of 1946 was carved out of Truman's proposal and appropriated $75M for new hospital construction. Truman also intended that separate hospitals for BIPOC people, a tradition in the US since

Now that Black Americans were ‘free’ the scientific narrative necessary to perpetuate the myth of Black inferiority needed revision. “Medicine had once justified slavery on the basis that Blacks were heartier than whites and so were ideally suited to survive and to work in extreme climates that would have meant death to whites. Now it was African Americans who were too delicate to survive.” [20] According to this myth, Black Americans simply did not have the energy, fortitude, imagination, intelligence, and resilience necessary to navigate life as free persons. Scientists were on alert to identify and prove the existence of Black diseases and maladies that would point to the frailty of these people from birth. Thus the ‘science’ of eugenics met the challenge. The term, *eugenes,* means ‘well born.’ Eugenic scientists and their disciples constantly confused the concepts of biological hereditary fitness with those of class and race, seeking always to establish a

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1832, be abolished. To ensure Southern votes for Hill-Burton, that provision was removed. Instead, it was explicitly stated that patients could be segregated according to the separate but equal formula. In 1954 the Supreme Court ruled that the principle of separate but equal established in Plessy was unconstitutional in Brown v. Board of Education (347 U.S. 483 (1954). In the summer of 1964, the second Civil Rights Act was passed which ended segregation in public places and banned employment discrimination based on race, color, religion, sex, or national origin. In 1965 the Voting Rights Act finally gave the vote to Black women, banned the use of literacy tests, and provided federal oversight of voter registration, authorizing federal authorities to investigate the use of poll taxes and other practices designed to prevent persons from voting. In 1974 the Supreme Court ruled in Milliken v. Bradley (418 U.S. 717 (1974) that schools may not be de-segregated across school districts, but segregation of inner city and suburban districts is legal (paving the way for bussing as a method to achieve equity). The Violent Crime Control and Law Enforcement Act of 1994 created the 3 strikes mandatory life-sentencing rule, provided funds to hire 100,000 new police officers, provided $9.78B to build prisons, expanded the death penalty, stopped Pell Grants for prisoners who want to do college level study, established the rule that one conviction for a crime can cause you and your family to be evicted from public housing and allowed 13 year-olds to be tried as adults. The fear of super-predators, a termed coined by Princeton professor John Dilulio in the 1990s, refers to persons who have a genetic pre-disposition to violent crimes. The fear stoked by this label was one impetus for this legislation. Dilulio’s theory was later widely discredited. In 2013 the Supreme Court struck down section 4 of the Voting Rights Act of 1965 in Shelby County v. Holder (529, 133 S.Ct. 2612, 186 L.Ed. 2d 651 (2013) so that Federal review is no longer necessary for states to change voting rights. The beat goes on.

[20] Washington, *Medical Apartheid,* 153.

connection between race, inferiority, and illness. An opportunity came early in the 20th century.

SCD and the Myth of the Black-Only Disease

In 1904 Walter Clement Noel, a Black dental student from Grenada presented to the Presbyterian Hospital in Chicago with excruciating pain. Dr. Ernest Irons, an intern to cardiologist Dr. James Herrick, took Noel's medical history and a blood sample. Under a microscope Irons saw pear and crescent moon-shaped red cells in Noel's blood. Herrick published the results of the blood test, identified it as Herrick's anemia and speculated that people of African descent were the only victims of this mysterious ailment.[21] Noel completed his dental degree and practiced in Grenada for 8 years until he died at the age of thirty-two. His cause of death, Herrick's anemia, soon became known as sickle cell disease.

> "This disease affects millions of people worldwide, everywhere malaria is found. The common denominator of sickle cell disease is not race but living in proximity to the malaria-bearing Anopheles mosquito. Possessing the gene for SCD affords protection against some forms of malaria. White people also get sickle cell disease, often mis-diagnosed as a related blood disorder. This was tantamount to the discovery of an occult Black biological heritage, rather than simply a case of the disease had it been identified in a white person. However, within a decade of its identification, the erroneous belief that SCD strikes only Black people became firmly entrenched, thus reinforcing the belief in the inherent inferiority of African Americans."[22]

Dr. Linus Pauling first identified the precise genetic trait for SCD in blood hemoglobin in 1949. A person must carry two of the SCD genes, one from each parent, to

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[21] Keith Wailoo, *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health* (Chapel Hill and London: The University of North Carolina Press, 2001), 4.

[22] Washington, *Medical Apartheid*, 156.

develop the illness. If both parents carry the trait their child has a 50% chance of having the trait and a 25% chance of having the disease. Those who carry the SCD trait never develop the disease. A patient managing SCD can live to be a senior citizen with informed management of this chronic illness. McNeil Laboratories ignored these facts and seized on SCD as an opportunity to develop a screening test that revealed the presence of the trait, but not whether the disease was present.

The National Sickle Cell Anemia Control Act of 1972 advanced McNeil's screening test. This legislation also provided $5 million for SCD research sponsored by the National Institutes of Health. It was not widely known, however, that this was not an increased appropriation. President Nixon re-directed funds from hypertension research which impacts more BIPOC people than SCD.[23] It was hoped that publishing this re-allocation of funds would increase Black voters' support for President Nixon and southern white Republican congresspeople. There is no proof that this action achieved that objective. What is clear is that shedding new light on SCD resulted in consequences for the BIPOC population. The image of SCD as a Black disease carried connotations of inferiority. It underscored pronouncements from the medical establishment which suggested that Black population control might be an appropriate response to SCD. This statement from Dr. Pauling in a 1968 UCLA Law Review article illustrates the point. "I have suggested that there should be tattooed on the forehead of every young person a symbol showing possession of the sickle-cell gene or whatever other similar gene…. If this were done, two young people carrying the same seriously defective gene in a single dose would recognize

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[23] Wailoo, *Dying in the City of the Blues,* 193.

this situation at first sight and would refrain from falling in love with one another."[24] "The notion of publicly labeling carriers and controlling their childbearing in the name of public health had become respectable."[25] When screening revealed the presence of the trait, persons received a brochure and one piece of advice: you should not have children. Physicians recommended abortion to pregnant women who had the trait.

In 1973 the US Air Force Academy (USAFA) banned admission, after mandatory SCD screening, to applicants with the SCD trait. Commercial airlines followed suit, refusing jobs to pilots and co-pilots with the trait. In a 1980 article in *The Nation*, Richard Severo asserted that the DuPont Company tested its Black employees for the sickle cell trait and used the results to screen for employment.[26] In response to a lawsuit brought by USAFA Cadet Stephen Pullens, who was expelled from the Academy when he tested positive for the SCD trait, the USAF ended these sanctioned practices in 1981.[27]

It is a harmful misunderstanding that carrying a gene for a disease means that you have the disease. But this illustration is a cautionary tale as we become more able, through such advances as the Human Genome Project, to appropriate science for whatever social construct we wish to maintain. The National Sickle Cell Control Act did not produce an SCD cure or improvements in the remediation of pain and suffering. It did, however,

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[24] Ibid., 186.

[25] Ibid., 187.

[26] Ibid., 136, 218.

[27] Pullens filed suit against the USAF Academy in November 1980 in the US District Court in Minneapolis. The Air Force responded by dropping its ban on students who had the SCD trait on February 3, 1981. The case was settled out of court. There is no public record of Pullens graduating from the academy.

convince many Black Americans that they could be denied employment, health insurance and reproductive rights if they tested positive for the trait.

The following section provides additional illustrations of structural racism in the treatment of SCD patients, underscored by a comparison to patients with Cystic Fibrosis (CF).

SCD and the Healthcare System in the United States

Dr. Charles F. Whitten founded the Sickle Cell Disease Association of America in 1971. This organization remains active today providing educational materials and patient services in 30 states in the US. Its annual funding is miniscule; $4.2 M consisting of $2.9M from a federal grant with the remainder being sourced by local agency fundraising. SCD research has continued under the National Heart, Lung, and Blood Institute (NHLBI). These initiatives have contributed to increased public awareness of SCD.[28] Yet securing research funding remains a challenge. In 2018 Congress passed and President Trump signed the Sickle Cell Disease and Other Heritable Blood Disorders Act. Although celebrated, the Act provided less than 50% of the funds authorized for the same program in 2004.[29] SCD research funding is lower than that provided through the NHLBI for other inherited diseases. When compared to Cystic Fibrosis, between 2008 and 2018, SCD and CF received a similar amount of federal government research

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[28] Damilola Ashorobi and Ruchi Bhatt, *Bone Marrow Transplantation in Sickle Cell Disease*, (Treasure Island, Florida: StatPearls Publishing, 2021), 2.

[29] Gary L. Freed, “A Missed Opportunity to Address a National Shame,” *JAMA Pediatrics* 173, no. 8 (2019):715, doi:10:1001/jamapediatrics.2019.1536.

funding. Yet, SCD is 3 times as prevalent as CF which almost exclusively impacts white children.[30]

SCD and CF do share a common characteristic in hospitalization patterns; about 80% of the healthcare costs associated with each condition is spent on hospital care.[31] In 2012 people with SCD had the highest number of hospitals stays, with four or more stays in 12 months consisting of 57% of all hospital stays for Medicaid super-utilizers."[32] "Another study identified that 6 of the 18 unique SCD patients accounted for more than 50% of the emergency department (ED) visits and 40% of hospitalizations while 60% of patients visiting the ED did not have a primary care provider or individual health care plan."[33] The annual cost for the treatment of SCD in the US exceeds $2.5 B.[34]

In many states in the US metabolic newborn screening includes SCD, since symptoms can present as early as 5 months of age. The use of penicillin as a prophylactic for SCD patients under 5 years of age and the use of Doppler screening to assess for stroke were recommended additions to the Centers for Medicare and Medicaid Services (CMS) core set of 25 pediatric quality measures in 2018. CMS ignored the almost

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[30] Faheem Farooq, MD. et.al., "Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated with Research Productivity," *JAMA Network Open* 3, no. 3 (2020): 3, doi.10.1001/jamanetworkopen.2020.1737.

[31] p.4.

[32] Jill Brennan-Cook, et. al., "Barriers to Care for Persons with Sickle Cell Disease: The Case Manager's Opportunity to Improve Patient Outcomes," *Professional Case Management*, 23, no. 4 (2018):217, doi.org/10.1097/ncm.0000000000000260.

[33] Robin R. Leger, et.al., 'Stigma in adults with sickle cell disease and family members: Scale development and pilot study in the USA and Nigeria," *International Journal of Africa Nursing Sciences* 9 (2018): 24, doi.org/10.1016/j.ijans.2018.06.003.

[34] Miriam O. Ezenwa, et.al., "Coping with Pain in the face of Healthcare Injustice in Patients with Sickle Cell Disease," *Journal of Immigrant and Minority Health* 19, no.6 (2016):1449, doi.org/10.1007/s10903-016-0432-0.

unanimous recommendation (19-1) of the Pediatric Measure Application Partnership (P-MAP) and declined to include these measures. These measures have not yet been added to the core set. Gary L, Freed, MD, MPH calls this omission "a national shame, (an example of) the poor state of care provided to children with SCD."[35] Furthermore, "direct evidence of racial inequities in the quality of treatment for children with SCD is not available in the current literature, likely because of the low prevalence of SCD in those who are not Black."[36]

Although CF and SCD patients both experience frequent hospitalizations, these patients do not have an equivalent experience. "Consideration of SCD as a black disease in the United States has permeated the hospital experience for patients since the first description in the Western medical literature. The interaction of Black individuals with the healthcare system is associated with distrust between patient and practitioner which can lead to conflict resulting in suboptimal medical care and worsening patient medication adherence."[37]

Individuals with SCD face many obstacles to receiving care, but stigma is one of the most challenging. In a recent study 96.4% of the SCD patients comprising the study sample endorsed experiencing episodes of racial bias and health-related stigma; half believed that race influenced the poor quality of healthcare they received. Youth with

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[35] Freed, "Missed Opportunity," 715.

[36] Lanetta Bronte' Hall, et. al., "Real-World Clinical Burden of Sickle Cell Disease in the US Community Practice Setting: A Single-Center Experience from the Foundation for Sickle Cell Disease Research," *Blood,* 134 (2019):780, doi.org/10.1182/blood-2019-128700.

[37] Faheem Farooq, MD., et. al., "Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated with Research Productivity," *JAMA Network Open,* 3, no. 3 (2020): 7, doi:10,1001/jamanetworkopen.2020.1737.

SCD who experienced more perceived racial bias and health-related stigma also experienced greater pain burden.[38] In a 2018 systematic review of the literature on the stigma of SCD, researchers Dominique Bulgin and Paula Tanabe conclude:

> "Stigma of SCD is a pressing health concern. Factors that contribute to stigma include disease status, pain and opioid use, racism, disease severity and sociodemographic characteristics. Stigma stems from institutions, healthcare providers, general public, family, and friends. Current literature surrounding stigma in SCD reveals that stigma has detrimental consequences for individuals with SCD including negative social consequences, impairing healthcare interactions, and hindering physiological and psychosocial well-being." [39]

Finally, a study conducted in 2020 explored the application of spiritual care and religiosity as a support and coping strategy for depression in chronic illnesses, highlighting SCD. The authors define religiosity as the use of individual values, beliefs, practices, and rituals related to faith. Spirituality is akin to religiosity, but is viewed as an individual, not a communal practice. The authors found only one prior study that explored the relationship between spiritual care and coping.[40] It concluded that patients who talk to God or family and friends about their SCD pain had positive psychological adjustment, were more likely to seek care and exhibited lower awareness of disease stigma. No studies were found that proposed spiritual support or religiosity to cope with SCD-related depression; these elements were never considered. The study concluded that

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[38] Emily O. Wakefield, et. al., "Perceived Racial Bias and Health-Related Stigma Among Youth with Sickle Cell Disease," *Journal of Developmental and Behavioral Pediatrics* 38, no.2 (2017):133, doi.org/10.1097/dbp.0000000000000381.

[39] Dominique Bulgin, et. al., "Stigma of Sickle Cell Disease: A Systematic Review," *Issues in Mental Health Nursing* 39, no.8 (2018): 686, doi.org/10.1080/01612840.2018.1443530.

[40] VJ Derlega et. al., "How patients' self-disclosure about sickle cell pain episodes to significant others relates to living with sickle cell disease," *Pain Medicine* 15, no.9 (2014):1496-1507, doi:10.111/pmc.12535.

spiritual support and/or religiosity present a valid option for healthcare providers to intervene in treating SCD, [41] thus providing encouragement for this CHN pilot.

Ethics for All?

The American healthcare system leads the world in many disciplines. It makes advances through research that is dependent upon willing participants who want to make a positive difference in their own lives and the lives of others. We have demonstrated, through several cases in our history, that BIPOC people are not always assured of exercising voluntary participation in and receiving informed consent for such research. BIPOC prisoners have been particularly vulnerable. We appear to believe that once you are in debt to society, your human rights (including volunteering for a study and clearly understanding the purposes and the risks) evaporate.

The assumption that these rights are available for purchase guided the medical experiments in dermatology at the Holmesburg Prison directed by University of Pennsylvania physician Dr. Albert Klingman. Between 1951 and 1973 Dr. Klingman used prisoners, the majority of whom were BIPOC, to assess the burn tolerance and injury recovery timeline of human skin. He inflicted wounds of varying depth and severity and applied an array of medicines, lotions, shampoos, topical creams, and remedies to his subjects without informing them of side effects. In addition, he freely evaluated drugs to treat Hepatitis C on these individuals again without discussing risks, long and short-term impact. Although his subjects received payment, dozens were mutilated and sickened.

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[41] Delores P. Quasie-Woode, et.al., "The Use of Religion in the Management of Depression in Sickle Cell Disease: A Systematic Review," Journal *of Religion and Health* 59, no. 6 (2020): 3112 and 3122, doi.org10.1007/s10943-020-01039-y.

When large numbers of subjects suffered permanent injuries and side-effects from the work of Klingman and others, it was determined by prison, state, and local elected officials that controls must guide these studies.

In 1973 Senator Edward Kennedy responded with hearings that led to the establishment of the National Commission for the Protection of Biomedical and Behavioral Research (CPBBR). These hearings and the task forces resulting from them produced the Belmont Report (required reading today for every Drew student doing research) and the Institutional Review Board (IRB) process. The existence of these rules that outline informed consent, voluntary participation, and other pillars of ethical research are helpful and necessary. The fact that they exist does not guarantee their application in practice. Our skewed values make us hard-pressed to see the plank in our own eyes, oblivious to the assumptions and the omissions we make. “Father, forgive them, for they do not know what they are doing.” (Luke 23:24, NRSV) Not yet. We know what we are doing because it is what we have always done. Practitioners often assume that the legal system will protect them when they overlook best practices. The case of Johnson vs. Columbia University is one example that illustrates this point.

Intentional Unintentionality or Unintentional Intentionality?

During the civil rights era, Title VI of the Civil Rights Act of 1964 became the weapon of choice in the fight to dismantle segregation.[42] Title VI prohibits discrimination and/or the denial of benefits provided by federal funding to any person based on their

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[42] Dayna Bowen Matthew, *Just Medicine: A Cure for Racial Inequality in American Healthcare* (New York: New York University Press, 2015), 11.

race, color, or national origin by permitting two types of lawsuits: (a) disparate **impact** claims where the plaintiff alleges that an organization's **policy** has a disproportionately adverse effect on minorities; and (b) disparate **treatment** claims where the plaintiff proves that the **defendant's discriminatory acts were intentional**. But by 2001 the hope that Title VI brought was beginning to wane as the Supreme Court declared in Alexander v. Sandoval (532 U.S.275 (2001) that private parties may not bring disparate impact claims based on **unintentional** discrimination. "I didn't realize, I didn't know, I didn't mean to" became acceptable defenses for racist actions and practices. This was the conclusion of the courts in *Johnson v. Columbia University*, No. 99 Civ. 3415 (GBD) (S.D.N.Y. Mar. 28, 2005). In the search for the super-predator gene invented by Princeton Professor John Dilulio, researchers at Columbia University ignored the principles of ethical research to administer a drug to 156 Black and Hispanic boys (each had a sibling in the penal system) intended to reveal the presence of a genetic pre-disposition to violence. When their son emerged from the experiment forever diminished and wounded the Johnson family sued the university. Although the court ruled that the actions of the researchers were sufficient to demonstrate discriminatory intent, their actions were deemed unintentional.[43] It is very difficult for me to see how the demonstration of discriminatory intent results in actions being deemed unintentional.

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[43] Between 1992 and 1997 New York City's New York State Psychiatric Institute and Columbia University's Lowenstein Center for the Study and Prevention of Childhood Disruptive Behavior Disorders conducted studies that sought to establish a link between genetics and violence. (This work occurred while Princeton Professor Dilulio brought forth his theory of 'super predators.') The Columbia researchers performed experiments on at least 156 boys. The IRB-approved protocol specified that eligible participants must be African American or Hispanic. The researchers selected subjects whose older brothers had contact with the probation system. The researchers claimed that the drug fenfluramine could suggest a genetic basis for aggressive or violent behavior in boys. The FDA banned this drug in 1997 as a cardiotoxin. A 2004 study revealed that fenfluramine may trigger behaviors such as increased aggression. (Washington, 278) If this study indicated the presence of a genetic link to destructive behaviors, any efforts to address the impact of the social determinants of health would be discredited and diminished, proving that Eugenics is alive and

The quote that follows from attorney Dayna Bowen Matthew summarizes the inequitable state of healthcare access and quality where the shameful treatment of the Johnson family, and so many others, flourishes. Unlike the Johnsons, many do not have the confidence, courage, or resources to hire counsel to ask for the right to privacy and the simple courtesy of being told the truth by physicians and researchers.

It is fair to say that today Americans share a collective belief that racial and ethnic discrimination is morally wrong. However, we divide along racial lines on the question of whether, despite this belief, racial and ethnic discrimination does in fact continue to occur today and whether one's race or ethnicity matters in 21st century America. Americans

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well in the 20th and into the 21st centuries. "Locating BIPOC violence in the genetic complement of BIPOC boys nourished excuses to abandon social therapeutic approaches. What good is better education, nutrition, safe, clean housing, social and psychological support and a more nurturing home and school environment to a born monster?" (Washington, 283)

Columbia University researchers recruited six-year-old Isaac Johnson to participate in the Fenfluramine study. They explained (to his parents) that Isaac would go to the hospital for a series of interviews and tests culminating in a onetime overnight stay to determine if he had any medical problems. His parents received a $125 one-time payment and Isaac received a Toys R Us gift card. Isaac's mother Charisse Johnson signed the consent not knowing how the researchers got her name, that fenfluramine would be administered to Isaac, that prior to this experiment the drug had never been administered to anyone under the age of 12 years, that no white children would be recruited for the study or that Isaac was at risk to develop behavioral changes and even heart problems from the drug. When severe consequences of the administration of fenfluramine appeared in Isaac (headaches, anxiety attacks, hyperventilation, nightmares, and aggressive behavior) the Johnsons sued the City of New York, Columbia University, the researchers, and the Columbia University Office of Protection from Research Risks (OPRR).

In Johnson V. Columbia University, *Johnson v. Columbia University*, No. 99 Civ. 3415 (GBD) (S.D.N.Y. Mar. 28, 2005) the Johnson family made 5 claims: (1) that by specifically excluding white children from the study, Isaac was deprived of his equal protection rights under the 14th amendment; (2) that the City of New York violated Isaac's privacy and (3) his brother's privacy by releasing information on his brother's incarceration; (4) that the selective and discriminatory administration of fenfluramine to the African American and Hispanic boys in the study violated their constitutional rights and (5) that the researchers engaged in medical malpractice against the children. The Court ruled that Columbia did not engage in purposeful and systematic discrimination, neither were they responsible for the conduct of their employees. Columbia did not have a policy, patterns or practice that caused the alleged injury. *However, the court did rule that the actions of the researchers were sufficient to demonstrate discriminatory intent.* The court rejected the privacy claims due to lack of standing because the injured party under the law was Isaac's brother, not Isaac. The court dismissed their claims of violation of Constitutional Rights and medical malpractice. However, the court did uphold a claim of negligence and breach of statutory duty to obtain informed consent against the scientists who conducted the study. The failure of the Johnsons to obtain any relief centered on the weakness of their case in making a connection between a constitutionally protected liberty that has been interfered with by the state and the process through which the interest was denied. The Johnsons' suffering was not overt, intentional, authoritative, or conspiratorial. The actions of the researchers demonstrated discriminatory intent but were not intentional. Drs. Pine and Wasserman who were affiliated with the NY State Psychiatric Institute settled in the amount of $400,000 with the Johnson family on May 5, 2009. In exchange all claims against the defendants were dismissed with no admission of liability.

> who are members of minority groups all report varying degrees that race still matters and that race discrimination, in their personal experience is alive and well. Surveys show that few whites, on the other hand, believe that race is an important consideration in American life. Even fewer whites believe that discrimination continues to occur. Physicians and other health providers contribute to disparate treatment of disease and sickness between majority and minority patients without even knowing they are doing so and without any intention or awareness that they hold racially skewed viewpoints." [44]

This is America

Recently a father brought his son to the SCD clinic where I serve so that his son might have his prescribed blood transfusion. After the boy was settled in the treatment room, his father situated himself in a corner of the waiting area and re-lived, aloud, a disagreement he had with his wife that morning. He swore at the walls and cried openly. There is no question that his conduct was inappropriate in that setting. He did not confront anyone. He just pulled his hoodie over his head, swearing and weeping.

A hospital worker was unnerved by his conduct and instead of approaching him to ask if he was OK or what might be done to help him, the worker began an internet search. It was discovered that as a juvenile an abuse complaint was made against this parent which was posted on the sex offender register. Although the offense was eligible for expungement, the hospital worker called security. The father was told that he would need to have a security escort from now on to bring his son to the hospital.

When I was able to talk with this father, he told me about the challenges he faces in caring for his 8 children and that our clinic had broken his spirit; he felt no better than a dog; his life seemed worth nothing more than a number. As an artist, he mentioned that the work of Donald Glover, a.k.a. Childish Gambino inspires and speaks truth to him. Therefore, an excerpt from Gambino's "This is America" is quoted at the beginning of

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[44] Matthew*, Just Medicine*, 31-32.

this chapter. I am not aware of any action taken to educate the person who decided to do the internet search. But I am sure their actions were 'unintentional.'

It must be said that conversations among the clinic team revealed a deep sorrow that this encounter took place. I believe that our practitioners in every discipline want to help all people. But when these entrenched, biased behavior patterns emerge, we are strangely unable to talk with each other about it, to ask helpful questions and to work to change such behavior as a team. We suffer from *dialogus phobia* (fear of honest conversation). So, we refer these situations to the Human Resources department, further separating ourselves from each other. This reality is a sorrow.

During the conversation with Brandon that started my journey he said, "Pastor Pat, my sorrow is in my blood." A fellow student, who works with persons managing HIV, and I composed this poem in which we tried to express the pain of the patients we serve.

> *My sorrow is in my blood, from birth and from life lived.*
> *I have seen the death of those I love, and I pray for the day when I'm not cursed.*
> *From where does my help come?*
> *I know what I must do but cannot always follow through.*
> *There is stigma, there is shame, there is no money, no time, no way.*
> *I am alienated and erased.*
> *Because my sorrow is in my blood.*[45]

We must consider the fact that amid his pain, the question Brandon chose to ask is "Why has God cursed me?" It implies the existence of a Divine perspective on human suffering from physical maladies. Has God cursed the bodies and blood of some of God's children? Is the sorrow we face located in our blood? Is blood life-giving, life-limiting, an

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[45] Written by Ralph Merante and Pat Weikart, July 2022, used with permission.

instrument of reconciliation or division? These theological questions are the focus of the next chapter.

CHAPTER THREE

MY SORROW IS IN MY BLOOD

“Then the Lord God formed man from the dust of the ground and breathed into his nostrils the breath of life; and the man became a living being.” Genesis 2:7

“And the Lord said, “What have you done? Listen; your brother’s blood is crying out to me from the ground! And now you are cursed from the ground which has opened its mouth to receive your brother’s blood from your hand.” Genesis 4:10-11

“If anyone of the house of Israel or of the aliens who reside among them eats any blood, I will set my face against that person who eats blood and will cut that person off from the people. For the life of the flesh is in the blood; and I have given it to you for making atonement for your lives on the altar; for, as life, it is the blood that makes atonement.” Leviticus 17:10-11

“So, Jesus said to them, ‘Very truly, I tell you, unless you eat the flesh of the Son of Man and drink his blood, you have no life in you. Those who eat my flesh and drink my blood have eternal life and I will raise them up on the last day; for my flesh is true food and my blood is true drink. Those who eat my flesh and drink my blood abide in me and I in them.” John 6:53-56

“From one ancestor he made all nations to inhabit the whole earth, and he allotted the times of their existence and the boundaries of the places where they would live so that they would search for God and perhaps grope for him and find him—though indeed he is not far from each one of us. For in him we live and move and have our being; even as some of your own poets have said.” Acts 17:26-28

“All racisms are attempts to ground discrimination, whether social, economic or religious, in body and reproduction.” [1]

“Blood was sacred before it was sacrifice. If all blood is the blood of God, the blood of my neighbor and the blood of my beast, then all blood is God with us. What if we acted that way?”[2]

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[1] Eugene F. Rogers, *Blood Theology: Seeing Red in Body-and-God-Talk* (United Kingdom and New York: Cambridge University Press, 2021), 164.

[2] Ibid., 25.

All Blood is God's Blood

Blood is fluid connective tissue essential to human life. The human body contains between 8 and 10 pints of blood. It consists of approximately 55% plasma (water, protein, ions, nutrients, and waste) and 45% formed elements (white blood cells, red blood cells and platelets). Its function is to carry essential oxygen, nutrients, and hormones to all parts of the body and to remove carbon dioxide and other waste materials. The protein hemoglobin is the bearer of oxygen in the red blood cells. 95% of human blood cells are manufactured in the bone marrow (the remainder in the lymph nodes) through a process (hematopoiesis) initiated by the release of a hormone from the kidneys. Stem cells in the marrow, which can produce every kind of blood cell, respond to this hormone, divide, and replicate as needed into red and white blood cells and platelets. This process is the same in all mammals. Different colors of blood reflect the different pigments that oxygenation creates in the blood-like fluids that circulate in all creatures. The iron in hemoglobin gives human blood its red color.

None of this information was known to ancient peoples. "Blood is one of the fluids that originate in the body in a way inexplicable to ancient man and are thus regarded as bearing secret power. Of these (fluids) blood is identified to a special degree with vitality. The belief in the enormous power of blood results in a conflicting attitude: on the one hand, man treats blood with reverential awe and surrounds it with a series of taboos; on the other hand, he hopes to make use of these powers in appropriate rites."[3] This conflicting attitude is evident in the Biblical text.

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[3] G. Johannes Botterweck and Helmer Ringgren eds., *Theological Dictionary of the Old Testament Volumes I-XVI* (Grand Rapids, MI: Wm. B. Eerdmans, 1978), III, 237.

'Dam' is the Hebrew word for blood; *'dam ha'adham,'* is the phrase meaning 'the blood of the human.' This word and phrase occur about 360 times in the Old Testament.[4] "Hebrew '*dam'* also means reddish and is the etymological basis for a people (Edom) and the ground itself (Adamah); '*dam*' speaks not just to genealogical but also to social and environmental bonds."[5] The special power of blood is illustrated in Genesis 4:10-11, above. "God's profound statement to Cain echoes even if the body is not there; blood 'cries out' for one's defense. Abel's blood stains on the ground were his identity. It was visual evidence of Cain's immoral act. In the same way, the blood shed of countless Black bodies by the institution of slavery, Jim Crowism, lynchings, medical experimentation, race riots and police brutality are not forgotten. Throughout the centuries, God has heard 'black blood' crying out for justice. Black ancestors are gone, but their blood still speaks." [6] Even in death, blood speaks to life. Blood tells a story that is not always seen. But the one who sheds the blood of another knows something about the story. What is their liability?

"Bloodguilt is the liability that inevitably attaches to the shedding of human blood. In cases of murder, ancient Israelite tradition allowed for a near male kinsman of the deceased to exercise vengeance by killing the murderer without incurring bloodguilt. But the fog of war clouds the issue of blood guilt. Ordinarily killing in war did not incur

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[4] Ibid., 234.

[5] Kenneth N. Ngwa, August 17, 2023, dissertation review comments.

[6] Kirk A. Johnson, "A Black Theological Response to Race-Based Medicine: Reconciliation in Minority Communities," *Journal of Religion and Health* 56, no. 3 (2017): 1102, doi:10.1007/s10943-017-0373-5.

bloodguilt.” [7] But the battlefield is the locus of the most significant sources of impurity: corpses, blood, and semen. These elements represent the boundary between life and death, which belongs to God; humans become unclean when they approach that boundary.[8] Completing a purity ritual offers a path to restoration. By remaining out of the community for 7 days and using fire and water to cleanse weapons, clothing and personal effects, the soldier can be made clean and be restored to the Israelite encampment.[9] Revenge and ritual can redeem blood.

In the Old Testament blood can defile (Isaiah 59:3) or cleanse (Leviticus 14:14, 49-51). Blood that defiles include menstruation and childbirth. Cleansing blood is illustrated by the purification of the ancient sanctuary through animal sacrifice twice each year (Ezekiel 45:18-20). Blood protects, over the lintels and doorposts of the Passover story (Exodus 12:13, 23), reconciles humankind to God in right relationship (atonement), through the sacrificial acts on the altar (Leviticus 17:11) and affirms the making of a covenant (Luke 22:20). “One who offers a sacrifice puts back into the hands of God a life contained in the blood.”[10] In the sacrificial system the blood of beasts represents the *dam ha’adham.* But not everyone could find the time, access or means (the grain, pigeon, lamb, or ox) to complete the available rituals and sacrifices. It follows that unredeemed

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[7] David A. Bosworth PhD, “You Have Shed Much Blood and Waged Great Wars: Killing, Bloodguilt, and Combat Stress,” *Journal of Religion, Disability, and Health* 12, no.3 (2008), 241.

[8] Ibid., 243.

[9] David A. Bosworth endorses the development of modern purity rituals by medical and spiritual practitioners to reduce post-traumatic stress disorder among veterans of war.

[10] Johnson, “Black Theological Response,” 248.

impurity, both internal and external, can persist and give way to isolation, judgment, and stigma, all in the name of blood.

There is another dimension of blood to be considered, which is the relationship between blood, breath, and life. In Genesis 2:7 God animates Adam by breathing the breath of life into his nostrils. *Dam* is semantically close to *'nephesh,'* which means the breath of life, to the extent that this can denote life as such.[11] How, then, is the relationship between blood, breath, and life to be understood? Richard Whitekettle's exploration of this relationship begins with a question: "What difference, then, did (ancient Israelites) see between fish and land/aerial animals such that they permitted the consumption of fish blood but prohibited the consumption of land/aerial animal blood?" [12]

Whitekettle asserts that since the ancients knew that fish die in the air, it was reasonable to conclude that fish do not breathe air, therefore the blood of land/aerial animals was not to be consumed because they breathe air, while the blood of fish could be consumed because they do not.[13] "Given that Israelite understanding of physiology and physical space was that every creature drew its life from the medium with which it was situated and through which it moved, there was no breath blood amalgam in the body of aquatic animals as it was in land/aerial animals." [14] But '*nephesh'* points to a deeper

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[11] Botterweck, Ringgren, *Theological Dictionary*, 240.

[12] Richard Whitekettle, *"A Study in Scarlet: The Physiology and Treatment of Blood, Breath and Fish in Ancient Israel,"* Journal of Biblical Literature 135, no. 4 (2016): 688.

[13] Ibid., 697-698.

[14] Ibid., 704.

understanding. We now know what ancient physicians were beginning to comprehend, that blood had a clear relationship to breath. Blood is the bearer, through hemoglobin, of oxygen, the breath of life, that all creatures need to live. Gills extract oxygen from the water and hemoglobin in the blood of fish carries that oxygen to all parts of the body to sustain life. God breathed oxygen into the nostrils of Adam, and the hemoglobin in his blood carried breath into his whole body. Breath, blood, and life cannot be separated. Had this relationship been thoroughly understood by the ancients, the prohibitions on blood consumption may have been applied to all living creatures, giving us more confidence to assert that all living beings are children of God, equitably sustained by the same breath and blood.

Then Came Jesus

In the New Testament the word *aima,* meaning the *'blood of man',* appears 101 times. Here, humankind is now flesh and blood, a frail, material creature in contrast to God. "Despite the firm prescription against ingesting blood, one breakaway Jewish sect of the 1st century AD made the idea of doing so central to its rituals. Its leader, Jesus of Nazareth, told his disciples that the bread and the wine at the Last Supper were his body and blood, and should be consumed thereafter in memory of him. The ritual of the Eucharist became a cornerstone of early Christianity and with it the doctrine of transubstantiation, that a literal, not just figurative transformation (of bread into flesh and wine into blood), occurred during the Sacrament."[15]

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[15] Jerome Groopman, "The History of Blood," *The New Yorker online*, 1 (January 7, 2019): newyorker.com/magazine/2019/01/14/the-history-of-blood, 4.

This stark reversal from forbidding the consumption of blood to sanctifying it as a bridge to the Divine might have been a cultural adaptation. As Paul carried the Gospel to the Greeks, the “agape feast” mirroring Dionysian rites, became an occasion for Christians to symbolically consume their God’s flesh and drink his blood. Another viewpoint is that when the Gospel writer of John (6:53-56) speaks of eating the flesh and drinking the blood of Christ, the blood is only a graphic term for death: the Lord’s supper unites Christians with the Christ who gave up his life to death.[16] A full exposition of the debate between the adherents of transubstantiation and symbolic consumption of the body and blood of Christ in the Sacrament of the Lord’s Supper is beyond the scope of this work. It is, however, important to note that the blood of Jesus, became a unifying symbol of Christianity and a vehicle for separating Jesus from his Jewish roots. “Christians simultaneously invented the community of substance as the community of blood. Beginning with the conception of the human as ‘flesh and blood’ it became the first community ever to understand and conceive of itself as a community of blood.” [17] Christianity was set apart, despite the reminder in the Book of Acts that we are united by one blood, the blood of God, the progenitor of the bond which unites all humanity. By drinking the blood of Jesus, one was drinking the blood of God, blood superior to all other bloods. Over time this superior blood came to define a superior people.

The Blood That Divides Us

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[16] Gerhard Kittel ed., *Theological Dictionary of the New Testament Volume I* (Grand Rapids, MI: Wm. B. Eerdmans, 1979), 175.

[17] Gil Anidjar, *Blood: A Critique of Christianity* (New York: Columbia University Press, 2016), 38.

Consumption of human blood continued in ancient times as a curative. According to the second century physician, Galen, the human body was composed of 4 humors (yellow bile, black bile, white phlegm, and red blood). Maintaining balance between these elements was essential to life. Bad humors needed to be released (thus the practice of bloodletting) and good humors needed to be replenished (ergo blood consumption). Kings and popes consumed human blood as a curative and re-vitalizing agent.[18]

These secular/medical practices occurred while Christians and Jews continued to clash over blood. "In 1144 the death of William of Norwich was attributed to Jews who had crucified him to use his blood as a sacrifice. This was the first documented case of what became known as blood libel. In 2015 a Hamas leader in Gaza declared that Jews were still killing children and using their blood to knead into special Passover bread."[19] The devastation caused by the Black Death in Europe (1347 to 1351) was thought to be a plot devised by Jews to destroy Christianity. Pogroms against Jews continued. Spain was the only multi-racial and multi-religious country in Western Europe during this time. Blood became a tool in Spain for classifying and dividing the people. "Blood was the red fluid that circulates within the body, and an important cultural and social element. It was a symbol that synthesized and represented the most relevant social principles: individuals, families and groups were defined according to the alleged nature of their blood."[20]

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[18] Groopman, "History of Blood," 6.

[19] Rose George, *Nine Pints: A Journey Through the Mysterious, Miraculous World of Blood* (London: Granta Publications, 2018), 4.

[20] Pablo Ortega-del-Cerro and Juan Hernandez-Franco, "Debates on the Nature of Blood and the Forging of Social Models in Early Modern Spain," *Journal of Early Modern History* 26, no. 4 (2022): 335.

Emphasis was placed upon ensuring the superiority of Christians over Jews. Many Jews converted to Christianity in acts of sincerity or self-preservation. These ‘New Christians’ were called *conversos,* known to be of impure blood. Old Christians had pure blood. Blood purity laws (*limpieza de sangre*) were instituted in 14th and 15th century Spain which severely limited the opportunities for *conversos* to contribute to society and to flourish as citizens. They could not hold public or ecclesial office, could not testify in court against Christians and could be expelled from the country for a variety of minor infractions. “The belief in the existence of two types of blood, one clean and the other tainted, lay at the heart of a far-reaching intellectual debate with very real implications for everyday life.” [21] These laws were finally repealed in 1865. It is worth noting, however, that Christopher Columbus sailed to the Americas as a man born and bred under *limpieza de sangre*.

Old Blood in a New Land

Forced conversion to Christianity became one of the hallmarks of those who came to establish a ‘new world.’ There is irony in this statement, of course, because so many came in search of religious freedom. But the notion that Christianity would save and tame the Indigenous peoples and ensure the civilization and subjugation of the enslaved peoples set us on a grievous journey. Rousseau famously asserted, “Man is born free, and everywhere he is in chains.”[22] Rousseau’s context was his search for the society that

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[21] Ibid., 339.

[22] Jean-Jacques Rousseau, *On the Social Contract*, 1762 (Mineola, NY: Dover Publications, Inc, 2003), I.

reflected the true will of the people. But in the new world, the land of the free, blood became chains for too many.

As white people sought to subdue Native Americans and to seize their land and property, colonial blood management systems were applied to determine the status of individuals. Using tribal documents, the US Department of Interior distributed cards attesting to one's "Certified Degree of Indian Blood". This card included a quantum/quantity or fraction of blood used to assign or remove an indigenous person from a tribe. Starting in the Virginia colony, the 1 drop rule was a legal principle of racial classification that extended into the 20th century. Any person with even one Black ancestor throughout multiple generations was considered Black. In 1850 the US Census Bureau developed categories for racial classification. The net result of the blood quantum and the one-drop rule was to reduce the 'official' number of indigenous people and to increase the 'official' number of Black people. In summary, the results of these measures were to deny benefits to displaced peoples and to increase the free labor pool for the burgeoning cotton economy. They also preserved the political order by denying the opportunity to vote to those 'officially classified' as BIPOC.

We continue to search for proof of the distance between us, even as science continues to narrow the divide. SCD is one example. "SCD trait is now known to protect against malaria which is why SCD is found frequently but not only in people of African heritage because malaria thrives in Africa. The reason why ethnicity comes into the picture is that human leukocyte antigens (HLA), present in ALL blood, encodes the immune system, and our immune systems go through particular conditions based on where you are."[23] It is not about the difference in our blood; it is about the differences in where we live and grow. When we dare to claim that one person is superior to another; that this classification is written in our blood; that the act of conversion or conformity still renders one suspect, there is indeed, sorrow in our blood.

A New Design

Travis Harris and M. Nicole Horsley pose this important question: "Is there redeeming power in the blood for people of African descent? They believe that in the United States we live with a Christology which places whiteness at the top and Blacks near the bottom. 'Whiteanity' is the religious ideology of White Supremacy."[24] Thus, the blood of Jesus saves us from the curse of Black skin. JoAnne Marie Terrell asks a similar question in *Power in the Blood?* "How is the gospel message of the Atonement, or reconciliation of sinners with God through Jesus Christ's death on the cross, to be construed by Black people who are similarly persecuted and simultaneously indicted as sinners?[25] It is important to understand that the literature on blood theology hinges on the scholarship of white male theologians. "If sin is found in White supremacist institutions, then the goal should not be atonement, rather it should be dismantling oppressive systems."[26]

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[23] Rose George, "The Intersection of Race and Blood," *The New York Times Online* CLXVIII 58, no. 327 (May 14, 2019), nytimes.com/2019/05/14/well/live/blood-type-race-racial.html. quoting Dr. Abeer Madbouly, Senior Scientist, Be the Match, National Marrow Donor Program.

[24] Travis T. Harris and M. Nicole Horsley, "Da Blood of Shesus: From Womanist and Lyrical Theologies to an Africana Liberation Theology of the Blood," *Religions* 13, no.688 (July 2022):1,2, https://doi.org/10.3390/rel13080688.

[25] JoAnne Marie Terrell, *Power in the Blood? The Cross in the African American Experience* (Eugene, Oregon: Wipf and Stock, 2005), 3-4.

[26] Harris and Horsley, "Da Blood," 4.

I claim Jesus Christ as my first love, because my spiritual journey has been one of constant expansion from my upbringing in the protestant traditions. I voluntarily left the pulpit ministry of the Presbyterian Church (USA) in 2016 for hospital chaplaincy because I could no longer claim Jesus as my Lord and Savior based on the traditional rationale, that the ONLY value in Jesus' life was his substitutionary death on the cross as atonement for my sin. I wear no crosses. To me, it is the same as wearing a gun around my neck or on myself. I cannot comprehend that the only way that I could be reconciled to God, to stay on good terms with my Creator, was through an act of profound violence. As I see it, Jesus' crucifixion (read that state-sanctioned murder, on par with lynching) occurred at the order of a Roman prelate because Jesus' message had the power to upend the socio-economic and spiritual balance of the Empire. Jesus preached the redesign of the world order. His message was radical enough to get him killed. Crucifixion shed little blood. Jesus' death was by asphyxiation not bloodshed.[27] I agree with Womanist theologian Delores Williams who asserts: "Jesus does not conquer sin through death on the cross. Jesus conquers the sin of temptation in the wilderness (Mt 4:1-11) by resistance—by resisting the temptation to value the material over the spiritual. Jesus conquered sin in life, not in death. Through resurrection, God clarified the power not of Jesus' blood, but of his life," [28] and the life of every human being.

Williams continues. "I don't think we need folks hanging on crosses and blood dripping and weird stuff. I think we really need to see the sustaining, the sustenance

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[27] Although, in John 19:34, NRSV, a Roman soldier confirms Jesus' death by piercing his side with a spear causing blood and water to flow out of Jesus' body.

[28] Harris and Horsely, "Da Blood," 8-9.

images, the faith that we are to have. The fish and loaves, the candles we are to light, that our light will so shine before people so that we can remember that this message that Jesus brought, I think is about life, and it's about the only two commandments that Jesus gave; they were about love." [29]

Ancient conceptions of 'god' were limited to a superior being who wields unlimited power to judge, to destroy, to dispense justice that was largely retributive. Love was not the first word that came to mind in Jesus' time as the primary characteristic of God.[30] This added to the challenge of explaining how one who is God can die by human hands. That Jesus' blood became salvific was a useful explanation. It leverages the ancient traditions of atonement through sacrifice and ritual purity. It preserves Jesus' godly power and makes his blood, able to cover the sins of all humanity for all time, superior over all other blood. That his blood overshadowed his ministry and message is tragic. Even the Apostle's Creed pays no attention to his teaching. As I continue working to expand the number of collaborators in the CHN, I have been told by countless church leaders that there is no need for them to join the CHN because Jesus' blood sacrifice alone has assured their salvation, ergo, there is nothing else that they need to do. How then do we honor Jesus' life, affirm, and embody his resurrection?

As I see it, the heart of Jesus' message is that we are all children of God, of one blood that heals us and draws us together in love. In his name, instead, we have created a system where his blood separates and harms us based on constructs promoting superiority

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[29] Delores Willliams, Re-Imagining Jesus, as quoted in Terrell, *Power in the Blood?* , 121.

[30] "Although there was language about love of God and neighbors in the Hebrew scripture, within the context of empire love could be obeisance to the imperial overlord." Dr. Kenneth Ngwa, February 2, 2024.

of one group over another. To this day, specifically October 7, 2023, a former President of the United States asserted "undocumented immigrants are poisoning the blood of our country." [31] Suffice to say this individual was not referring to white immigrants from Norway, but people of color running north in search of healing. We have lost the understanding that all blood is God's blood; meant to unify not to divide, meant to empower not to enslave. I support my sisters and brothers in the faith who believe in the redemptive power of Jesus' blood sacrifice; but that cannot stand alone as the singular element in their salvation. Jesus' blood calls us to a new life, a transformed existence where we actively apply the gift of our lives to transforming the lives of others.

We still devote precious energy, mainly through the discipline of science,[32] to proving our differences instead of embracing all that we share. The recent statement of Connie Westhoff, Executive Scientific Director of the National Center for Blood Group Genomics at the New York blood center, has not dissuaded us: "much of the variance in blood has been driven by bacteria, malaria and parasites."[33] We are not rendered different and unequal by our biology, but by our ecology, by the world we have made, not the one God ordained. In the words of Kenneth Ngwa commenting on the parable of the Sower (Matthew 13:3-9); "The seed is good; it is the ecosystem that hurts the seed."[34]

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[31] Donald J. Trump as quoted in a live interview with the National Pulse, reported by CNN on October 8, 2023.

[32] Which I humbly define as the carefully and consistently managed exploration of the mind of God.

[33] George, "The Intersection of Race and Blood," May 2019.

[34] Dr. Kenneth Ngwa in Lecture at Drew University, Madison, NJ WOMA Book Signing, January 18, 2023.

I wish I had Ngwa's statement at the ready when I talked with Brandon. Still, I managed to tell him, after a while in conversation, because there is no quick assurance when one asks if God has cursed them, "God has not cursed you or anyone, but the system we have created does not treat you or care for you properly. Blood is God's gift of life and we, as human beings, are all the same blood. The construct of racism is the source of our separation and sorrow." This construct must die, and white people must join this work, sharing every ounce of their power and privilege in allyship with BIPOC people. It is time to re-design the way we treat our diagnoses and care for each other. Our shared blood does not need to be the locus for sorrow; new methods, original approaches, new bridges are needed that allow us, together, to re-design our systems and our relationships and become our best, HEALED selves. This mindset will help us honor Jesus' life, affirm and embody his resurrection. The Congregational Health Network is one approach, one possibility, one promise that we can make as we re-vision a portion of our healthcare delivery system and test its efficacy for mutual good. The evolution of that promise is the subject of the next chapter.

CHAPTER FOUR

WHAT CLINICIANS DON'T KNOW: THE POTENTIAL FOR SPIRITUAL CARE TO IMPROVE PATIENT OUTCOMES THROUGH THE CONGREGATIONAL HEALTH NETWORK

> **"You (members of the World Health Assembly) are the guardians of the dream of "Health for All." You have the opportunity and the responsibility to lead the world into a healthy place. You are the enactors of justice: justice in the distribution of a country's wealth for health; justice to save the lives of your people and enable them to prosper and build healthy nations. God is watching. The people are waiting. You are commissioned to go wipe the tears away from all faces and bring forth lives filled with strength and purpose which will make for peace."**
> **Archbishop Desmond Tutu, May 20, 2008[1]**

> **Religion is important as a social determinant of health because, while it mostly aligns with better health, it does not necessarily align with greater economic and social advantage. Religious social capital may play its most important role precisely for those individuals and in those communities where there is little secular capital. The picture of social determinants of health is simply not complete without it.[2]**

A Missed Opportunity

During my first over-night on-call in the hospital in 2017, I was paged to the oncology floor. My mission was to support the clinical team, who was about to deliver unwelcome news, and the patient and family who were about to receive it. The attending and oncology physicians took their places next to the nurse, the social worker and me.

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[1] Ellen Idler, ed., *Religion as a Social Determinant of Public Health* (New York, NY: Oxford University Press, 2014), 315.

[2] Ibid., 233.

We were facing fifteen-year-old Mike and his parents. Mike’s diagnosis was osteosarcoma: cancer found in his thigh bone. The clinicians presented a treatment plan and each member of the interdisciplinary team, including me, was given an opportunity to offer their support for Mike and his family.

I was the last in the group to speak. I had no medical information to offer; but I did have a question. “Mike”, I asked, “do you have a faith tradition?” His reply was swift and sure. “Yes, I do, and I would like to pray now!” Within 10 seconds I was alone in the hospital room with Mike and his parents. I was careful to appreciate that Mike did not ask me to pray *for* him, but *with* him. He wanted a witness. In his prayer I heard his sadness at the diagnosis, but not surprise. I heard him give thanks for his greatest strengths: reliance on God and his close-knit and loving family, his intelligence, his strong body. I heard his biggest fears: that the treatment would be worse than the disease and he wanted to know how to prepare for and respond to that. He was worried about losing his leg, his hair, his appetite, his strength. He wanted to make sure his parents and sisters would be informed and cared for. Finally, I heard him pray for us-- the interdisciplinary team—that we would make good decisions for him.

All of this was extremely useful information in designing his treatment plan and it showed the courage, open mind, and open heart that Mike was bringing to this battle. But the providers didn’t receive it because ‘spiritual stuff is private and not necessarily relevant to what we need to do’ (as they explained to me when I asked later why they left Mike’s room at the mention of prayer). One colleague had the temerity to declare, “In our world, religion is usually a liability, an obstacle to getting the job done.” Chaplains were not even allowed to enter information into the patient’s electronic medical record, other than to record that a visit had taken place. Mike’s providers had missed an opportunity to get to know their patient in a profoundly personal way and receive information which would help them do their best in caring for him. All they had to do was stay in the room for just a couple of minutes. But the divide between medical treatment and spiritual care was too entrenched. It wasn’t always that way and it certainly isn’t how things must be forever.

Science and Religion Used to be Partners

The Apocryphal book Sirach states: “Honor physicians for their services, for the Lord created them; for their gift of healing comes from the Most High and they are rewarded by the king. The Lord created medicines… and he gave skill to human beings that he might be glorified in his marvelous works. By them the physician heals… God’s works will never be finished and from him health spreads all over the earth.” [3] Biblical scholar Isabel Cranz paints a portrait of medical providers based on this text. Cranz suggests that “physicians cannot claim an immediate link to the divine world, although they are appointed by God. What is certain in all this is that God is still responsible for healing, by originally providing the source of medicine that allows the physician to guide the patient toward recovery.” [4] Physicians do not heal alone; they are agents of God’s grace. Healing comes through the relationship, dare I say, partnership between God and our clinicians.

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[3] Sirach 38:1, 4, 7-8, NRSV, Catholic Edition.

[4] Isabel Cranz, “Advice for a Successful Doctor’s Visit: King Asa Meets Ben Sira,” *The Catholic Biblical Quarterly* 80, no. 2 (2018): 245-246.

Dr. Tracy Balboni, Associate Professor at Harvard Medical School and her spouse, Rev. Michael Balboni, pastor of the Longwood Christian Community and Park Street Church in Boston, MA, have collaborated on a book that traces the evolution of this relationship between God and those who practice medicine. "During the latter half of the 19h century a medical-religious partnership within Europe and the United States was common in both launching and managing hospitals. Changes in the relationship occurred as medicine became dominated by impersonal and mechanistic factors."[5] Balboni and Balboni use art to illustrate this evolution.

In his 1891 painting, Sir Luke Fildes depicts "The Doctor". "Even though medicine may be exhausted, the physician's presence, gaze and posture depict a social ideal of patient-centered care. Spirituality is integrated within and expressed by the physician. [6]

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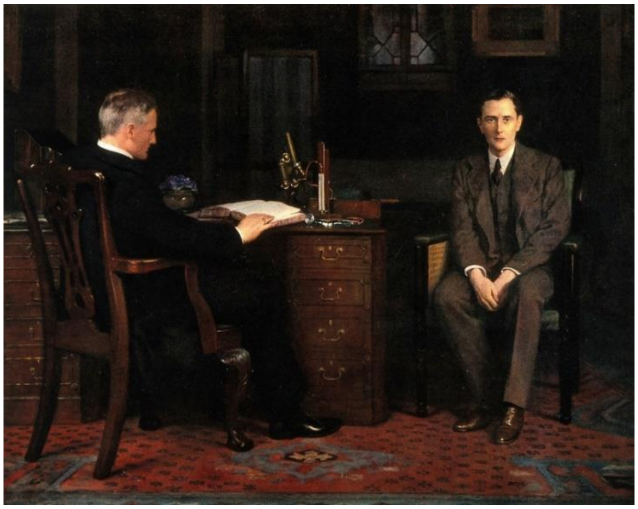
[5] Michael J. Balboni and Tracy A. Balboni, *Hostility to Hospitality: Spirituality and Professional Socialization Within Medicine* (New York, NY: Oxford University Press, 2019), 2.

[6] Ibid., 3.

“Pablo Picasso’s ‘Science and Charity” is based on the death of his sister Conchita. In this 1897 painting, there is a stark contrast between the physician, whose eyes are fixed on his watch while taking the pulse, and the nun whose focus is the patient (and the care of her child).” [7]



In 1908 John Collier created ‘The Sentence of Death’. “Having received the diagnosis, the patient expresses some combination of despair, shock, and resignation. The

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[7] Ibid., 4.

patient stares at the viewer, pulling us into the room. The physician's indifference is expressed by his slouching in his chair, his eyes diverted, his whole bearing expressing the inability to offer comfort because medicine is unable to undo the young man's death sentence."[8]

"Over a period of 18 years, these three paintings capture the transfer of spirituality and religion in the context of medicine from the caring physician to the religious representative before showing the final collapse into its visible absence." [9] Dr. Richard Cabot is credited with supporting the development of the disciplines of social work and chaplaincy in the 1930s to help provide vital patient care that doctors used to provide. But hospitals have become places of cure, not places of care. "The physician as scientist is a metaphor that emphasizes the physician as an objective observer and the patient a passive sufferer within (their) illness."[10]

Dr. Balboni's concern is evidence-based, informed by data from the Religion and Spirituality Cancer Care project. "Patients perceive the frequency of nurse-provided spiritual care to be 'rarely' offered and physician-provided spiritual care to be between never and rarely offered. In contrast nurses said that on average they occasionally provided spiritual care and physicians said they provided it seldom. Patients think they receive spiritual care less often than how often clinicians think they provide it."[11]

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[8] Ibid., 5.

[9] Ibid., 6.

[10] Ibid., 165.

[11] Ibid., 63.

Faith is Key in Managing Chronic Disease

We have not formally studied patients' experience of spiritual care at our hospital, but my project shows that faith is a key element in managing chronic disease, specifically for our patients and families managing SCD, who are largely BIPOC. Ayanna Wells and her colleagues conclude that "Nearly 2/3 of Americans will be affected by chronic disease in their lifetime with over 40% experiencing multiple chronic conditions. African Americans disproportionately face unfavorable social conditions that create greater risk for chronic disease." [12] Kirk A. Johnson introduces Black theology as another asset in managing chronic disease. "Healing is not just a physical practice: it includes spiritual practice. The spiritual discipline of black theology can be used as a tool to mend the harm of race-based medicine."[13] "Race-based medicine continues the racist language of labels and stereotypes exclusively associating medical conditions and diseases to a racial group." [14]

I believe that the faith that our patients managing SCD rely upon offers them a source of strength beyond their own and the resilience to cope with the unfavorable social conditions and the health challenges that disproportionately impact them. A brief overview of the history of health initiatives for BIPOC people in the United States

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[12] Ayanna Wells, et. al., "Engaging Faith-Based Organizations to Promote Health Through Health Ministries in Washington, DC," *Journal of Religion and Health* (2022): 1, doi.org/10.1007/s10943-022-01651-0.

[13] Kirk A. Johnson, "A Black Theological Response," 1096.

[14] Ibid., 1098.

illustrates the importance of the Black church caring for the health of their congregants. The CHN can expand this web of care beyond the Black church to all communities of faith.

In 1906 Dr. WEB DuBois published *The Health and Physique of the Negro American* stressing that the health of human beings was the consequence of social, political, and environmental labels.[15] DuBois' landmark study of tuberculosis concluded that it was not a racial disease, but a social disease linked to poverty, housing and working conditions. His efforts and those of other health workers contributed to the founding of the National Negro Health Week (NNHWM) initiative that flourished between 1915 and 1951.

In 1921 the US Public Health Service (USPHS) began publishing the National Negro Health Week Bulletin. This was followed by the establishment of the Office of Negro Health Work through the USPHS in 1932. The grassroots advocacy of the NNHWM was centered in the Black church.[16] Churches promoted National Negro Health Week annually beginning with Sunday services outlining the 7-day locally designed schedule; each day had a particular focus. Monday was Home Hygiene Day. Tuesday was Community Sanitation Day. Wednesday was Special Campaign Day, designed to address the prevention or care of a disease specific to the congregation. Thursday was Adult Health Day. Friday was School Health Day and Saturday was General Clean-up Day. The Civil Rights Movement was interpreted by many as a sign that significant progress had been achieved and that the Office of Negro Health Work and the National Negro Health

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[15] Ibid., 1106.

[16] Ibid., 1107.

Movement were now superfluous and could be dismantled. They were abolished in 1951. Regardless, health advocacy efforts in the Black church continued.

"The Black Panther Party (BPP), notorious for its brash response to a racist society and its political activism, was also instrumental in health advocacy and outreach reflected through the People's Free Medical Clinics (PFMS)." [17] 13 of these clinics were established in major US cities between 1968 and 1970, affiliated with registered chapters of the BPP and local congregations. The clinics supplied first aid and basic services such as childhood vaccinations and screening for high blood pressure, lead poisoning, tuberculosis, and diabetes. Community education and screening for SCD began in 1971. These clinics were often harassed by city health inspectors, subject to police raids and had difficulty retaining volunteers. Today, only the Carolyn Downs (a BPP community organizer) Family Medical Clinic is still open in Seattle, WA.

Ayanna Wells and her colleagues believe that BIPOC people perceive and live a strong connection between their health and faith. "Faith based organizations (FBO) are often described as the hub of the African American community, supplying not only opportunities for worship, but also community resources and connections related to education, housing, social support, and food."[18] Five FBOS in Washington DC serving the African American community through the 'Faithfully Fit" initiative were the subject of their research. All five FBOs had one key element in place, a certified Health Minister trained through an innovative program offered at Wesley Theological Seminary. These Health Ministers initiated, coordinated, and connected health services for congregants

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[17] Ibid., 1105.

[18] Wells, "Engaging FBOs," 2.

sometimes in partnership with health professionals. Blood pressure screening and arthritis management were focus areas for these FBOs.

In 1999 the Rev. Jesse Jackson was instrumental in setting up the Churches to Stop HIV (CUSH) initiative. This program involved 2850 faith leaders and supplied HIV prevention to over 32,000 people. The National Conference on the Black Family/Community and Crack Cocaine involved 1200 churches which partnered with Jackson to alleviate drug use. In 2012 the Progressive National Baptist Convention partnered with the National Cancer Institute to use 1100 Black churches in 22 states to organize “Body and Soul”, a nutrition program for cardiovascular disease prevention.[19]

Faith Communities are Assets in Patient Care

These successes are notable, but challenges remain. Gandara et.al. shed light on these realities.

> “Pastors noted that not having a health minister in place and disconnecting physical, mental, and spiritual health from each other can act as barriers. Other barriers included not having enough volunteers to coordinate health programs, as well as church congregants not having health insurance or provider access. There is also a lack of connection among community leaders, churches, (hospitals) and schools that focus on sustainable church health promotion programs. Further research needs to be done on how to help bridge and create co-partnerships between policy initiatives and African American (AA) churches to not only meet the needs of the AA community from within; but to move beyond a traditional top-down approach.”[20]

Rev. Dr. Gary Gunderson and James Cochrane built the first Congregational Health Network (CHN) to clear many of these barriers.

The Congregational Health Network Model is Born

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[19] Johnson, “A Black Theological Response”, 1109.

[20] Eduardo Gandara, et. al. “Facilitators and Barriers When Conducting Adult Health Programs Within the African American Church: A Systematic Review,” *Journal of Religion and Health* 62, no. 4 (2022): doi.org/10.1007/s10943-022-01532-6.

Gunderson and Cochrane open their paradigm-shifting book with a powerful illustration: the collaboration between Dr. John Snow and Rev. Henry Whitehead which ended the cholera outbreak in 19th century England. Dr. Snow was able to diagnose and treat the disease, but Whitehead, through his knowledge of the community, its people, and their habits, was able to track the path of its spread through the population. "No one heals alone," is the lesson. [21]

Gunderson and Cochrane propose a new approach for improving the health of the public rooted in their work with the African Religious Health Assets Program. In South Africa the health needs of the BIPOC population were so pervasive and dire, it was easy to throw up one's hands and declare the situation and the people beyond saving. They shifted their perspective from looking at the overwhelming need to taking account of the *assets* that were present in the community. They assert that Religious Health Assets (RHAs) are powerful enough to change the ecology of healthcare, the environment in which we seek to maintain good health. In clear contrast to my colleague's assertion at the beginning of this chapter, that religion, at least where it intersects disease and treatment, is largely a *liability*, Gunderson and Cochrane offer this list of RHAs: *accompanying* a patient/congregant through a diagnosis; *convening* groups to support or educate the community about health; *connecting or linking* faith-based and other community assets to achieve a shared goal; *storying* through scripture to offer informed hope, coping strategies and encouraging outcomes; *sanctuary,* providing refuge when encountering difficult passages; *blessing*, reminding one of what they have, not what they

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[21] Gary R. Gunderson and James R. Cochrane, *Religion and the Health of the Public: Shifting the Paradigm* (New York, NY: Palgrave Macmillan, 2012), 29.

lack; *praying*, thereby invoking a strength beyond ones' own and *enduring;* by its own example, faith communities have outlived many a people and many crises.[22] When these assets are acknowledged, they can be appropriated, and shared with the gifts and talents of health scientists. "We do not have to choose between science and faith, we have to find ways to use all of the assets, all of the time, for all of the families in every community."[23]

Gunderson and Cochrane built a consortium of faith communities in collaborative relationships with providers and hospital systems in South Africa and Memphis, TN to care for adult patients and families managing chronic diseases. Gunderson also carried this work to Wake Forest, NC. Their work began with continuous conversations focused on a theme that is central to the improvement of public health: that technical, expert-driven, and facility-oriented medicine has limited impact on more disadvantaged populations who bear the greatest burden of ill-health because fundamental determinants of health go unanswered.[24] Faith communities, especially those that serve the BIPOC population have been addressing these social determinants of health, through their mutual strengths and care, for decades, with volunteers, limited resources, and limited knowledge. The power in the Congregational Health Network is bringing these two forces, science, and faith, together, "restoring the historical commitment of public health to social justice."[25]

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[22] Ibid., 104-116.

[23] Ibid., 58.

[24] Ibid., 146.

[25] Ibid., 153.

The work of Gunderson's research assistant, who ultimately became his spouse, Teresa A Cutts, firmly supports the value of the CHN model in transforming health outcomes. After 25 months of operation in Memphis hospital admissions were reduced by 37% for patients managing congestive heart failure, kidney disease and diabetes with the support of a CHN congregation. Readmissions were reduced by 55%, total patient days reduced by 41% and average charges per patient from $127,922 to $74, 819.[26] In the United States there is only one measure of success, and it is expressed in dollars. The CHN is certainly validated by that criterion alone. But Gunderson and Cochrane have opened my eyes to a slightly different way of seeing value in investing in health equity: by gaining an understanding of what is present, not absent, for the patient and the community and leveraging those resources while building the relationships that will improve communication, trust, and partnership. Assets in our hands and relationships that allow us to use them for the benefit of all, will help us build a beloved community, a society that believes in good health for every single child of God.

But first, I must remember the context in which I labor. The hospital is a bastion of science, and no project is supported without proof of concept. So, a pilot CHN had to be built to demonstrate the potential in the vision. The construction of the pilot, the research that supported it and the utilization data that resulted are the subjects of the next chapter.

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[26] Teresa A. Cutts, *The Memphis Model: ARHAP Theory Comes to Ground in the Congregational Health Network.* (Memphis, TN: Methodist Le Bonheur Health System, 2017), results updated and presented to Grand Rounds at Nemours Children's Health, October 12, 2022, presentation slide 22.

CHAPTER FIVE

A WAY OUT OF NO WAY: BUILDING THE CHN PILOT

“When our days become dreary with low-hovering clouds of despair, and when our nights become darker than a thousand midnights, let us remember that there is a creative force in this universe working to pull down the gigantic mountains of evil, a power that is able to make a way out of no way and transform dark yesterdays into bright tomorrows.”[1]

“Change will not come if we wait for some other person or if we wait for some other time. We are the ones we’ve been waiting for. We are the change that we seek.”[2]

“Then Moses answered, “But suppose they do not believe me or listen to me, but say, “The Lord did not appear to you.” The Lord said to him, “What is that in your hand?” He said, “A staff.” Exodus 4:1-2, NRSV

“If you build it, he will come.”[3]

A Way Out of No Way

Fresh from Dr. Ngwa’s introductory course on Faith, Health and Social Equity and armed with Gunderson and Cochrane’s book, the calling to build a Congregational Health Network within a hospital system in the service of children like Brandon, grew louder every day. The first person I consulted was my former medical supervisor, and

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[1] Martin Luther King, Jr. quoted August 16, 1967, in his address to the Southern Christian Leadership Conference, Atlanta Georgia.

[2] Barack Obama quoted February 5, 2008, in his speech after the Super Presidential Primary Election Day, Chicago, Illinois.

[3] Kevin Costner as Ray Kinsela in the Gordon Company Universal Pictures Production of “Field of Dreams,” screenplay by Phil Alden Robinson, May 5, 1989.

Chief of the Pediatric Advanced Care Team (PACT). Our department is very familiar with patients managing sickle cell disease since our clinicians write many of the prescriptions for pain management medicines. With this physician's blessing, I created a presentation on the CHN concept. I called Dr. Teresa Cutts for input and arranged an appointment with the Office of Health Equity and Inclusion at the hospital. With their slightly skeptical endorsement, it took three months for me to obtain a slot during regular rounds at the SCD clinic to present my idea. 32 meetings followed within the hospital to finally gain initial, and guarded, institutional support of the CHN. But as I continued to present my idea to anyone who would listen, champions began to emerge. A PICU intensivist and palliative care physician lent her support as did the inpatient nurse practitioner for SCD patients, the Director of Nursing Research and physicians practicing in other hospitals. These women came alongside whenever the representatives of legal, compliance, the foundation, human resources, the Institutional Review Board (IRB), volunteer office, the pastoral care department and others had questions or challenges about who, what, when and how, the hospital would manage the risk of collaboration with religious entities.

In June 2022 I was able to begin asking my research questions in conversation with our patients in the clinic. I did not want to engage in any paternalistic prescribing of what I thought patients might need to help manage their SCD. I felt called to LISTEN and then CO-CREATE a helpful response, learning all the way.

Patients and families were screened by the clinic nurses during outpatient appointments, introducing the purpose of the CHN and asking permission for me to have a conversation with the family. I completed interviews, using the questionnaire in

Appendix 2, with 121 respondents: 62 patients and 59 parents and siblings. 46% were female; 54% male with a range of ages from 1 to 21 years with a mean age of 10 years and 2 months. The answers to the research questions follow.

What percentage, based on sampling, of sickle cell patients and families profess a faith and a connection to a faith community strong enough to impact healthcare decisions? Of this group, 90% professed a faith and a connection to a faith community strong enough to impact healthcare decisions.[4]

What percentage of SCD patients have 1 or more unmet care needs? Of this group 85 of 121 or 70% of respondents mentioned at least one unmet need, some mentioned multiple unmet needs.

What unmet care needs can be addressed through a Congregational Health Network? This is a deeper question that could only be answered by a pilot implementation. But first, iterative thematic analysis was applied to the data to provide some structure to the responses.

The Time is Now to Identify the Themes That Define Care

When I asked the best way to honor the faith of patients and families as we care for them, the overwhelming response was the request for prayer. 55% of the respondents asked to be prayed for immediately, in the clinic, as part of our conversation. I was happy to do so, and I tailored their prayer to what I learned in our conversation.

When respondents were asked what is the biggest challenge they faced in managing SCD, four themes emerged: (1) The need for **tangible items** was predominant. Healthy food, transportation to and from appointments and to the emergency room,

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[4] Some examples of how faith impacts patient healthcare decisions can be found on page 7.

childcare during hospitalizations and sometimes during appointments for the child or children that were not managing SCD, prescribed vitamins (which are not always covered by insurance or Medicaid) and money, most particularly for small immediate and emergency expenditures that are not always in the family budget (such as an application fee to renew a driver's license). (2) The second theme was **immediate concerns** detailed as fear of pain and how to manage it, fear of hospitalizations, the need for more education and knowledge about choosing whether to visit the clinic, the ER or just taking Tylenol and staying home when symptoms were present. (3) The third theme was the **future**, specifically not knowing what to expect, not having any other patients to talk to, and how to transition to adult care. (4) The fourth theme was **humanitarian concerns** in treatment defined as wanting to receive patience in gaining understanding, humility from clinicians (saying you don't know when you don't know), being treated like a person, someone to advocate for me and more listening and mutual communication.

When we explored what would be most helpful in making these challenges less difficult, again four themes emerged. (1**) Support** in the form of peer groups for parents, patients and families, mentors, and more volunteers to help with short-term or one-day needs like a ride to an appointment. (2) **Tangible assets** such as a food pantry, free vitamins, and childcare. (3) A **cure** for SCD in the form of more bone marrow donors and more information on emerging opportunities such as CRISPR.[5] (4) **Education** in the form of more community awareness, videos or information that can be shared with family

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[5] Clustered Regularly Interspersed Short Palindromic Repeats is a potential curative therapy for SCD which is explained in additional detail in Appendix 1.

members, teachers, and coaches who need to know how to help an SCD patient reach their full potential.

When asked if there might be ways a faith community could support you on your journey, three themes emerged: Faith communities have **people, safe spaces, and access to tangible resources**. These assets can be used to help patients and families manage SCD. 39% of the respondents belonged to and were active in a faith community; 55% identified a faith community from which they had received some support in the past. I asked for the name of those communities and permission to visit without revealing any of their healthcare information or the source of the referral. All but 2 respondents granted me that permission. I began visiting these congregations on Sunday mornings to introduce myself and the CHN concept. 90 individual follow-up meetings were required to assemble our pilot launch group of 10 collaborators. As these visits were taking place I worked with our clinic social worker, pastoral care department chaplains, and the variety of organizations that helped me find my way to develop tangible responses to our patients' unmet needs. An example follows, representing dozens of encounters, of how one meeting led to one tangible CHN offering.

What is that in your hand?

The CHN is not about creating something from whole cloth. It is about stitching those patches of goodness that are already present in our lives and in our communities by seeing our patients as people, building institutional support to embrace new assets, and nurturing the resources and relationships that are already part of our communities. Just as God advised Moses to face a challenge with what was already in his hand, the CHN opens our eyes and hearts to see what is already available to make something new and life-giving for and with each other.

Elder Ellen Casson of the Hanover Presbyterian Church agreed to have lunch with me after I attended Sunday worship there. She gave me a list of community resources that she thought might have something to offer our patients through the Congregational Health Network, one of which is Lutheran Community Services (LCS). She mentioned they did a lot ‘with food”. The next day I called the director and asked for a meeting to introduce the CHN. He was kind and skeptical, suggesting a pilot would be the first step. I noticed that in addition to a regular neighborhood food pantry, LCS operated something called a Food Farmacy, an extension of the Food is Medicine research that has led to hospitals and community-based-organizations collaborating to provide specific prescribed foods known to improve the health of persons managing diabetes, kidney, disease, heart disease and obesity. [6] LCS was already collaborating with an adult hospital system. “Would you consider cooperating with our hospital to help pediatric SCD patients?”, I asked. The director said he would think about it. When I followed up, he suggested that he would be willing to provide up to 6 months’ worth of free healthy food to six families of any size so that they could transform their diets if we could provide case management services, i.e., a helper or coach that would work with the patient families to ensure that they kept to their diet, were able to use the food, tried some new recipes, and developed a personal plan for long-term food security.

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[6] S. Downer, E. Clippinger, C. Kummer, *Food is Medicine Research Action Plan*. (Aspen, CO and Cambridge, MA: The Aspen Institute and the Center for Health Law and Policy Innovation at Harvard Law School, 2022), Food-is-Medicine-Action-Plan-Final_Aspen20%Institute_012722.pdf.

When I visited Saints Andrew and Matthew Episcopal Church to introduce the CHN, first from the pulpit and then through 4 committee meetings, they were happy to join as volunteer food coaches for the families receiving food through the LCS Food Farmacy. The hospital dietician came alongside to approve the food prescriptions; she and I prepared a 90-minute training session for the coaches which was delivered over ZOOM. This response to the expressed and tangible unmet need of our SCD patients and families for healthy food was launched on April 17, 2023, as one of ten programs in the CHN pilot. It took 3,000 hours of preparing presentations, sermons, follow-up meetings, and persistence to put the pilot together. It must be said that at times my frustrations and fears were overwhelming as I expected to be shot down at almost every turn. Often, I was. But I continued to commit this work to God through morning meditations at the foot of my ‘crying tree’—a place in a local park. It was there that I sat in God’s lap regaining my strength for the journey and re-dedicating this effort to God, whose work this really is. I understand my role as the vessel who carries God’s work into the hospital and community for the love of our patients, their families, and the medical staff. Details on the initial service offerings for the CHN pilot can be found in Appendices 3 and 4.

If We Build It, Will They Come?

The internal test applied to measure the success of the pilot was patient utilization of the services that were offered. The goal was to have 30 patients (10%) using at least one CHN service. The pilot concluded on December 9, 2023. The final pilot utilization data is provided below.

	Patients	**Family Members**	**Volunteers**
The SCD Family Fellowship			
Over 3 Meetings	**16**	**37**	**17**
NOURISH Food Support	**10**	**25**	**8**
Sunny Day Vegetables in Clinic	**38**	**76**	
Smart/911 Transport	**6**		
St. Patrick's Transport	**4**	**4**	
Free Vitamins	**24**		
Life Skills Mentors	**1**		**10**
Totals	**99**	**142**	**35**

In addition, 130 heating pads were sewn, or donated from 3 congregations. A video was produced by the hospital and distributed on June 18, 2023, to the local Presbytery, Dioceses of the Catholic and Episcopal Churches and the United Methodist District, with the potential of raising SCD awareness in over 300 faith communities. Due to a restructuring of the hospital's own transition program, the life skills mentor program was not officially launched until November 2, 2023. However, with the target participation percentage clearly exceeded, it does appear that if we build it, indeed they will come.

CHAPTER SIX

A VISION OF AN EQUITABLE HEALTHCARE SYSTEM: THE HEALING TREE

“Do not despise these small beginnings, for the Lord rejoices to see the work begin.’ Zechariah 4:10, NLT

“They shall all sit under their own vines and under their own fig trees, and no one shall make them afraid.” Micah 4:4, NRSV

The Small Beginning

On July 12, 2022, I walked, with great trepidation, into the worship service of the first congregation recommended by one of my patients, to begin the work of recruiting collaborators for the CHN. The members of the Abundant Life Apostolic Church did not visibly react to the shock they must have felt in seeing an old white lady crash their service. They were uniformly warm and welcoming. But when I was asked to stand and introduce myself, I burst into tears and sputtered, “I am not sure I belong here.” Pastor Leonard Briddell responded, “Yes, you do—you are a child of God, too, please tell us how you were called to us today.” Those compassionate words fueled my journey and filled my heart with humility, hope, and a willingness to experience a new way of worship.

As an ordained pastor in the Presbyterian Church (USA), I was aware of all the reasons we were labeled as the ‘frozen chosen’. Our way of worship was formulaic, repetitive, written in a bulletin, with no moments of silence, or room for any diversion from the script, no matter how persistent the Holy Spirit might be. The rote order allowed us to celebrate God’s great favor for the gift of another week where we were continually blessed—most often by our own initiative and efforts—with, it was often said, ‘God as our co-pilot.”. Hymns were sung by straight-backed participants who preferred the music of the choir which was sometimes populated with paid vocalists to supplement the voices of volunteers. The sermon had to be a contemporary application of the Biblical text but was not to address any issues of the day for the fear of becoming ‘political’ and insulting those that contributed the most money to the weekly collection. All of this had to be concluded within one hour at the risk of witnessing a partial walkout. This understanding of worship was one of the reasons why I left the pulpit ministry after 16 years of service and fled to chaplaincy.

This was not the experience I had at Abundant Life, Cornerstone Fellowship, the Praying Ground, Saints Andrew and Matthew, or Bethel AME. The first part of every worship service was unbounded praise to God for all the ways we were blessed. It dawned on me that the BIPOC church was the only place on earth where slaves and their oppressed descendants experience equity. Everyone was dressed to the nines in celebration and to the glory of God. People sang praises on their feet, addressed each other as sister and brother and devoted sincere respect to the officers of the congregation. The preacher’s text-centered message was inspired by the Holy Spirit, whose presence was invoked through the delivery method often referred to as ‘whooping’—spending the preacher into visible exhaustion. As for me, I never felt more connected to God; this experience renewed my faith.

The point is this: until I experienced people of color in the presence of God, I never fully understood the power of their faith and their congregations as the places of respite from the harsh realities and terrible impact of systemic racism. Their congregations were places where their humanity could be restored. In these places I met

Rhodes Scholars, doctors of every discipline, scientists, teachers, government workers, railroad engineers, secretaries, nurses, orderlies, maintenance personnel, restaurant workers, people of every walk of life celebrating gratitude, peace, joy, and possibility, sharing their burdens, and seeing one another as equals before God. And God, not their own gifts, talents, or initiative, was celebrated as the source of all blessings. This is not to say that these congregations were perfect; as a pastor I knew the challenges we all face. But they were authentic in their struggles, honest in their lament about the state of the world, and clear in their need for meaning making and for God in every aspect of their lives. There was nothing smug, self-congratulatory or rote about it. These people were alive and ready to give whatever they had to help one another. These congregations were fertile ground for the planting of the Congregational Health Network.

What I Have Learned So Far

Through the research, recruitment, and pilot launch of the Congregational Health Network, I have learned the following. (1) Faith and spirituality are vital components, most especially for people of color, in maintaining stamina, hope and strength and in making decisions to choose between recommended protocols, in their management of chronic disease. (2) Challenges remain for BIPOC patients in the US healthcare system. Whereas practitioners are aware of the existence of structural racism on an intellectual level, we continually strengthen it through ignorance and unintentional bias. This ignorance and bias seeps into our policies where it is still assumed that there are race-based diseases such as SCD which do not deserve equitable treatment in access to health insurance or research funding. (3) Although the literature on social drivers of health is widely recognized and many hospital systems employ assessment tools to identify barriers to treatment, most do not place actual resources and remedies in the hands of the patients who need them most. More detailed conversations about unmet needs reveal a host of opportunities to help patients care for themselves. The time, tool set and skills to engage in these conversations are not yet widely available in the clinic. (4) Spiritual care and the application of religious health assets to help patients thrive are still viewed with some skepticism for those who see science-based treatments as the only path to healing. (5) The Congregational Health Network pilot for patients managing SCD has demonstrated that congregations can collaborate with a hospital system to address unmet needs that equip patients to take care of themselves. (6) The CHN cannot cure SCD, but it can contribute to a new model for healing, which I define as flourishing in life, under a canopy of care, while managing, not controlled by, a diagnosis. My model of more equitable healthcare, the Healing Tree, encompasses the essential role of the CHN.

The Healing Tree

The Healing Tree grows in soil that is nourished by mutual trust, where clinicians, caregivers and patients treat each other as persons practicing acceptance, kindness, respect, careful listening, mutual engagement, and participation in research that will yield new knowledge pertaining to chronic diseases which enriches the lives of everyone. This soil is the fruit of relationships nurtured in clinic encounters as well as through CHN offerings. For example, as clinicians and patients continue to meet through the SCD Fellowship and learn more about each other as people, without white coats, stethoscopes and prescription pads, mutual understanding grows, and care plans become more collaborative and individualized. Trust can grow in this soil, as patients learn more about the disease process and possibly increase their willingness to participate in research believing that it is not a mere invasion of privacy but a gift of knowledge that we can share to improve outcomes for many.

Medical treatment, defined as the transactional, mostly billable, encounters which apply a protocol, supported by data, to manage or cure a diagnosis and its symptoms, forms the trunk of the healing tree. These science-based remedies include disease screening, genetic counseling based on test results, medicines, blood transfusions, immunizations, hospitalization, surgery, subspecialty care (examples include respiratory, vision, dental, orthopedic services that respond to the impact of SCD on the body), and finally, curative therapies such as bone marrow transplant and gene-editing. Treatment, however, does not tell the whole story in managing SCD or any other chronic illness. “Medicine is concerned with the problem of keeping you alive; but chronic illness asks the question for you, ‘what is life for’? [1]

Brandon’s question from chapter 2 rings in my ears at this juncture: “Why has God cursed me?” To flourish one must comprehend the meaning of their life, their purpose, their calling, their reason for being. It is hard to grasp this while in the grip of a chronic disease that can rebel at a moment’s notice against the treatment protocol. Care, defined as the relational encounter where one is fully present, listening and responding to unmet needs that restore human dignity and meaning, forms the branches of the healing tree. These branches secure the canopy that can cover our patients through a lifetime of chronic disease management.

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[1] Arthur Kleinman, M.D., *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, Perseus now HBG Books, 1988), 215.

The in-hospital care provided largely by social workers, dieticians, chaplains, and psychotherapists, is essential to healing and includes dietary advice, cookbooks reflecting the research in food as medicine, instructions for home care and symptom management, screening for social determinants of health, monitoring of appointment adherence, recommended over the counter medicines, and case management services including referrals to government and community-based resources. Occasional donations include cards for convenience stores, gas, groceries, school supplies and holiday gifts. But, when a patient is asked to consume a healthy diet rich in fruits, vegetables and lean protein and that patient is a member of an 8-person family who presents to the chaplain that one chicken in the freezer constitutes the total family food supply for the next 2 days before payday, it is not sufficient to send them home with a prayer. "If a brother or sister is naked and lacks daily food, and one of you says to them, "Go in peace; keep warm and eat your fill," and yet you do not supply their bodily needs, what is the good of that?" (James 2:15, NRSV)

This is where the CHN comes into play by placing assets into the hands of the psycho-social-spiritual worker in the clinic who can share them immediately with the patient and family. It is important to remember that not all families managing SCD live in poverty; but many experience a lack of information, support, community, connection, and mentorship. These assets, shared by faith communities, form the caring canopy of 'leaves' filling out the healing tree and include **tangible resources** (Food Farmacy provisions, free vitamins, emergency funds, heating pads, weekly seasonal vegetables), **people** (volunteer drivers, adopt-a-family, in-hospital caregivers, transition mentors, Smart/911 and food coaches), and **safe spaces** (the SCD family fellowship, ZOOM spaces for meetings with coaches and mentors, and the Sickle Cell Gardens at the Praying Ground). These assets impact the socio-economic determinants of health as their availability transforms the circumstances in which our patients live. Healthy food in the pantry, necessary medicines on the kitchen counter, assurance that an appointment will be kept, someone to support you with your diet and your transition journey; knowing that these resources are in your hands reduces a patient's stress and multiplies their agency and self-esteem. As these resources grow, and mature, are renewed and refreshed through the seasons (as the leaves flutter from the tree to the ground), and more collaborators join the Network, they continue to fertilize the soil that nourishes the Healing Tree.

Arthur Kleinman, whom I consider to be the father of palliative and supportive care, quotes Gregory Bateson's assessment of the double bind that hurts the chronically ill. This bind is multiplied by the intersectionality of the patient managing SCD who not only bears the burden of a life-time blood disorder, but faces the barriers presented by being a person of color, living in or near poverty, as a child with a small voice and even smaller agency, searching for a source of strength outside his or her own. This double bind is "the conflicting demands placed on the seriously ill by their (clinicians); first, be independent, not passive and dependent, and be active in your care BUT when you have a serious exacerbation, place yourself submissively in our hands and we will blame you for what you did or did not do to worsen your disorder." [2]

We tighten the double bind when we track appointment compliance in a patient's electronic medical record, but never ask WHY an appointment was missed and what we can do to help. We tighten the double bind when we administer a questionnaire on the

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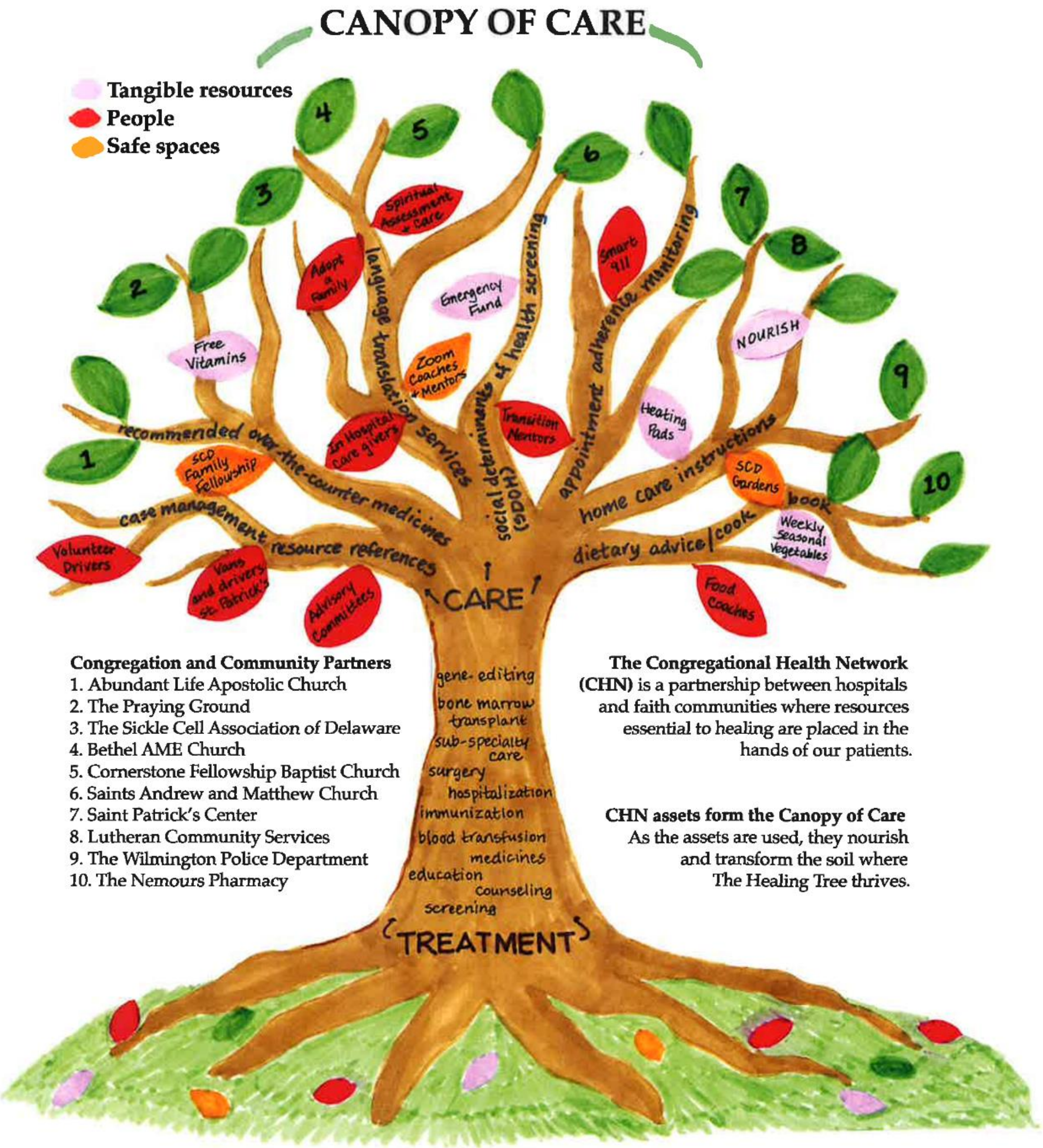
[2] Ibid., 170.

social determinants of health only to count the challenges a patient faces, but do not provide any answers to the challenges. We tighten the double bind when we intentionally or unintentionally do not trust the patient to tell us what they need from their own experience with their own body, such as refusing to prescribe appropriate pain medicines for fear of feeding a drug addiction. Leveraging the people, spaces, and tangible gifts of the faith communities where our patients have found their strength for the journey can loosen the double bind by giving them the tools to thrive, encouraging their agency in relationships with caregivers and clinicians, restoring their confidence in caring for themselves and the clinician's confidence in their management of their SCD. This is the journey taking place under the healing tree—where a patient can see a path to his or her own calling and purpose, a path to abundant life and peace, leveraging the congregations where they have found refuge, embracing the healthcare providers who bring their gifts of expertise.

THE HEALING TREE

> "and they shall sit under their own vines and their own trees and
> no one shall make them afraid."
> *Micah 4:4*



Congregation and Community Partners
1. Abundant Life Apostolic Church
2. The Praying Ground
3. The Sickle Cell Association of Delaware
4. Bethel AME Church
5. Cornerstone Fellowship Baptist Church
6. Saints Andrew and Matthew Church
7. Saint Patrick's Center
8. Lutheran Community Services
9. The Wilmington Police Department
10. The Nemours Pharmacy

The Congregational Health Network (CHN) is a partnership between hospitals and faith communities where resources essential to healing are placed in the hands of our patients.

CHN assets form the Canopy of Care
As the assets are used, they nourish and transform the soil where The Healing Tree thrives.

Equity Trust Acceptance Kindness Respect Listening
Research Mutual Engagement

Limitations of this Study

The establishment of the CHN pilot has been yeoman's work but it is just the beginning. Now that we know that patients will use these services, we need to develop outcome measures that can demonstrate the value of the CHN fully in an environment that will remain science dominant. Comparing patients who have used services with those who have not is a good place to start. Building on the wisdom of Gunderson and Cutts, chart reviews can help us track hospitalizations, repeat hospitalization, appointment adherence and Medicaid utilization of patients who are part of the CHN. There are other opportunities within specific service offerings. For example, vitamin levels, changes in dietary habits and weight management can be tracked for patients who are part of the NOURISH program.[3] Qualitative opportunities include offering additional healthcare resources to CHN partners such as clinicians leaving the hospital and coming to the community to host SCD awareness Sundays, screening for children who may have missed the opportunities now mandated and screening for adults who want to know if they have the SCD trait. Application of clinician/patient trust measurement tools such as the Discrimination in Medical Setting Scale, Group-Based Medical Mistrust Scale and Microaggressions in Health Care Scale, [4] can tell us whether the CHN is able to improve patient/clinician relationships and increase research study participation. Strong outcome data is necessary to institutionalize the CHN.

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[3] As we planned to continue work with Lutheran Community Services, we were asked to distinguish our SCD program for pediatric patients from the Food Farmacy program in place at the adult hospital. Therefore, we changed our name to NOURISH.

[4] Crystal E. Brown, M.D., M.A., Arisa R. Marshall, BS, et. al., "Perspectives About Racism and Patient-Clinician Communication Among Black Adults with Serious Illness," *JAMA Network Open* 6, no. 7 (July 2023): 6-7, e2321746.doi:10.1001/jamanetworkopen.2023.21746.

While pursuing these data, it is also necessary to make plans to move the Health Navigator role, in which I have been serving as a volunteer, to a paid position. The hospital rule is that outside sources of funding for a period of two years must be secured before any new non-billable position can be included in the annual budget. The Human Resources department has reviewed the position of the Health Navigator (provided in Appendix 5) and sized the two-year funding requirement at a total of $180,000. The hospital is supporting me with grant-writing assistance in search of this funding. As of this writing $100,000 has been raised toward this effort.

Finally, there have been clear, non-scientific benefits from building the CHN. Clinicians have begun to appreciate the power and creativity available in faith communities who become partners in patient care. I see this through the increased enrollment from the SCD Clinic in our Spirituality in Medicine course. Patients have expressed new hope in managing their health because of the resources made available to them through the CHN, making them less fearful of the medical establishment (remember *iatrophobia* from chapter 2?). In the words of one patient "I never believed that anyone understood what we feel until I came to the SCD fellowship and saw my doctor outside the hospital."[5] The hospital clinicians are beginning to see the CHN as a vehicle for mutual engagement in building care plans. Clinicians and psychosocial workers have more tools to offer our patients and patients are increasingly empowered to care for themselves as they take up these offerings. This is good news indeed for the hospital, the patient, and our collaborators. This is a small beginning, but it is not to be despised.

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[5] Ms. K, April 29, 2023, at the Cornerstone Fellowship Baptist Church, SCD Fellowship program.

As for me, my prayer every day before coming to the hospital is a simple one, “God, make me, in any way you choose a blessing to just one person today.” The CHN pilot is an answered prayer because it is God’s work and I have been the one blessed every day by this project.

EPILOGUE: GOOD TROUBLE

"Get in good trouble, necessary trouble and help redeem the soul of America."[1]

"God does not will everything, but God wills GOOD from everything." Rev. Dr. James Forbes

"For I am about to create new heavens and a new earth; the former things shall not be remembered or come to mind. But be glad and rejoice forever in what I am creating." Isaiah 65:17-18a, NRSV.

A Very Difficult Day

On the morning of Monday December 11, 2023, I attended a meeting with my physician supervisor. Recently, I made administrative errors in the management of the CHN pilot, and my supervisor was helping me to correct them. The errors that I know about are three in number, described to the best of my ability below.

(1) I failed to provide adequate written consent from patients to offer them CHN services. Although there were no explicit requirements in place at the hospital to gain consent for a patient to obtain a CHN flyer, once they asked to be referred to a specific program, such as NOURISH, their signature was required on a consent form and this consent had to be documented into the patient Electronic Medical Record. (EMR) As a hospital volunteer I had no access to the EMR, and I had to rely on colleagues to document consent as I received it, often through an email. At this writing a draft form was still being

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[1] Congressman John Lewis at the Edmund Pettis Bridge in Selma, Alabama, March 1, 2020.

reviewed by the legal department. The resulting notes in the EMR were inconsistent in format and not always up to date.

(2) On November 2, 2023, I was falling behind schedule in getting the word out to our patients about the start of the Life Skills Mentor Group. I acted quickly and thoughtlessly to remedy the situation by sending out a text message to patients who met the age criteria to be offered a mentor. To make matters worse, I sent the text on my own phone. A hospital phone was not available to me as a volunteer. I realized my mistake as a potential exposure of Protected Health Information according to the HIPAA law and self-reported within 20 minutes of my error. I followed the remediation process outlined by the Compliance Department. During follow-up meetings about this error, my supervisor agreed to meet with me weekly to ensure that all CHN activities were properly structured. As I reviewed our offerings in detail it became clear that the Emergency Fund was a problem. We had begun the process of moving this fund to be administered under the direction of one of our church partners, but the process was not complete.

(3) I established the Emergency Fund using donations that were made payable to me for the express purpose of helping patients with specific one-time needs through the CHN. A social worker colleague assisted me in establishing the fund. No payments from these funds were made directly to any patient but were used for the benefit of 4 patient families. We helped one family to supplement a mortgage payment, one family to extend their stay in a local motel while they waited for their insurance payment since their house burned

> down. We supplemented one patient's monthly rent and helped one patient satisfy a nursery school tuition bill in extreme arrears, preventing a gifted and talented patient from expulsion. I disclosed all bank records to the hospital investigators who determined that the fact that the funds were transferred into the Emergency Fund from my bank account meant that this could be considered co-mingling of funds. I was also given a policy statement from the hospital based upon their interpretation of the federal anti-kickback law. Our emergency fund could be interpreted as an inducement or bribe to attract patients to the hospital health system.

Having made these mistakes, the meeting on the morning of December 11 resulted in my being escorted from the hospital and the termination of my role as a volunteer. All activities of the CHN were immediately suspended and my social worker colleague, a woman of color with 19 years of service to her credit, was fired. I was devastated, embarrassed and angry. Although I had initiated over 30 meetings inside the hospital to explain the CHN, asked for clarity and support repeatedly from as many people as would meet with me, functioned in the clinic for almost 2 years to build the pilot and serve our patients with regular updates on all of the activities, it was ultimately determined that my administrative errors presented an untenable risk of legal liability to the enterprise. I take responsibility for my actions, thank the hospital with all my heart for being the incubator for the CHN and mourn, most of all, the dismissal of my colleague.

On the Third Day

I did not think I would ever stop crying, but as I wept at the crying tree, another question was written on my heart, "Pat, do you want the Healing Tree to grow?" [2] To answer this question, I decided I needed to explore the law and regulations that led to the cancellation of the CHN program so that I could fully understand my errors and not repeat these mistakes. I began my research with a copy of the hospital policy entitled "Patient Inducement" which I was given on November 11, 2023.[3] It is based on the hospital's interpretation of the Federal Anti-Kickback Statute [4], the Stark Law [5] and the Civil Monetary Penalties Law[6]. Given that I am not an attorney my interpretation of these statutes is clearly subject to legal review. Therefore, I sought commentary from two reputable law firms. I can, however, offer some intelligent questions about the application of these laws to the CHN pilot. It is important to note that the purpose of all of these laws is to protect taxpayers from fraud in the federally funded Medicare, Medicaid and Tricare programs (the health coverage program for uniformed service members, retirees and their

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[2] At this point the crying tree becomes the healing tree. As I experienced this transition, I thought about King David's mourning of the death of his first child with Bathsheba. I know that the circumstances in the Scripture are very different from this project. But David fasted and wept while the child (this project felt a bit like my baby) was still alive, but when it was clear that the child had died, he rose and ate food. I couldn't change the fact that the CHN was no longer viable within the hospital. I knew I couldn't bring it back in its original form, but there might be new life in the healing tree. So, I got up, wiped my tears, ate some food, and set my face in a new direction. See 2 Samuel 12:15-25 NRSV.

[3] Patient Inducement, policy #5.4.6, effective date 11/16/20, owned and administered by the Chief Compliance Officer.

[4] November 7, 1986, 41 United States Code section 51 et. seq. Codified as 42 U.S.C. section 1320 a-7b(b).

[5] 1989, section 1877 of the Social Security Act, 42 U.S.C. section 1395 nn.

[6] 2015, 42 United States Code section 1320a-7a.

families around the world) and "to ensure that medical services and recommendations remain as free from financial influence as possible."[7]

The Federal Anti-Kickback Statute passed in 1972 and amended in 1977 and 1986 is intended to prohibit individuals and entities from "knowingly and willfully soliciting, offering, receiving or paying any form of remuneration to induce referrals for any items or services for which payment may be made by any federal healthcare program unless the transaction is structured to fit within a regulatory exception." [8] The definition of remuneration was established as "anything of value which was solicited, received, offered or paid directly or indirectly, overtly or covertly in cash or in kind."[9] The Stark Act passed in 1989 is built upon the principles outlined in the Anti-Kickback Law and specifically prohibited referrals by a physician to a healthcare entity in which the physician or a family member held a financial interest.[10] Examples of violations of these laws include cash payments to physicians for referrals, or patient kickbacks where a provider offers cash or other incentives to choose their services over others; entertainment such as a pharmaceutical company providing lavish meals or vacations in exchange for a physician prescribing a certain drug; discounted or free services; and/or

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[7] Tycko and Zavareei, LLP Whistleblower Practice Group, "The Anti-Kickback Statute and Stark Law Explained", *National Law Review* XIII, no. 360 (2022): 1-2.

[8] Kim Stanger, "Patient Inducements: Gifts, Discounts, Waiving Co-pays, Free Screening Exams, etc.," *Insight*, Washington, DC: Holland and Hart, April 4, 2023: 1.

[9] Chinelo Dike'-Minor, "The Untold Story of the United States' Anti-Kickback Laws," *Rutgers Journal of Law and Public Policy* 20, no. 2 (2023): 111.

[10] Amrita Shenoy, Gopinath N. Shenoy, and Gayatri G. Shenoy, "The Stark Law from inception to COVID-19 blanket waivers: a review," *Patient Safety in Surgery* 16, no. 19 (2022): 2, Doi: 0.1186/s13037-022-00326-9.

fee-splitting where a physician agrees to split fees with another provider in exchange for certain referrals. [11]

In 2015 the Civil Monetary Penalties Law (CMPL) gave the federal Office of the Inspector General (OIG) within the Department of Health and Human Services the power to create safe harbors for certain services that may be made available to patients and to specifically define boundaries for remuneration. The CMPL defines goods and services given to patients valued at $15 or less individually and not exceeding $75 annually to be acceptable.[12] This definition is specifically included in the hospital policy on Patient Inducement. Speaking directly to the CHN services, the value of the food provided through the NOURISH and Sunny Day programs, the transportation provided through the St. Patrick's Center and the housing and preschool tuition assistance provided through the Emergency Fund posed a risk of violating these important laws because they could influence/induce a patient's decision to receive care at a particular hospital.

Yet, there are some important clarifications to this law offered by the OIG that warrant consideration. The AKS applies only if one purpose of the free item is to induce referrals for such items or services. The CMPL is only violated if the provider knows or should know that the remuneration is likely to influence a patient to receive such items from a particular provider. So long as there is no such improper intent or influence, then the statute is not violated. [13] Furthermore, the OIG has stated, "We recognize that there are socioeconomic, educational, geographic, mobility or other barriers that could prevent

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[11] Tycko and Zavareei, *National Law Review*, p. 2-4.

[12] OIG-Policy-Statement-Gifts-of-Nominal-Value, pdf. 81 Fed. Reg. 88394, OIG Special Fraud Alerts 2/29/94 hhs.gov/fraud/docs/alertsandbulletins/121994.html.

[13] Stanger, *Insight,* 4.

patients from getting necessary care (including preventive care) or from following through with a treatment plan. Our interpretation of items or services that promote access to care encompasses giving patients the tools they need to remove those barriers." [14] This exception protects items or services that should improve a patients' ability to access care and treatment. The service must provide a low risk of harm, i.e. (1) unlikely to interfere with or skew clinical decision-making; (2) unlikely to increase costs to Federal healthcare programs or beneficiaries through overutilization or inappropriate utilization and (3) not raise patient safely or quality of care concerns.[15] The harm to be avoided is an overall increase in health care costs. Assuming the free services are not simply marketing ploys, but rather identify or assist with necessary care, they could fit in the exception and be protected. [16]

A broader exception covers items or services given to patients with financial need. To qualify these conditions must be met: (1) The items or services given to patients are not advertised.[17] (2) They are not tied to the provision of other items or services reimbursed by Medicare or state healthcare programs. (3) They are 'reasonably connected" to the patient's medical care defined as related to the treatment and management of an illness or injury, preserve the patient's health, or reflect services

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[14] Ibid., 10.

[15] Ibid., 11.

[16] Ibid., 12.

[17] It is relevant to note that the Emergency Fund in question was never publicly advertised. Its existence was known only to me, the social worker, and the director of the SCD clinic. It was understood that it was to be used only in emergency situations (usually revealed through SDOH screening) that, if not rectified, could clearly threaten the health and well-being of a patient. Homelessness was widely acknowledged as a clear risk to the well-being of a patient and family managing SCD.

offered by a medical, dental, pharmacy, nursing, or allied health professional. (4) The patient must be in financial need.[18] This is the exception that allows the University of Pennsylvania to offer a transportation service, in partnership with Ride Health, to its patients in need to increase their appointment compliance and enhance their care. [19]

There was no attempt to evaluate the CHN services against these criteria. Nor was the decision to end the CHN made with any direct input from the medical team in the SCD clinic. Administrative errors were made, no doubt, and a 'thin' (my term) risk that a patient or third party might claim that the services provided were somehow an inducement was avoided, but no attention was paid to the specific benefits and potential positive health outcomes that patients might receive. Compliance lawyers made the decision to close the project, a project that could have benefitted tremendously from an interdisciplinary evaluation of the potential benefits, and an interdisciplinary plan for institutionalization. The implementation of the CHN pilot clearly caused trouble within the hospital's legal and compliance divisions. It also brought improved relationships between patient and provider, the beginning of measurable changes in nutrition and vitamin levels, increased appointment attendance and research participation (a benefit of improved relationships and trust) and placed resources in the hands of providers that increased patients' ability to care for themselves building light and hope for 99 patients and 142 of their family members.[20] I do not regret the time and energy I invested in

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[18] Alice G. Gosfield, JD., "Patient Inducements: The New Dos and Don'ts," *Family Practice Management* 25, no. 4 (2018): 18.

[19] Sarah Gantz, "Penn started giving cancer patients free rides to appointment. It helped reduce no-shows and increase clinical trial enrollment", *The Philadelphia Inquirer* 194, no.211, online, www.inquirer.com, December 28, 2023.

[20] Members of the clinic team and I had begun drafting questions for a second submission to the Institutional Review Board seeking support for research on detailed outcomes from the CHN project. This

developing this pilot with my clinic partners. If trouble was brought to the institution, I claim it was ‘good trouble’ indeed.

A New Thing

It is important to note that in the fourth section of the hospital policy on inducements, it is stated that ‘community-donated gifts which are provided for distribution to patients/families are not subject to the patient inducement restrictions in this policy’.[21] Clearly the concern about a potential violation of the federal law arises when the patient believes that a benefit is a gift from the hospital. One must also consider who the primary users of government healthcare programs might be. Neither the AKS, Stark Act, nor CMPL apply to private health insurers. Is it possible that patients who have private health insurance can receive unlimited benefits/inducements? These questions led me to the following observations. (1) The interpretation of the laws designed to prevent healthcare fraud in the government system seem to disproportionately impact those struggling with the social determinants of health. That would be the poor, our BIPOC patients and families, and anyone who does not possess the means or the employment that affords them private insurance. This group comprises a significant portion of the SCD patients served in this hospital. (2) Without more care and consideration to applying the law, our hospitals can deny these patients the support services they need and, thereby, become complicit in reinforcing structural racism. The OIG safe harbor provisions are one tool that can help structure a program that does not

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research would have required access to the EMR. Some of our questions were based on outcome data collected by Gunderson and Cutts in the Memphis CHN implementation.

[21] Patient Inducement Policy, section D. page 2.

run afoul of potential kick-back violations and can serve patients in need. (3) The help that our patients received during the CHN pilot was life-affirming as demonstrated by the email I received from a patient on December 11, 2023. [22] (4) The work of the CHN can live and grow as an independent community-based organization. (5) Finally, our healthcare system cannot improve patient care from within. Help is needed from outside the system. The CHN pilot was over; the program was not dead. It could be restructured as an outside organization and potentially serve more than one hospital. The model for a new thing was already present in The Healing Tree. It was time for a resurrection.

From Pilot to Non-Profit

I filed the paperwork, supported by an attorney and accountant with the Internal Revenue Service on December 22, 2023, to re-create the CHN as a new non-profit to be named “The Healing Tree”. The Healing Tree will be a community-based organization designed to provide support for families managing SCD. It exists to transform the ecology of healthcare, provided in multiple hospitals, beginning with SCD patients and families. The Healing Tree promotes equity, trust, acceptance, kindness, respect, listening, mutual engagement and research by placing essential resources in the hands of patients and families managing chronic disease through a range of volunteer collaborations. The IRS approval process can take up to six months, but a pending status can be used to build the necessary infrastructure. This time will allow me to create the initial two-year plan and pro-forma (budget), enlist a proper accounting service to

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[22] “From the bottom of my heart, I’d like to say, “Thank you.” I cried out to God in my distress, and He sent me to you. Through the NOURISH program I have had the honor of meeting a host of other Angels on earth, the many people behind the scenes I never got to see, yet who have been with me in various ways (prayers, emotional and some financial support). I am truly blessed to have all of you in my life. My sons are so much better off because of you. Wishing all of you and your families the very best of this Christmas season and the happiest of new year’s. Love, X.”

facilitate fund-raising and grant writing, find office space, hire some paid part-time help (I will continue indefinitely as the Volunteer/Director) and recruit a Board of Directors, likely from the existing Advisory Committee. Other options are also coming to light such as joining an existing non-profit or re-framing a non-profit that has run its course and is seeking a new direction.

It is a bit too soon for me to thank the hospital compliance department for freeing me, so to speak, from the restrictions established in their policies, but this work is a calling, and other forces are at play. This is God's work, healing work, and it is in God's name that I will continue this effort. The Healing Tree might yet grow. So be it.

The Journey Continues

As this dissertation project ends, I have discovered that working toward a healthcare system that is equitable and accessible requires understanding, prayer, and reflection on multiple levels. (1) We must embrace our **history.** The interactions of generations before us define who we are to each other in the present. Changing those relationships can happen only if we know and own what has brought us to this point. (2) It is amazing how a single **faith** tradition, Christianity (which still represents the majority in the United States and certainly binds the BIPOC community together) can be interpreted in so many ways to justify a wide range of behaviors. We must be willing to evaluate our actions against our standard-bearer's life—Jesus—sans the theology we have woven around him to justify ourselves. (3) Medicine is a magnificent calling that may have lost its way in **practice**. Its foundation, science, is a powerful gift from God but it is not to be applied as the power and insight that makes us gods. We are called to be healers—to make it possible for each other to live abundantly while managing all the challenges of life. We would be wise to remember that only God is the source of cure, and it is always given freely. (4) Our history, faith and practice have brought us to behaviors that distance us one from another. We need to make time in all our relationships to see each other as individuals, gifted, fearfully and wonderfully made brothers and sisters who are made superficially diverse by our Creator and our various ecologies in this beautiful world, but whose hearts pump the very same **blood.** (5) The rule of **law** is a powerful instrument, and it certainly has a role in organizing a society. God gave us 10 laws; Jesus gave us 2. But ultimately law derives from our inability to trust each other to consider the common good. Law encodes standards of behavior, proper procedure, and genuine hope for a better, more organized world. Law also encodes our fears, our desire for consequences (dare I say 'justice'?) and the detritus of relationships forged by conflict. Laws should be obeyed, but they should also be carefully examined to determine if they remain faithful to promoting equality and goodness for all.

The Congregational Health Network and the Healing Tree provide and will provide an opportunity for volunteers and patients/families to regard each other anew as, together, we work to transform how we care for each other. Both entities are about opening our hearts and minds to see each other not according to our proscribed roles, doctor-patient, pastor-parishioner, rich-poor, black or white, more-than or less-than but as children of God working together to help those most in need to see the goodness and compassion that still lives in the world and in each other. We can claim together that we have the power to make a difference.

I still struggle in my faith about the identity, origin, and purpose of Jesus' life, but I know one thing for certain; in all his relationships he led with love. That is my ultimate hope with the Healing Tree, that it will help us wrap our history, faith, practice, blood and law in love and lead with that in every dimension of our lives—always.

APPENDIX I

A PRIMER ON SICKLE CELL DISEASE (SCD)

Overview

SCD is a group of chronic, progressively debilitating inherited red blood cell disorders affecting about 100,000 persons in the United States and millions worldwide. SCD occurs in about one of every 365 births of children of color. Nemours Children's Health currently treats about 300 patients managing SCD.

SCD impacts hemoglobin, a protein in red blood cells responsible for transporting oxygen in the blood. "Healthy red blood cells are round, and they move easily through small blood vessels carrying oxygen to all parts of the body. In SCD the red blood cells become hard and sticky and look like a C-shaped farm tool called a 'sickle'." [1] Sickle cells die early, so a person with SCD suffers from a constant shortage of red blood cells. Sickle cells can also get stuck in small blood vessels, blocking oxygen to organs in the body. These blockages can cause vaso-occlusive crises (VOC) which are periods of horrible pain. Patients managing SCD may experience infection, swelling of hands and feet, eye disease, stroke, hemolytic anemia, where red blood cells die more quickly than they can be made, and blockage of blood flow to the lungs causing a serious condition known as acute chest syndrome. Life expectancy for patients managing SCD is approximately 42 years for males and 48 years for females. [2]

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[1] Centers for Disease Control and Prevention, "Data and Statistics on Sickle Cell Disease," US Department of Health and Human Services (May 25,2022): 1-5, CDC.gov/ncbddd/sicklecell/index.html.

[2] Brennan-Cook, "Barriers to Care," 213.

SCD is most common among people whose ancestors come from sub-Saharan Africa. The sickle cell trait (SCT) developed in response to a parasite called Plasmodium which causes malaria. This parasite lives inside the Anopheles mosquito. The sickle cell trait, not sickle cell disease, provides some protection against malaria because it reduces the number of parasites in the blood should one receive a mosquito bite. The development of SCT and SCD is therefore associated with regions where malaria is present.

Types of SCD

There is more than one type of SCD. Sickle Cell Anemia (SS) occurs when a patient inherits 2 hemoglobin S genes, one from each parent. These genes produce an abnormal form of hemoglobin that cause red blood cells to become rigid, and sickle shaped. Sickle cell C occurs when a patient inherits an S gene from one parent and a C gene from the other. SC disease is usually a milder form than SS. Sickle Cell Beta Thalassemia occurs when a patient inherits an S gene from one parent and a beta 0 or beta + gene from the other parent. Thalassemia causes the body to produce insufficient beta globin causing red blood cells to be misshapen, impeding oxygen transfer. Beta 0 is generally more severe than beta +. There are other rare types of SCD such as HbSD, E and O where the patient inherits the hemoglobin S gene from one parent and a D, E or O gene from the other that codes for an abnormal hemoglobin type. The severity of these types of SCD varies.[3]

If one parent has SS disease and the other parent has no SCD indicators, all their children will have SCT. If one parent has SS and the other has the trait, there is a 50%

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[3] CDC, “Data and Statistics,” 1-2.

chance (1 out of 2) of having a baby with either SCD or SCT with each pregnancy. When both parents have SCT they have a 25% chance (1 of 4) of having a child with SCD with each pregnancy. [4]

Diagnosis and Manifestations of SCD

Since 2008 screening for SCD, through a blood test, has been included in all newborn screens completed across the United States. Pre-natal DNA analysis can also be performed. Prior to standard screening, SCD was often diagnosed after the patient suffered symptoms such as a VOC or stroke. One diagnostic tool for stroke that is not yet included in standard screening is a cranial Doppler (ultrasound examination) [5]

Chronic hemolysis is a continuing breakdown of red blood cells that occurs because sickled cells have a lifespan that is approximately 1/7 that of a normal red blood cell. As this condition persists, the process whereby new blood cells are generated can stall and hemoglobin drops. This is called aplastic anemia. This often occurs following an infection. A blood transfusion is then necessary.

Splenic Sequestration is caused by a drop in hemoglobin secondary to a vaso-occlusive event. This occurs in about 30% of pediatric HBSs patients. Sickled blood cells become trapped in the spleen causing swelling and pain. Infection is a common consequence of this condition which is another reason why immunizations for our

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[4] CDC, “What is Sickle Cell Trait?” *Sickle Cell Fact Sheet*, US Department of Health and Human Services (December 14, 2020): 1-2, CDC/gov/ncbddd/sicklecell/index.html.

[5] Freed, “Missed Opportunity,” 715.

patients need to be kept up to date. Repeated episodes are usually treated by removing the spleen.

Nervous system injuries are a common feature of SCD. As many as 11% of patients experience a stroke before age 20. Silent cerebral infarctions impact over 25% of affected children before age 5. Seizures and epilepsy have been demonstrated to occur three times more frequently in the pediatric SCD population. [6]

A **Vaso Occlusive Crisis** is acute and episodic pain in any part of the body where sickled cells form a blockage preventing oxygen to be carried to an organ, bone, or tissue. Leg ulcers, bone deterioration and eye damage can occur. When occlusive symptoms occur in the pulmonary system, the result is called **Acute Chest Syndrome** (ACS). Fever, pain, and cough are part of the presentation of this condition. Repeated ACS can lead to hypertension, heart failure and kidney disease. Acute pain crises due to SCD are the most common cause of emergency department visits and hospitalizations, directly accounting for $1.1 B in healthcare costs annually. VOCs can start as early as 6 months old when fetal hemoglobin is replaced by hemoglobin S.[7] VOCs generate an average 197,000 emergency room visits each year. This is 4 times the number for patients suffering with heart disease and 13 times the number for patients suffering with HIV. [8]

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[6] Jacob Fiocchi, et. al., “A Comprehensive Review of the Treatment and Management of Pain in Sickle Cell Disease,” *Current Pain and Headache Reports* 24, no. 17 (2020): 6.

[7] Ibid., 3.

[8] “SCD Involves All Blood Cells.” www.rethinkscd.com/.

The incidence of **clinical depression** in the SCD population is five times that of those who are not impacted. [9] Anxiety, low self-esteem, and behavioral difficulties have been documented in SCD patients. These conditions have also been associated with patients' experience of racial bias [10]

Preventive care could be expanded for patients managing SCD. Daily antibiotic treatment for children with SCD younger than 5 years of age has been shown to markedly decrease the risk of sepsis and has been recommended by national authorities for more than 20 years. Yet studies across several states have shown that less than 20% of children with SCD receive such care. Doppler screening has proven to be effective in helping prevent stroke in patients with SCD. However, only 22% to 44% of children are screened each year.[11]

Available Drug Treatments for SCD

The drug **hydroxyurea** was first tested in SCD patients in 1984. Although it was developed as an anti-cancer drug, hydroxyurea is a mediator of inflammation. It increases fetal hemoglobin, lowers the amount of hemoglobin S; improves the shape and function of red blood cells, thus improving overall blood flow. It was approved for use in the adult

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[9] Delores P. Quasie-Woode, et. al., "The Use of Religion in the Management of Depression in Sickle Cell Disease: A Systematic Review," *Journal of Religion and Health*, 59, no.6 (2020):3111, doi.org/10.1007/s10943-020-01039-y.

[10] Emily O. Wakefield, et. al., "Describing Perceived Racial Bias Among Youth with Sickle Cell Disease," *Journal of Pediatric Psychology*, 43, no.7 (2018): 780, doi.10.1092/jpepsy/jsy15 and 5 Leger, et.al., "Stigma in adults with sickle cell disease," 24.

[11] Freed, "Missed Opportunity," 715.

population in 1998 and the pediatric population in 2017.[12] It has been found to be effective in lowering the number of VOCs (thus reducing damage to internal organs) and hospitalizations for pediatric patients. Dosing can begin at 9 months of age. It may reduce the white blood cell count which is why monitoring through regular blood tests is needed to ensure the correct dosage.

Oxbryta is also an oral medication that is taken daily. It interferes with the sickling (clumping) of hemoglobin inside red blood cells which results in the formation of long, stiff chains (polymerization). In this way hemolysis, the breakdown of red blood cells, bilirubin, the by-product of this breakdown, and reticulocytes, new, but not fully developed, red blood cells, are all reduced, thus improving blood flow to the organs. This drug is used with patients who are at least 4 years old.

Crizanlizumab is a medication administered through infusion for patients who are 16 years of age and older. It is a monoclonal antibody that binds to P-selectin thereby blocking interactions between endothelial cells that line the interior walls of blood vessels, platelets, red and white blood cells, so that they do not stick together or to blood cell walls. In this way, VOCs and hospitalizations are reduced. Crizanlizumab was approved by the FDA in 2019.

There are several drugs available to reduce SCD pain. Among them **Endari** (l-glutamine oral powder), a variety of opioids, **NSAIDs** (non-steroid anti-inflammatory agents like ibuprofen) and **Ketamine** (which has also been effective in reducing depression). Chronic use of **opioids** can encourage misuse. Their use can also create

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[12] Nirmish Shah et.al., “Treatment patterns and economic burden of sickle-cell disease patients prescribed hydroxyurea: a retrospective claims-based study,” *Health and Quality of Life Outcomes* 17, no.155 (2019):2, doi.org/10.1186/s12955-019-1225-7.

opportunities for patients to experience healthcare injustice during medical visits such as the assumption that patients are drug-seeking and/or over-reacting to their pain.[13] These attitudes often result in sub-optimal treatment for pain demonstrated by the fact that 40% of patients admitted to hospitals for SCD pain management are re-admitted within 30 days. [14] Time is also of the essence in administering these drugs. When an SCD patient presents at the Emergency Department (ED) seeking treatment for pain, best practices dictate that treatment begins within 30 minutes of triage or 60 minutes from registration.[15] Speed in starting treatment is one of the best predictors as to whether a hospital re-admission will be required to respond to a subsequent pain crisis.

Apheresis and Blood Transfusion

Apheresis is a procedure whereby an SCD patient's sickled cells are removed and replaced with healthy red blood cells from donor blood. This procedure is often done monthly and helps to prevent complications of SCD. The patient's blood is removed through a needle or catheter and then cycled through a machine which separates the blood by cell type: red, white, platelets and plasma. Red cells are sifted, and healthy red cells taken from donor blood are circulated into the patient's other blood products. This therapy can take between two to three hours.

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[13] Miriam O. Ezenwa, et.al., "Coping with Pain in the Face of Healthcare Injustice in Patients with Sickle Cell Disease," *Journal of Immigrant and Minority Health*, 19, no. 6 (2016):1450, doi.org/10.1007/s10903-016-0432-0.

[14] Ibid., 1449.

[15] Brennan-Cook, "Barriers to Care," 217.

Blood transfusions are given to patients managing SCD before surgery to reduce complications. They are also prescribed for patients who have had an abnormal transcranial Doppler (TCD) ultrasound, because they can reduce the chance of having a stroke. Transfusions may be used when patients suffer too many complications from drug treatment. [16]

Pioneering work in the management of SCD pain and other chronic pain is underway using **integrated therapies**. It is important to note that SCD patients will likely experience pain before they can talk; a range of helpful responses is essential. These include Healing Touch, Child Life interventions, Massage, Art, Music, Occupational Therapy, Physical Therapy, Talk Therapy (Psychology), Yoga, Guided Imagery, Virtual Reality, Hypnosis, Spiritual and Pastoral Care and Acupuncture.

What is it like to live with and manage SCD?

Simply stated, living with, and managing SCD can be hell. Symptoms seem to develop randomly. Treatment and care are not consistently administered due to lack of familiarity with the disease, population distribution, equity issues, the impact of the social determinants of health and bias, both intentional and unintentional. I am not a patient managing SCD so I cannot represent the pain of our patients and families with actual experience or knowledge. I can, however, offer these quotes gleaned from my research interviews. They are informative and heart-breaking.

"I am cursed; who will bless me?"

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[16] US Department of Health and Human Services, Sickle Cell Treatment, July 15, 2022, nhlbi.nih.gov/health/sickle-cell-disease/treatment, accessed May 24, 2023.

"The pain is like shards of glass stabbing me everywhere."

"I have no idea what to expect. Who can, who will, prepare me for this journey?"

"God! Fix my blood!"

"My Mom had to pay a fine to the school because I had too many detentions. I am supposed to stay hydrated with SCD, but that means I need to be excused to the bathroom more and that ends up giving me detention."

"We need to build awareness and I need somebody to listen to me."

"Where can I get vitamins, antibiotics and supplements for cheap?"

"Stress, always stress, stress, stress. I can feel a VOC coming on—a paper due, a broken-down car, a fight with my boyfriend—then I know I will be on my way to the hospital!"

"Please think about your words—I am managing SCD, I am NOT SCD."

"Please don't judge me. I am dealing with SCD, and I am gay. No church wants to help me, but the church can help others."

"I don't know if I can trust my body enough to even think about a future much less plan for one."

"I don't want people to think they know us because we have SCD in our family. We just had a baby sister and if she has SCD I do not know what we will do. That could send my Mom and Dad over the edge."

There is Hope and There is Help

It is 'all hands-on deck' every Monday morning at 9 am when SCD clinic rounds take place. The clinic medical director, 3 nurse practitioners (one who cares for inpatients, two who care for outpatients), 2 psychiatrists, 1 social worker, 2 research associates, 4 community health workers, 2 nurse schedulers, a chaplain and others related to clinic management and transition of patient care to adult providers, gather in hope and anticipation to review the care plan for patients scheduled to be seen in the coming week.

With attention to the preservation of patient privacy, a wide range of goals and concerns for every patient is reviewed. Some need a different prescription, others need a procedure, bone marrow transplant candidacy is discussed as well as psychiatric, social, economic, and spiritual needs. The point is that in this weekly space, patients are discussed not as patients, per se, but almost like family members. SCD is a chronic condition and relationships develop over years of treatment and care. We are just as likely to discuss the joy of a patient’s high school graduation as we are the fact that a family might not be ready to accept a new prescription. But with an average of 10-15 clinic appointments each day while inpatients also need care, there is not always the time to assess every patient need, to explore the social determinants of health or to engage the chaplain who might offer time to process information and to pray.

I want you, the reader of this work, to know that the care that is provided to our patients managing SCD is of the highest quality possible and is intended to be entirely patient-centered. Every practitioner I know wants to do their very best to care for each patient. I believe our patients are loved by our team. But there are constraints: time, resources both human and monetary (there is only 1 social worker, for example, who also covers the HIV clinic), insurance challenges, research and publication demand, and the fact that each division in the hospital carries a profit goal, to produce monies that will fund extraordinary health innovations. (Our CFO calls these ‘moonshots”.)

Our healthcare system is broken in many ways, but the spirit of those who labor every day in the clinic is not broken. My work is to strive to support them AND our patients. Their work and my calling are indeed sacred.

Is there a cure for SCD?

A blood/bone marrow transplant is currently the only cure for SCD. Its success is dependent upon having a donor, preferably a relative, who is well-matched to the recipient. In 2009 a low-toxicity method of performing stem cell transplants was developed whereby healthy cells from a matching donor were infused into the sickle-cell patient after the patient's immune system is suppressed using chemotherapy. This method is most effective in pediatric patients; it is too toxic for adults who have had years of accumulated organ damage.

CRISPR, Clustered, Regularly Interspersed Short Palindromic Repeats, is a gene-editing tool and component of bacterial immune systems that can cut DNA. Emmanuelle Charpentier and Jennifer A. Doudna shared the 2020 Nobel Prize in Chemistry for the discovery of the CRISPR/Cas9 genetic scissors. Fifteen years ago, scientists pinpointed a gene called BCL11A that works like a dimmer switch controlling the amount of fetal hemoglobin produced by the body. The CRISPR tool can edit this gene to turn fetal hemoglobin back on. Getting to that point in the treatment is not a smooth path. Stem cells need to be collected from the patient and edited to disable the BCL11A switch. Chemotherapy is required to kill existing cells in the marrow so that edited cells can have room to engraft and grow. 31 patients have been successfully cured through this approach, which is currently being reviewed by the FDA.[17]

Another trial run by Bluebird Bio uses a different gene therapy approach. A patient's stem cells are removed, then a virus inserts a gene into them that codes for a non-sickling version of beta-globin, a component of hemoglobin. Bluebird has treated 50 sickle cell patients, six of whom have been followed for six years and submitted its data to regulators in April 2023. Bluebird has announced that it could roll out this therapy in 2024. The beauty of this treatment is that a donor match is not required; the cure is within the patient. [18]

Presently, access and cost are formidable barriers to these treatments. Whereas FDA approval has occurred, treatment centers, for other than clinical trials, are not yet identified. The cost of treatment is estimated at $2 to $3 million per patient. Insurance companies and the Medicaid system have yet to weigh in on whether this cost will be covered. However, there is some encouragement. The Gates Foundation is funding research into how to alter blood stem cells inside the body. This research could lead to 'off the shelf" treatments that could be given to everyone, greatly reducing cost. [19] A cure would also be a good investment in reducing poverty.

"If a cure were applied today across the BIPOC population with SCD, over a lifetime, the net present value of their earnings would increase by a projected $341,929,

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[17] Carolyn Y. Johnson," A new era for treating sickle cell disease could spark a healthcare revolution," *The Washington Post* 146, no. 56470 (April 28, 2023): 4.

[18] Ibid., 6.

[19] "A Costly Cure for sickle cell disease," New Scientist International Edition. March 18, 2023, p.23. *Gale in Context: Middle School*, Link.gale.com/apps/doc/A742065238/MSIC?u=maine-orono&sid=summon&xid=ef911c70. Accessed May 17, 2023.

closing the gap between earnings of persons with and without SCD by 20%. Racial disparities in health, education and wealth are endemic to the US and are exacerbated for patients managing SCD. Equal disparity is NOT the goal, but making a cure for SCD widely available would be a step to facilitating a more equitable society across demographic lines." [20] Our patients with SCD are worth it.

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[20] Marlon Graf, et. al., "Value of a cure for sickle cell disease in reducing economic disparities," *American Journal of Hematology* 97no. 8 (May 23, 2022): 4-5.

APPENDIX II

PROJECT SUPPORTING DOCUMENTATION

Faith Communities and a Children's Hospital Collaborate to Address the Care Needs of Patients and Families Managing Sickle Cell Disease (SCD)

Patient Interview Guide **Rev. Patti V. Weikart**

Date of Interview______________________

MRN______________________________

Respondent Notes

I begin the interview with a brief description of the Congregational Health Network Pilot and frame our conversation as an invitation to help co-create this project.

Respondent would like to receive follow-up information on this project/process.

Yes____ No ____

1. Do you have a faith/spiritual tradition? Yes________ No ________

2. If so, is this faith important when you make healthcare decisions for your child or yourself?
Yes________ No ________

3. Do you belong to a faith community? Yes________ No ________

4. If so, may I know which one?
    a. Do I have your permission to visit your community?
    Y_______ N______

5. How should we address/honor your faith as we care for you?

6. What is the biggest challenge you face in managing SCD?

7. What would be most helpful to you in making this challenge less difficult?

8. Are there ways you can think of that a faith community could help/support you on your SCD journey?

APPENDIX III

CHN PILOT SERVICES

Care Beyond Medicine through the Congregational Health Network (CHN)

Help for our patients and families managing Sickle Cell Disease June-July 2023

The Congregational Health Network (CHN) is a group of faith communities and service organizations in Delaware that are collaborating with our hospital to meet the needs of our patients. Through confidential conversations with Pastor Pat, you told us what your needs are in making your sickle cell journey easier. This list will be update bi-monthly. **No religious or church affiliation is required to take advantage of any of these offerings**. We want to serve ALL our patients equitably. Please take the time to review these services and let us know how we can help you.

Support group for patients and families

Come meet families managing sickle cell disease.

SCD Family Fellowship on Saturday July 8, 10 am to 12 noon at the Cornerstone Fellowship Baptist Church 20 W. Lea Blvd. Wilmington, DE. **We will discuss how to collaborate with your provider in developing a treatment plan for your child.** Guest speaker, Nurse Practitioner, J.H, DNP.

Light breakfast and box lunches provided at no charge.

Parents will meet separately from children. Nursery care can be requested for infants.

RSVP with the total number of family members attending by July 1 to Pastor Pat pat.weikart@_______.org. We hope to see you there!

Ready to Transition from Pediatric to Adult Care?

You can connect with an adult mentor to help you navigate life skills like preparing college or job applications, obtaining references, signing up for insurance or banking, obtaining a first apartment, or financing a car.

The first meeting of our **Life Skills Mentor Group** will be in the 4th quarter via ZOOM. We start with questions to learn about your individual life goals and then partner you with a compatible mentor. Please contact Pastor Pat by email to make suggestions and ask questions about this group.

Do you need help with dietary options for staying healthy as you manage sickle cell disease?

Consider becoming part of our **Food Farmacy Trial.**

Lutheran Community Services will provide ten meals per week up to six months. A Food Coach can help you adjust to a healthier diet; we can also help with equipment to store and prepare food. You will be asked to give feedback on the program. We can welcome twelve families over the next six months. Register with Pastor Pat, your nurse or social worker.

Need a ride to the Emergency Department, but your usual contacts are busy?

Register now for Smart911 at **smart911.com on your telephone or computer.** You can specify that you are a patient managing SCD and that you need a ride to the ED. When you call your pre-registered telephone number will connect you to a Smart911 dispatcher who can arrange for pick-up.

Need a ride home from the hospital?

Transportation, courtesy of the St. Patrick's Center, to homes within a 5-mile radius of the hospital is available in late morning and early afternoon. Let your nurse or social worker know you need this service, and a ride can be arranged the same day as discharge on a first come first served basis.

Free vitamins are available from the Hospital Pharmacy

Ask your provider to send **an escript ahead** to the pharmacy with these prescribing instructions: **"Directions for use + (Care Beyond Medicine)."** Take this sheet to our outpatient pharmacy and show them the Redcap code at the bottom of this document to receive your vitamins.

Free heating pads are available. Just ask your nurse for one.

Volunteer Services

Are you or your child facing a lengthy hospitalization?

Would you welcome **a volunteer to check in with you or your child during the day?** Let your nurse, social worker or Pastor Pat know so we can introduce you to a potential care partner for you.

Please take a picture with your phone of the redcap code when you use one of the services listed. This will give us a count of services being used. No personal information is revealed when you do this. Thanks so much for helping us determine if these offerings are helpful to you.

We are grateful for the support (so far) of our congregation and community partners.

Abundant Life Apostolic Church, The Praying Ground, The Sickle Cell Association of Delaware, Cornerstone Fellowship Baptist Church, Saints Andrew and Matthew Church, Saint Patrick's Center, Lutheran Community Services, The Wilmington Police Department, The Hospital Pharmacy

APPENDIX IV

IF WE BUILD IT, WILL THEY COME? THE SERVICES THAT COMPRISED THE PILOT

There is not room in this paper to describe the detailed process through which each of the specific pilot offerings were developed; suffice to say the example of the Food Farmacy is representative. Once I had some idea of the possible service offerings, I sent a draft list to all 296 patient families to inform them of the project and to receive any additional input. Five families responded with an enthusiastic endorsement. The pilot service offerings are listed in Appendix 3; a summary of them follows.

The Food Farmacy partnership with Lutheran Community Services was designed to answer one dimension of the need for healthy food. When I visited the Praying Ground Church, located in the Wilmington city zip code where the largest number of our patients lived, I discovered that the congregation had tried to establish 30 + community gardens. Due to a problem with the city water system, the water supply to the gardens was cut off, but the bill for services continued. The pastor and I agreed that if the CHN could help bring the water bill current, the congregation would contribute a share of their produce yield to our patients. We used a portion of the funds earmarked for the CHN pilot to pay the water bill. This was our first Opportunity Grant to a collaborator. The water was restored, the gardens planted, and our patients have enjoyed fresh and free produce on a bi-weekly basis since the second week in May 2023.

During a community walk with the Praying Ground, I met an officer of the Local Police Department. I mentioned the CHN project and the need for transportation assistance. He put me in touch with the developers of the existing Smart911 service. With their help we were able to modify SMART911 so that families who sign up in advance for emergency transportation can specify their status as an SCD patient while also requesting a single vehicle rather than the usual 4 or 5 that respond to a 911 call. Once the online sign-up process was complete, a Smart911 icon appeared on their phone so that emergency transport was literally a keystroke away. I think Brandon would have found this application useful. The same officer was a member of a Catholic congregation which ran an adult day care program. Their vans were not in use between 9 am and 1:30 pm daily. The St. Patrick's Center joined the CHN pilot to provide transportation to and from clinic appointments for our patients and families during the vans' idle hours.

With the help of the hospital pharmacy, the CHN negotiated another Opportunity Grant to pay for vitamins at cost and then offer them for free to our patient families. The Presbytery of Southern New Jersey came alongside to seed a small fund which operates under the direction of the clinic social worker who can write a check to a patient who needs to meet a small, unexpected expense. This same congregation engaged their women's organization to make over 50 heating pads for our patients.[1]

One of our patients in transition to adult care, who is also a communications major at a local university produced a video to increase SCD awareness. We posted this on National Sickle Cell Awareness Day, June 19, 2023. The Sickle Cell Association of Delaware (SCADE) joined us in this effort, and we remain in close communication and coordination in the roll-out of CHN services. The Cornerstone Fellowship Baptist Church provided the space and volunteers to host the SCD Family Fellowship, an open meeting

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[1] Heating pads are an essential tool for SCD pain management as they help stabilize body temperature to avoid VOCs.

where patients and families can meet with clinicians outside the hospital, engage each other as people on equal footing, share information and gradually build mutual trust. Cornerstone has also provided over 2 dozen heating pads to our patients.

From the initial collaborators, and as we recruit more, we are building a roster of volunteers who can check in on hospitalized children so their parents can maintain their paychecks.

The final pilot component is the Pediatric to Adult Care Transition Mentor program. The clinic had offered a similar program which was cancelled due to the COVID pandemic. When my research reinforced the need to re-start this program, the clinical team decided this was an opportunity to re-organize and strengthen transition support by introducing transition concepts early, at age 12, by building skills in personal health and medical treatment management. The CHN program would provide volunteers who would offer life skills mentoring to patients over the age of 16 to prepare them to navigate challenges such as how to obtain a driver’s license and insurance, apply for college, find a job, open a bank account, secure an apartment, etc. Developing the training program for the volunteer mentors was, by far, the most challenging portion of the pilot. I am grateful to our nurse practitioners, social worker, and team psychologists who continue to support and refine this offering.

We launched these pilot services with multi-colored flyers, which are updated monthly and distributed through email to all patients and families, and in person during clinic visits and hospitalizations. Two of our families made video recordings of personal invitations to the SCD Fellowship which were attached to the emails. The CHN video was distributed to over 300 congregations through various denominational contacts. In

June 2023 I established a CHN Advisory Committee to plan for future institutionalization of the network within the hospital. The question remained, now that we have built a pilot, will our patients use the services?

APPENDIX V

HEALTH NAVIGATOR JOB DESCRIPTION

Health Navigator for the SCD Congregational Health Network (CHN)
Center for Cancer and Blood Disorders
Reports to SCD Clinic Director
Salary Range: Position is full time $62,000 to $72,000 per year depending upon experience.

Position Summary

The Congregational Health Network (CHN) is a collaboration between our hospital and communities of faith designed to serve our patients and families managing sickle cell disease by responding to their unmet care needs. The Health Navigator is the glue between patient families, clinicians and faith communities who identifies patient needs, engages collaborators to meet these needs, involves hospital resources to support these efforts, resolves issues, improves offerings, and evaluates impact and outcomes. This position cannot be fulfilled from a desk alone. At least two days per week will be spent in the community visiting collaborators and patient families. The CHN Health Navigator must be comfortable in the dual roles of chaplain and/or faith leader as well as interacting and partnering with clinicians who provide medical treatment to our patients. The Health Navigator holds loving service as a core value, supporting patients, faith communities and clinicians to provide the best treatment and care for our families managing this chronic disease.

Job Responsibilities

(1) Serving our Patients and Families

The Health Navigator will maintain regular contact with patients and families to determine the effectiveness of our services and to address necessary revisions and upgrades. This includes developing appropriate job descriptions for our volunteers, as well as developing and delivering needed training/orientations; administering periodic surveys with patients in clinic, coordinating opportunities with clinicians to touch base with patients and accompanying volunteers on service activities. Measuring outcomes of programming and interventions is also an essential part of determining which offerings should be sustained and which are no longer viable.

(2) Maintaining Relationships in the Community

The Health Navigator will attend weekly worship services with our Collaborators, as appropriate. The Health Navigator will also prepare necessary presentations for various congregation committees to inform, develop interest and support their processes to join the CHN. This includes participating with congregations in the activities that support our patients (i.e., packing food for Food Farmacy recipients), initiating meetings with government agencies, private foundations and other organizations that serve our patients to determine how the

CHN complements these offerings and to provide information and resources to hospital social workers and community health workers so that we create efficient and informed partnerships to care for our joint patients/clients.

(3) Maintaining Institutional Requirements and Support

The Health Navigator will maintain relationships and excellent communication with all hospital stakeholders. This includes updating Collaboration Agreements between the hospital and faith communities with Legal and Compliance, maintaining patient privacy, adhering to the HIPAA, upholding IRB standards and the principles for research governance, ensuring patient informed consent for all phases of patient interaction and outcomes measurement. Regular participation in patient rounds, weekly research updates, continuing presence in the clinic and providing quarterly updates on CHN activities for clinic partners are required. Maintaining complete and auditable project management notes is an essential component of this work.

Knowledge, Skills, and Experience

Education Level:	Bachelor's degree from accredited institution. Master of Divinity or Theological Studies Ordination in a community of faith preferred but not One unit of Clinical Pastoral Education preferred but not required. Master of Social Work or 3-5 years' experience in caring ministry or community service.
Skills:	Ability to learn and utilize hospital-based computer applications including but not limited to EPIC, WORD, EXCEL, POWERPOINT, TEAMS, ZOOM, etc. Project management experience 1-3 years. Excellent personal communication skills, team-player, compassion, desire for mutual understanding, flexibility, self-starter, resilient, open mind, and heart.
Travel Requirements:	Periodic and limited participation in relevant conferences

Signature of Candidate: ____
Date: __________________

ANNOTATED BIBLIOGRAPHY

Anidjar, Gil. *Blood: A Critique of Christianity*. New York: Columbia University Press, 2016, 1-258.

This volume, recommended to me by Drew Theological Librarian, Dr. Jesse Mann, is a dense treatise on the significance of blood in the creation of our current systems of nation, state, and capitalism. It is relevant to this work because Anidjar asserts that blood was a unifying characteristic of humanity until the life of Jesus when it became an instrument of redemption. Through the life of Jesus, blood became a pure or impure substance which set humanity on a course of conflict, war, and racism. The notion of pure or impure blood carries over into the stigma of sickle cell disease. I consider this an essential work for this paper because Anidjar does the groundwork in Old and New Testament scripture concerning the significance of blood, an essential piece for the exegetical work required for this project. His meticulous work includes a footnote section of 246 pages which is as valuable as his text of 258 pages.

Balboni, Michael J. and Balboni, Tracy A. *Hostility to Hospitality: Spirituality and Professional Socialization Within Medicine.* New York: Oxford University Press, 2019, 1-315.

Michel Balboni is a Christian pastor, Tracy Balboni is a radiation oncologist. They are married. This joint effort makes the case that scientific medicine needs faith; without it, science is bereft of purpose. This volume traces the history of the disconnect between science and medicine, presents evidence to frame illness as a spiritual event, raises concern about the lack of spiritual care offered to patients at end of life, articulates barriers to spiritual care in the clinic, examines in detail the secular-sacred divide in medicine and presents a theology of medicine. Their work concludes with the outline and proposal of a host-guest model of hospital care. This volume is a powerful ally in providing interdisciplinary care in the clinic, but it does not encourage community involvement in total patient care. That is the space that can be filled by the Congregational Health Network.

Bosworth, David A. "You Have Shed Much Blood, and Waged Great Wars": Killing, Bloodguilt and Combat Stress." *Religion, Disability and Health* 12, no. 3 (2008), 236-250.

This article is relevant to chapter 3 which addresses the theology of blood. It considers an aspect that I did not foresee, blood guilt, which manifests in bloodshed in war. The ancient response to this was purity rituals which allowed soldiers who violated the boundary between life and death, which belongs to God, to return from combat to home life. The author suggests that blood guilt is a contemporary cause of PTSD and that modern purity rituals could be developed to help soldiers heal from the scars of war.

Botterweck, G. Johannes and Ringgren, Helmer, eds. *Theological Dictionary of the Old Testament Volumes I-XVI.* Grand Rapids, MI: Wm. B. Eerdmans, 1978, 234-251.

According to Drew Theological Librarian Dr. Jesse Mann, this resource, and its companion later cited for the New Testament, is the authoritative Biblical reference and commentary.

Brennan-Cook, Jill, et.al. "Barriers to Care for Persons with Sickle Cell Disease: The Case Manager's Opportunity to Improve Patient Outcomes." ***Professional Case Management 23,*** **no. 4 (2018): 213-219. doi.org/10.1097/ncm.0000000000000260.**

Using a single case study from the Duke University School of Nursing, supplemented by a thorough literature review, Brennan-Cook identified the following barriers to care for adults with sickle cell disease: perception of addiction, implicit bias, frequent hospitalizations and Emergency Room visits, patient knowledge deficits, SCD stigma which all impede the provision of evidence-based care. The author asserts that patient case managers are the key to coordinated care to improve patient outcomes. Brennan-Cook does not take the time to examine the extreme demands on social workers (a.k.a. case managers) in the average metropolitan setting, nor does the author examine the possibility of using chaplains and trained volunteers to fill the gaps. This work would also be strengthened by an examination of the difference between treatment and care since case managers are not clinicians and cannot fill the gaps that the author discovers (such as adequate pain management impacted by the perception of addiction. Brennan-Cook leaves openings that a CHN might fill.

Bronte' Hall, Lanetta, et. al. "Real-World Clinical Burden of Sickle Cell Disease in the US Community Practice Setting: A Single-Center Experience from the Foundation for Sickle Cell Research." ***Blood*** **134, (2019): 58-56. doi.org/10.1182/blood-2019-128700.**

This retrospective study conducted in a community practice, not a hospital, setting, examined the Electronic Medical Records of 172 adult sickle cell patients to understand the impact of regular blood transfusions and hydroxyurea therapy on the frequency, length, and severity of vaso-occlusives crises (VOCs). VOCs occurred less frequently in patients over the age of 40 who were receiving these interventions. The authors highlighted two (disturbing, in my view) findings: (1) that the age of these patients pointed to existing ischemia-related tissue injury and organ damage, thus lessening the impact of current VOCs (in the spirit of 'the damage has already been done") and (2) there are possibly higher than expected unmet care needs in this community setting. This is a gap my quality improvement project might help address.

Brown, Crystal E., MD, MA, Marshall, Arisa R., BS, et. al. "Perspectives About Racism and Patient-Clinician Communication Among Black Adults with Serious Illness." ***JAMA Network Open*** **6, no. 7 (2023): 1-15. doi:10.1001/jamanetworkopen.2023.21746.**

This qualitative study of 25 Black patients was recommended to me as a member of the Stakeholder Advisory Board for the pediatric palliative care practice at Emory University. Using tools, heretofore unknown to me, including the Discrimination in

Medical Setting (DMS) scale, the Group-Based Medial Mistrust Scale and the Microaggressions in Health Care scales, participants reported epistemic injustice as the most common manifestation of racism. This is defined as silencing of their own knowledge and lived experiences about their bodies and illness by healthcare workers. Although this study included only adult patients, I will be using this article as a resource beyond this dissertation to adapt outcome measurements for the CHN that might help us to determine whether its approach to care helps to dismantle epistemic injustice in the pediatric SCD clinic.

Bulgin, Dominique, et. al. "Stigma of Sickle Cell Disease: A Systematic Review." ***Issues in Mental Health Nursing*** **39, no.8 (2018): 675-686. doi:10.1080/01612840.2018.1443530.**

This systematic analysis of 27 peer-reviewed studies published between 2004 and 2017, examined the psychological and social impacts of stigma on adolescents and adults living with SCD, their care-seeking behaviors and relationships with providers. The authors introduced the concept of 'layered stigma' with racial, colorism, culture, internalized, social and familial dimensions. They conclude that all stigma has negative social consequences, impairing healthcare interactions, and hindering psychological and psycho-social well-being.

Capp, Alyson Isaksson. "They Make You Feel Less of a Human Being: Understanding and Responding to Milwaukee's Racial Disparity in Infant Mortality." ***Maternal and Child Health Journal*** **26, no. 4 (November 2021): 736-746. https: doi.org/10.1007/s10995-021-03281-6.**

One of the most important indicators of quality and equity of healthcare is the rate of infant mortality. Capp built a 13-member focus group under the auspices of the University of Wisconsin School of Medicine and Public Health comprised of clinicians and mothers designed to explore the reasons for the following disparity: in the US, Black infants die at twice the rate of their White counterparts. (US Department of Health and Human Services, 2021). The focus group raised the following themes that contribute to this disparity: public apathy, violence and stress, discrimination, mistrust, lack of spiritual and social support, and reproductive justice (the right to maintain bodily autonomy). Investment in group prenatal care and doulas were two recommendations to improve the situation. Increasing cultural competence and humility was a third approach. Although the study size was small and the geography limited, it reinforces the importance of attention to improving the social determinants of health as part of improving healthcare equity and outcomes for our youngest citizens.

Chapman, Mark D. "Action Research Ethics for Doctor of Ministry Students." ***Journal of Christian Ministry*** **7 (2018): https://journal.dmineducation.org/2018/04/04/action-research-ethics-for-dmin-students.**

Especially in Doctor of Ministry work, researchers are often able to exert power and/or influence over their research contexts (such as a senior leader in a particular faith community). Chapman offers a methodology to minimize the possibility of a researcher ordaining an outcome or an implementation of a project by virtue of their authority. This method is Participatory Action Research (PAR) which I have attempted to implement in this CHN pilot project.

Cranz, Isabel. "Advice for a Successful Doctor's Visit: King Asa Meets Ben Sira." ***The Catholic Biblical Quarterly*****, 80 no. 2 (2018), 231-246.**

Using 2 Chronicles 16:12 in which King Asa turned to physicians in his time of sickness, Cranz argues that the King was admonished because he did not turn to YHWH. Referring to the Apocryphal book Sirach 38:1-15, the author analyzes how the physician should be situated in relation to God. Cranz concludes that physicians are divinely appointed but cannot claim the same proximity to God as prophets or priests. God is responsible for healing, and physicians are appointed, guided, and supported by God. This article reinforces the idea that collaboration between faith and science is a model for delivering equitable healthcare. I hope I've built a foundation for that model in chapter 4.

Cutts, Teresa. ***The Memphis Model: ARHAP Theory Comes to Ground in the Congregational Health Network*****. Memphis, TN: Methodist LeBonheur Health System, 2017.**

This is the first publication outlining the analytical process and results for demonstrating the value of the Congregational Health Network in Memphis, TN, implemented by Gunderson and Cochrane. Using cross-sectional snapshots based on data recorded in the patient Electronic Medical Record, Cutts demonstrated that the Memphis Model produced a reduction in total admissions (from 159 to 101), total readmissions (from 37 to 17), average length of hospital stay (from 25 to 14) and average annual charges per patient (from $129,922 to $74,8192) for the 473 patients served by the Congregational Health Network after 25 months of operation.

Derlega, VJ, et. al. "How patients' self-disclosure about sickle cell pain episodes to significant others relates to living with sickle cell disease." ***Pain Medicine*** **15, no.9 (2014): 1496-1507: doi:10.111/pmc.12535.**

Researchers in this study used a series of self-reporting questionnaires to determine to whom and how fully SCD patients talk to others about SCD pain. 73 adults reporting an average of 8.61 pain episodes in the previous 12 months participated. Patients were treated at the Eastern Virginia Medical School (Norfolk) and Virginia Commonwealth University Clinic (Richmond). Results indicated that participants talked more fully about their thoughts and feelings about pain episodes to God and their primary medical providers than either parents, siblings, intimate partners or close friends. The amount and helpfulness of talking to God were associated with lower depression and higher pain self-efficacy; when this talk is perceived to be helpful, patients may feel more empowered and in control. This research points to the importance of faith in coping with SCD and may indicate a willingness of SCD patients to trust faith communities who wish to respond to their unmet psychosocial, economic, and spiritual needs.

Dickman, Samuel L. et. al. "Trends in Health Care Use Among Black and White Persons in the US, 1963-2019." ***JAMA Network Open*****, no. 5 (June 2022): 1-12. e2217383.doi:10.1001/jamanetworkopen.2022.17383.**

This article is the most up-to-date assessment of the trends in healthcare use and accessibility for BIPOC patients in the US, produced through the 'gold-standard' research arm of the American Medical Association. This is a literature review covering decades of studies involving over 600,000 patients, both Black and White, tracing and comparing long-term trends. The study's findings indicate that racial inequalities in healthcare have persisted for 6 decades and widened in recent years. Suggested responses to this reality are addressing shortages of Black health care professionals and managers, investing in Black-serving medical facilities, increasing community outreach efforts and enacting measures that help earn Black patients' trust in the healthcare system. I read this article as an encouragement given that my research focus is on developing a community outreach effort intended to foster collaboration and relationship between the hospital and faith communities. If my pilot can demonstrate that our BIPOC patients will use the services that the Congregational Health Network offers, we can assess its longer-term impact on building trust and improving patient outcomes.

Dike'-Minor, Chinelo. "The Untold Story of the United States' Anti-Kickback Laws." ***Rutgers Journal of Law and Public Policy*****, 21 no.2 (Spring 2023): 103-161.**

This comprehensive survey traces the evolution of federal legislation both defeated and enacted to protect the American taxpayer from fraud in the Medicaid, Medicare and Tricare programs. The emphasis is on the fact that despite numerous efforts, the protections that were adopted still do not apply to health insurance offered by private insurance companies. This remains a valuable resource for legal novices to gain a working understanding of the issues involved in fraud prevention and punishment.

Downer, S., Clippingert, E., Kummer, C. ***Food is Medicine Research Action Plan*****. Aspen, Colorado and Cambridge, Massachusetts: Aspen Institute and the Center for Health and Law Policy Innovation, Harvard Law School, January 22, 2022. Food-is-Medicine-Action-Plan-Final_Aspen%20Institute_012722.pdf, 1-119.**

This report was brought to my attention by one of our volunteers, who is a medical doctor, from the Saints Andrew and Matthew congregation. This work is instrumental in the development of outcome measures for our Food Farmacy program. Through its detailed summary of relevant literature, we were able to correctly label our program as an offering for Medically Tailored Groceries and plan for applying the following outcome measures to support future funding requests: vitamin levels (through pre and post chart reviews), impact on food security, healthy eating index assessment through a pre and post "What's on your plate?" survey (this was developed by the US

Department of Agriculture), confidence in preparing new foods and reduced trade-offs in the management of limited financial resources.

Enns, Elaine, and Ched Myers. *Healing Haunted Histories: A Settler's Discipleship of Decolonization*. Eugene, Oregon: Cascade Books, 2021, 3-312.

This book compassionately and convincingly informs the reader of the fact that all land in the United States and Canada was once the property of indigenous people, and it was seized in the most de-humanizing variety of methods ever exercised between human beings. Commenting from their own perspectives as a Canadian Mennonite and an American Christian living in southern California, Enns and Meyers offer their testimonies and life stories in a three-part framework: Landlines, which connotes places of personal, communal and ancestral inhabitation, past and present; Bloodlines which describe members of a family group over a period of time; and Songlines which refer to traditions of individual and collective conscience and liberation. As I read this book, feeling increasingly shamed by my ancestors and my past, I forged ahead because of a quote from Adrienne Maree Brown on page xxiv: 'Things are not getting worse, they are getting uncovered." Thank God for those words and their encouragement. Chapter 6 Bloodlines II on dissimilating and Chapter 8 Healing Hauntings are most relevant to my research, but I am beyond grateful for this book and its mission to transform us into treaty people. May we continue to uncover our sins, bring light and reconciliation to them and never repeat them.

Ezenwa, Miriam O. et. al. "Coping with Pain in the face of Healthcare Injustice in Patients with Sickle Cell Disease." *Journal of Immigrant and Minority Health* 19, no. 6 (2016):1449-1456. doi.org/10.1007/s10903-016-0432-0.

Ezenwa's research question is a simple one: How do patients cope with SCD pain in the face of healthcare injustice? This is a descriptive, comparative study of 52 patients using the PAIN Report Healthcare Justice Questionnaire and Coping Strategies Questionnaire, validated tools for SCD patients. When justice is experienced or felt, patients in pain exhibit prayer, calming self-statements, diverting attention (such as through meditation) and increased behavioral activity including requesting more care. When patients experience injustice they exhibit catastrophizing, isolation, extreme fear and anger including threatening self-statements. Brandon's behavior tracks with patients perceiving injustice according to Ezenwa's research.

Farooq, Faheem, MD et.al. "Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated with Research Productivity." *JAMA Network Open* 3, no.3 (2020): 1-12. doi10.1001/jamanetworkopen.2020.1737.

A thorough analysis of Federal and foundation funding, publications indexed in PubMed, clinical trial registrations and new drug approvals yielded the following disparities between SCD and CF. From 2008 to 2018 federal funding was greater per person with CF compared with SCD, significantly more drug approvals occurred for CF than SCD (4 v.1). The total number of clinical trials was almost equivalent. The findings indicated that disparities in funding between SCD and CF may be associated with decreased research productivity and drug development for SCD. More resources are needed for diseases that disproportionately affect poor groups.

Fiocchi, Jacob, et. al. "A Comprehensive Review of the Treatment and Management of Pain in Sickle Cell Disease." ***Current Pain and Headache Reports,*** **24, no. 17 (2020): 1-10.**

This article provided an excellent review/checklist of pharmacological and non-pharmacological treatments for SCD pain, essential to the development of the SCD primer in this paper. The work of Dr. Katie Parisio in integrated therapies at the Nemours Clinic is an excellent expansion of this comprehensive literature review.

Freed, Gary L. "A Missed Opportunity to Address a National Shame." ***JAMA Pediatrics*** **173, no.8 (2019) :715-716. doi100/jamapediatrics.19.1956.org/10.**

The author is outraged by the refusal of the Centers for Medicare and Medicaid Services (CMS) to include SCD screening in the core set of 25 pediatric quality measures. Simple, available, and inexpensive interventions such as antibiotics and Doppler screening are consistently defeated when brought to vote. These measures applied in response to early SCD diagnosis can help offset the most severe symptoms of SCD, reducing hospitalization and enhancing patient well-being. About 90% of children with SCD are enrolled in Medicaid. It would seem a missed opportunity to avoid actions that would clearly reduce the Medicaid cost burden. Freed does not invoke the "R" word (racism or racist) in his essay. I do not know whether that is an act of courage or cowardice.

Gandara, Eduardo and Shevon-Harvey, Idethia, at. al. "Facilitators and Barriers When Conducting Adult Health Programs within the African American Church: A Systematic Review." ***Journal of Religion and Health*** **Published online March 18, 2022: 1-36. doi.org/10.1007/s10943-022-01532-6.**

This article summarizes a comprehensive and systematic literature review conducted under the auspices of the Texas A&M School of Public Health. 29 articles were included from a survey of 288. The purpose of the review was to identify the perception by pastors and church leaders of facilitators and barriers to adult health programs or interventions within African American churches using the socioecological model (SEM). The articles covered church-based health programs for patients managing HIV/AIDS, cardiovascular disease, depression, cancer and goals to increase physical activity. The following items were identified as facilitators of adult health programs: budget, lay health advisory teams, partnerships with health organization and displays/availability of printed of health information. The following barriers to adult health programs were identified: pastors constrained by time and training, theological concerns about certain diseases such as HIV/AIDS, the challenge of balancing sex education with theology, the belief that outsiders do not see the church as a place where education can occur, sufficient volunteers and church congregants not having access to providers or health insurance. None of the articles identified policy as a facilitator or barrier to a health program. The authors conclude that further research needs to be done on how to help bridge and create co-partnerships between policy initiatives and African American churches. Although the CHN is not a policy initiative it is an opportunity to create a collaboration between faith communities and healthcare providers reinforcing the belief that the church, synagogue, mosque, etc. are places where health education can effectively occur.

George, Rose. "The Intersection of Race and Blood." *The New York Times* CLXVIII, 58, no. 327 (May 14, 2019): nytimes.com/2019/05/14/well/live/blood-type-race-racial.html.

George, Rose. *Nine Pints: A Journey Through the Mysterious, Miraculous World of Blood*. London: Granta, 2018, 1-313.

The first article cited is a review of George's book. In nine chapters that read like a combination of a mystery novel, medical journal and *People Magazine*, George explores the history of human curiosity about blood, the practice of leeching, the founding of the NHS (she is British) and its blood donation and transfusion service, HIV in Africa, the plasma donor industry and the concerns about tainted blood, the stigma of menstruation in Nepal and other developing countries, bias and entrepreneurship in the feminine hygiene industry, blood and its role in saving trauma victims and the future of synthetic blood. Her book concludes with this quote from Dr. Nick Watkins of the NHS who is commenting on future treatments for sickle cell disease. "I can imagine a scenario in the future, in the Western world where patients with sickle cell disease might be faced with a choice of how they are treated. Do they receive donated blood, manufactured product or do they have an autologous genetically engineered stem cell transplant? That is where the field will go in ten or twenty years. There will be more choice for the patient." (p. 311) Perhaps that will be the case in a place where a history of enslavement doesn't define our relationships and the political will has been summoned to prioritize health equity. George's book is informative, aspirational, and exquisitely not American.

Gosfield, Alice G., JD. "Patient Inducements: The New Dos and Don't's." *Family Practice Management* 25:4 (2018): 16-19.

Stanger, Kim. "Patient Inducements: Gifts, Discounts, Waiving Co-pays, Free Screening Exams, etc." *Insight,* Washington, DC: Holland and Hart, 2023: 1-15.

These articles are presented together because they build upon one another. Gosfield provides a detailed explanation of the nominal value, transportation, financial need, and access exceptions to the AKS. Stanger extends this analysis by providing the background, context and detailed citations in the United States Code for establishing these exceptions.

Graf, Marlon, et. al. "Value of a cure for sickle cell disease in reducing economic disparities." *American Journal of Hematology* 97, 8 (May 23,2022) E289-E291.

The authors bring a unique perspective to understanding the socio-economic impact of SCD by examining the potential quality effects of a cure on annual income and future earnings. Using a cohort-based microsimulation model, a representative sample of 6352 individuals (SCD:3176 and non-SCD :3176) showed that individuals with SCD earned between 42% and 46% less annually than the healthy comparison group. A cure for SCD could produce a meaningful reduction (20%) in earning inequities between individuals with SCD and matched controls.

Groopman, Jerome. 'The History of Blood." ***The New Yorker Online*** **94, no. 2 (January 7, 2019): newyorker.com/magazine/2019/01/140the-history-of-blood. Accessed 1-20-23.**

This article is a review of Rose George's *Nine Pints,* also annotated in this bibliography. Groopman produces a 10-page summary of George's 313-page book highlighting the medical/technical advances in the discovery of blood's essential life-giving role, beginning with Medusa and Galen through the first reported blood transfusion (1492) through the development of car-T-cell therapy, in the early 2000s. He does not examine the relationship between flesh, blood, body and spirit, leaving us dangling at the conclusion of his essay with the Hebrew wordplay between 'dam' (life lost), also the Hebrew word for 'blood' and 'nephesh' meaning 'breath' and also 'life saved'. I decided after reading this article to read George's book, and, perhaps, that was the point and purpose after all.

Gunderson, Gary R., and James R. Cochrane. ***Religion and the Health of the Public Shifting the Paradigm*****. New York: Palgrave Macmillan US, 2012, 1-170.**

In the book that inspired this project Gunderson and Cochrane evaluate the importance of the social determinants of health in the treatment and care of adults with diabetes, congestive heart failure and kidney disease. Together they approach the underutilized resource of Black congregations to collaborate with the Methodist LeBonheur Hospital system in Memphis to build a web of care for specific patients in each congregation. Their primary method was unsophisticated: face-to-face relationship-building. Yet, after four years of the demanding work of building trust, they were able to demonstrate significant reductions in hospitalizations, length of hospitalizations and cost of patient care for the Black community. Teresa Cutts documented these results in the above citation.

Hannah-Jones, Nikole, et. al., eds. ***The 1619 Project.*** **New York: One World Random House, 2021, 45-161, 293-404.**

The first slaves arrived in the American colonies in 1619. This book is a faithful telling of the impact of enslavement on all aspects of American life: democracy, race, industry, fear, dispossession, capitalism, politics, citizenship, self-defense, punishment, inheritance, medicine, church, music, healthcare, traffic, progress, and justice. Comprehensive and eye-opening, this is a must read for every American who wants to be an ally in the fight for equity. I read these pages through my own tears. For the purposes of my research, the chapters on medicine, healthcare and progress were most useful. This is a powerful indictment of white privilege; it can also be a powerful incentive to get off our complacent behinds and begin to do something to free us all. These powerful words close this volume: “Citizens inherit not just the glory of their nation but its wrongs, too. A truly great country does not ignore or excuse its sins. It confronts them, and then works to make them right.” p. 476. My prayer is that my project is one drop in the ocean of challenges that we must meet to heal our racial divide.

Harris, Travis T. and Horsley, M. Nicole. “Da Blood of Shesus: From Womanist and Lyrical Theologies to an Africana Liberation Theology of the Blood.” *Religions* 13, no. 688 (July 2022): 1-16. doi.org/10.3390/rel13080688.

After months of worship in Black non-denominational congregations in Delaware I was curious that I had not yet celebrated the Eucharist in any of these churches. As I engaged some new acquaintances in conversation about this observation, I noticed a reluctance to discuss the issue. There was clear uncertainty about the meaning of drinking the blood of Jesus. This article seemed to shed light on this circumstance. The scholarship herein is undeniable in taking a critical look of the salvific value of Jesus’ blood according to the church fathers through Augustine. Incarnation, resurrection, and atonement are examined in detail. The authors remain dissatisfied. There is a longing for a perspective that speaks to the oppression of Blacks that is somehow justified through Christian theology, re-named ‘Whitianity’. A new understanding is offered in the writings of womanist theologians including Monica Coleman, Kelly Brown Douglas, Jacquelyn Grant, JoAnne Marie Terrell, and Dolores Williams. This article helped me find the words to express the transformation that has occurred in my own faith, as well as that which I hope to achieve for this project. The authors’ new vision of the value of Jesus’ life and blood is as a liquid that flows, coalescing all of us into one human family. It is given when we all make sacrifices on behalf of others, not at the demand for suffering in the process of reconciliation that comes from an angry and entitled God.

Hill, Zelee, et. al. “Are verbatim transcripts necessary in applied qualitative research: experiences from two community-based intervention trials in Ghana.” *Emerging Themes in Epidemiology* 19, no. 5 (June 2022): 1-6. Doi: 10.1186/212982-022-00115-w.

The authors describe two studies completed in Ghana which used a qualitative research technique called ‘fair notes’ for primary data collection. The studies assessed the impact of vitamin A supplementation on maternal mortality and the impact of home community health worker visits on neonatal mortality. Fair notes, which are made by the interviewer during and immediately after the respondent encounter, do not rely on recording equipment which has been a barrier to engaging participants. Recordings were also demonstrated to decrease reflection and analytical thinking by the researchers. Interviewers were trained to have a clear understanding of the purpose of each question, and to properly attribute any comments (from respondent and researcher alike). The conclusion was that fair notes are particularly useful when research questions are simple and straightforward. It was also determined that fair notes can decrease data collection and analysis time while still providing detailed and relevant information to the study team. Fair notes were not as useful in focus group discussions where interaction and richness of the discussion couldn't be fully captured.

Idler, Ellen L. ed., *Religion as a Social Determinant of Public Health*. New York: Oxford University Press, 2014, 1-382.

Idler and her contributors set out on mission almost impossible: helping the medical profession understand that there are things that science cannot teach them. Even though healthcare and hospitals originated from faith-based ministries, the exploration and consideration of the religious/spiritual dimensions of human beings in the development of a whole patient care plan, have been separated from provider care (when Richard Cabot, MD, defined the practices of social work and chaplaincy as adjuncts in the mid-1930s). I see this book as a call to bring these disciplines back to help form a true interdisciplinary care team for patients. For the purposes of my research, Chapter 18, "Religion and Physical Health from Childhood to Old Age" by Idler herself, will be most important in supporting the potential of the Congregational Health Network. I also see applications of this volume for the interprofessional spiritual care education curriculum that I team-teach with Dr. Mindy Dickerman. We are working to open the eyes, minds, and hearts of clinicians to the power of patients' spirituality as a key component in healthcare equity.

Johnson, Carolyn Y. "A new era for treating sickle cell disease could spark a healthcare revolution" *The Washington Post*, 146, no. 56470(April 28, 2023): 1-8.

Johnson summarizes CRISPR the current state of clinical trials for CRISPR and autologous transplant therapy for SCD patients. Although the barriers of FDA approval, cost, accessibility, and insurance coverage need to be addressed, these therapies can be curative for SCD patients. This is an essential update for the primer portion of this paper.

Johnson, Kirk A. "A Black Theological Response to Race-Based Medicine: Reconciliation in Minority Communities." *Journal of Religion and Health* 56 (2022): 1096-1110: doi:10.1007/s10943-017-0373-5.

I was immediately drawn to this article because Johnson is an alum of the Drew Medical Humanities graduate program. His history of Black church health initiatives in the United States was invaluable in writing chapter 4 of this paper. But his willingness to define race-based medicine left a bigger impression on me. He defines race-based medicine as that which 'continues the racist language of labels and stereotypes exclusively associating medical conditions and diseases to a racial group." (1098). This perfectly describes SCD. The courage it took to compose and publish this definition is a gift to my research and many others, I am sure.

Kendi, Ibram X. and Nic Stone. *How to be a (Young) Antiracist*. New York: Penguin Random House, 2023, 13-173.

I read Kendi's first edition of *How to be an Antiracist,* which was an inspiration for much of my work. However, seeing is re-cast by Nic Stone at this point in my journey, riveted me. She embodies Kendi in this re-write made especially accessible for young people. It also made it especially accessible for me. The clarity of definitions of terms, the clean, direct assertions make this a manifesto for anyone hoping to become an ally in the fight against racism. Without shaming any of us, this is a clear call to action. And when I think my work is too small to make any difference at all, Kendi and Stone endorse 'humble beginnings'. This is a practical, spiritual, actionable work. I thank God for this book.

Kittel, Gerhard ed. *Theological Dictionary of the New Testament Volumes I-X.* Grand Rapids, MI: Wm. B. Eerdmans, 1979, 172-177.

According to Drew Theological Librarian Dr. Jesse Mann, this resource, and its companion earlier cited for the Old Testament, is the authoritative Biblical reference and commentary.

Kleinman, Arthur, M.D. *The Illness Narratives: Suffering, Healing, and the Human Condition*. USA: Basic Books, Division of Perseus Book Group, 1988, 3-267.

In my view, in the call to compassionate care for the chronically ill, Kleinman sets the foundation for the terms and disciplines that will flow from his work. Using three key case studies Kleinman illumines the path that moves the clinician from diagnosis and treatment to care. The author examines the social determinants of health and their impact on disease trajectory before the term ever existed. He reconceptualizes medical care as empathic witnessing of the experience of suffering and practical coping with the major psychosocial crises that constitute the menacing chronicity of that experience (p. 10). His work is the ancestor of palliative care, the "expander" of pastoral care and the start of the many paths we now take to pursue wellness, even in the midst of diagnosis. My work would not exist without this breakthrough volume.

LaMotte, Julia E., PhD., et. al. "Understanding the roots of mistrust in medicine: Learning from the example of sickle cell disease." *Journal of Hospital Medicine* 17 (2022): 495-498.

This article is pertinent to my paper because it validates the ongoing presence of bias in the clinic using SCD as the lens which frames the literature review. The authors provide a brief history of bias in medical treatment and propose a "Model of contributory factors that impact patient-provider trust": patient-provider interaction, individual, hospital, and socio-cultural factors in the context of the undertreatment of SCD pain. They advise practitioners to truly listen to their patients' lived experiences, their own internal biases and the language that is shared around practitioners. "Trust is built on respect and requires humility." (p. 497) I could not agree more. However, notable omissions include no guidance on how to interrupt bias or any inclusion of spirituality as one avenue to explore and to improve patient care. My work might encourage practitioners to view spiritual assessment as an opportunity to improve patient relationships and care, not an element that is off-limits to providers steeped in science.

Leger, Robin R. et. al. "Stigma in adults with sickle cell disease and family members: Scale development and pilot study in the USA and Nigeria." ***International Journal of Africa Nursing Sciences*** **9 (2018): 23-29, doi.org/10.1016/j.ijans.2018.06.003.**

Using the SCD Scales Adult and Family Assessment Tool, Leger interviewed 42 participants to determine the types of stigma experience by adult SCD patients in the US and Nigeria. She discovered that stigma is related to psychological distress, depression, fear, delay in diagnosis and poorer treatment prognosis. In the US, however, she noted a unique factor, that service providers do not necessarily believe patients with SCD have a disability or intractable pain. This bias leads to other types of stigmas: shame, rejection, sense of burden, isolation, loss of self-esteem, social exclusion and expected discrimination. The author notes these differences but does not attempt to explain why they might exist.

Loo, Stephanie, et. al., "Addressing unmet basic needs for children with sickle cell disease in the United States: clinic and staff perspectives." ***BMC Health Services Research.*** **21 no. 55 (2021): 10.1186/s12912-020-06055-y.**

Using six focus groups at four urban pediatric hematology clinics in the Northeastern United States, Loo and others examined the unmet needs of families of children with SCD and evaluated the clinic staff's ability to address these needs. The authors acknowledged that the guidelines of the American Academy of Pediatrics encourage all pediatricians to screen families for unmet basic needs. They further cite a study which indicates that over 90% of children with SCD have at least one unmet basic need. (Sonik, R.A., et. al., Child Youth Serv Review, 2018.) The authors' analysis of the responses of 46 staff members uncovered 4 basic themes: (1) families of children with SCD experience numerous unmet needs; (2) staff believe they have a role in addressing these unmet needs; (3) staff felt their ability to address unmet needs depended upon caregivers' capacity to act on staff recommendations and (4) the ability of the staff was limited by organization and systemic factors beyond their control. The desire for more sickle cell resources was clear. Medical-legal partnership was mentioned, but not detailed, as one path to obtaining more resources, but spiritual resources were not included. This study reinforced my belief that spirituality and faith communities are an underutilized source of help for our SCD families.

Matthew, Dayna Bowen. ***Just Medicine: A Cure for Racial Inequality in American Health Care*****. New York: New York University Press, 2015, 1-231.**

In this impeccably researched volume Attorney Matthew provides a history of structural racism in the laws that have governed medical care in the U.S. and in the application of these laws by physicians 'on the ground.' She proposes her own model of "Biased Care" in the clinic. She believes the solution to the inequities she identifies through her thorough desk research is a concerted effort to reform Title VI of the Civil Rights Act that will (1) specifically prohibit policies and practices that have a disparate impact based on race, color or national origin; (2) restore the private cause of action for disparate impact claims read out of Title VI by the US Supreme Court in Alexander v.

Sandoval (2001), and (3) to introduce a new disparate impact claim, based on a negligence standard of care. The question remains, does the political, communal, and spiritual will exist in our nation to enact this change?

McCormick, Marie, Awo Osei-Anto, Henrietta and Martinez, Rose Marie, editors. ***Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action. A Consensus Study Report of the National Academies of Sciences, Engineering and Medicine.*** **Washington, DC, The National Academies Press, 2020, 19-338.**

This sweeping study was commissioned by the US Department of Health and Human Services to provide a comprehensive approach to the management and potential interventions for sickle cell disease (SCD). The study covers societal and structural contributors to disease impact, screening, registries and surveillance, complications of the disease, healthcare organization and use, the need for a prepared workforce for healthcare delivery to patients managing SCD, delivering the next generation of therapies, community engagement and patient advocacy. The summary conclusions of this study are: “Whereas there has been substantial success in increasing the survival of children with SCD, this success has not been translated to similar care as they become adults. SCD exists in a context of racial discrimination, mistrust of the healthcare system and the effects of poverty. Receipt of appropriate treatment is influenced by the opioid crisis. Recommendations include organizing healthcare delivery at the local, state and global levels with a workforce knowledgeable about SCD including greater engagement with the educational system, community-based organizations and research groups.” p. xii

After plowing through the 496 pages of this report, I admire the effort, but this work was thoroughly anti-climatic because there is no funding for the outlined recommendations. Once again lip service seems all that patients managing SCD are destined to receive. I will use this volume, however, as a baseline for proposing a model for re-designing care for patients managing SCD.

Ngwa, Kenneth N., Let *My People Live: An Africana Reading of Exodus*. Louisville, Kentucky: Westminster John Knox Press, 2022, 12-32, 55-95, 133-185.

As my dissertation advisor, Dr. Ngwa is an enormous contributor to my work. His book has inspired me in the following ways. He speaks about the transformative power of whites engaging empathetically out of the black space. His recounting of Moses’ encounter with God through the burning bush when Moses is asked, ‘What is in your hands?”, is the question I carried to potential faith and community partners. He cautions against the impact of shifting from Egypt to Canaan without changing the underlying social, political, and ideological determinants of marginalization as transferring a problem rather than resolve it. The CHN seeks to meet, not move, the unmet needs of our patients managing SCD. He encourages the reader to consider how life can be created out of death. The latter is a bridge to far for my humble interpretation of the Congregational Health Network. But Ngwa’s retelling of the Exodus story has been my bread for the journey and speaks to the aspirations I have for this humble beginning.

Nguyen, Kim Hanh and Cembralli, Anupama G. et. al. "Applying a socioecological framework to chronic disease management: implications for social informatics intervention in safety-net healthcare setting." ***Journal of the American Medical Informatics Association (JAMIA OPEN),*** **5 no. 1 (2022): 1-19. doi:10.1093/jamiaopen/ooac014.**

The objective of this study is to increase understanding of the interrelated nature of social needs within patients' everyday lives to inform effective informatics (the science of how to use data, information, and knowledge to improve human health and the delivery of healthcare services) interventions to advance health equity. The researchers conducted 10 in-depth interviews of patients with diabetes in underserved San Francisco neighborhoods and 10 interviews with community leaders serving those neighborhoods. The interviews were supplemented with neighborhood tours and clinic visit observations. The needs identified at the individual level include physical disability, comorbidity, language barriers, history of substance abuse and health and digital literacy. At the interpersonal level many patients lacked supportive social/family relationships and had additional caretaking responsibilities. At the community level availability of supermarkets, affordable housing, public spaces, and transportation posed barriers. At the societal level laws and policies pertaining to housing and transportation, as well as racism and economic inequality posed structural barriers. Food (one interviewee asked, "I have only a small fridge and a microwave, what healthy food can I eat from that?") and housing were identified as key concerns. The authors concluded that chronic disease disparities are a systemic public health problem. No mention was made about the possibility of using spiritual resources to respond to these barriers, creating, again, an opportunity for the CHN concept to be tested.

Ortega-del-Cerro, Pablo, and Hernandez-Franco. "Debates on the Nature of Blood and the Forging of Social Models in Early Modern Spain." ***Journal of Early Modern History*** **26, no. 4 (2022):335-360.**

This article appearing in a rare Dutch journal is an excellent summary of the blood purity laws that were developed in medieval Spain and in effect until 1865. Three different perspectives are offered: (1) those who wanted to abolish any notion of blood-purity, (2) those who wanted to preserve it and (3) those who wanted to reform it. The authors are careful to emphasize that there was never unanimity in an approach to the concept of blood-purity. The Dominican Agustin Salucio was one of the main advocates of limiting and restricting blood purity laws. He was representative of a group who argued that social divisions by blood could lead to civil war. Jimenez de Paton saw many of the evils and dangers that threatened Spain in Judaism. He saw the laws as central to maintaining social order. Brother Geronimo de la Cruz believed that blood could be cleansed and purified over generations. Those who had converted to Christianity and displayed honest and sincere Christian behavior, seven generations from the conversion were to be believed and embraced. Throughout these debates, the notion that society was divided in two—the pure and the impure—persisted. Racism, the division because of religion and blood origin was perpetuated and carried by Old Christians into the New World.

Power-Hays, Alexandra, et. al. "Household material hardships impact emergency department reliance in pediatric patients with sickle cell disease." ***Pediatric Blood and Cancer*** **67, no. 10 (2020): e28587.**

This article is relevant to my research because it focuses on social determinants of hospital emergency department (ED) utilization specifically for pediatric sickle cell patients served by the Boston Medical Center network. The authors noted that an average of over 232,000 SCD patients visit emergency departments (ED) annually; 2/3 of these patients are children. Using a self-reported paper questionnaire administered during routine clinic visits, 115 patients claimed hardship in obtaining housing, food, and utility services. Patients who reported hardship in obtaining housing and utility services also utilized emergency department services at a significantly higher rate than those reporting no hardships. Lack of transportation and parent stress level were also identified as barriers to accessing outpatient care. The authors offered social work or patient navigation services as potential responses to these material needs. Utilization of spiritual resources or faith communities were not mentioned. I view this article as an encouragement to my work in appropriating faith communities and faith-based resources to assist in responding to patient hardships. It is worth noting that research by Gunderson and Cutts indicated that the presence and utilization of a CHN significantly reduced ED utilization.

Pulchalski, Christina M. and Romer, Anna L. "Taking a Spiritual History Allows Clinicians to Understand Patients More Fully." ***Journal of Palliative Medicine*** **3, no. 1 (Spring 2000): 129-37.**

Dr, Mindy Dickerman, Pediatric Intensivist, and I attended Dr. Pulchalski's pilot for the Interprofessional Spiritual Care Education Curriculum at the George Washington Institute for Spirituality and Health in July 2018. This curriculum is designed to help clinicians become spiritual generalists in the care of patients in partnership with spiritual specialists (chaplains) so that patients may receive Total Care, as outlined by Dr. Cecily Saunders at the beginning of the palliative care movement. It is a standard of care that all patients receive an assessment and the taking of a medical history before any treatment is prescribed. The validated FICA tool was introduced to Dr. Dickerman and me at this course along with guidelines for taking a spiritual history. Both tools can reveal information that is essential to clinicians so that we can provide complete care for our patients.

Quasie-Woode, Delores P. et.al. "The Use of Religion in the Management of Depression in Sickle Cell Disease: A Systematic Review." ***Journal of Religion and Health*** **59, no.6 (2020): 3112-3122. doi.org10.1007/s10943-020-01039-y.**

This study is a systematic literature review conducted to describe depressive symptoms in SCD patients and to explore religiosity as a coping mechanism for relieving depressive symptoms. Religiosity is defined as the use of individual values, beliefs, practices, and rituals related to faith. Spirituality is defined as a process of recognizing the importance of orienting one's life to something intangible that is beyond or larger than themselves. Fourteen studies were included in this review. Two themes emerged: (1)

the physical symptoms of depression in SCD were identified as increased pain intensity, anxiety, sleep disturbance, cognitive difficulty, and frequent VOCs; (2) the psychosocial implications of such depression included discriminatory remarks from significant others, suicidal thoughts and ideations, stressful economic situations, loneliness, self-hate, stigma and somatic complaints. The authors concluded that depression screening should be considered in the care of SCD patients. Furthermore, the incorporation of religious practices into depression treatment would offer a complementary or alternative method to increased medication. The relevance of this study to my work is the pathway it provides to offer spiritual care, both in hospital and in the community, to SCD patients and its reinforcement of the consideration of religion/spirituality as a social determinant of health.

Rockich-Winston, Nicole, et. al. "All Patients Are Not Treated as Equal: Extending Medicine's Social Contract to Black/African American Communities." ***Teaching and Learning in Medicine*** **34, no. 3 (2022):238-245.**

Rockich-Wilson et. al. assert that medicine's social contract has not been extended to Black patients because underlying medicine's contract with society is the racial contract which favors white individuals and de-legitimizes the treatment of those who are not white. The researchers applied a qualitative approach to examine the professional identity formation of Black African American trainees and physicians in the southern part of the United States. A brief history of inequity in the provision of healthcare to people of color was the preface to assembling responses to this key question: In what ways do Black/African American physicians attempt to fulfill the social contract with Black patients considering the country's racial contract? The primary response to this question was to ensure that Black/African American communities are educated about their healthcare. This is not just the responsibility of Black physicians, but the profession itself. The authors further suggest that medical education needs to consider not just patients' social determinants of health, but also ways to instill trainees with a sense of moral determinants of health. The article did not mention spiritual care or assessment as a dimension of moral determinants of health. My research may help to fill this void.

Rogers, Eugene F., Jr. ***Blood Theology: Seeing Red in Body-and God-Talk*****. Cambridge, UK, and New York: Cambridge University Press, 2021, 3-226.**

I had to read this book twice to comprehend it. Rogers begins his work with a compelling personal challenge that I think became a calling in drafting this book: "the trouble with same-sex couples is they impugn the blood of Christ." This was asserted at a meeting of the Episcopal House of Bishops in 2008. The author could not grasp the meaning of the statement and embarked on the journey that produced this volume. Rogers painstakingly explores the themes of blood sacrifice, atonement, expiation, sanctification, purity, impurity, healing, creationism (yes, amazingly!) and communion. He concludes with a beautiful framing of the Eucharist as that which joins all humanity together by the blood of God, but he never answers the question that started it all. I found parts of his work helpful in framing chapter 3 of this paper as Rogers sharpens his view of blood as a unifier of humanity. But like blood, this book circulated through so many veins (dare I say topics?) and never stopped to settle (coagulate?) on a conclusion (at least one that I could discern). This did not stop the author, however, from excoriating Anidjar in an appended review of his book.

Shah, Nirmish et. al. "Treatment patterns and economic burden of sickle cell disease patients prescribed hydroxyurea: a retrospective claims-based study." ***Health and Quality of Life Outcomes*** **17, no. 155 (2019): 1-11.**

Hydroxyurea (HU) was the first medication approved for treatment of sickle cell disease for adults in 1998 and children in 2017. This medicine helps to reduce VOCs. A total of 3999 SCD patients in the study were prescribed HU. Nearly half of the study participants were under the age of 18. Discontinuation of use over the four-year period of the study totaled 58.9%. This was largely due to poor adherence to treatment. Further examination indicated that the costs and inconvenience of monitoring required during HU therapy as well as recall barriers and forgetfulness all contribute to the low HU treatment compliance.

Shenoy, Amrita, Shenoy, Gopinath N. and Shenoy, Gayatri G. "The Stark law, from inception to COVID-19 blanket waivers: a review." ***Patient Safety in Surgery*** **16, no. 19 (2022). doi:10.1186/s13037-022-00326-9.**

This article, applied the context of Covid 19, illustrates how safe harbor waivers and protections allow patient services that might otherwise be interpreted as inducements, to be provided within the boundaries defined by the AKS, Stark Act and CMPL laws.

Taylor, Charis. "Why African Americans Are Affected More by Sickle Cell Anemia and Multiple Myeloma." ***There Goes My Hero*** **6 (June 17,2021): https://theregoesmyhero.org/author/ctaylor. Date accessed November 3, 2021.**

This website provides excellent, accessible information on a variety of topics relevant to blood cancers and blood disorders. Patients and families directed me to this resource. It is maintained in cooperation with the *Deutsche Knochenmarkspenderdatei*, DKMS (German Bone Marrow Donor File) organization which was founded in 1991 in Tubingen, Germany, by the family of a blood cancer patient who could not find a suitable bone marrow donor match. In 2008 Erik Sauer, a patient treated in the Penn Health System in Philadelphia, PA, survived leukemia with the help of a donor through DKMS. Sauer and his family cooperated with DKMS to publish *There Goes My Hero* entries. Anyone who is searching for a concise, accurate description of any aspect of blood disorder treatment or care can access information through this valuable tool.

Terrell, Jo Anne Marie. ***Power in the Blood? The Cross in the African American Experience.*** **Eugene, Oregon: Wipf and Stock Publishers, 1998, 2005.**

As a doctoral student at Union Theological Seminary, Terrell posed this question: "How is the gospel message of the atonement or reconciliation if sinners with God through Jesus' death on the cross, to be construed by Black people who are similarly persecuted and simultaneously indicted as sinners?" Terrell begins her quest by exploring how Black and womanist theology has been informed and contributes to African Americans' understanding of the cross as either sacrificial or sacramental. She reviews the work and legacy of John Wesley, Richard Allen, Frederick Ross, Albert Barnes, Martin Luther King, Jr., Albert Cleage, Jr., James Cone, Anselm, Aberlard, Luther, Jacquelyn Grant, Kelly Brown Douglas, Delores S. Williams, Rita Nakishima Bock, the Black Power Movement and Malcolm X. She asserts that the moral and legal codes of slavery gave the reverence due to God to whites with priority given to the authority and persons of white males while continuing to teach that women brought sin into the world. (p. 42) She makes a powerful case for Black women's agency and concludes that anyone's death has salvific significance if we learn continuously from the life that preceded it, thus aligning with Brock that the traditional view of atonement can be construed as "divine child abuse." Jesus' sacrificial act was not the objective, rather it was the tragic, if foreseeable, result of his confrontation with evil. I am grateful to Terrell for the words she gave me to express my inner thoughts and fervent prayer. I join her in her quest, "for holistic spirituality which she defines as communion with God and all of my neighbors and freedom ever more to work, love and enjoy life." (p. 144)

Tycho and Zavareei Whistleblower Practice Group. "The Anti-Kickback Statute and Stark Law Explained." ***National Law Review*** **8 no. 360 (2023): 1-5.**

This article, written in layman's language provided an excellent comparison between the provisions of the AKS and the Stark Law as well as a list of examples illustrating the type of kickback activity that these laws are designed to prevent. Accessible and informative.

Villarosa, Linda. ***Under the Skin: The Hidden Toll of Racism on American Lives and on the Health of our Nation*****. New York: Penguin Random House, 2022, 1-218.**

Ms. Villarosa is a journalist and journalism professor at the City University of New York. In this volume she explores and explains how RACISM, not RACE drives health inequity in the United States. She challenges the assumptions, expressed most clearly in the 1985 Heckler Report (Margaret Heckler was Ronald Reagan's Secretary of Health and Human Services) which, unintentionally (?) assumed that Black people, individually and collectively were irresponsible, careless, uneducated, and unable to make choices that led to their good health. Chapter by Chapter Villarosa dismantles assumptions, thoroughly supported by data, about the sterilization of Black women, death in childbirth, low birthweight babies, environmental justice, the relationship between addiction and despair, life expectancy differences and the impersonal, and clueless healthcare system. Using a term first coined by Bruce McEwen, 'allostatic load', she explains how the biomarkers released by the Black body in the face of sustained stress, are largely responsible for the horrendous health outcomes suffered by people of color. She concludes with the words of Audre Lorde who when asked about the longevity of racism in America replied, 'racism will fight to the death, desperately clinging to life and going out ugly." Many more will die before racism takes its final ugly breath.

Wailoo, Keith. ***Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health.*** **Chapel Hill and London: The University of North Carolina Press, 2001, 1-234.**

Keith Wailoo is a medical historian and professor of history at Rutgers University. This book traces the evolution of treatment and care for sickle cell patients specifically in Memphis, TN. Wailoo examines three issues: (1) the tension in scientific medicine between research in molecular biology and patient pain management; (2) the use of sickle cell disease as a mechanism to define race relations on the local, state, and federal levels and (3) the role of sickle cell disease in defining local, state, and national healthcare policies. This book is a guiding light for me in the development of section II of this paper. Wailoo chose Memphis as the living laboratory for this work because it is a majority BIPOC city in the south with an economy in transition from dependence on cotton production to the provision of healthcare. He uses SCD as the thread that weaves the elements of practice, people, and policy together. He also provided valuable insight to the development of the original Congregational Health Network in Memphis. This contextual framing broadened my understanding of the CHN, its growing pains and its eventual contribution to the local healthcare system. Besides being a comprehensive volume, it is also a source of encouragement to me as I labor to build the CHN pilot.

Wakefield, Emily O., et.al. "Perceived Racial Bias and Health-Related Stigma Among Youth with Sickle Cell Disease." ***Journal of Developmental and Behavioral Pediatrics*** **38, no. 2 (2017) 129-134. doi.org/10.1097/dbp.0000000000381.**

Wakefield and her colleagues working at the Connecticut Children's Hospital in Hartford, interviewed 28 youth, ages 13-21 using measures of perceived racial bias and health-related stigma. Their objective was to determine the impact of health-related stigma on psychological and physical well-being and to determine whether the experience of stigma was characterized as disease-based or racial discrimination-based. Their evidence suggests that health disparities among Black children are related to 3 factors: (1) difference in life opportunities; (2) differences in access to healthcare and (3) differences in care available within the health system. They conclude with this statement: "The prevalence of differential care within the health system is not well studied." I hope to shed light on this issue.

Warnock, Raphael G. ***The Divided Mind of the Black Church: Theology, Piety, and Public Witness.*** **New York: New York University Press, 2014, 1-189.**

Warnock offers an answer to this question: "What is the true nature and mission of the church, the meaning, message and mission of the black church?" He believes that the black church is divided between a pietistic orientation to individual salvation and a public witness orientation as bearers of Jesus' mission to liberate the oppressed. Warnock dismantles and examines the tension between these two identities, creating a stirring and shaming indictment of the white church and the black church's allowing the white church to define Christianity for all. Warnock believes that the black church is evolving through four stages: the formation of a liberationist faith, founding of a liberationist institution, a church-led liberation movement (the civil rights movement) and the formation of a selfconscious black liberation theology. Warnock advocates honest and on-going dialogue between black theologians and pastors that will prepare a path to the formation of a self-critical black liberationist community. I think that Warnock has sincerely tried to bridge the divide between piety and protest in his very life as pastor of the Ebenezer Baptist Church and US Senator from Georgia. There is a special integrity in his work and in his life of ministry.

Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. New York: Random House Anchor Books, 2006, 1-404.

In this three-part volume Washington addresses the role of African Americans in the development of medical practice in the United States. She focuses on racist, exploitative research practices that began at the dawn of slavery and extend into the 21st century. As a medical ethicist, Washington proposes the repair of our system of Institutional Review Boards (IRB), revision of the informed consent mandate, coordinated systems of mandatory subject education and the development of a single standard of research ethics. I appreciated this work for its illumination of the contributions that people of color have made to the advancement of medicine and the suffering that was brought upon them, without prior understanding. How can it be that a group of human beings have contributed their very lives to the improvement of healthcare and have benefitted so little from their selflessness and bravery? This work exposes the malpractice that continues to render people of color slaves in the American healthcare system. I consider it an essential resource for anyone who wants to understand the evolution of inequity in healthcare.

Weber, Jeremy and Lee, Morgan. "The Black Church Explained by Pew's Biggest Survey of African Americans." *Christianity Today* 2 (February 16, 2021): https://www.christianitytoday.com/news/2021/February/black-church-african-american-christians-pew-survey. Accessed November 2, 2022.

The Pew Survey is among the largest and most respected research organizations on socio-economic and spiritual dimensions of American life. Their results are consistently based on sample sizes larger than 10,000 respondents which is the case for this survey. The Pew survey then becomes an excellent cross-check/validation tool for research efforts, like mine, that are smaller in scope. In addition, with a sample this size, Pew can interrogate various dimensions of responses and details (such as specific worship practices) that generate additional knowledge and areas for further exploration.

Wells, Ayanna, McClave, Robin, Cotter, Elizabeth W. et. al. "Engaging Faith-Based Organizations to Promote Health through Health Ministries in Washington, DC." *Journal of Religion and Health,* September 10, 2022, doi.org/10.1007/s10943-022-01651-0.

The researchers working under the auspices of American University examined five faith-based organization (FBO) programs designed to promote congregants' health and well-being. The authors claimed that FBOs have been an underutilized setting for health promotion. Each program was led by a certified health minister who had completed an online program called ‘Faithfully Fit’ offered at Wesley Theological Seminary. Health ministers are trained in the use of data collection tools that can help tailor a program to a specific faith community. Data collection and analysis indicated that the most common health or medical issues that interfered with congregants’ daily lives were hypertension, arthritis, diabetes, stress, and obesity. Health ministers were successful in partnering with the local YM/YWCA to offer a blood-pressure self-monitoring program and partnering with the Arthritis Foundation to implement their “Walk with Ease” initiative. The role of the health minister was the unique characteristic of this study; but partnerships between hospitals and FBOs were not discussed, which again points toward the unique potential of the CHN model to positively impact the health of the public.

“What Is Sickle Cell Disease?” Sickle Cell Disease Association of America Inc. Accessed August 9, 2022. https://www.sicklecelldisease.org/.

The Sickle Cell Association of America works with the Centers for Disease Control and the National Heart, Lung, and Blood Institute, to track the latest data on diagnoses, treatment protocols, clinical trials and research funding through the federal government and private sources. The information on this website is updated bi-monthly and is an essential source for tracking the latest progress and challenges in treating and managing sickle cell disease.

Whitekettle, Richard. “A Study in Scarlet: The Physiology and Treatment of Blood, Breath and Fish in Ancient Israel.” *Journal of Biblical Literature* 135, no. 4 (2016):685-704.

The author tackles a question that never occurred to me until it was raised by Dr.Kenneth Ngwa: “What difference, then, did the ancient Israelites see between fish and land/aerial animals such that they permitted the consumption of fish blood but prohibited the consumption of land/aerial animal blood?” Whitekettle’s answer is that the difference was breath—spirit if you will. The ancients knew that fish die in the air, thus, they did not breathe air. Perhaps what they did not know is that fish blood also contains ‘breath’ in the form of oxygen extracted by their gills. I couldn’t help wondering whether the author had ever considered that all blood is tasked with the transmission of oxygen—breath or spirit. All blood is God’s blood, and all animating spirit, breath, is God’s as well. Perhaps if the Israelites had known this, fish blood would have been prohibited as well. This article is instrumental in the writing of chapter 3 of this paper.

Williams, Latiena F., and Cousin, Lakeshia. “‘A Charge to Keep I Have’: Black Pastors’ Perceptions of Their Influence on Health Behaviors and Outcomes in Their Churches and Communities.” *Journal of Religion and Health* 60, no. 2(2021): 1069-82. doi.org/10.1007/s10943-021-01190-0.

Building on research conducted at the University of Memphis in 2018, Williams and Cousin extended the analysis of the perception of Black pastors’ influence on congregants’ health behaviors and outcomes. This research confirmed the belief among most Black Americans that God, not the physician, is the ultimate healer. The study also identified barriers to pastoral influence on congregants’ healthcare: congregants do not regularly attend the activities provided by healthcare ministries, nor do congregants tend to believe that being faithful to God translates into a desire to be healthy. Pastors indicated that community partners are needed to provide healthcare services within the church. Quoting one participant: “One of the programs I would love to see is, within the community and I am talking about health professionals, would come into the church and we’d be partners.” (pg. 1077) This is the CHN model, which provides a Health Navigator to the participating congregations to keep them updated on SCD findings, and to respond to the specific healthcare interests and needs of the congregation. This finding is an encouragement to my project which seeks to create these partnerships.