

Somehow, somewhere

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Somehow, somewhere it occurred to *somebody* that there was a little bit more to illness, disease and the suffering that goes along with it.

Even though we can try and trace back to when and who was the first person to document such insight into this matter, and look at disease itself like a narrative, frankly, I don't think that is the point. At the end of the day, what is important, is that each and every one of us as future healthcare professionals, learn this point of view, and feel it. Moreover, with this feeling, this new understanding, and the passion mixed with a little bit of love that we have for medicine - we go and use it, that we can apply it to our future, and the care and service that we will one day assume and provide. At the same time, how is it possible to take this and teach it to someone? Is it truly something that can be taught? At least for me, the 'student' has to be somewhat intrigued due to the fact that listening, observing, and reading, among other things are required to actively learn, in order to be able to take on this not only comprehensive but also complex point of view; that disease can be transformed into a narrative; not only transformed, **but that in all of its entirety it has and always will be one.**

If we take the word narrative and simplify it into, what some can understand it to mean, a story -maybe the ability to transmit this to those around us would be that much easier. I mention this, taking into account, my difficulty with understanding what the word narrative really meant and how to apply it. The first thing I did, was look up the definitions of these terms on Wikipedia, to be able to identify that what my intuition was telling me these terms

meant- actually applied when taken into reality, and society all around.

*"A **disease** is a particular abnormal condition, a disorder of a structure or function that affects part or all of an organism." "A **narrative** a spoken or written account of connected events; a story."*
*"A **narrative medicine** is a medical approach that utilizes people's narratives in clinical practice, research, and education as a way to promote healing."*

Of course, if we take a look at disease and illness as a story, it wouldn't be that much farther of a leap to take a look at why our lives as a whole are just that; a really, really long story that everyone out there has. Some like to think that we can attach our stories to others. Maybe some think that others have some influence on what we theoretically write down on our pages, and yes it is true that others may guide us, they may accompany us, or hold our hands and support, teach and love us along the way; however, up until this point in time, what stands true before all of us, is that each individual has their own pen.

So narrative medicine helps us to be able to understand this, to see on paper or hear in the voice of others as they tell their personal stories - that unfortunately, involve some type of disease. If we take the time to recognize this, we can place the value and significance an illness/disease may take in someone's book of life. Here we can come to reaffirm that the similarities are present - a story has a beginning, middle and end, and whether it's a not so happy ending or not, disease usually does too.

I would like to take a moment to tell my story, my personal experience that is engraved in the pages of my book. The illnesses

and diseases that have marked me as a person, and have helped to shape who I am today. Usually, my telling of the story goes a little something like this; Hi, my name is Danielle Marina Narvaez. I've had asthma since I was a little girl; I mean I was born with it I suppose. My grandfather, father and brother all three also suffer from asthma, but have not really had it as bad as me. I had my first attack when I was a year old. I don't really remember, but they tell me that I had upper respiratory infections, that I suffered a lot from attacks, and so at 6 years old, in between the doctors, my mother, my grandpa, they removed my tonsils and adenoids. Here I have a brief glimpse of memory, that I don't know if is actually real, or if it is something my subconscious came up with along the way because I heard it over and over again told as so - apparently I was allowed to eat tons of ice cream and jello afterwards, at any time during the day.

From there on out, like I said, I don't really remember, but my mom says that this is when it all started going downhill. My asthma actually started getting worse after the surgery. I think for anybody with a little bit of knowledge in regards to medications for asthma, can understand that at this point I was being treated with oral medications for allergies and asthma, as well as used preventative inhalers on a daily basis.

The next thing I know, I am maybe around ten or eleven years old, in the doctor's office, more often. I can remember some visits, but not in full - just glimpses. However, I have read some of my clinical progress notes from that time frame, and something that stayed with me was a description that my childhood pulmonologist wrote and quoted from my young self; "I just can't breathe", while crying. I can imagine my little self, suffering from this, and just wanting to be okay. To breathe normally.

After a little bit, I fell into a couple of years of a really severe stage of my asthma. I was controlled orally with steroids, specifically prednisone... and not just your simple 5 day bursts, but I was treated with it as the only thing that would control my condition for this time frame of 2-3 years. Of course, the doctors switched around with different drugs, orally and all the inhalers. I even at one point was taking theophylline, what to me has been referred to as an old drug, used as last resort. They tried everything, looked for everything, but nothing would control my asthma, and therefore at the end of every weaning process - I would end up in the hospital.

When I say that for a long period of time I was hospitalized, due to my asthma exacerbations - I'm not exaggerating. Somewhere along the way a Doctor told me that I had been hospitalized (not just emergency room visits, lengthy, extensive days on end visits) over 22 times in one same year. With many of those being in the ICU. I practically lived there. But when I was healthy, my life continued, I was the happiest and most smiley girl around. I take it as, well when I'm sick I am sick, and when I am not, I am not. It didn't have too much effect on my social development, but at one point it did affect me academically. The end of this period of time in my own head leads up to a point in time when, after months of trying to convince us, to try a new once monthly injection for asthma treatment called Xolair, we did so.

I remember the day they took me to the allergist and he applied the drug. Beforehand, they nebulized me and I was on prednisone at the time. The injection was given, I was observed and they sent me to my house. That being done, everyone was satisfied. However, 15 minutes away from the clinic where it was performed, while crossing a famous bridge in Florida, USA - Th Skyway, I had an anaphylactic reaction. My throat closed up but it was different,

and to my mother all I said was, Yaya, I can't breathe - I don't know what it is. She took one look at me, and thank the Lord we had an 'epi-pen' on hand for this, and she basically slammed the pen into my thigh. I remember she called 911, I had started to cry. They sent an ambulance, and I don't even know what else. As a result I was hospitalized in ICU, and I remember them explaining to my 12/13 year old self that the bag around my heart was inflamed.

Since then, actually since I was 10 years old I have suffered through many ailments -Kidney stones, PUD with ulcers, iron-deficiency anemia, nasal polyps, ruptured/bleeding ovarian cyst without surgical intervention. They had diagnosed me with a slight level of osteopenia, result of the therapy with the corticosteroids.

In second and third semester I suffered from countless kidney stones. Last December, 2016, I had an operation for the removal of a kidney stone. Just last week I came out of one of my many crisis because of catching the cold/flu.

On top of it all, I'm the girl that hiccups in class. Not a day goes by without a hiccup.

All these things, I have learned to live with, and live by. They do not define me as a person, do not make me any weaker, and I give thanks to God that they have solutions, and it's not any worse.

I guess, the shorter version would be like; Hi, I am Danielle Marina Narvaez. I used to be a red-alert, steroid dependent asthmatic. I suffer from repetitive kidney stones. I have a lot of other things in my medical history too. But, **that's only one part of my story...** and all of that history is part of who I am today.

So.

Somehow, somewhere it occurred to *me* that there was a little bite more to illness, disease and the suffering that goes along with it.