

Between two stories: building an identity as a chronic cancer patient

Falling ill changes one's personal identity. The hopes and dreams need to be reconsidered. It changes the course of life entirely. An autobiographical break comes to be, followed by a challenge; the story that previously had been guiding life has to be re-evaluated, and a new story created.

I got diagnosed two years ago. Before this, my blood values had fluctuated for a few years. To be honest, I had already diagnosed my own illness before the doctors, based on my blood values. I knew my illness couldn't be cured. My attending doctor wanted me to get a bone marrow biopsy. I was afraid of painful tests and treatment. I switched over to another doctor. Due to strong headaches I got sent to a neurologist. At the end of the appointment I mentioned my blood values. I was sent into a hospital for tests.

Stories tell of real life, but they also create realities that people pursue. As one of the pioneers of the cognitive psychology, Jerome Bruner said: *Narrative imitates life, life imitates narrative*. Narratives about survival under extreme circumstances have always enthralled people. Survival in the face of adversity is present in myths and stories that tell of a great hero who pulls through hardships. A similar pattern repeats itself in these stories. The story has a hero, who has a task. Something or someone is stopping the hero from accomplishing this task, but the hero fights and pulls through these hardships.

The opposite of this heroic story is tragedy. In a tragedy the hero can't accomplish the task. The hero suffers. In the worst case, the hero dies.

Cancer has a similar story; either you beat it or die because of it. Due to this I was afraid. Suddenly I understood I could die of this illness. I lay awake in bed at night, and in the daytime I searched the internet for information about the illnesses the doctors said I had.

I will remember getting my first diagnosis for the rest of my life. The day before, I said to my husband, analytically and calmly; if I have a mutation, that's it. When the doctor told me I had a mutation, I almost fainted and threw up. I cried in the examinations, I don't want to die, I'm a mother. The final diagnosis was a relief; I got the best possible outcome from the three possible illnesses (which happened to be the very same illness that I had diagnosed myself a few years before). The doctor said that she had never seen anyone as happy about getting diagnosed with a chronic cancer, as I was.

After the diagnosis, I looked in the mirror and saw a person, who was so similar to the person she was a few months ago, but so different. I remember one specific morning. I watched the blood vessels in my hands and greeted the mutation that they carried. I understood that we were going to be together for the rest of our days.

There are four types of stories in the western culture: Heroic story, tragedy, irony and comedy. A person's life varies depending on what type of story he or she is making of it. Illnesses usually bring up one of two types of stories; the heroic story, or the tragedy. In a heroic cancer story, the hero faces his or her enemy, goes through the exhausting treatments and defeats the illness. These are the kinds of stories on newspapers: a brave woman beat cancer! The tragedy is also known to us: a person falls ill of cancer, fights, but doesn't make it, instead dying of the illness. With a chronic illness neither of these outcomes happens. The person waits for the battle to begin and when it does, it can only end up in defeat, as the illness never heals.

With a chronic cancer, creating a story is difficult as long as its metastories are linked only to surviving the illness or dying of it. If stories really imitated life and life imitated a story, then stories about living with a chronic cancer should be created alongside the heroics and tragedies. Narrative research on illness has noticed, that chronically ill people seek the role of a hero despite being ill. They want to be the heroes of their own lives. The problem with cancer is that the heroes of these stories are mainly thought to be the doctors that struggle to find new medicines with which to ease the lives of the patient. The patient is an object who gives in to medical treatments and just hopes for the best.

It takes time to adjust to knowledge that one is ill. The illness has shattered one's identity. Many factors influence the development of a new identity. Some of them prevent, and some support the development of a new heroic story.

The people around the ill person have a big impact on what possibilities are given to him/her. My own personal health is good, but not without its flaws. I have told about my illness and found my role in a new situation. As the metastories concerning cancer are usually linked to either being heroic or tragic, other people's reactions to my disease have varied between the two. It influences my role. From time to time my superiors offer me a sick leave, yet want me to play the role of a healthy person. My colleagues tell me about their own illnesses a lot more than before. After the initial interest no one asks or wants to hear how I'm doing. I've become an expert on experiencing cancer. I listen and assess the situation of others, but I don't talk about my own situation, because no one wants to listen to the chattering of a chronic. I think this is tragic, but I can't help it.

There are some things you can make a difference in. I decided in the beginning of my illness that I would actively take part in decisions regarding my illness. I'm going to find out about things and I will read all the newest findings and take part in decisions about my treatment. I'll make decisions about my work that support my coping. I've negotiated with my doctors and superiors. I've argued and justified my point. The doctors think these arrangements are an exception. I've questioned the need for a sick leave when I won't get well. The idea of a sick leave is that during the sick leave the person gets well so he can come back to work. Sick leaves won't take away my illness, so I have to create circumstances in which I can work effectively. I have planned these circumstances. In this way, I could be considered the hero of my own life. I have kept my expert's identity despite the illness.

I hope for improvement for myself and other chronically ill people. I justify my argument not only with empathy from my own experience, but also with economic reasons. If the treatments get better, chronically ill people's life expectancy will rise. If chronically ill people are seen only as ill, their expertise will remain unseen and unused. We are not only experts in our own diseases, but also experts in our own field. Despite our illnesses, we can still contribute to the growth in our own societies.

I started following the blog of chronically ill "Goldfish" in the beginning of the year. His situation is very different from mine. For years he had gone through rough cancer treatments. His expertise hasn't gone anywhere; he's simply making diverse and analytical observations about his own situation but also about the surrounding world. With his own performance he is providing the discussion with the expertise of his own area. Is this level of know-how recognized well enough? I don't think so. However, it is necessary to recognize this level of expertise so that people who have been chronically ill for years could participate in building our community. We should create stories and information about how being chronically ill does not strip the ability of an individual to make a difference.

Many cancers can be treated and handled nowadays, so it would be only fair to see cancer itself in a different way. In other cases it would be very costly to us to have chronic cancer patients just waiting for death without doing anything. I doubt this is what tax payers and especially the chronically ill people themselves would want - I definitely wouldn't.