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Research Article

Uncovering How Occupational Therapy Could Benefit Individuals Living with Sickle Cell Disease in Ghana

—Carolyn D'Olympio

My first day in Ghana consisted of a five-hour bus ride from Accra to Kumasi in the pouring rain. Granted, I love the rain; it's just much more enjoyable when it isn't paired with jet lag and traffic. My second day in Ghana I celebrated the 100th birthday of a Seventh Day Adventist monk and attended a wedding reception in the evening. Amidst this excitement, my real purpose for traveling to Ghana in the summer of 2017 was to conduct research.

As an occupational therapy student at the University of New Hampshire (UNH), I am captivated by the lived experiences of others. My coursework challenges me to consider the viewpoint of individuals who are living with disabilities or are presented with environmental, social, or any other adversity that negatively impacts their quality of life.

Occupational therapy is a holistic healthcare profession that considers the person, the environment, and the person's disorder, and how these factors influence an individual's ability to engage in the activities, or "occupations," that are meaningful to him or her. In occupational therapy, the term *occupation* refers to the meaningful ways in which people occupy their time, rather than exclusively their jobs or professions. Occupational therapists use evidence-based evaluation and intervention methods to create solutions that allow individuals, groups, and communities to engage in meaningful life activities. Interventions vary greatly depending on circumstances, but often involve the therapist making adaptations to the individual's environment or activity to support engagement. Simple examples of occupational therapy interventions include teaching a child with a visual-spatial impairment how to tie their shoes by using shoelaces with contrasting colors that aid in distinguishing appropriate steps, or hanging simple-to-follow instructions on a kitchen cabinet so that a patient experiencing dementia can independently sequence the steps of cooking.



The author with her friend Simi, a US medical student in Ghana for a rotation in dermatology.

Occupational therapy addresses almost every aspect of human life—an endeavor not simply explained in even the most well-articulated and rehearsed elevator speech. But, here, I will do my best to paint a picture for you of what we do as occupational therapists, why my research study in Ghana is so heavily grounded in the profession’s philosophy, and how my experiences in Ghana helped me better understand the relationship between culture and disease.

The Road to Ghana

I was initially attracted to Ghana as a location for research when it became an official member of the World Federation of Occupational Therapy and graduated its first class of occupational therapy practitioners in 2016. I was eager to find out more about Ghanaian society’s opinion and acceptance of occupational therapy as the country made the transition to include this profession into its healthcare model.



Komfo Anokye Teaching Hospital (KATH) early in the morning before crowds arrive.

Dr. Lou Ann Griswold, my UNH mentor, was both supportive and experienced in taking on projects that seemed larger than life. We coordinated with Dr. Gene Harkless, the chair of the nursing department at UNH, and Dr. Martin Agyei, a well-respected physician at the Komfo Anokye Teaching Hospital in Kumasi, Ghana. I was awarded a Student Undergraduate Research Fellowship (SURF) Abroad grant to support my travel and research in Ghana over a ten-week period during the summer of 2017. My research would focus on the experiences of individuals living with sickle cell disease in Ghana, and seek to determine potential environmental and occupational adaptations to support chronic pain management and

engagement in meaningful activities pertinent to Ghanaian culture.

Upon arrival in Ghana, I settled in with a family I had been connected to through Dr. Harkless, who has been to Ghana multiple times for her work in nursing. My host family was large and consisted of many more than just those living in the house that I shared. Abi, the woman who took me into the home, became a mother figure, and I am exceptionally grateful to her for teaching me everything I now know about how to navigate and live in Kumasi. Without Abi’s support, it would have seemed impossible to navigate the streets of Kumasi on my own and to embark on my summer exploring occupational therapy and life in Ghana.

On weekdays after leaving the hospital, I went to a restaurant owned by Ma Angie, my host mother’s cousin. Here Ma Angie taught me the ins and outs of the Twi language (pronounced “chi”) and Ghanaian cuisine, including how to eat and love fufu—a cassava and plantain dough in a soup you eat with your hands. Ma Angie and Abi taught me my Ghanaian name, which, since I am female, born on

Friday, and figuratively born in the Ashanti tribe, is Afia Caro. On Saturdays, we went to church along with the rest of the extended family and then we all gathered down the road for an afternoon meal. We sat on the cool concrete, shared stories, and played games until the sun left.

Sundays were laundry day, and my favorite day of the week. Surrounded by smiles, tied back hair, and sun-kissed faces, the women in my host family—from young to old—gathered buckets, bars of soap, and piles of clothing to wash together under the sun. Straddling wash buckets, we sat on little wooden stools and talked for hours. I loved that the activity took from morning to afternoon, and not a single person felt rushed. All that mattered were our conversations, our time together, and my new favorite chore. I loved the routine because of the sense of community it brought.

I was honored to be taken in by a family so proud of their heritage, and so willing to share it with me. The exciting cultural experience of living like a Ghanaian was an invaluable backdrop to my research on occupational therapy.



The author with some of the members of her host family.

The Research Process

My research process began by getting to the hospital each morning. Our home was located in Kotei, Kumasi, about an hour from Komfo Anokye Teaching Hospital. Each morning I walked to the main road, where I waited for a tro tro.

The tro tro is a public carpool van with open windows, a driver, and a mate who hangs out the side of the vehicle yelling its destination to anyone and everyone it passes. The tro tro, which easily became one of my favorite parts of living in Kumasi, took me from Kotei to Tight Junction (which looks exactly like it sounds), and then from Tight Junction to Adum, the town closest to Komfo Anokye hospital. From there I walked to the hospital or took a taxi, depending on whether I was running late. Thankfully, I found that according to Ghanaian time, I was usually safe from showing up late to anything; it is very common for people to be at least an hour late for . . . everything. The laid back way in which time flows there became another one of my favorite things about life in Ghana.



The view from inside a tro tro.

Once I arrived at the hospital, the real fun began. In order to learn about individuals' experiences with sickle cell disease, I first had to meet the individuals themselves. For two weeks I recruited patients at the hospital with the help of my foreign mentor, Dr. Martin Agyei. Dr. Agyei is a physician at Komfo

Anokye dedicated to helping medical students learn and navigate the world of medicine and patient care.



The author with her mentor, Dr. Martin Agyei.

Eventually, five patients agreed to return to the hospital weekly for a total of five weeks so that I could interview them. This small sample size allowed us to arrange reoccurring, in-depth interviews, and to develop rapport so that I really got to know their life stories. Additionally, these patients each agreed to welcome me into their homes for one interview each, where I observed how they interacted with their environment and how their environment influenced their ability to carry out daily activities while living with sickle cell disease.

In addition to interviewing patients, I also interviewed sickle cell specialists to learn more about current treatment and practices used to support patients and to explore the level of awareness healthcare practitioners in Ghana had about occupational therapy. By interviewing individuals living with sickle cell disease and their practitioners, I investigated the potential benefits occupational therapy may have for enhancing the quality of life of individuals with this disease.

Sickle Cell Disease in Ghana



Ghana is in West Africa, and Kumasi is in south central Ghana. *Maps by VoodooIsland, 2010, and Flusus, 2015.*

Sickle cell disease persists among 20 to 30 percent of Ghana's population (World Health Organization [WHO], 2017). The disease is characterized by distorted hemoglobin protein that changes the shape of red blood cells. Because of the blood cells' irregular, sickle shape, the body can't easily move them—or the essential oxygen they carry—through the bloodstream. The decreased ability of the body to distribute oxygen throughout the bloodstream often causes chronic pain, immobility, and other complications associated with fatigue and tissue damage. These complications can interfere with many major aspects of life, including education, employment, and psychosocial development (WHO, 2015).

As an occupational therapy student, I cared less about the genetics and biological diagnosis of

the disease, and more about how the disease presents itself in the everyday life of individuals. I wanted to know how individuals in Ghana experience sickle cell disease, what activities it disrupts, and what types of coping methods are currently used to manage it. I asked the patients questions about their daily tasks, social roles, psychological well-being, and overall quality of life. My ultimate goal was to determine if occupational therapy services could be used to improve the well-being and quality of life for these individuals, and how services would need to be adapted to fit the context of Ghanaian culture. I hoped my study would show the potential benefits of occupational therapy for sickle cell patients in Ghana, and that I could contribute to literature supporting the emergence of the profession into Ghana's healthcare model.

What It Means to Live with Sickle Cell Disease in Ghana

The results of my study present multiple themes. First and foremost, the study suggests individuals living with sickle cell disease in Ghana experience occupational limitations in socialization, education, taking care of the home, and engaging in the workplace. Roles affected by sickle cell disease in the study include mother, trader, cook, TV mechanic, pastor, student, and teacher. The study also suggests that a stigma regarding sickle cell disease in Ghana remains problematic to the social well-being of these individuals.

I wish I could include entire novels about each of the patients in my study, but for this article I will highlight the experiences of one individual, Abena (name changed for privacy). Abena, a forty-five year old woman, sells an array of household items in front of her home, beads sandals when sitting idle, and has a strong feminist attitude despite her soft-spoken voice.

Abena was just one of the patients who expressed not being able to pursue a degree specifically in nursing due to restrictions linked to her disease. Overall, individuals shared that pain crises contributed to major difficulties while pursuing university education. Many were encouraged by family members and healthcare practitioners to complete educational degrees that are deemed less strenuous or less challenging in order to protect the individuals' physiological and mental well-being. Pursuing such courses contrary to their ambitions, in turn, resulted in decreased job satisfaction and, in some cases, financial instability.

In Abena's case, her mother refused to allow her to attend university and become a nurse in her early twenties. Abena told me that although her grades were outstanding, her mother considered her schooling a "waste of money," after a doctor told her that Abena would die from sickle cell at age seventeen.

Every individual interviewed reported concealing the fact that he or she lived with sickle cell disease from friends and, in some cases, family, in order to avoid negative misperceptions associated with the disease. These misperceptions include being deemed as "lazy," because the disease often causes fatigue. Abena found that her social network of friends diminished as she grew older. While she remained reluctant to reveal to her friends her secret of having sickle cell, most of them accused her of being lazy and unwilling to engage in the necessary activities of everyday life that are important for maintaining relationships.

Another misperception in Ghanaian society is that sickle cell disease is associated with infidelity within the family. Because the disease is genetic and can be passed on by a carrier who doesn't display symptoms, some families misunderstand how a daughter can have the disease while the parents do not. As a result, the family sometimes believes the daughter came from another relationship, causing tensions between family members.

A third misconception is that sickle cell disease is associated with witchcraft in Ghana. Individuals living with the disease often have open wounds, such as leg ulcers, that can take multiple years to completely heal. Due to the longevity of these wounds, society sometimes believes these individuals practice witchcraft by using their leg as a surface for "cut[ting] meat." While these beliefs are lessening, they are still affecting patients in my study.

If Abena could give advice to doctors and parents of children living with sickle cell, she would tell them, "They are as the normal human beings . . . We are as the normal woman is. We can do it. We can do it. We can do it." She says, "I'm a sickle cell patient. I'm living, so why do we think we will die? We won't die." With proper medication for managing sickle cell and access to occupational therapy services, individuals like Abena may be able to fully participate in everyday life and excel in education, relationships, and employment.

Implications for Occupational Therapy

My interviews made it apparent that there was discord between patients' and practitioners' understandings of the severity of pain and patient capabilities while living with sickle cell disease. Although most practitioners were confident that the hospital's prescription and care recommendations allowed patients to live with minimal life limitations, patients described multiple limitations in everyday life, even when taking prescribed medications. Individuals also cited difficulties in consistently obtaining medication. Two female patients reported that the level of pain from sickle cell disease was worse than childbirth, a sentiment that shocked one physician at the hospital.



These are some of the few wheelchairs and adaptive devices the author saw for sale in Kumasi.

At this time, most sickle cell patients are unfamiliar with occupational therapy services in Ghana. But through my research there, I concluded that occupational therapy could provide several valuable services for individuals living with sickle cell disease. In addressing chronic pain management of sickle cell disease, occupational therapists in Ghana could play a key role in educating clients on mechanics that move the body in ways that are less likely to aggravate pain, as well as energy conservation techniques to prevent the abrupt onset of pain crises. As incorrect weight distribution linked to sickle cell-induced leg ulcers can lead to complications such as bone fractures, further injury, or permanent

deformity, occupational therapists can demonstrate body-positioning techniques for patients to prevent overcompensation.

Low-cost, low-tech, assistive technology could also support engagement in everyday life activities for individuals living with sickle cell disease. Cultural adaptations must be considered when implementing assistive technology, as some activities in Ghana are different from activities commonly practiced in the United States. Cooking in Ghana, for example, involves devices such as the *eta* and earthing bowl, which are used for mashing traditional Ghanaian dishes. The *eta* and earthing bowl would require creative adaptation, such as an adapted *eta* handle to lessen the required force for mashing the ingredients, to support engagement in cooking.

I determined that it is important that practitioners providing care for individuals with sickle cell disease are provided holistic information regarding these individuals' daily experiences with the disease and how services like occupational therapy may be beneficial. It is difficult for nursing practitioners to collect this depth of information at the second largest teaching hospital in Ghana, especially when waiting rooms are as crowded as they are at Komfo Anokye, and patients travel from so far to be treated. I hope to complete an educational handout that nursing practitioners at the hospital can refer to. The handout will have simplified, evidence-based tips on how to manage everyday pain from sickle cell disease, based on knowledge from certified occupational therapy practitioners and the insight I have gained from the patients who have shared their in-depth experiences with me through our interviews during the summer of 2017.

The Impact of Researching in Ghana

The opportunity to travel to Ghana and conduct research in occupational therapy has been a major stepping-stone in my learning experience as a student. My passion for occupational therapy is strongly linked to understanding how culture influences occupation, adaptation, and experience with disease. This spring I will complete my bachelor's degree required fieldwork with International Diagnostic Solutions, a teletherapy practice focused on ensuring accessibility to therapy services for families and children in remote areas of the world. In April of 2018, I will present my research study at the American Occupational Therapy Association (AOTA) Annual Conference in Salt Lake City, Utah, and will then head to Cape Town, South Africa, just after graduation to present my findings at the World Federation of Occupational Therapy (WFOT) Congress, 2018. Following graduation, I will return to UNH to complete my master's in occupational therapy.

Studying occupational therapy in Ghana during the summer of 2017 enhanced my interest in professionally pursuing occupational therapy in areas of the world where these services may be inaccessible. Next spring, I will complete my level two fieldwork with Utah Health and Human Rights, an organization that provides therapeutic services for survivors of severe human rights abuses in living fulfilling, dignified, and productive lives. I hope to continue researching after fieldwork, with a focus on how occupational therapy may benefit the well-being and quality of life for individuals seeking refuge and asylum from human rights abuses and political conflict. My research in Ghana has made me excited to continue conducting research and listening to the stories of as many incredible people in this world as I can.

I would like to thank Dr. Martin Agyei for mentoring me during my time in Ghana. Dr. Agyei was one of the most kindhearted, student-oriented, and supportive physicians I met in Ghana, and deserves recognition for his constant willingness to help his students succeed regardless of how much of his voluntary time and energy this required. Thank you, Dr. Lou Ann Griswold, for becoming my UNH research mentor and providing your guidance and endless knowledge throughout this process. Thank you, Dr. Gene Harkless, for connecting me with the most wonderful community in Ghana; none of this would have been possible without you. Thank you, Dr. Georgeann Murphy and Peter Akerman, for overseeing the SURF program, and thank you to the Global Education Center, the Hamel Center for Undergraduate Research, and Mr. Dana Hamel for funding my research. Lastly, thank you to the patients in my study, for the afternoons spent together and the conversations I'll never forget.

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Author and Mentor Bios

Carolyn D'Olympio's hometown is Wakefield, Massachusetts. She came to the University of New Hampshire (UNH) to study occupational therapy, with a concentration in global public health and a minor in studio art. She hopes that her research trip to Ghana was just the beginning of international work as an occupational therapist. She has been involved with student United Nations organizations throughout her undergraduate years and, in the future, she is interested in working internationally to help people who have experienced the traumas of war and displacement. In Ghana, Carolyn found the qualitative research process of in-depth, one-on-one interviews very fulfilling; she learned that "you can communicate and understand another person, regardless of language barrier, as long as you are dedicated to listening." Carolyn decided to write for *Inquiry* to educate the public about

occupational therapy and to inspire other undergraduates to undertake international research. Carolyn is a member of the University Honors and Honors in Major programs and has enrolled in the accelerated master's program in occupational therapy at UNH; she will earn her bachelor's degree in May 2018 and her master's in 2019.

Lou Ann Griswold has been at the University of New Hampshire (UNH) since 1989. Currently, she is associate professor and chairperson of the Department of Occupational Therapy. Her interests include the importance of conducting occupational therapy evaluations during naturally occurring activities. She believes that it is important to “evaluate what we are wanting to promote: doing meaningful activities,” rather than assess physical and cognitive abilities in isolation. Her collaboration with a colleague and eight occupational therapy students from UNH led to a new occupational therapy assessment tool now used worldwide. Dr. Griswold believes that student researchers need mentors who are supportive but allow students to take the lead in their research projects. Carolyn's research provides an example of allowing a student to lead the research project while complementing a faculty member's research. Carolyn learned about daily life tasks for people in Ghana and observed the challenges experienced by people living with sickle cell disease. Dr. Griswold recognizes the importance of Carolyn's work to better understand how occupational therapy can promote participation in desired activities for people in Ghana who experience a condition. Carolyn's study will help inform the profession of occupational therapy as it emerges in Ghana.

Martin Agyei is a physician specialist, dermatologist, and lecturer at Kwame Nkrumah University of Science and Technology—Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana. He specializes in skin diseases among people with diabetes and HIV. Carolyn is the second University of New Hampshire (UNH) researcher and *Inquiry* author whom he has mentored. Dr. Agyei was connected with Carolyn through his acquaintance with Dr. Harkless, who has visited KATH. Dr. Agyei was very supportive of Carolyn's research, including recruiting patients, translating interviews, and driving Carolyn to some subjects' homes. He was impressed with Carolyn's commitment to her project and recalls that Carolyn provided life-saving compassion for one patient, who felt others had given up on her. Dr. Agyei's mentorship to UNH undergraduate researchers has been invaluable.