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Rwanda June 2012

What I have learned based on my goals

Before leaving on the trip, my goal was to assist my group in putting together a health education pamphlet to be distributed at the community center in Rwanda. Each person in the group researched hearing loss prevention and we ended up finding and using the CDC's manual on hearing lose prevention. In this was a technique to safely clean ears, which two group members taught at the center. In addition, we found information on how to make an oral rehydration mixture to treat dehydration, which I helped to teach while at the center. From this, I learned that it is important to research and use all your resources to obtain the information you need to adequately teach new material that you are previously unfamiliar with. You do not want to teach something wrong, and so it is essential to understand your health topic before instructing others.

My goal of learning two new words in Kinyarwanda each day helped me better understand the difficult communication process involved in international health care. I struggled to remember how to pronounce the words I learned, but with practice I was able to recall them and use them appropriately. I only learned a small amount of phrases and words and so I can imagine how hard it would be to try to learn a language if I planned on staying in a foreign country for an extended period of time. Therefore, since we did not know the language, we used a translator who spoke relatively good English. This was the best method of communication and worked well. But what I have learned through this process is that although it seems using a translator is working, there is always the question of how well your statement gets translated to the other language. You will not know if the full meaning of your message gets translated accurately and so this is something that should be considered when providing health care services through a language barrier.

Another goal was to learn about cultural practices of the Rwandan citizens and observe how these influence their health care decisions. I was able to see a drastic difference between Rwandan health care and United States health care. The government in Rwanda pays for doctor visits, medicine, physical therapy, and even provides mosquito nets to citizens and requires them to be hung up. If a person buys a health card for 3,000 Rwandan francs a year, about US \$6, then they have access to this government assistance. But many people do not even have the money to afford those cards and so cannot receive medical attention. Also, when a person goes to the doctor, they line up outside and wait until they can be seen; there are no appointments. From observing the health care practices of Rwanda I have learned that you cannot travel and try to impose the American health system on other cultures. You must understand how their system works and figure out how to work within that to help people. If a clinical practice does not relate to the people culturally, they will not want to continue it once you leave. The main goal for international clinical care in developing countries is to help the citizens develop care that is sustainable; therefore it must be culturally relevant.

Another one of my goals was to make at least one adaptive device to improve an individual's quality of life. I was able to achieve this goal by creating an adapted spoon for a child who could not previously hold a spoon with her hand. Instead she would eat with her feet and had to sit outside on the ground instead of inside at the table with her fellow classmates. The spoon was adapted so that it would fit on her hand and not slide off and it had a built up handle so that she could grasp it easier. She was successful in using the spoon independently and this

will improve her quality of life since it decreases repetitive strain injury to her hip and allows her to socialize with her friends during lunch. From this experience I have learned that, like with the previous goal, it is essential to provide something that is relevant to the individual. We wanted to make a long handled shower sponge for another lady so she could bathe herself but we determined that she would not use it because she did not want to be independent in bathing; she liked relying on others. Therefore, if the device is not something a person wants or is willing to use, they will not use it and you cannot force them to. They need to understand the purpose of the device and see how it can improve their life. This is especially difficult in countries where you do not speak the language because you must rely on translators to communicate how to use the device and the importance of it.

My last goal was to keep a daily journal of my experiences, highlighting what I learned that applied to occupational therapy, and how to work with cultural differences. Although this took a lot of time each night, I find it an important part of traveling, so that I can remember my experiences later. We interviewed the directors of the community center for our needs assessment. Much of the information I tried to write down and then transfer to my journal, but there was many times when we were talking and I did not have paper to write on. Therefore I had to rely on my memory to put that information in my journal. This has taught me how important it is to document what you are doing, what you are learning, and what you could do in the future. If you don't write it down quickly you may forget important facts, and months later it will be even more difficult to remember. Therefore, if I travel on another health care trip, I will make sure to take notes even more than I did on this trip to Rwanda. It is essential to have this information for groups in the future to go to the same place, so that they have a better idea of what they can do.

Discussion of Autism in Africa

While in Gisenyi, Rwanda we got to visit the local hospital and go on a tour by the doctor. While talking to the physiotherapists, we learned that they did not know what autism is and had never heard of it. Later in the week we went on a home visit and met a 16 year old boy who had autism and was nonverbal. However, his parents did not know what autism was either and said that when taking him to the doctor, no one could figure out what he had. I found it interesting that these people we talked to did not know about this disorder, even though their son had it. It makes me wonder how prevalent autism is in Rwanda and in Africa as a whole, and how many people have heard of this disease and are educated about it. Therefore this paper will look at autism in the developing countries of Africa and why children are not receiving care.

There have not been an abundance of studies performed in Africa in regards to autism, but from the ones that have occurred, it has been established that autism does indeed exist throughout the continent. However the prevalence rate is difficult to estimate based on the limited research, and is therefore unknown (Lotter, 1979). Several studies on the incidences of autism in different African countries have found the average male-to-female ratio to be 3.8 to 1, which is about the same as the 4 to 1 ratio of Western countries (Ametepee & Chitiyo, 2009). However, the age of onset has not yet been identified in Africa; autism is typically believed to become apparent at age three in the West (Ametepee & Chitiyo, 2009).

According to the DSM-IV 2000, criteria for diagnosis of autism includes impairment of social interaction, impairments in communication abilities, restricted repetitive and stereotyped behavior patterns, and restricted interests and activities (Mubaiwa, 2008). Stereotypical behaviors, such as rocking, hand flapping, and self aggression that are common in the West, have been found to not be as common among the African samples being studied (Ametepee &

Chitiyo, 2009). Studies have demonstrated that there are more cases of non-verbal children over verbal children with autism in the samples the researchers have seen; "patients often fail to develop expressive language ability, with little or no speech at all" (Bakare & Munir, 2011).

This lack of language ability is a common trend among patients who do not see a medical doctor until later in childhood (Bakare & Munir, 2011). Without early detection and adequate educational and behavioral interventions, children may never develop language skills. Reasons for not seeking medical assistance earlier in the child's life are hypothesized in studies. One possible explanation is that there is a general lack of knowledge and awareness about autism in Africa (Bakare & Munir, 2011). Therefore, it is not known to seek help for this particular disorder because the signs are not known and recognized by the general public, or the health care practitioners do not have enough education about autism and cannot provide the necessary diagnosis and treatment (Bakare, Ebigbo, Agomoh, & Menkiti, 2008). This leads most children with autism in Africa to be misdiagnosed and not receiving appropriate interventions because of this lack of awareness of the disorder (Mubaiwa, 2008).

Spiritual beliefs of Africans regarding the causes of neuropsychiatric disorders may also deter a family from seeking western medical attention. Instead they may seek traditional healers, which will delay the process of recognition and treatment of autism (Bakare et al., 2008). Even if a family wanted to go to an orthodox medical clinic, they may not be able to afford the health care if they come from the lower class. In addition, infectious diseases that have a high mortality rate overshadow neuropsychiatric disorders and receive most of the limited resources and funding (Mubaiwa, 2008). The large burden of infectious diseases may make them become a more urgent matter to be educated about and spend money on treating rather than disorders such

as autism, that do not have the same mortality rate and are not contagious. This leads to autism not getting the same attention that other diseases receive.

Behavioral intervention is the main method of therapy for children with autism in developed countries, and hopefully can be used in some form in developing countries. It is important that a child receives some type of intervention in order for the symptoms to be controlled. Therefore, it is essential that community health workers be trained to identify and manage children with autism (Mubaiwa, 2008). Many children with autism will be completely dependent for care and only a small percent will "acquire social and occupational adaptive skills" (Mubaiwa, 2008). Without education and awareness of this disorder, children will go without the proper attention and will be even more dependent on the family than may be necessary.

Since autism has been found to be a global disease, it is important that education is brought to countries in Africa. Health workers and the general public both need an increased awareness in order to begin to recognize the cases of autism and allow the children to receive care. Also, the resources need to be available when a family does seek intervention for autism. Even if there is education and awareness but not easily accessible healthcare and treatment geared toward autism, than the problem of untreated children will continue. This is an important topic for global health workers to become familiar with and capable of teaching to others. These international health professionals can help guide the process of preparing the countries in Africa to better handle autism. It is a global issue and with further research more will be known about its prevalence and presentation in developing countries of Africa, and more can be done to provide care to the children.

Summary of my experience

On this trip to Rwanda I was one of two occupational therapy students. In addition we had a medical student, a physical therapy student, and a pharmacy student. One of my responsibilities was to write occupational therapy related questions for the needs assessment, ask the directors of the center these questions, and take notes on their answers. While we had one on one meetings with individuals at the center, I was responsible for asking them any questions that related to occupational therapy that I felt was needed. Along with the other occupational therapy student, we were solely responsible for making the adapted spoon and instructing her how to use it. All five of us helped make wheelchair cushions for multiple people at the center. This included finding the materials at the markets, taking measurements, preparing the materials, and assembling the cushions. I was one of two students who taught the teachers at the center about the oral rehydration program. This included reading and understanding the process before we got there, finding the materials at the market, and the actual demonstrated how to make the mixtures, and answered their questions.

The site for this trip, the Ubumwe Community Center in Gisenyi, Rwanda was an excellent site. The programs that are being implemented at the center are well developed and client centered. They seemed to allow each person to work on the skills that were important to them. For the adults, that included learning craft skills such as sewing, weaving, knitting, or bead making, so that these crafts can be sold. For children, there were classes for mentally challenged children, for deaf children, and also sports activities. There was a computer program and a "moving into action" program for adults to move from the center to working at a local cooperative. These programs provided people with disabilities wonderful opportunities that they

wouldn't find other places. The people we met all seemed enthusiastic about what they were making and seemed appreciative of the center. The community center's programs were geared toward making these people find meaning and accomplishment in their lives and allows them to know that just because they have a disability, it does not make them any less important than a person without a disability. I really enjoyed the community I experienced at the center; it is evident that everyone cares about each other.

I do wish that I had been further along in my program before coming on this trip. I then would have had more general knowledge of medical conditions, and ways to teach people how to modify their environment and resources, or just supply people with information from an occupational therapy standpoint. Although I have only had a full year of classes, which is half of my program, I was able to apply what I have learned to the trip, but I feel like having two full years would have been even better.

At the same time, I wouldn't discourage students with only one year of classes from going on an international health related trip. I feel like this trip was a wonderful opportunity for my education and allowed me to see how people from different disciplines approach the same situation and the same person's occupational problems. Besides allowing me to apply what I have been learning in class, this trip helped me to gain much knowledge from observing and talking with the other students. It was a great benefit to each of us that this trip was interdisciplinary; I would not have learned as much as I did if it had only been occupational therapy students.

Throughout the week we went on home visits to see the people who are not able to come to the center because of their disability. Frederick, one of the center's directors, is the person who usually does this. He goes and talks with and counsels the families. Therefore he was excited to have us come and meet the families and see what we could do to help them. But we were not given any information about the family before we got there. This made it difficult for us to know what we were supposed to be doing at the homes. We talked with the families and came up with ideas for them to manage their pain or made someone a wheelchair cushion, but we didn't have a complete understanding of what they were wanting from us. So, in the future it would be helpful for the group to first gain a better idea of what exactly the families are wanting from having the group visit them and what Frederick wants from the group. He seemed pleased with us just going and talking to the families, but I'm sure there are more things that we could have done if we would have had the time and could have met with them more than once.

Overall, going to Rwanda was one of the most enjoyable and educational international trips I have been on. I was so appreciative of the hospitality and generosity of all the people we met at the hotel and at the center. Zachary and Frederick, the two directors of the center, were always willing to answer our questions, show us around the country, and were excellent hosts. The dedication that they put into the center is very evident. I would highly recommend that this trip be continued in the future and would encourage students from any graduate health discipline to be a part of the experience.

References

- Ametepee, L. K. & Chitiyo, M. (2009). What we know about autism in Africa: A brief research synthesis. *The Journal of the International Association of Special Education, 10,* 11-13.
- Bakare, M. O., Ebigbo, P. O., Agomoh, A. O., & Menkiti, N. C. (2008). *Clinical Practice and Epidemiology in Mental Health*, *4*.
- Bakare, M. O., & Munir, K. M. (2011). Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa- a trend possibly resulting from late diagnosis and intevention. *South African Journal of Psychiatry*, 17, 118-120.
- Lotter, V. (1978). Childhood autism in Africa. *Journal of Child Psychology and Psychiatry*, 19, 231-244.
- Mubaiwa, L. (2008). Autism: Understanding basic concepts. SA Journal of Child Health, 2, 6-7.



The Umubano Hotel in Kigali that we stayed at the first night.



Our cottage at the Presbyterian Guest House that we stayed at the rest of the week in

Gisenyi.



The Ubumwe Community Center (UCC) in Gisenyi that we helped at all week.



Zachary (director of the UCC), William (med student), Cara (PT student), Elena (OT student), Frederick (director of the UCC), Kristi (OT student), and Evelyne (pharmacy student)



Crafts made by the adults at the UCC.



Seated volleyball team practicing at the UCC



Visit to a local pharmacy



Dr. Emmanual gave us a tour of the Gisenyi Hospital



OT and PT students with the Gisenyi Hospital physiotherapist



"OT" at Lake Kivu



At Lake Kivu



Buying lumber at the lumber yard for the wheelchair seat cushions



Working on the wheelchair cushions



Finished cushions



Chantal and the spoon we made for her



Learning sign language from Henry, the deaf classroom teacher, and one of his students



Teaching Clementine a hand game





Kids at the center



A few years after the genocide, violence still continued. One day Frederick was told to kill all the people on the bus he was on, but he refused and so his attackers cut off both of his hands. He recently taught himself how to paint!