

Meaning of Illness

When I was in the 8th grade, my family had the pleasure to host four boys from Ghana who came to the United States with the hope to continue to play soccer and also get an education. Quickly these boys became an integral part of our family and over the years I have learned so much from them. Not only about their culture in Ghana, but a lot about myself as well. It was all a huge adjustment for them to come over to the states and get situated here; and as part of that process they had to get physicals in order to be cleared to play high school sports. One of the boys, Waid, went in for his routine physical exam and the doctors found something that would, in turn, prevent him from playing soccer at the level he was expected to. He grew up playing soccer, his life revolved around soccer and he never noticed that anything was wrong; so it came to a shock to us all when we found out. The doctors had discovered a problem with his heart.

All of the sudden his life had been turned upside down. He had been told that he had to sit out the upcoming season and that he will need to get surgery to place a pacemaker on his heart. That was not anything that he was expecting to hear when he went in for that physical. It was difficult for him to sit on the sidelines while he watched his teammates play the sport he was so passionate about. However, he is not the type of person to let situations like this drag him down.

Soon after he found out he had a problem with his heart he was in and out of the doctors office, traveling three plus hours to get the best care possible. He ended up getting surgery to place the pacemaker on his heart and began the adjustment to

the way his heart was now working. He continued to have follow-up appointments and after several months he was back to being a normal teenager, with several lifestyle modifications. He had to manage his new medications and get used to exercising at a lower intensity, but nothing that stopped him from living his life. The support that he received from our school community, his soccer community, our family and other families in the area was incredible. He was able to remain involved in everything just as before and he also discovered more of his personal role in school, on the soccer team, and in the community in general.

After high school Waid went to the University of California at Santa Barbara (UCSB) with a soccer scholarship. He was able to play in many games at the highest collegiate level. Towards the end of his college career he was playing less and less, but was still a key player. Not only did he help the team out on the field, but he was also a key player for his teammates and coaches off the field. His knowledge and passion towards the game led him to be a huge role model.

Currently, Waid is working at UCSB and is still a part of the men's soccer team. He has also used his life experiences and fantastic ability to speak in public to deliver inspirational speeches around the country. Although Waid is mainly responsible for paving the path that he is on, there are many people in his life that have contributed, big or small, to where he is and how he got there.

To start, the faculty both at our high school and at UCSB was very involved in making sure that he remained caught up in school so he could graduate high school and continue on to college to remain a part of the team. They constantly checked on him throughout his recovery to make sure that he was on track. All of his doctors

were friendly and worked with him to provide him with the treatments that suited him best. His primary doctor called him frequently to check in and made sure that Waid was comfortable to call him at any time. My Aunt is also in the medical field so she helped do research and utilize her connections to find Waid the best care possible.

Before and after Waid's surgery, my role was to be a supportive sister and try and take his mind off the medical side of what was going on. He was going through a very big adjustment and a lot of change that I wanted our relationship to remain the same goofy, easygoing relationship it was before the surgery. Also, at our house, my family made sure he had what he needed for a smooth recovery. My brother, many of our friends from school, and I made sure he had all the material he needed to be able to keep up with the schoolwork from home. Many of our high school friends and Waid's soccer teammates came to visit him at the house. There was never ending support, which I believe made the healing process more comfortable for Waid, especially being in a new country far from home.

Not only did Waid have a huge support system here in the United States, he had his family back home as well. In the beginning he chose not to tell them all the details about the severity of his condition because he did not want to scare or worry his family, being so far away. Overtime, he learned more about his condition and felt more comfortable with sharing that information with his family. He has been able to go home and be with his family several times since his surgery and they now know all the details about what is going on with him.

It was very enlightening to talk to Waid about his condition and find out his perspective on it. He described his problem as a heart disease where he has a weak right ventricle that is not efficiently pumping blood through the heart and as a result his overall circulation is slow. He described this as, "lifting weights with one arm." He is not sure what caused the problem, but he said that the doctors predicted that it is a genetic family trait. They said it was something that, had it been detected earlier on, could have been improved so it was not a birth defect. Because it was not detected until he came over to the United States, he is not even sure when it started.

I then asked him to elaborate on the process he went through with the doctors to figure out what the problem was. Due to the fact that he had been playing sports at such a high level for his age, the doctors were able to notice that something was wrong. The first diagnosis he was given was that his heart was swollen. The doctors then wanted to figure out more of what was really going on, so he went in to get an MRI, CT scan, echocardiogram, and an EKG. The last thing they had him do was the Bruce Treadmill test and that is where they found that the right ventricle was weak.

As far as the severity of the disease, he said that it can only get worse, but it depends on his level of activity. This is why he had to stop playing competitive sports, especially at the elite level he was playing at. However, he still has to exercise at a designated level of intensity to keep his heart healthy. Over time his heart will get worse, and the only way to improve it is to get a heart transplant. Currently, he is not on the list.

The treatment he received for this was the placement of a pacemaker on his heart. The way he explained his pacemaker to me was that it has the ability to communicate with him what his heart is doing in any situation, whether he is sleeping, exercising, happy or sad. I was surprised to hear that even his mood influences how his heart works, and the pacemaker communicates that to him. Furthermore, the pacemaker will recall and send information to his doctor on a monthly basis. It is also responsible for waking up the heart if it is slowing down or stops. He used to take medication that would help slow the upper chamber down to match with the lower chamber so they were more in unison but he no longer takes that.

He stated that the chief problem of his condition is the fatigue. He says that the fatigue is especially bad when he is dehydrated, which subsequently causes migraines. He says that his body is working extra hard on a daily basis, so it is easy for him to get fatigued and dehydrated. To avoid his fatigue from worsening he has to replenish his body with electrolytes and make sure that he is staying hydrated. He said that his biggest fear about his illness is that there is a chance he could pass it on to his children. He says that he is not afraid of dying, but all he wants from his heart is to not pass the disease on to his children.

I concluded our interview with my own question of if he could explain what it is like when the pacemaker turns on when his heart stops. He said, "it is really scary and not fun at all." He said that the scariest part is that he is able to anticipate when it is about to happen and it is completely out of his control at that point. In his situation, "he feels his heart beats incredibly fast and then it feels like a bomb

explodes in his head and that he just got hit by a truck.” His heart then stops and he blacks out temporarily until the pacemaker kicks in and gives his heart a shock to wake it back up. He explains it that it is like your computer shutting down and then you have to reboot it. After he is woken back up he experiences pain in his muscles throughout his body and in his neck that continues for several days. Unfortunately, there is no particular time when this happens, so he is unable to know which activities to prevent. He has continued to remain active at a modified intensity level and hasn’t experienced any shocks with that.

The meaning of illness can be interpreted in many different ways. It all depends on whose perspective it is coming from and to what degree that illness has impacted them. In Waid’s case, the meaning of his illness to me has more of an emotional meaning versus a medical meaning. Waid has been such an inspiration and positive influence in my life. He is someone that I look up to as a role model. The ways in which he dealt with his disease and how I watched him go through his recovery and discovering himself has given me great appreciation of him, my family, and life in general. His story is one I will never forget, and one that I can learn from in order to become a better physical therapist.

To the doctors, Waid was not just another illness to diagnose or another surgery to perform. They went out of their way to make sure that he received the best care and communicated with one another to send him to the best surgeon. His surgeon truly cared about Waid’s recovery by constantly checking in on him, and even though he was three hours away, he would make sure that Waid could get an appointment whenever necessary.

To Waid, he does not use his illness to define himself. It is and always will be a part of him, but through his illness he has been able to find so much meaning in life and that is the true meaning of illness, being able to find your way in life without illness being a defining characteristic. He is still the same funny, hard working, and good spirited person he has always been. Although he never expected to have to stop playing soccer as soon as he did, he has still been able to find his role in life. He is able to be involved in the soccer community from a different perspective, which has let him become such a well-rounded individual. He has touched many people's lives through his inspirational speaking, his drive to help others, and his positivity in life.