A Neglected Disease - Sickle Cell Diagnostic Test Strip Sierra Leone
Lehigh University
Fieldwork | SicklED - Advocacy for Sickle Cell Education and Diagnosis

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Currently, 50 to 90% of children affected by sickle cell disease (SCD) in low-to-middle income countries across Sub-Saharan Africa die before the age of five years, which is due primarily to a lack of accessibility to resources such as money, laboratories, and electricity. To reduce this high child mortality rate, our team has developed a low-cost point-of-care lateral flow device to determine whether an individual has SCD, carries the trait (SCT), or is healthy.

Currently, the project is working on optimizing the device in terms of sensitivity to specificity because the long-term goal is to implement it as a standard neonatal screening procedure in Sierra Leone to ensure early diagnosis. Therefore, the team decided to focus their time in-country on two aspects of the project: social and technical.

The social aspect of the project involves understanding and identifying the current SCD and SCT screening, diagnosis, and treatment pathway from the local community's perspective. The team determined the locals' perceptions and understanding of SCD through interviews with various individuals such as workers from health care units, sickle cell advocacy groups, and individuals who suffer from the disease. By visiting local health care units and district hospitals, the team was able to talk to community health workers (CHWs), clinic workers, doctors, nurses, physician assistants, midwives, patients, and community members in rural and urban areas to gauge the community-level knowledge of SCD. Regarding the technical aspect, the team tested our device's accuracy on real SCD blood samples. A pilot test of the device was performed at the headquarters of the Sickle Cell Carers Awareness Network (SCCAN) by running our product alongside another SCD diagnostics device in the market to compare results.

This project is a part of the Global Social Impact Fellowship program at Lehigh University, which has had a partnership with World Hope International (WHI) in Sierra Leone for several years. This made the experience of navigating and expanding our project in-country easier through pre-developed connections of WHI. Also, in 2019, previous members of the team visited Sierra Leone for fieldwork and connected with sickle cell advocacy groups such as Sickle Cell Society, SCCAN, and the Sickle Smart Foundation. The team only had to reconnect with these individuals this year. These local relationships made setting up interviews and meetings much easier.

Furthermore, while in Sierra Leone, our team continued to build networks with various individuals, such as professors, healthcare workers, sickle cell advocacy groups, and patients. The team hopes to build these relationships so the project may continue to develop and grow in the future. Additionally, many hospitals and clinics were very cooperative by being flexible with appointments, which allowed a wide range of interviews with various staff members. Medical staff would sometimes demonstrate the tests they perform for suspected sickle cell disease patients and offer suggestions for other locations to visit that would benefit our research based on their knowledge and experiences.

The original plans for fieldwork included running a pilot test of the device on patient blood and conducting interviews with a variety of locals, such as those who work in healthcare, patients with SCD, or general members of the community. The pilot test was completed as planned without any adjustments, but the goals for our interviews were constantly updated as we collected new information. For example, one of the critical locations we wanted to conduct interviews at was the local government hospital because a significant number of individuals get referred here to get tested for SCD. However, this was not possible as the government official that would have allowed us to conduct interviews there had recently changed, which

made it difficult for us to meet with and gain the approval of the newly assigned government officer. Adjustments were made to learn more about the government hospital by gathering information about the facility through other people's understanding or experiences. This allowed the needed information to be collected without access to the particular establishment while being a crucial alteration to the initial strategy.

The team did not have any other fundraising efforts but Lehigh University and the Office of Creative Inquiry helped to fund numerous necessary expenses of our fieldwork in Sierra Leone such as food, transportation, lodging, and others. There will be many more opportunities to continue working on SCD in LMICs and, specifically, in Sierra Leone. Members of the team will work on the project at all times of the year, except for winter break, until the device is fully developed and ready to be implemented. The current objectives are to optimize the device, network to gain pertinent knowledge from expert sources, apply for grants, and attend conferences to bolster our work. Our project operates through Lehigh's Creative Inquiry office and, more specifically, the Global Social Impact Fellowship program, so the team will always have the opportunity to work continuously towards our project goals.

From the team's perspective, peace is a state of internal and external tranquility and relief from conflict, war, or pain. The concept of peace can be applied to a variety of circumstances and different scenarios, and therefore, it does not have a singular defined meaning.

With the development of a point-of-care diagnostics device for SCD, early screening for the disease is promoted so that individuals who test positive can seek treatment as soon as possible. Starting treatment earlier would lower the patient's chances of having extreme symptoms and ensure a more peaceful life and well-being. The symptoms of SCD, characterized by intense pain crises from the bone marrow in different parts of the body, can be extremely severe, causing sickle cell patients to be far from a state of peace. By using the device, individuals will be provided with a sense of peace and have control over their health. If individuals test positive, they will be notified of available treatment options and, when taken as early as possible, can alleviate the painful symptoms of SCD.

The venture's short-term goals are continuing to optimize the device in the lab and learning more about the perception and prevalence of the disease in Sierra Leone. During fieldwork in Sierra Leone, the team gained insight into the general public's lack of knowledge about SCD, even though the prevalence of the disease is higher there compared to other countries. Many individuals do not have a foundational understanding of SCD and some associate these patients with witchcraft and other harmful misconceptions. Our project raises awareness of the need for sickle cell education, testing, and treatment in Sierra Leone. Long-term goals include implementing the device as a standard operating procedure through the Sierra Leone Ministry of Health, which would allow sickle cell patients to live in unity and peace among their community members. The project will continue to grow and create positive change over the coming years, as the team travels to Sierra Leone in future years for fieldwork.

In Sierra Leone, the team learned that SCD is not as prioritized and focused on compared to other diseases, such as malaria, even though the prevalence is high throughout the country. This is a problem because many people experience symptoms of SCD, such as bone pain and anemia but do not associate it with the disease. Sometimes, it is also associated with witchcraft and the supernatural. People are also unaware of available medications and treatments to alleviate the painful symptoms. Many use traditional and herbal healing methods to alleviate the pain of those suffering from bone pain attacks. The team is not aiming to discourage traditional forms of medical treatment, but would like to integrate conventional and traditional medicine in Sierra Leone while tackling the misconceptions about SCD. Lastly, there is a lack of specialized clinics for sickle cell disease testing and treatment.

The project has shifted its perspectives on medicine and healthcare from a global standpoint and how it differs between various countries. The team is inspired to make a global social impact and positive changes within the healthcare systems of low and middle-income countries, specifically Sierra Leone. During fieldwork, the team conversed with several medical staff such as doctors, nurses, pharmacists, and SCD patients to learn about their perceptions of sickle cell disease and their country's healthcare system. Many interviewees stressed the need for some improvement in the healthcare system. One doctor wisely stated how, in higher-income countries, such as the U.S., resources are readily available and clinicians follow clear instructions and protocols to decide on proper diagnosis and prescriptions for treatment when practicing medicine. However, in lower-income countries, such as Sierra Leone, resources are limited and

physicians have to work with what they have currently available to treat patients and save lives, as there often are not defined protocols and guidelines for diagnosis and treatment. The goal for the test strip device is for it to be widely distributed within the Sierra Leone healthcare system to help medical staff better manage the prevalence of sickle cell disease. Overall, the team learned that not everything in life is black and white, and there are always many gray, complicated areas when trying to resolve targeted issues. From this insight, the team is motivated as a team to apply our creative minds, critical thinking, and problem-solving skills to continue to propel our project forward.

The team accomplished a lot during our trip to Sierra Leone. We learned how sickle cell disease is perceived in the country, specifically the ostracizing that patients diagnosed with SCD or SCT often experience from their communities. Patients had plenty of stories of hardship, but also hope. They didn't want their community members to struggle like they have and had plenty of tips for living healthily with SCD. Doctors and patients alike expressed interest in a rapid SCD diagnostic device like ours and increased awareness for this disease that likely kills many more than we know. This trip reaffirmed the passion of our team members to continue working hard on our project and the perfection of our device. We are excited at the opportunity to return to Sierra Leone - hopefully soon and with an optimized device.