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This summer I spent 7 weeks in Uganda spending most of my time in Kampala while also getting to travel to Eastern Uganda and Northern Uganda. My research was focused on sickle cell education programs and sickle cell clinics and the ways that education changes family health practices and improves the lives of children with sickle cell disease. I was working closely with an NGO called Sickle Cell Network Uganda (SCNU). This organization works as an outreach program traveling to schools, health centers, and communities around the country educating people on what sickle cell is and how a person gets sickle cell. In addition, they are beginning to roll out free sickle cell screening to the communities they visit. I was lucky enough to go on a few of these campaigns and be a part of screening almost 1,000 people for sickle cell. For the education classes I primarily just observed, but it was very interesting to see the education classes with nurses and med students. Many nurses, healthcare workers, or even doctors knew very little or even nothing about sickle cell. When asked “does anyone know where sickle cell comes from” or “how does a child get sickle cell disease” in a room of up to 30 health care professionals, only a couple would be able to explain the inheritance of the disease, the others were unaware. During the education sessions, the nurses were taught to recognize the first signs and symptoms of sickle cell disease. Usually at around six months old children will come in with swollen wrists or ankles and be crying in pain. This is because of the sickled nature of their cells they cells can not filter through the body effectively so blood vessels clog resulting in pain and swelling. The primary treatment for pain is to use painkillers, and there were a couple different brands and medicines used in hospitals. However, the primary obstacle is the

availability of these drugs. Hospitals may not have the necessary drugs in stock. The education classes that were made to students were slightly different. The primary objective for the education at schools was to get the students to understand where exactly sickle cell comes from, that is, how it is inherited and the importance of being screened and knowing your sickle cell status. Because sickle cell is genetic and you must receive one sickle gene from each parent, the students are encouraged to obviously know their own sickle cell status and to know the status of their future partners before they decide to get married and have children. If two sickle cell carriers are married and have children there is a chance they will produce sicklers (the common term used to describe people with sickle cell disease).

The main part of my research was interviewing families that are affected by sickle cell disease and how being educated on the disease and having resources for their sick children has changed their healthcare practices related to the disease, in addition to how it has, or has not, changed their perception of the disease. Before going to Uganda and really beginning my research, I had an idea that sickle cell may be stigmatized but I did not know if it was just regional, or country wide, and I also did not know the extent of the stigmatization. After the 21 interviews I conducted, in addition to talking with the people who work with SCNU, I can say with certainty that there is a wide spread stigmatization of sickle cell and the stigma itself is pretty severe. In regards to the stigma, I heard stories about parents who did not let their children leave the house if they had sickle cell because they were too embarrassed about the social harm it would bring to the family if others knew. Many people believe the disease is associated with demons or witchcraft and will take their children to witch doctors or religious leaders for treatment before going to a

hospital. Lastly, sometimes husbands will leave their wives if they have a child with sickle cell. The belief is that sickle cell is related to demons and men do not want their families or their bloodlines to be associated with such horrible things. I was actually surprised to hear how common it can be for husbands to leave wives. Not all husbands leave their wives, but some who do not leave still may blame the wife for the child's sickness and domestic violence can come as a result. The clinic I interviewed at had a partnership with another NGO that helped victims of domestic violence because of how many mothers would talk about their husband's abusing them. The stigmatization surrounding sickle cell is worse than I would have imagined before beginning my research, but it is a problem that can be solved through good healthcare education. The families that have accepted the fact that their children are sick and can understand that it came from both parents are much better off.

Sickle cell disease is not a very well known disease to the uneducated population of Uganda, and even the educated population does not give much thought to it. Unless a family has a known history with sickle cell (as in older family members who have the disease), when a child falls sick sickle cell is hardly the first thing that comes to mind. In the villages out east, parents did not know what to do with their kids who were crying and in pain. They would try their best to stop the pain or the crying at home because they did not have easy access to a hospital. Eventually when they noticed a pattern of sickness in the child they would bring them to the doctor and in some cases the doctors would just prescribe medicine or diagnose liver problems, malaria, or other diseases before eventually testing for sickle cell. In some cases, the doctor would test for sickle cell the first time the child was brought to a doctor. Upon finding out that their children have sickle cell disease almost

every parent was immediately terrified of the diagnosis because they thought sickle cell was a death sentence. Sometimes the nurses would even tell the parents not to bother treating the child because he/she will die soon anyway. This thought is extremely untrue. With the proper care and drugs, children with sickle cell disease can grow up to be functioning members of societies. Many parent's initial worries are about how their child will grow up, if their child will grow up, and how this disease will affect the rest of their child's life. However, once these parents receive education on sickle cell and visit clinics regularly, they begin to understand that sickle cell children can grow up relatively healthy. Some of the parents I interviewed at a clinic talked about how their children used to have to miss days or even weeks of school because of crises with sickle cell, but now that they know how to manage the sickness and have medication the children rarely miss school and if they do it would only be a day. Overall, from talking to parents at hospital clinics I have realized that wide spread education on sickle cell is very important in order to reduce the stigmata and many incorrect connotations associated with the disease. Additionally, parents knowing how to take care of their children and having support from other families in their situation drastically improves the health of the children.

Overall, I am extremely happy with my experience and the results I got. I do wish I had a little bit more time to interview more families in Kampala, but the information I got from the few families I did interview has given me good grounds to work off of. The families I met and the people I work with were all incredible. To listen to stories and see and hear first hand the difficulties of living in a developing world is something I could never have learned from a textbook. The people who work at the hospitals and at the NGO are so passionate about their works that, even though there are very little resources

available, they continue to do everything in their power to keep moving forward with what they are aiming to accomplish. The people I worked with continually thanked me for the work I was doing and for being interested in such a necessary yet under appreciated effort to raise sickle cell awareness. It felt good to know I was helping them, but these people inspired me more than they know.