

Health Narratives and Healing

By Emmanuelle Descours

When visiting a new doctor, I am often asked the question, “Do you have any previous health conditions?” As soon as this is asked, I try to think of the easiest way to answer this, but I am not able to just simply list off my injuries and surgeries. The best way to explain everything that has happened is by telling my health narrative. This story will say more about my injuries and me than I even realize I am revealing. When patients are telling their health narrative, they are able to express concerns they might not have noticed they had. In *Communicating About Health*, Athena du Pré explains, “... Since patients are often nonassertive about *expressing* these feelings, caregivers may find that narratives offer valuable insights. Subtle cues may be the only indications that a patient is dissatisfied, in despair, reluctant to cooperate, overly anxious to please, or so on” (123). Health narratives are often the key to success in medical care.

Narratives are used throughout everyday life. Susan Chase’s chapter, “Narrative Inquiry: Multiple Lenses, Approaches” in *Collecting and Interpreting Qualitative Materials* explains that a narrative “...may be (a) short topical story about a particular event and specific characters such as an encounter with a friend, boss, or doctor; (b) an extended story about a significant aspect of one’s life such as schooling, work, marriage, divorce, childbirth, an illness, a trauma, or participation in a war or social movement” (59). Narratives help a person explain things that have happened in their life while being able to put it in story form. Health narratives follow the same idea and help patients express their feelings while also informing someone about their illness. They not only help a patient explain their health situation, but also assist with the diagnosis and actual treatment of their illness. In the *Journal of Applied Communication Research*, Lynn Harter and Arthur Bochner discuss the benefits of health narratives, and the different things that narratives can make an impact on. They explain that “Healthcare providers are realizing how narrative capabilities such as imagining and plotting offer advantages in diagnostic and treatment processes, and in bearing witness to the suffering of others” (113).

Chase explains that researchers use the term “Life History” as a way to express a narrative about all, or most, of a person’s life that can be either written or oral. Some researchers prefer to use the term “Life Story” if a person is telling a birth-to-present biography. These stories do not only have to be about a person’s whole life, they can also be about a certain period of time. Chase discusses how narratives may also just be about a certain event, saying that “A life story may also revolve around an epiphanal event or a turning point in ones life” (59). These types of narratives are often used when a patient is communicating with a health caregiver and trying to express what has happened, or is happening, to their body.

Health narratives are not only formed by the person whose story is being expressed, but also by the people around them. The people that surround a person have an impact on his

or her life in different ways, and this results in an impact on a person's personal narrative. In a chapter in *Narratives, Health, and Healing: Communication Theory, Research, and Practice*, Christina Beck discusses narratives in a social aspect. She explains that health narratives cannot be constructed from just the person with the illness, but that they are relational and co-constructed with those who surround the person throughout their illness and healing. Beck goes into detail about the relational aspect of health narratives, saying, "Although healthcare narratives may stem from an individual's experience with disease or disability, the individual cannot construct the narrative in isolation; others inherently contribute to the emergent, temporal enactment of health narratives, and as such, those narratives constitute relationship constructions" (64). As a person experiences illness and treatment, she or he will have people who are constantly surrounding and caring for them. Friends and family are constantly caring and sympathizing, but do not fully understand what that person is actually going through. This can cause a negative experience at times, with patients feeling as if they are alone during their treatment; they may also have a hard time grasping that they are different from their caregivers.

The interaction between a professional healthcare giver and the patient can have a huge impact on how a person reacts to a diagnosis and handles his or her treatment. Not only does narrative medicine help patients, but it also helps physicians. Physicians must be able to listen to their patient's health narratives in order to work harder for the patient and care more for them. In the journal article, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," Rita Charon discusses health narratives and narrative medicine, and how they are influenced by the theories of biopsychosocial medicine and patient-centered medicine. These two theories help develop a better connection between the physician and the patient. Charon states, "Narrative medicine simultaneously offers physicians the means to improve the effectiveness of their work with patients, themselves, their colleagues, and the public" (1898). When physicians have both a professional relationship and a personal relationship with their patients, a positive impact is made on the treatment process and how the patient will handle the emotional aspect of what they are going through.

My health narrative is one I have told many times over and over again. It is something that has helped me heal emotionally and helped others have a better understanding of what happened to me. When a new doctor asks me to explain my medical history, I never know where to start. Sometimes not all the details are necessary, but they play a large role in my life and how I react to treatment for different things. By expressing my health narrative, I feel like the doctors understand me on a deeper level and treat me as if I'm the only patient they have, not just as another number.

It was July 5, 2002, and my father and I were on our way back from a road trip we had taken to Ohio to visit my grandparents. I was eleven at the time and I had plans to try out for a traveling softball team three days after we got home and then leave for camp the day after that. I had never experienced any medical problems before and was very healthy and active. I never thought about what it would be like to not be able to walk, and not be able to perform simple, everyday tasks. As we continued through Arkansas, an event happened that would forever change my life, both physically and emotionally.

As we made our way down highway US-71, my dad realized that a trailer was on the side of the road and part of it was parked onto the main part where we were driving. Before he had time to try and steer out of the way, our car clipped the back corner of the trailer and my side of the car was sheered off, and my seat belt ripped in half. As our car continued moving, I was trapped between the trailer and the car before I was ejected and thrown across the

highway where I eventually skidded across the pavement and landed. Our car finally came to a stop, and my dad was trapped yet perfectly safe.

While I lay on the side of the road, I was in shock. I could not feel any of my injuries and barely registered what had happened. A large group of people instantly came to my help before an ambulance arrived. I had a man on my right side holding my arm together, a woman holding my ankle with a towel, and another woman was trying to reassure me I was okay. People were off to the side praying, while another group was trying to get help. I complained about the sun being in my eyes and a man brought an umbrella over to block the sky. The ambulance could not transport me, and Life Flight was called to take me to the emergency room. The nearest children's trauma center, Le Bonheur Children's Hospital, was in Tennessee and it would be my home for the next three weeks.

I woke up in a room where doctors were trying to stabilize me and fix some of my minor injuries without surgery or extensive medical procedures. They put a tube down my nose and down into my stomach to remove blood I had from internal bleeding. As blood came up, dirt also came up with it. The doctors discovered that I had received a laceration on my liver and it was causing me to bleed internally. The next thing I knew I was in the ICU, waking up from surgery and not able to move.

As I lay there watching people walk by, completely healthy and going on with everyday life, I tried to comprehend what had happened to me. "I'm Emma. I'm eleven years old and I was on a road trip with my dad. We were in a car wreck." I repeated this to myself several times before I realized that I did not know where my dad was. I fell asleep and then woke up to him sitting next to me, trying to explain what had happened and that he was okay. This is when I learned the full extent of my injuries and why I was in so much pain. My body had suffered multiple injuries; these included my right arm, which had snapped completely in half, the right femur was broken, my left lower leg had broken and the Achilles tendon snapped, and my pelvis had completely shattered. I lost enough blood for the doctors to question how I had survived and I had deep cuts and scratches all over my body. The worst injury I suffered was one that would impact me the most: My right ankle was completely torn out while the ankle was crushed; also I had lost 16 millimeters of my leg bone.

After suffering from either a diagnosis of an illness, or some type of medical trauma, patients tend to go through different stages of identity and accepting what is happening and how their life will change. In *The Wounded Storyteller: Body, Illness, and Ethics*, Arthur Frank discusses how someone suffering from an illness accepts their new life, explaining why people should tell their narratives because of the "... need of ill people to tell their stories, in order to construct new maps and new perceptions of their relationships to the world" (31). By expressing their narratives, a person can better accept his or her new identity and have an easier time when going through the different stages.

In the chapter of *Chronic Illness: Impact and Intervention* entitled, "Management of Self: Identity Development," Ilene Lubkin and Pamela Larsen discuss the four stages of identity transformation that a person goes through when reacting to an illness. They go into detail about identity, stating, "This hierarchy of identity takes into account a reconstruction toward a desired future self, based on past and present selves, and reflects the individual's relative difficulty in achieving specific aspirations" (101).

During the first few weeks after my wreck, I went through the first stage, which is when a person has a supernormal identity. I told myself the wreck was something that would not change me and that I would be completely normal again. I refused to accept that the

injuries would have a lasting impact on my life. As I continued to recover, I would soon learn this was not the case and that my life was going to be very different.

After three weeks and 15 surgeries at Le Bonheur, I was stable enough to have an air ambulance transport me back to Houston, where I would be checked into Texas Children's Hospital for the next three months. Three days later, my parents were told that the doctors would have to amputate my right leg. It had a severe infection and the bones were so badly broken they did not think I would ever be able to walk on it again. My parents were heartbroken and did not know how to tell me the news. I did not know this was going to happen and before my parents could even tell me, a doctor who had been friends with some people my parents knew, walked in and told us he could save my leg.

The first part of my recovery process was to have a muscle flap surgery, which took 16 hours. Little did I know, Dr. Klebuc, the doctor who performed the surgery, would become someone I would develop a deep friendship with. The operation required microsurgery, and he spent hours merging different cells in my leg back together. He then took a muscle from my back and placed it in my lower leg, and ended the surgery by using a skin graft from my left thigh to cover my ankle. This surgery resulted in me not being able to move my leg for weeks, and having to wait until things had started to heal before being able to sit up properly.

After this surgery, I slowly moved into the second stage of identity transformation, "restored self", where I realized what had happened would make a large impact on my life. I knew I was different, but I felt I was the exact same person as before. "...the individual has simply assumed that there is no discontinuation with a former self" (Lubkin & Larson, 102).

As the weeks passed, I started to feel like I would never get out of the hospital. I became depressed and less motivated to do anything that would help my recovery. The doctors told me I would never walk again and if I ever did, I would have to have some sort of walker or crutches, or a walking boot on my leg. This added to my depression, and I was quickly losing my identity and did not understand why this was happening to me. Around this time, I began to enter the third stage of identity transformation, which is "contingent personal identity." When this happens, "...one defines oneself in terms of potential risk and failure, indicating the individual still had not come to terms with a future self but has begun to realize that the supernormal identity will no longer be viable" (Lubkin & Larsen 102). I knew what was happening to me, and I knew I would be different, but I still refused to think about a future where I was any different from what I was like before the wreck.

During the time I was checked into the hospital, I gained three very important friendships with my caregivers: my first nurse, Christy, my aunt Claire, and my doctor, Dr. Klebuc, all became key to my recovery and my emotional wellbeing. While I was building these relationships, I did not notice at the time that they were the ones helping me cope so much with the aftermath of the wreck. When a patient is going through trauma, she or he often has the need to express what is happening and to tell his or her health narrative. In order to share this, patients need someone to listen to them. The three relationships I gained were people who took the time to listen to me and show they cared about what I was saying. In the journal article, "Narrative Medicine: Attention, Representation, Affiliation," Rita Charon discusses patient-caregiver relationships and the type of effect they can have on the patients healthcare experience. She explains, "If the telling cannot go on without a listener, those listeners know that they become themselves implicated, traumatized in their acts of listening. This is all highly salient to the practice of medicine, so impoverished is it by its recent positivism and reductionism that it can't even hear itself think" (264). By having someone to express their

feelings and concerns about what is happening, patients can help reduce their fears about what the future holds.

My Aunt Claire stepped in to help my parents with my health. She would stay at the hospital with me every other night and took over all the medical details to relieve my mother of the stress. Claire was a producer in California and decided to retire early and travel the world. When my accident happened, she was in a small village in China and it was hard to contact her. When she found out what had happened, she immediately flew back to America to help my family and make sure I had the best care possible. Spending so much time together and having her there every step of the way meant more to me than she will ever know. In the fifth chapter of *Chronic Illness: From Experience to Policy*, Sue Estroff discusses health narratives in her work titled, "Whose Story Is It Anyway? Authority, Voice and Responsibility in Narratives of Chronic Illness." She explains, "When we engage in producing knowledge about persons with chronic illness, first and foremost we enter into a relationship with a person who may be vulnerable, impaired, pained, and lonely" (96). Claire not only helped save my physical self, but she also saved me emotionally. As I would go through physical therapy, surgeries, and random procedures, she was always there and kept everything organized. Without her, I would not be the person I am today.

The first nurse I had after arriving at Texas Children's Hospital, Christy, quickly became my motivator and friend. Whenever she worked, she was scheduled to be my nurse and our friendship resulted in an article written about us in a magazine produced by the hospital. She knew how to make me feel better, and she would always encourage me to do what the doctors said. She motivated me to work hard and to prove my doctors wrong and show them I would walk again. With Christy by my side, my time at TCH was much more enjoyable, and I became more cooperative with my doctors about the treatments they wanted me to do.

I eventually checked out of Texas Children's, and checked into Texas Orthopedic Hospital, where I would begin the process of actually healing my leg bone and get on the road to walking again. Dr. Gugenheim was my orthopedic surgeon and became the second most important doctor in my life. He was able to ensure that my leg healed and begin the second part of saving my leg. He performed a seven-hour surgery that helped re-align my bone and put an Ilizarov on my leg. When I woke up after my surgery, I refused to look at what had been put on my body. I made my family always keep a blanket over it, and I did not want to talk or hear about it. I was avoiding reality, and slowly, I had to accept what was happening. This was a set back in my identity transformation, and I was beginning to deny what was happening to me again. Lubkin and Larsen explain that people have to be willing to change, which I did not want to do. They state, "The willingness to change to different and unknown norms is just a first step, one that often takes courage and time" (101).

An Ilizarov is an external fixator that has metal, halo rings surrounding the limb it is attached to, with pins going through the bone. They are mostly used for bone lengthening on those who were born with short limbs, and it will have about 4 rings and 8 pins going through the bone, and on average will stay on a person for six to eight months. This was used on my leg to re-grow the bone I was missing and also to help fight the infection my body was trying to fight. The Ilizarov on my leg had six rings and 24 pins going through my bone. Attached to the Ilizarov are little screws that are turned once a day and only move 1 mm each time. I lived with this contraption on my leg for 16 months.

When the Ilizarov was finally removed from my leg, I felt like a whole new person. I became happier and began to feel a little bit more normal. I started to enter the fourth stage of my identity transformation, which is the stage of Salvaged Self. This is when "...the individual attempts to define the self as worthwhile, despite recognizing that present circumstances invalidate any previous identity" (Lubkin & Larsen 102). I still had severe pain every time I moved, and my scars were still fresh, but this is when I made the decision to prove everyone wrong. My friends and family would encourage me to try and walk again, but they would still remind me not to get my hopes up. I was in physical therapy every day, getting frustrated that patients all around me were making progress, yet I couldn't seem to take one step without the aid of a walker or crutches.

This continued for another few months, when one day I finally took my first steps. I was in the bathroom at school and had put my crutches against the wall. I was washing my hands when I realized I was standing by the sink and my crutches were still on the other side of room. I had taken my first three steps without even realizing it. I looked around for someone to share this moment with, but no one was there to share my excitement. I grabbed my crutches and walked outside the bathroom, where my best friend had been waiting for me. She stood up when she noticed I was holding my crutches, not using them. She started to jump up and down and we hugged until we remembered we were late for class. This moment marked the first day of the rest of my life, and I thought that maybe my dream of proving everyone wrong would come true.

After I took my first steps, it was just a matter of time before I was walking on my own again. It was painful, but the fact that I was able to move on my own was the best feeling in the world. I continued physical therapy to help reduce the limp I was walking with and to strengthen my body. As this continued, I moved into the reconstructive and plastic surgery stage of my healing process.

My leg was left with severe scars that prevented me from going in public most of the time. I was embarrassed and people would often point and stare, which resulted in me being ashamed of my leg, instead of proud that I still had it. Many adolescents who go through medical trauma and are left with physical scars are self-conscious. Many people do not realize that although someone is healed, the psychiatric part of the trauma has a lasting affect. In the article, "Incidence of Long-term Psychiatric Complications in Severely Burned Adults," the authors discuss the emotional toll that burn patients have. They explain, "Several recent studies of long-term psychiatric sequelae in the pediatric group suggest that both children and their parents have significant and often severe adjustment problems" (Andreasen, Norris & Hartford 785). The doctor who had done the original microsurgery and muscle flap began a series of reconstructive plastic surgeries that would span over the next 8 years.

Dr. Klebuc performed 10 surgeries on my leg to help it return to as normal a state as possible. My lower right leg had scars that ranged from my ankle to just below the knee. My lower leg was also shaped differently than my left leg, which was a result of the muscle flap. These surgeries were painful and took up much of my time, but I felt each of them was worth it if I could have a normal ankle again one day.

The second to last surgery that was performed on my leg was the most painful procedure I experienced out of everything done to me after the wreck. My doctor inserted two skin expanders into my leg where my skin did not have any scars on it. Two small pouches were placed right under my skin, along with a small port to put saline into it. Every Monday, for seven weeks, I went to the doctor, and he would add one syringe full of saline into each

expander. These eventually expanded my skin enough so that he could use the skin to cover some of the scars on my ankle. This surgery was one of the most time consuming and painful experiences I had after the wreck, but it was also one of the most rewarding. After this procedure, I could finally see a difference in my ankle and I noticed that all the hard work I had been putting into getting back to normal was starting to pay off.

Between meeting Dr. Klebuc for the first time and the final reconstructive surgery he performed on me, we gained a friendship that was unlike any other. He was a doctor who constantly made sure I understood what was going on and that I was okay with it. Rita Charon's book *Narrative Medicine: Honoring The Stories of Illness* discusses narrative competence, and the impact it has between a patient and physician. Charon explains, "By developing narrative competence, we have argued, healthcare professionals can become more attentive to patients, more attuned to patients' experiences, more reflective in their own practice, and more accurate in interpreting the stories patients tell of illness" (107). When Dr. Klebuc would make his rotations in the hospital and came to see me, I did not dread it like I did the other doctors. He understood what I was feeling and would take as much time as necessary out of his busy schedule to make sure I was healing properly and feeling better.

As I grew older, he asked about my social life and anything new that was happening, and he would tell me about his son who had been born about three years after my wreck. When I would go to homecoming, prom, or any other big event in my life, my mom and I would send him pictures and show him that I was starting to live a normal teenage life, all because of him. Dr. Klebuc was, and still is, my hero. He not only saved my leg, he also saved my life. While I was doubting myself, about whether or not I would walk again, he was constantly encouraging me.

Looking back on my wreck, the experience after it, and how I am today, I can now say I am very proud of myself. Without the wreck, my life would be completely different. Although my family and I have suffered greatly from it, I do not resent that it happened. I was very close-minded before the wreck, and I did not think anything existed outside of my own life. I constantly took the smallest things for granted, including being able to walk and run. My life has been very different than most of what my friends have experienced. My childhood and teenage years were deprived and full of surgeries and recoveries, and I have had a hard time dealing with that. I was in therapy for years, coping with Post Traumatic Stress Disorder and depression.

My new self was one that I was not used to. The fact that I was now classified as being "disabled" haunted my thoughts at all times. I was racked with nightmares from the wreck, which prevented me from moving on with my life. Going on a short car ride would trigger my PTSD and I felt like I would never move past what had happened. At this point, my aunt suggested to me that I keep a journal. This journal soon became a lifesaver. I wrote in it throughout the day and explained how I was feeling, without being ashamed or embarrassed. I was able to write about what was happening without getting frustrated that people were trying to sympathize with me when they had no clue what I was going through. In *Making Stories: Law, Literature, Life*, Jerome Bruner talks about the impact that telling stories and narratives have on a person. He discusses how narratives help the person who is telling the story adjust to what is happening in his or her life. When people tell their narratives, they are adjusting to their new lives, "...narrative gives us a ready and supple means for dealing with the uncertain outcomes of our plans and anticipations" (28).

Health narratives are not only helpful to others, but they also help the person telling the narrative process what is happening. A narrative has no rules governing what it is supposed to be about or how it has to be told; a narrative is not meant to make a person feel worse. The person who is telling the narrative will often not even realize that by expressing what is happening, she or he is not only helping others understand her experience and what her body is going through, but she is also helping herself understand what is truly happening.

Emmanuelle Descours recently completed her Master's degree at the University of Houston where she focused her research on the communicative strategies physicians use to promote Patient-Centered Care. She hopes to get her PhD and continue this research with the goal of training healthcare providers to communicate more effectively with patients.

© 2015 *Intima: A Journal of Narrative Medicine*