Students in the Field: 
Juvenile diabetes: Understanding its impact beyond the pancreas

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Background

My name is Lawrence Yau and I am in my 5th year doing an Honours Specialization in Medical Sciences. My decision to pursue this degree was based on my interest in learning more about human diseases. Although I gained a lot of knowledge through my studies, it was a challenge to put a face on the diseases that I learned about at school. Consequently, I started volunteering at Rotoract’s Juvenile Diabetes Camp (JD Camp) three years ago. JD Camp is a weekend camp operating during the month of March and is open to both children and families affected by Type I diabetes. The camp experience offers a host of fun activities for the children and also provides many networking and educational opportunities for parents. As the food coordinator, in addition to planning and preparing meals for roughly 60 people each year, I had the opportunity to interact with both the children and their parents. Through my experiences at the camp, I gained a greater appreciation and understanding of not only the physical implications of Type I diabetes on the child but also its impact on the emotional, social, and financial well-being of the entire family. I believe that one challenge facing future medical research lies in improving the quality of life of patients afflicted with Type I diabetes and their families.

In North America, diabetes remains one of the most prevalent forms of chronic disease affecting both children and adults1. In fact, the rate of this disease is growing throughout the world, especially in impoverished countries2. Understanding how diabetes impacts individuals and families is therefore important, because there is a high probability that even those who do not suffer from the disease will eventually interact with someone who is struggling with it. What some people may not be aware of is that there are different types of diabetes. Among the most common is Type II diabetes mellitus, which is primarily caused by lifestyle factors3. As the presence of the disease often coincides with other comorbidities, many of diabetes’ symptoms are visible and apparent, which makes it easy to understand. In contrast, Type I diabetes mellitus or ‘juvenile diabetes’ is a much lesser understood form of diabetes4. However, it can be as devastating and emotionally difficult to suffer from as Type II. In fact, the emotional consequences of this disease are something that I have witnessed first-hand in the last three years, having volunteered as a camp coordinator for children with juvenile diabetes.

Like many students in the Medical Sciences program at Western, I have had the privilege of taking many different courses over the past few years, ranging from anatomy and physiology to pathology. These courses exposed me to information about a large variety of diseases and often taught me how to identify these diseases’ etiology, pathophysiology, symptoms, and treatment. Although I learned a lot from these courses, I know that my friends and I often wondered if the diseases that we studied were as simple and concise as described in class. I found it strange that we could easily recite all the statistics and mechanisms involved in a particular disease without really understanding the disease as something more than just words on a page. So naturally, I was excited when a friend told me that her club was looking for volunteers to help organize a weekend camp for kids with juvenile diabetes. I hoped that reaching out...
to these people would allow me to put a face on the disease and gain a better understanding of diabetes in a real world context.

For the past 12 years, a small group of students at Western has organized a three-day camp – known as “JD Camp” – each spring for families and children in the London area that have been affected by juvenile diabetes. The camp has two objectives: the first is to give the children the chance to enjoy the camp and make new friends who understand what they are going through. The second is to give the families the opportunity to find support and resources, and to gain valuable information from a number of guest speakers. For the past three years, I served as the food coordinator for the camp. My responsibilities included creating a diabetic-friendly menu for 80 people, securing sponsorships from local businesses, and managing a group of kitchen volunteers throughout the camp.

During my first year with JD Camp, I did not fully know what to expect. I learned from my classes that juvenile diabetes is caused by the autoimmune destruction of insulin-producing beta cells in the pancreas. Consequently, the lack of insulin leads to high amounts of glucose in the blood and urine, which results in symptoms such as frequent urination, increased thirst and hunger, and fatigue. I also knew that the most common treatment for this condition was either by insulin injections administered manually multiple times a day, or through the use of insulin pumps that can be programmed to automatically deliver insulin throughout the day. However, I quickly discovered that several of the diseases’ most significant impacts (for both the children and their parents) were still relatively unknown to me.

One of the benefits of being the food coordinator at JD Camp was that I was able to interact with both the children and their parents throughout the whole camp, which provided me with the knowledge to interpret the impact of the disease in multiple ways. What surprised me the most at the camp was how normal all the children looked, both physically and socially. Of course, there were always a few children who had some sort of learning disability or adjustment problem, but from watching them play, I would not have guessed that any of these children were suffering from a life-threatening disease. Similarly, any misconceptions that I had of diabetic children having weight problems were proven to be untrue. Unlike the people suffering from Type II diabetes, who often struggle with obesity, the children at the camp were mostly thin. In my role as the camp’s food coordinator, I discovered that the reason for this was because their diets were strictly regimented in terms of what and when they ate. For example, I would always have to keep the food labels of all the ingredients I used because every child would ask for these labels before meals. They had to know exactly how much insulin they needed after meals in order to buffer against a spike in blood sugar. By paying so much attention to their diets, these children were able to live what otherwise would be extraordinarily healthy lives. In fact, some of them could even take up varsity sports.

As the camp progressed, however, I soon realized that the children’s fit and active appearances could be deceiving. Hypoglycemia is not something that one would normally associate with juvenile diabetes, but it poses just as great a danger as hyperglycemia. Normally, when blood sugar is low, an enzyme called glucagon helps release glucose from stored reserves in the body. People suffering from juvenile diabetes do not have enough glucagon. Therefore, if low blood sugar is not treated promptly, it can quickly turn into a dangerous situation called hypoglycemic coma. Children can look perfectly normal at one moment, but can collapse in only a few minutes. To prevent such a situation, children at the camp carried purses or backpacks full of sugary snacks and drinks, and everyone at the camp was taught how to help feed the children if such a scenario arises. Luckily, nothing happened during the time that I volunteered at the camp. However, I could not imagine how stressful it would be to be constantly paying attention to what and when one ate, every single day of one’s life.

A lot of the burden of juvenile diabetes falls not on the children but on the shoulders of the parents. From the beginning of JD Camp, it was very apparent to me that the disease did not just impact the children, but also other family members as well. Whereas most of the children coming to the camp appeared lively, their parents’ faces told a different story. Their eyes looked weary, their foreheads were lined with crease marks, and they always seemed to be frowning. When I had the opportunity to talk to some of them, it was clear that the two main contributors to their stress were the financial
and psychosocial consequences of their child’s diabetes.

With respect to financial consequences, I learned that although the government would initially cover the cost of insulin pumps, this aid only supported a fraction of the subsequent costs such as syringes, testing strips, and swabs. Over time, these costs had added up and placed a lot of financial pressure on these families. This stress was further magnified by the weak economy, and as a result, many parents had to work (and still have to work) multiple jobs to support their children. Furthermore, I discovered that the psychosocial effects of juvenile diabetes were just as damaging as the financial ones. For example, simple things like eating at a restaurant became impossible because most establishments would not keep track of the amount of carbohydrates in their food. These types of limitations prevent children with juvenile diabetes from experiencing a normal family life, and therefore have a significant emotional impact on these children and their families.

I believe that as humans, we are naturally empathetic towards each other. One of the reasons that I chose to volunteer at JD Camp was because I found it disturbing that even after learning about many debilitating diseases, I did not really feel what people suffering from these diseases were going through. At JD Camp, I learned that it is hard to empathize with someone if you are only looking at numbers and statistics. It is only when you actually see how the disease impacts the person’s daily life that you start to draw connections to personal experiences or memories that you carry from your own childhood. These connections deeply humanized the disease for me because they helped build an emotional frame of reference that I could relate to. I believe that knowing how to look for connections will be very important when I become a healthcare professional, because I will want to know what my patients are truly going through so I can help lead them to a better place by delivering care that is both personable and tailored to the life that they want to live.

Finally, I contend that no significant advancement in the field of medical research can occur without an equal advancement in our understanding of a disease’s emotional impact on patients and their families. For the past few decades, healthcare professionals have been productively shifting from a purely disease-oriented model of research to a more patient-oriented model that focuses on quality of life just as much as pathophysiology. Quality of life includes the patient’s physical, mental, social, and spiritual wellbeing. To this end, my experience at JD Camp showed me that a disease like Type I diabetes could affect children and their families not just the biological level but on multiple levels. Furthermore, I discovered through this experience that many parents do not really understand or necessarily care about how many new technical features a certain medical device like an insulin pump may possess. What matters to them is whether the pump can allow their child live a normal life and participate in fulfilling activities, such as attending soccer practice or going to a friend’s birthday party. Understanding and addressing these often-complex issues, whether it is accomplished by scientists, healthcare professionals, or friends, is of the utmost importance because it is in these issues where the true human impact of the disease lies.

References


