

REFLECTIONS ON SICKLE CELL DISEASE RESEARCH: LESSONS LEARNED FROM AN AMERICAN STUDENT'S COLLABORATIVE RESEARCH EXPERIENCE AND TRAVEL IN GHANA

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This narrative describes the experience of an American student who traveled to Ghana in order to conduct sickle cell disease research. Intertwined with important lessons learned during the journey, are research experiences and reflections from a personal journal, a travel log, and insights gained through community service. The narrative discusses local barriers to accessible health care and encounters with limited resources. The aim is to offer insights into working effectively in Ghana as a foreign research assistant.

Introduction

In 2008, I traveled to Ghana to conduct clinical research through an internship with the Minority Health and Health Disparities International Research Training (MHIRT) program. The MHIRT program is funded by the National Institute of Health and allows faculty and students to engage in numerous health-related research projects in Ghana and many other countries. The University of Michigan and the University of Ghana are the collaborating sites for the "MHIRT Sickle Cell Disease Project." Sickle cell (SCD) disease is a significant public health issue in Ghana. One research aim is to investigate the clinical variability in the manifestations of SCD through studies involving twins and siblings with sickle cell disease.

Insights shared by past MHIRT interns facilitated more effective work on our part. I offer this narrative to students, researchers, advocates, volunteers, and helping professionals who may work or travel in Ghana. In addition to reflections on living and working in Accra (the capital of Ghana), and traveling to various regions in the country, I discuss the misconceptions of SCD. Of particular concern to me are barriers to accessible health care, disparity in the availability of resources, and education about sickle cell disease. I also describe the roles played by team members of the "MHIRT Sickle Cell Project."

A Perspective on the Cultural Transition

My senses were overwhelmed as I walked down the streets of Osu, a district of Accra, Ghana. Some women were carrying infants on their backs using traditional cloth. Many men, women, and children carried items neatly balanced on their head, such as mounds of fresh fruit, heavy bags of rice, sachets of pure water, *FanYogo* (frozen yogurt), stacks of T-shirts for sale, various artifacts, and much more. West Africa is notorious for its vibrant, crowded markets. Many Ghanaians make a living at the markets by selling a variety of things, such as food, clothes, household products, or by offering services such as sewing.

My research partner, Regina (a Ghanaian-American), and I lived in the International Student Hostel on the Korle Bu Teaching Hospital (KBTH) campus in Accra. I was quickly introduced to a lifestyle of occasional power outages, lack of running water, the heat of the dry season, and the fierce thunderstorms of the wet season. In response to the lack of running water, I adopted the method of taking cold, bucket showers. My daily routine involved taking malaria prophylaxis and spraying mosquito repellent. I happily adjusted to a significantly different pace in everyday life.

In addition to adjusting to a new lifestyle, I discovered a different system of racial

enculturation. "Obroni" is a Twi word that can be used as a racial or cultural term. Twi is one of over 49 ethnic languages spoken in Ghana. "Obroni" is often used to identify a foreigner from a Ghanaian perspective and is not derogatory. However, I was not thrilled by the attention given me as a foreigner because of the stereotypes that may be attached. On occasion, I encountered the belief that foreigners all have abundant resources. I developed a level of comfort in being asked: "Are you South African?" I would respectfully explain that I am from the United States and not South African, but a multiracial American. Memorable conversations often followed those encounters.

After viewing a historical display of the Atlantic Slave Trade and the "Brazilians of Africa" in Jamestown (another district of Accra), Regina and I chatted with a few local children. Two young children around the age of five captured my heart and my attention with their smiles. We all walked over to a sandy, trash-ridden beach and the children proceeded to play a game called Mancala. Ironically, the breeze from the Atlantic Ocean gave me a sense of calm, even though I was standing on land with a tragic, painful history.

Preparing to depart from Jamestown, Regina and I boarded a *tro-tro* (a passenger van). With the help of friends and locals, we learned to navigate the *tro-tro* system in Ghana. I peered out the window at a group of children making hand gestures near their mouths. Regina explained that they were asking for food. I had leftover food from lunch, plantains and *jollof rice*, a popular West African dish. Wasting food is often a tourist's habit, even in a country where children die of malnutrition and starvation every day. It was an inherent reflex to want to share this leftover food, but the *tro-tro* pulled away before I registered the meaning of their gestures. On the other hand, I did not want to perpetuate the image that foreigners have unlimited resources. My purpose in Ghana, in part, involved conducting clinical research on sickle cell disease and learning about life in Ghanaian culture.

Sickle Cell Disease in Ghana

The MHIRT Sickle Cell Project recruited participants for the study at the sickle cell clinic at Korle Bu Teaching Hospital (KBTH), where Ghana's first and largest sickle cell disease clinic is located. The University of Ghana Medical School is affiliated with Korle Bu Teaching Hospital and many medical workers live on the campus. KBTH is the primary health care facility in Ghana, and the only tertiary hospital in southern Ghana. The government supports a large portion of the nation's health care through the Ministry of Health (MOH). The MOH is responsible for providing public health services, as well as building hospitals and supporting the medical educational system (see http://www.ghana.gov.gh/index.php?option=com_content&view=article&id=332:ministry-of-health&catid=74:ministries&Itemid=224).

Sickle Cell Disease is a pressing public health issue in Ghana. SCD is an inherited disorder characterized by abnormal hemoglobin due to a mutation (see <http://www.sicklecelldisease.org/index.cfm?page=about-scd>). Hemoglobin is the iron-rich protein found in the red blood cells and is responsible for oxygen transport in the human body. When red blood cells containing abnormal hemoglobin are deoxygenated, they form a sickled shape similar to a half moon shape. Sickled red blood cells cannot flow through blood vessels as easily as normal hemoglobin and are prone to getting stuck. Such blockages can form in blood vessels and prevent oxygen from traveling to where it is needed. This often induces attacks of severe pain called a "pain crisis," a common complication for those with this disease.

In Ghana, sickle cell disease affects one in every fifty babies (see http://www.sicklecellghana.org/index.php?option=com_content&view=article&id=48&Itemid=55), and is the most common genetic disease in all of Africa; more than 400,000 babies are born with sickle cell disease per year. In comparison to the United States, for example, it is estimated that SCD occurs in one out of every 500 African

American births and in one out of every 36,000 Hispanic American births (see <http://www.sicklecelldisease.org/>). Sickle cell disease is considerably prevalent in sub-Saharan Africa and in African-Americans, but it is not a "Black" disease. SCD is also common among people whose ancestors come from East Indian, Caribbean, Arab, and Mediterranean countries. These regions tend to align with the "malaria belt," parts of the world where malaria is a common infectious disease.

Newborn screening allows healthcare workers to educate families about the needs of children with SCD. Early diagnosis and treatment is important because those with SCD are at an increased risk for infection and other health problems. Efforts of the Sickle Cell Foundation of Ghana, Ministry of Health, and international collaborative projects have helped launch newborn-screening programs for SCD in Ghana, and have helped develop psychosocial support programs. Additionally, Ghana has received financial support for the construction of a SCD diagnostic lab center in Kumasi, located in the Ashanti Region. This support was made possible through a partnership between the Ministries of Health of Brazil and Ghana (see <http://www.ghananewsagency.org/details/Health/Brazil-commits-13-66-million-for-Sickle-Cell-Centre-in-Ghana/?ci=1&ai=22751>).

MHIRT Research Experience and Clinic Days

At Korle Bu Teaching Hospital, we often shared the same space with doctors and medical students in the sickle cell clinic. However, we frequently had full use of a room to interview patients and families. When I was near KBTH for work or during my walks around the campus, it was heart-wrenching to observe long lines and groups of people seeking medical attention. Each person has a story and a history; I yearned to learn more about them. It is common for people to travel many hours in order to receive medical care in a clinic or hospital in Ghana. I had a strong desire to be in a position that would allow me to better serve those in need of medical care. Part of me felt inadequate as a student and

merely a prospective health care worker. I wished that I had extensive medical training that would allow me the opportunity to directly help patients. For the time being, I accepted the role as a student-researcher. I also formed relationships with people that provided the opportunity to shadow health professionals in clinics and various wards at the hospital.

The partnership between the MHIRT research team and families affected by sSCD in Ghana allowed us to formally gather data that contributes to the greater knowledge of this prevalent issue, with the hope of improving health outcomes and quality of life for people with SCD. The MHIRT Sickle Cell Project collected data from patients on-site at Korle Bu between 2006-2009, and from May to August of 2011. Questionnaires were administered to participating sickle cell patients in the pediatric SCD clinic at Korle Bu on Thursdays (see <http://www.korlebuteachinghospital.org/?pid=6&cid=40>). The questionnaire in our study was designed to collect information regarding demographics, socioeconomic status, and a medical history of the patient. Other variables related to the severity of SCD were included.

Each child's medical history was obtained through review of medical records. Their medical histories were hardcopy notes, with test results in tattered, bright yellow folders. No medical records are kept online or are available through other sources. By contrast, in the United States most patient medical information has transitioned to electronic filing systems. Dr. Onike Rodrigues, a pediatrician in Ghana, gave the patients a professional physical examination. Finally, blood samples were obtained from each participant in order to acquire current laboratory data.

Jonas Tetteh, a worker at Korle Bu, coordinated the recruitment process of sickle-cell patients for the project. Patients were reasonably compensated in Ghana cedi for participation in the study. Gameli Adzaho assisted with the project while completing his required year of National Service in Ghana. Gameli was incredibly helpful with organizing the blood sample collections and managing the flow of patients between stations on clinic days.

Because many families in the region spoke Twi and Ga, Jonas Tetteh also served as a translator during the interview process. In any cross-cultural research project, the wording of questions must be carefully scrutinized in order to ensure that patients understand what is being asked.

My research partner and I used a password-protected laptop for data entry. The Department of Pediatrics Library at Korle Bu was where we could more reliably access the Internet. Although there are many commercial cyber cafés in Ghana, accessing the internet can still be problematic. Depending on the location, it can take a long time to upload documents and send e-mails. For example, one afternoon it took 30 minutes to send a short, one-paragraph e-mail at an Internet café near campus. Unpredictable power outages were also a factor.

A Reflection on SCD Research

Formal and informal information gained through the MHIRT Sickle Cell Project contributes to a greater understanding of sickle cell disease medically and socially. Data gathered through the research study is meaningful because it can be used to educate people with SCD and improve medical care. Data on over 200 patients has been collected since the project began in 2006. The majority of sickle-cell patients in this study lived in the Greater Accra Region and indicated Korle Bu Teaching Hospital as their primary health care facility. Most families reported that they rely on *tro-tros* as the primary means of transportation to get to the clinic. Very few Ghanaian families in this study owned a car; thus, one can imagine the predicament that a sickle-cell patient and their family may face when in need of emergency medical care. On average, the travel time to Korle Bu was nearly one hour.

Ideally, the questionnaire administration, physical examination, and blood collection were scheduled on the same day for a set of siblings. Multiple visits for families were avoided in order to minimize participants' travel time. Young adult siblings usually made individual visits without family members present.

In retrospect, we should have anticipated obstacles and prepared our materials prior to arrival in Ghana. Because we were not prepared to collect blood samples during the first four weeks of our research project, a few families were asked to return to Korle Bu after completing the questionnaire and physical examination phase of the study. During the first year of blood sample collection, tubes were ordered through a company in Ghana. The order arrived almost four weeks later. In retrospect, the tubes for blood samples could have been brought with us, along with the other materials (i.e., questionnaires, consent forms, flash drive, a 3-ring hole punch, manila folders, labels, pens, and markers). Adhering to airline guidelines for luggage, our team should have considered the space and weight of the research materials or found another means of supplying a site with necessary materials. Start-up time and research progress could be greatly enhanced by preparation in advance.

Student Sympathy: Invisible Nature of Chronic Illness and Accommodation in Schools

As a student-researcher, I pondered the issue of accommodations in the educational system for those with chronic health conditions in Ghana. I volunteered at Ministry of Health Basic School on the Korle Bu campus twice a week. Through this volunteer work and other conversations, I was able to glimpse the Ghanaian educational system and the learning environment in classrooms in a primary school. I also had the opportunity to meet a few students attending the University of Ghana.

As an American student, I struggled with other chronic health ailments throughout undergraduate school. I evaluated my understanding of accommodations for students in the States and my observations in Ghanaian educational institutions. Aspects of chronic health issues in a vulnerable population (such as children) often have an "invisible" nature, but represent real needs that should be of serious concern. Many Ghanaians hear about SCD and often share the popular view that people with SCD are doomed to an early death. It is a misconception that there is no hope for

a child born with sickle cell. It is true that SCD is a challenging, painful genetic disorder, and that people with SCD have a shorter average life expectancy and require continual medical monitoring. However, there is no firm data on the life expectancy of people with sickle cell disease in Ghana. The median life expectancy for people with SCD in the United States in 1994 was estimated to be 42 years for men and 48 years for women (World Health Organization, 2006). In sub-Saharan Africa, the estimated lifespan is considerably shorter. Some Ghanaians shared stories about people with SCD dying in childhood due to infections, malaria, or untreated sickle-cell complications.

There has been progress in raising awareness and developing forms of support for those affected by SCD. Public awareness of the disease must continue to increase, as most education is on a societal level. The Sickle Cell Foundation of Ghana is a non-governmental organization formed in 2004. The organization strives to improve the quality of life and provide psychosocial support services for those with SCD (see <http://www.sicklecellghana.org/>).

There appears to be little assistance offered by educational institutions. For instance, if a student misses class for an extended period of time due to illness, there is no system in place to enable these children to catch up on coursework. This lack of support leaves these students susceptible to falling behind. Considerable progress needs to be made in medical and psychosocial support. The efforts on behalf of the Sickle Cell Foundation and other projects addressing the needs of sickle-cell patients are that the societal perception of SCD and health outcomes can continue to change over time.

Coda

Sustaining relationships and lines of communication between the collaborating research sites was crucial to the MHIRT Sickle Cell Project. It takes commitment and sustained effort for such collaborative work to be successful. As the lessons learned increased, communication between the teams of MHIRT students each year ensured that questionnaire administration, data collection,

and analysis improved. The progression of projects will likely vary depending on the topic, location, and nature of the work. Our research team anticipated obstacles to the best of our abilities. Creative problem solving for mishaps along the way and adjusting our framework to adapt to a situation allowed our research team to successfully maintain a productive pace in data collection. In addition to our research mentors, Dr. Rodrigues, Dr. Campbell, Gameli Adazho, and Jonas Tetteh (Ghanaian research assistants) played fundamental roles in the project, particularly in the recruitment of patients. In addition, they helped the research team overcome barriers in language and cross-cultural communication during interviews with families and individuals affected by SCD in Ghana.

The understanding of SCD continues to grow, as does the identification of varying factors that affect SCD clinical heterogeneity. The overall goals in terms of the implementation of research findings is to further improve the outlook for sufferers of this chronic condition, and support those with SCD as valuable members of society. Socially lifting the burden of such chronic illness is a tremendous challenge. The desire to improve the quality of life for those facing chronic illnesses such as SCD is a motivating reason to engage in clinical research.

While working in a clinical setting, I observed the need for basic supplies. At Korle Bu Teaching Hospital, for example, they lacked medical supplies, such as latex gloves, cotton swabs, and sanitation materials. The same held true for a group of MHIRT colleagues working in a scientific laboratory in Mampong-Akwapim, a town in Ghana's Eastern Region. My colleagues conducted many procedures using cracked laboratory beakers, or the same latex glove (note singularity), which was recycled for several days. Materials are exhausted before they are deemed waste. At times I had deep concern for the sanitation safety of patients and medical workers. I was reminded of non-governmental organizations that recycle medical supplies from American hospitals to hospitals in other countries. This is an example of connecting one country's needs with another country's

excess, which still requires people to interact within a committed partnership.

Other valuable observations stemming from this travel-research experience involve identifying regional disparities in resources and living conditions that exist in Ghana. Nine out of ten people live below the poverty line in the rural north, and seven out of ten people live below the poverty line on average in the nation (<http://www.wfp.org/countries/ghana>). My travels between northern and southern Ghana visually highlighted Ghana's diversity in terms of development. There are regional economic disparities, with more economic opportunities in southern Ghana, which is characterized as urban in contrast with the rural north. In particular, Ghana's Northern, Upper East, and Upper West regions significantly lacked infrastructure.

The 10 administrative regions and 170 districts in the Republic of Ghana exhibit differences in infrastructure (see <http://www.ghanadistricts.com/districts/>). Access to resources and cultural features specific to a region are considerations in the development and implementation of projects. For instance, Nzulezo is a stilt village in the western region. Nzulezo is literally built on stilts over a body of water, and all materials are transported via canoes to the village. This example serves to illustrate the importance of preparing for what methods and resources may or may not be available to a research team in relation to the people or issue of interest.

Komfo Anokye Teaching Hospital (KATH) is in Kumasi, which is located in the Ashanti Region. KATH is the second-largest hospital in Ghana (following Korle Bu Teaching Hospital) and is the only tertiary health institution in the Ashanti Region. Komfo Anokye Teaching Hospital serves as the main referral hospital for the Brong Ahafo, Northern, Upper East, and Upper West regions in Ghana. Kumasi is located approximately six hours away from Accra, over dangerously rough and crowded roads via *tro-tro*. For someone traveling from Wa (the regional capital of the Upper West Region), it may take up to 36 hours or more to travel to Kumasi in order to receive medical treatment at KATH. In addition, the overcrowded wards and long wait-

time cannot escape observation. For example, the obstetrics and gynecology wards at KATH are heavily crowded. Women are frequently expected to share a bed with one or two other women. Similar conditions can be found at Korle Bu Teaching Hospital.

Furthermore, reliable transportation between regions tends to be more time consuming and complex than traveling within a region. More roads are paved in the Greater Accra Region (in southern Ghana) than in the north, which is more rural and faces relatively harsher conditions than the south. Occasional violent disruptions between ethnic groups in Ghana may cause death or may halt the transportation of agricultural products between regions. While English is Ghana's official language, there are 79 ethnic languages, with considerable variation in dialects between regions. Furthermore, the majority of Ghanaians are Christian. Christianity is the predominant religion in southern Ghana, but Islam is the predominant religion in northern Ghana.

As an aside, it is wise to carry a photocopy of your passport when traveling in Ghana. My fellow MHIRT colleagues and I were unexpectedly stopped by authorities while riding a *tro-tro* after a hiking trip to Mt. Afadjato in the Volta Region. (Mt. Afadjato is the highest mountain in Ghana and is located near the border with Togo.) Ghanaian policemen asked for all foreigners' passports, although their intent was never made clear. After holding a 30-minute conversation in a combination of Twi, Ewe, and English between the policemen and our Ghanaian friends, we were allowed to continue. When traveling, it is advised to remain mindful of one's inevitable identity as a foreigner, particularly when one is unfamiliar with the culture, regions within a country, and the unknown connotations attributed to daily behavior as it is perceived within a different cultural context.

My travel and research abroad through the MHIRT program was a classroom-without-walls experience. I encourage students and community members to seek opportunities to engage themselves in complex social issues through service and research projects. Actively engaging in the meaningful

work of service or research projects helps other people and facilitates personal growth beyond one's imagination. Mahatma Gandhi stated, "The best way to find yourself is to lose yourself in the service of others." It was my privilege to have met and worked with numerous sickle-cell patients and their families. For a lifetime, I will recall this firsthand experience in Ghana with gratitude.

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