

Voices of Healing

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1. “Scarred for Life” Project

Every person with an illness, like a genetic disorder, has their own story. Everyone has different experiences, ways to cope, and specific memories that they remember throughout their healthcare journey. One specific person that I will talk about is Ted Meyer. He was diagnosed with a rare genetic disorder called Gaucher’s disease when he was five years old. Ted’s parents were carriers of this disease and passed it down to two of their three boys, one being Ted. The medical school of John Hopkins states, “Gaucher disease is a rare genetic disorder passed down from parents to children (inherited). When you have Gaucher disease, you are missing an enzyme that breaks down fatty substances called lipids. Lipids start to build up in certain organs such as your spleen and liver” (The John Hopkins University, 2023, Section: What is Gaucher disease). After being diagnosed, Ted would be in and out of hospitals throughout most of his life.

Ted experienced numerous symptoms and was even misdiagnosed at first. Ted stated to the National Gaucher Foundation, “I had severe bone pain, nose bleeds, low platelet count and a very enlarged spleen. I was first misdiagnosed with leukemia because of my high white count then re-diagnosed correctly. My brother was diagnosed soon after” (National Gaucher Foundation, 2023, Answer to the first question: When were you diagnosed with Gaucher disease? Briefly describe the events leading to your diagnosis). One of the main symptoms with Gaucher’s is an enlarged spleen due to the fatty build up. Ted experienced this and said that his stomach protruded, and he bled a lot. Later, he got his spleen removed to ease the pain and reduce further complications from arising.

Art Exhibit

The first hour of my day was focused on walking through an art exhibit that Ted Meyer put together. Several walls were filled of Ted's artwork that he made of other people's scars. Next to them was also a plaque with a picture of the person, their name, and their story. Ted wanted to demonstrate his artwork and also bring awareness to different conditions. Each story is a reminder to people all around that they are not suffering from an illness alone. His artwork brings them hope. Walking through the art exhibit and hearing him tell other people's stories was inspiring. One of the stories that surprised me the most was about a woman who had one of her heart valves replaced with a pig's valve. She was diagnosed with Congas Seven, had five separate septal birth defects, and later died after an unsuccessful heart replacement. Another story that I loved was about a family and their daughter who was diagnosed with spina bifida. The parents were told that their daughter would not survive for more than a couple hours after she was born. Defying odds, their daughter survived but was born paralyzed from the waist down. She later had to get a metal rod in her back to support her spine and correct it. Now today their daughter is still alive and in school. Looking at all the paintings and stories behind each scar was truly amazing and eye opening.

Another aspect of the exhibit was a scar board. There were papers at the check in table for everyone to fill out when they came in. The paper had a picture of the human body and then a couple of lines for writing. The paper said to mark on the body where, if any, was a scar that they have and then in the lines they were asked to describe what happened. All of the pieces of paper on this board were from students and faculty at IUPUI. There were several that coincided with the drawings and stories that Ted had put up for display. It was touching to see other people's scars at IUPUI and the stories they had to go with them. I admire everyone that put a piece of paper up on the board for their strength in the tough time that they went through.

2. Life Beyond Genetic Disorders

Discussion

The second half of the evening was spent listening to Ted Meyer himself. He had a PowerPoint presentation that was full of many pictures. The pictures were of his artwork before, during, and after his hospitalizations. He told numerous stories about his own journey suffering from Gaucher's and also the stories of other people who he painted scars of. Ted Meyer is popular around the world for tremendously inspiring others through his artwork. The National Gaucher Foundation blog states, "He is a nationally recognized artist, curator, and patient advocate" (National Gaucher Foundation, 2023, first paragraph). Ted first used art to represent his pain and then he began to signify other people's pains too. Starting off the discussion, Ted mentioned how he had always been in love with art. He always brought his art supplies to the hospital to cope with the long stays and pain that he was experiencing.

At a young age Ted did not blink an eye about going to the hospital because it was normal for him. It was not until he got older that he got incredibly angry. He wanted to go hangout with his friends but had to stay in the hospital instead. During this time, his paintings showcased isolation, loneliness, and anger. A lot of them to me looked like a person cramped in a box. After another one of his hospital visits the doctors brought a medication to Ted's attention. This medication would help with the pain, but it cost a quarter of a million dollars a year. This medication was extremely expensive for Ted and his family, so he just suffered without it. After a couple years later, a painkiller medication that was paid through tax dollars came along, so Ted received this medicine and stated that it helped relieve his pain. His bones were also becoming more brittle, so he got a hip replacement. After both of those reliefs Ted felt tremendously better. He was not in a great deal of pain anymore and his art also showcased this. He started to draw

more inclusive and sensual drawings. There were more people involved, more color was popped in, and the drawings just overall looked happier. Ted continued to draw floating people; that aspect of his drawings never changed. To me his drawings looked like a couple people twisted together; they were never the normal stick figure drawings. The interesting part was how his drawings portrayed his mood and the health state that he was in. His drawings started mostly black and white, sad, and compressed but then turned inclusive, colorful, and bright.

As Ted got older, he stopped drawing for his illness and ended up doing it for fun. His go to drawing was of a person with an animal on their head, normally a cat. It was not until he went to a convention and saw a woman with a scar along her spine that his whole mindset changed. He stated she was wearing a backless shirt sitting in a wheelchair. He exclaimed how it was not normal for people to flaunt their scars and that he admired her confidence and strength. After talking with the woman, he learned that her scar was from falling off a zipline and plummeting twenty-five feet to the ground. She broke her spine and then had to get surgery. Ted talked about his most recent paintings with her, which were the people with cats on their head. She explained how she thought his artwork was pointless. The woman told Ted that he should be painting meaningful artwork to help others that are suffering from an illness just like himself. Ted took what she said to heart and became encouraged to make meaningful artwork. He even reached out to her again so that she could be his first art piece focusing on someone else's story. For this new piece of artwork, he would paint the models scar to create a mono-print directly from their body. This way he would be able to perfectly resemble and embrace their scar and story. Ted's paintings become well-known, and more people wanted him to paint their scar. That day began Ted's journey of art.

Continuing to paint people's scars, he started to add a personal twist to them to incorporate the model's story. One of the scars that he painted was of a girl who went to fourteen different hospitals before a doctor would agree to perform the surgery that she needed. Ted incorporated the number of days it took for her to get the surgery into the scar painting. I believe that it took over one-hundred days. He also incorporated other people's artwork into his presentation. He mentioned how a lot of people suffering from an illness use artwork as a coping mechanism aside from himself. An article from the American Psychiatric Association states, "... a study of cancer patients found that four hour-long guided, creative art (drawing) therapy exercises improved participants' psychological well-being by decreasing negative emotions and increasing positive emotions" (American Psychiatric Association, 2020, 3rd paragraph). Art therapy is a great distraction for people suffering from an illness. They are not stuck thinking about the pain they are in or how unhappy they may be in their situation.

3. Patient Centered Care

Research

Patient centered care not only gives the patient a voice, but it also makes them feel more comfortable and safer within the hands of healthcare professionals. One of the number one goals in healthcare is to provide patient centered care. Everything that healthcare team members do is for the patient and their own good. Healthcare professionals must respect the patients' decision no matter which answer they think is best for them. Establishing this trust and comfort between the nurse and patient allows the best quality of care to be performed. This also encourages patients to talk about important and personal information with the nurse. It can be scary going to a hospital and being asked personal questions, but it makes it a lot easier to give information if you are comfortable.

Patient centered care also increases the chance of caring for patients without risk of harm or making mistakes. An article from Regis College states, “Patient-centered care reduces unnecessary procedures, honors patient preferences, and improves patient health” (Regis College, 2023, second paragraph). Healthcare providers using patient centered care will have all their attention focused on the patient at hand. The provider will personalize the care, pay closer attention to patients’ signs and symptoms, and in hand create a more positive and welcoming environment for the patient.

Discussion

Near the end of the discussion Ted mentioned patient centered care. He mentioned how important it is and also talked about how his healthcare team positively impacted him. Ted states to the National Gaucher Foundation, “My care team right now is one hematologist and one at-home nurse who starts my IV. I used to work with a much bigger team at Cedars but they no longer take my insurance, so I had to downsize. I keep up on events and medical advances at patient meetings and online. I like the at home IV better than going into the office” (National Gaucher Foundation, 2023, Answer to third question: Please describe your care team and the impact they have on your life?). Ted stated that what made the hospital feel more home-like was how the nurses facilitated conversation with him instead of just taking care of him. Healthcare professionals have a great impact on a patients’ healthcare journey, so becoming more than just their healthcare provider is a great way to establish trust.

Many people cope with illnesses through artwork, not only through drawings and paintings, but also by making sculptures. Ted noted while talking about other people’s artwork that there was a patient who pieced together a brain and spinal cord with a spring. Her goal was to portray the confusion and loss of control she felt with all the medical information given to her

throughout her illness. Ted then mentioned that when a doctor saw this structure, he misunderstood and only focused on how the spinal cord was in the wrong spot. The structure had the spinal cord in the middle of the brain, which is anatomically incorrect. The doctor did not understand what the patient was feeling when they made the art or even why they made it. Patient centered care allows healthcare professionals to understand a situation from their patient's point of view. Focusing the providers care based upon the patients' needs allows for optimal care and plans to be put into place. In a bio about Ted it states, "Ted seeks to improve patient/physician communications and speaks about living as an artist with illness. Telling stories about his own art and the stories behind his scar art collection, he offers insight into living with pain, illness, and disfigurement" (Ted Meyer/Art Your World, 2015, second paragraph). Ted's goal while showcasing his art is to just overall spread more patient awareness.

Questions

After the discussion the floor was open for questions. The person who helped put the event together from IUPUI got on stage and even shared some information herself. She told everyone an amazing story. She is from Ireland, so when she came to the U.S.A., she had to find a new doctor. What she thought was so unique about one of the doctors was when she had to get a screening done, he showed her a compare and contrast. On one side he showed her how the screening would have been done in Ireland and then on the other was how it is done in the U.S.A. He then let her choose which approach she would prefer. She felt respected, honored, and in control of the care that she was receiving. This doctor thoroughly explained the information to her, making sure she knew the difference between both screenings, and then had her play a role in creating a care plan. Overall, as a healthcare professional the best way to build trust, rapport, and give the best care possible, all starts with caring for each patient as a unique individual.

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