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Abstract

People experience trauma in many ways. Discussing the trauma in the form of illness narratives can be beneficial, not only to the patient, but for their families as well (Hydén, 1997). Illness narratives are becoming more popular in the medical field, but mostly are written from the perspective of the patient and their spouse. Little is written from the perspective of the children. In this article, my immediate family and I write our narratives detailing the experience of my father's cancer. Major themes that emerged from our stories are disbelief, unreliable memories, wanting to forge ahead, and a stronger family. Although we experienced the same event, our narratives differ. By sharing our perspectives, we were able to further heal. Illness narratives can be therapeutic but should be critically examined, as memories are not always trustworthy.

Keywords

Qualitative Research, Illness Narrative, Narrative, Case Study

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Surviving: One Family's Experience with Cancer

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People experience trauma in many ways. Discussing the trauma in the form of illness narratives can be beneficial, not only to the patient, but for their families as well (Hydén, 1997). Illness narratives are becoming more popular in the medical field, but mostly are written from the perspective of the patient and their spouse. Little is written from the perspective of the children. In this article, my immediate family and I write our narratives detailing the experience of my father's cancer. Major themes that emerged from our stories are disbelief, unreliable memories, wanting to forge ahead, and a stronger family. Although we experienced the same event, our narratives differ. By sharing our perspectives, we were able to further heal. Illness narratives can be therapeutic but should be critically examined, as memories are not always trustworthy. Keywords: Qualitative Research, Illness Narrative, Narrative, Case Study

Introduction

On the eve of my 16th birthday, my father was diagnosed with cancer. He had a tumor in his nose that had been growing for some time. He waited until after my Sweet Sixteen party to have the tumor excavated. He went through radiation to treat the cancer, and had his nose completely removed. A new nose was built, but collapsed due to the radiation, and my father got a third nose. Skin was stretched from his forehead to cover the nose. Cartilage was taken from his ear and bone from his rib to remake a nose. He endured surgery after surgery, procedure after procedure, to repair his face. Though he still has the scars from his many surgeries, he was declared cancer-free in 2003 and has been a cancer-survivor ever since. The ordeal affected us all and changed our perspectives on life and of each other.

Literatures Informing the Inquiry

Storytelling about events is common among humans (Salander, 2002). This human activity intensifies when we experience something dramatic, like an illness. Facing an illness, especially a potentially fatal one, leads to an emotional experience that is potentially life-changing (Anderson & Martin, 2009). Illness narratives are becoming more popular as doctors are focusing on the patient's journey through their illness, instead on just the diagnosis itself. Most researchers define a narrative as something with a beginning, middle, and end and is unique from discourse (Hydén, 1997, p. 50). Illness narratives are powerful, as they can be utilized to study not only medicine, but the experience of the illness and "its social and cultural underpinnings" (p. 48). Through illness narratives, patients "give voice to suffering in a way that lies outside the domain of the biomedical voice" and "discover new ways to talk about" and deal with the illness and themselves as cancer patients (Geist & Dreyer, 1993, as cited in Anderson & Martin, 2009, p. 134; Hydén, 1997, p. 49). Narratives can also be utilized to show how a shared experience or understanding can alter the interpretation of an experience (Garro, 1994, p. 775).

Patients feel more empowered and can heal through the act of writing an illness narrative (Anderson & Martin, 2009; Hydén, 1997). Illness narratives are conceived around what the narrator judges to be worth writing about (Garro, 1994, p. 785). Sufferers appreciate

the control, and can find writing about the experience soothing. These narratives give sufferers a way to explain the experience in their own words (Hydén, 1997, p. 51). This can be powerful, especially at a time when patients and their families feel powerless. However, most illness narratives are written from the perspective of the patient and their spouse. There is little written from an immediate family perspective, including children. In this study, I sought to explain my family's experience with my father's illness, and fill the gap by providing perspectives from his children.

Background Information Pertinent to the Study

My father, mother, younger sister, and I participated in this study. I asked each of them to write a narrative describing their experience with my father's cancer. I encouraged each to write anything they remembered, starting with my father's misdiagnosis and ending with him being cancer-free. I also asked them to include their opinion of how his cancer has changed or affected our family, and how we dealt with the illness.

Methodology

Research Question

I was interested in our stories of this event. The research questions guiding my inquiry were:

1. How did we each view the experience?
2. In what ways would our stories be different?

Though we all experienced the same phenomenon, we may have viewed it differently, thus having unique stories of the event. In order to answer the research questions, the most appropriate theoretical foundation for the inquiry was a phenomenological case study. A phenomenological study examines participants' shared experiences of a certain event, or phenomenon (Patton, 2002). A case study allows researchers to examine occurrences in a bounded system (Patton, 2002). I decided to have us each create a narrative of our perspective of my father's illness, since "we construct and portray our understanding of self through our narratives" (Rodriguez, 2002). Together, our narratives would tell differing sides of one event, showcasing all we went through and what we eventually overcame.

Data for the Inquiry

Data for the inquiry were the narratives from my parents, my sister, and me detailing our account of my father's illness. I obtained verbal permission from each of them to include and analyze their words as part of my study. No IRB was necessary due to the context of my study. Confidentiality and privacy are difficult to assure as I am a member of the study as well as the author. By publishing this piece, I make it known that my family experienced this trauma and these are our narratives. I explained this to my family and they agreed to participate, knowing their confidentiality and privacy would be compromised.

Getting Family On Board

My father was, at first, reluctant to participate. "These aren't pleasant memories," he told me. "I understand," I replied, because I did understand. I, too, was nervous about reliving

these events, and hesitant to ask my family to do the same. We tend to shy away from painful experiences, not bring them back up voluntarily. “I think, though, this would be a really good experience for us all. Yours is a unique voice, as you actually experienced the illness. You don’t have to participate if you don’t want to, and you can choose to not participate at any time.” “Do you need me?” “I don’t need you, but you have a unique voice, and I think the story would be better with you included.” He finally agreed, saying he was doing this for me. In the end, though, I think it served us all.

My mother, on the other hand, was much more willing to participate. “I think this is a *great* idea, honey. Tell me what you need.” She was eager to tell her story and interested to read our interpretations. “Send me what you write as soon as you’re done!” She could not wait to delve back into this experience. I wonder why this is. Why was she so willing and eager, while my father was reluctant? Was it because the illness happened to him? Did he somehow feel weak from the experience, and did not want to appear this way to others, especially his family? Anderson and Martin (2009) argue cancer survivors often feel their identity is too tied into their illness, and they become stigmatized by non-survivors. Perhaps this is a reason for his unwillingness. My mother has always been a more emotional person than my father, and always more willing to share thoughts and feelings. I attribute this partly to societal roles and their upbringing, but I wonder if more is underneath.

My sister was more willing than our father, but not quite as enthusiastic as Mom. She was more worried about her ability to recall the information. “Honestly J, I blocked out most of it. I was so young, too. I don’t remember much.” “That’s ok. Whatever you remember would be great. You have a voice in this story too, and I think it’s important to hear it. *Whatever* you can write will be useful.” She took the longest to write. She put it off for weeks, blaming work and lack of time. “I’m gathering my thoughts. I want to make sure I get it right.” “It doesn’t have to be right. It’s *your* story. Whatever you write will be right” I reassured her.

Once they all agreed, I sent an email with directions. I asked them to write their stories of Dad’s cancer. For my parents, I asked them to start with his initial misdiagnosis, detail the discovery of the cancer and his treatment up to the declaration he was cancer free. Since my sister and I remember little of Dad’s misdiagnosis, I asked her to start with what she remembered, and tell her story up to the same ending. I did the same. My father finished first, sending his narrative to everyone. I was worried this would affect everyone’s version of their narrative, but my mom and sister did not read his until they had finished theirs, to “make sure I write what I remember,” as my sister put it.

I employed constant comparative analysis techniques to analyze our narratives and search for themes (Glaser & Strauss, 1967; Stake, 2005). In constant comparative analysis, the researcher reads through all the data and chunks data that are similar. Then each chunk is labeled and compared with other chunks that emerged. These labels are grouped and a theme or idea is identified. I contemplated separating the words into chunks and describing each portion, but decided against it. Our stories are more powerful read as a whole. Through them, you understand our experience with cancer and how we dealt with it.

Our Stories: In Our Own Words

The following are the narratives as they were sent to me. I edited them only for grammatical and spelling reasons.

Dad: I Felt Like I Was Doing Pretty Well.

At the age of 41 I felt like I was doing pretty well. After-all, my dad had passed away at the age of 40 from a massive heart attack and I thought, every day I spent above ground that exceeded his short stay on the planet was a bonus!

To this point, I had worked hard to build a successful career as an executive in a hotel management company, had 2 beautiful daughters and a loving wife, great life-long friends and our future looked as bright as ever.

I was in pretty good shape physically and had never really had any major medical problems to be concerned with except this annoying issue that had developed where there was an unsightly bump that centered itself right on the bridge of my nose. Now mind you, I had always enjoyed more than my fair share of good natured ribbing from those that knew me regarding the excessive "prominence" of my schnoz. I thought it more of a proud badge of honor and heritage, since large noses seemed to be a hallmark handed down from my grandfather whom I loved and was very close to.

While I was content with simply letting the ominous bump be, I got my first inkling that something was amiss when I went to have my annual eye exam and subsequently tried to purchase a new set of glasses. None of the frames I tried seemed to fit correctly over the bridge of my nose and the technician, who tried masterfully to find a solution finally said "Sir, you may want to see your doctor about that bump, I'm afraid there is no eyeglass frame that we carry that will accommodate the width of your nose."

Not long after that I made the appointment with an ENT, Dr. Contrucci. He conducted a thorough examination and took X-rays. Following all of that he confidently announced, "You have a deviated septum which has caused some swelling, which is what is creating that bump." A deviated septum, he explained, was fairly common in many people but "we need to schedule outpatient surgery so I can correct the problem. This is pretty routine stuff."

Needless to say, I was relieved but remember being more than a little concerned with the amount of downtime the procedure would cause. I did not want to be away from work for long and summer softball practice for Samantha, my 10 year old outfielder, second baseman and sometimes third baseman and pitcher was well underway, and she needed her dad's coaching in a big way. Perhaps most of all, I was not comfortable with the idea of having to be seen publicly with the customary black eyes and "Rocky Balboa" nose bandages I was sure to be sporting for a while.

Nonetheless, in May we scheduled the procedure and I came through it without too much discomfort, except for all the nose packing they shoved inside. My follow-up visit 10 days later went well. Dr. Contrucci removed all the packing, examined his handy work closely and declared the procedure a success. When I commented that the bump on my nose didn't seem to change

at all, he assured me that was normal and that it would "gradually disappear as my nose healed up." That was good enough for me, as long as all would be fine and I would be all healed before our very much anticipated family vacation that was planned for Duck, NC in mid-August. We were going to be celebrating my best friend's 40th birthday and had rented a luxury beach house with 2 other close friends and their two daughters. We all were looking forward to that trip!

The vacation in Duck was absolutely wonderful, one of the best vacations I have ever had. My family was so happy and everyone enjoyed themselves immensely. It was perfect, except for the fact that I was experiencing frequent nose bleeds at random times throughout the week. While I had no pain at all, I found myself heading to the bathroom frequently to blow my nose, and end up with tissues full of blood and nasty nasal discharge. I didn't tell my wife what I was experiencing as I did not want to alarm her but I was concerned and came to feel that something was very wrong. I made my mind up that I was going to enjoy my family and friends as much as possible this week, but then was going to see a doctor about what was happening as soon as we got back home.

Not long after returning home from our trip, I told my wife that I was having some bleeding issues and that I was concerned the bump on my nose had not subsided at all. We searched for another ENT to visit for a second opinion and made an appointment to see Dr. Cooper. We brought him copies of the X-rays Dr. Contrucci had done and, after a fairly lengthy exam, Dr. Cooper said he noticed something on the X-ray that perhaps Contrucci missed. He then had me scheduled for a CT scan to get a better look at what was going on inside my nose. A couple of days after the CT scan was done, Dr. Cooper himself called and asked that I make an appointment to see him right away, and to bring my wife with me. *Uh oh...this can't be good*, I thought.

Sure enough, the doctor showed us what looked like a smudge or specs of dark matter on the CT scan of my nose. He said that while he wasn't certain what we were looking at, it obviously was something that didn't belong there and he wanted to biopsy it right away. He calmly explained that while he didn't want to jump to conclusions, he was approaching this as if it were a cancer situation and did not want to wait any longer than necessary. He said he wanted to take a biopsy so he could confirm exactly what was going on. That Friday, I went to Memorial Hospital's outpatient surgery pavilion and had the biopsy procedure. The results would be known on Monday. I don't think my wife and I ever had a more nervous, tension filled weekend in our lives except for the time when she was pregnant with our first daughter, and was told by her obstetrician that there "may be a problem" with her pregnancy, took some tests on a Friday and told us they would know more when the results were back the following Monday! Fortunately in that instance, all turned out to be just fine

Monday morning came and I got an early call from the doctor that he wanted to see us to discuss the results. At this point I figured it was something serious but I actually remember being more pissed off that this whole thing was

turning into a major ordeal, and starting to get in the way of my work, the things I liked to do and...Well, my life!

Dr. Cooper said that the biopsy was positive. I recall him saying the tumor seemed to be "very aggressive" in that it apparently grew through my nasal bone rather than growing over it. He said it needed to be dealt with immediately and recommended we see a specialist and put us in touch with Dr. Gerard Goodwin, the Chief of Otolaryngology and a top-notch oncologist and surgeon at the Sylvester Cancer Center/Jackson Memorial Hospital in downtown Miami.

I've often been asked what it was like when I first found out I had been diagnosed with cancer. I can think of only one word....numbing.

For me, it was also simply hard to believe... After all, I felt terrific physically and mentally. I was happy, active and could do all the things I always did without any problem. How the HELL can I have cancer?!

I think it was in the car ride home when I started to seethe, recalling the deviated septum surgery I had gone through, and Dr. Contrucci's subsequent proclamation that "all was corrected." It became painfully clear to my wife and me that I had suffered a misdiagnosis by a well-respected but severely flawed doctor. Later, when we sought legal advice, we would learn that suing for malpractice isn't as much a "slam-dunk" as one might think. Had my cancer killed me or severely limited my ability to earn a living, then the courts would look favorably upon us, but failing those two outcomes, we would simply be wasting our money and time.

The visit I had at Sylvester Cancer Center with Dr. Goodwin and his team confirmed the diagnosis. Dr. Goodwin said if I wanted to get another opinion I was welcome to do so but that I shouldn't drag things out. He reiterated the tumor seemed to be an aggressive variant and the sooner it was taken out, the better. He brought in Dr. Rick Davis, a facial plastic reconstructive surgeon and otolaryngologist who examined me as well. We talked about how extensive reconstructive surgery could be. Again, I raised my concerns with downtime but he reserved projecting any timeframes until the extent of my cancer surgery was known. "The main thing" he reminded me, "is getting the cancer completely removed, everything else comes after."

As sobering as this whole thing had become, at least I got them to agree to one thing about a timeframe. "My oldest daughter has her sweet sixteen coming up in September", I want to be there for her, without my face all cut up, can I wait until after then?" (Both Goodwin and Davis probably saw that I really wasn't asking. At that point I really wasn't sure what lie ahead for me but my family was what mattered most and, I was going to that sweet sixteen looking like the same dad I had always been...whether they agreed or not!) Reluctantly, they agreed to put the surgery off until October.

I don't remember the date but I do remember the World Series was on. I remember waking up in the recovery room, first with Dr. Goodwin hovering

over me saying, "Brian, we got it...we got it all!" My eyes then went to the TV behind him up on the wall, and I remember seeing the Yankees take the field. They swept the Padres four games to none that year! And after that first surgery and about 14 more procedures involving reconstruction of my nasal passage and my nose, I beat cancer. It turned out to be a good year after all!

I was officially declared "cancer free" in 2003. Through it all, I made a point to try not to allow the illness to change my way of life in terms of who I am, and in how I pursue my life's goals and ambitions. It's funny. Over time, my family has told me how proud they were of me as I battled my cancer. With all the surgeries, radiation treatment and procedures, they said I was strong and didn't show any fear. What they didn't realize, is that I was strong then, and stay strong now because of THEM...they are my reason for being, they are MY rock. The way I see it, it's easy to be fearless when you are as lucky a man as I am. The love of my family, two great daughters and the greatest wife and partner a man can have will keep me going for a long, long time.

Mom: I Should Have Made Some Waves.

My mother was right. It took me a long time to be able to admit that. I didn't think a deviated septum would produce a bump, but he was so damn sure the doctor was right. And the doctor seemed so sure. So I went along; didn't make waves. I should have made some waves. I really, really should have made some waves.

It all started with Brian looking for new glasses. When he couldn't find a pair to sit right, on the bridge of his nose, the salesman suggested he go to a doctor to get the bump on the side of the bridge of his nose looked at. Brian wasn't the doctor type. He didn't go very often, so it took a bit of prodding to get him to go. I found the ENT from our insurance plan, made the appointment and went with him. The doctor sent him for X-rays, said he had a deviated septum and would schedule outpatient surgery to fix it. The doctor said that fixing the deviated septum would fix the bump on the bridge of his nose. And we both believed him. Brian did, and I wanted to, so I did, too. My mother didn't, though.

About a week after the deviated septum surgery, when Brian still wasn't feeling as good as we both thought he should, and the bump was still there, I began calling the EMT's office to find out why. All they did was kind of pat me on the head, told me he should be feeling better soon and hung up. Brian got fed up as well, but neither of us felt like there was anything we could do about it.

And life went on. It was spring of 1998 and I was a stay at home mom, involved with the local schools, PTA, Advisory; Jenni was 15 and in 10th grade, Sam turning 10 and in 4th grade. Jenni was studying hard, babysitting on the weekends, and Sam was playing softball. That took up a lot of our life as a family. Extended family living close, all the responsibility that brings. I remember driving to pick up Jenni after school with Sam, singing to Jimmy Buffet's Greatest Hits CD. Every day we'd sing to that CD. Then school was

done and we were in camp mode. I think Jenni was a counselor or a CIT that summer. And we had softball every weekend. Practice two to three nights a week and every weekend. Then we took a real family vacation with another family and had the BEST time in Duck, NC.

When we got home after vacation, Brian decided he wanted to get a second opinion, as the bump on his nose was still there and he was uncomfortable. I chose another name from the insurance company list, made the appointment and went with him. Dr. Cooper was a young, attractive man who made me feel comfortable right away. He disclosed that he often covered for the previous doctor and wanted us to know upfront. I liked that about him. We showed him the CAT scans and he pointed out the last two – that there was “something there.” I really don’t like that phrase. I think he sent Brian for another, more in depth, CAT scan. At the follow up appointment, Dr. Cooper said there was definitely “something there” and he was scheduling a biopsy for the following Friday, which was two days away. That scared me. That really scared me since I figured it had to be bad, for him to react that quickly. I took Brian for the biopsy, all the while assuring him I didn’t think anything was wrong. It was about two hours later, when Dr. Cooper came to talk to me in the waiting room to tell me it was cancer. He didn’t know exactly what type of cancer, but he did know it wasn’t good. I don’t think I’ll ever forget that statement. He said they were going to send the sample to the lab at UVA for the pathology, and to make a follow up appointment with his office for the following Friday. I nodded, told him I understood and watched him walk back towards the patient area. I walked outside, shaking, put my back against a concrete pole and slid down to the ground, crying. Holy Shit, he has cancer. Cancer. What was I going to do with this information? We’d need to tell the girls. How were we going to do that?

Interestingly, I don’t remember how we told the girls. It would make sense that we sat them down and simply told them what we knew. It would also make sense that we told them Brian would be ok; that it would be a hard road, but ultimately, he’d be ok and we all would be ok. But I don’t remember. And that bothers me. What I do remember of those weeks after, is going into my closet late the night after I brought him home from the biopsy surgery and crying. I remember that being the only time that I cried. I was much more concerned that the girls have as normal a time during whatever we were going to go through. I knew Brian would be ok. I made sure Samantha got to practices and games and tried to get to as many as I could. Jenni got picked up after school, continued to excel, and seemed ok.

Brian’s surgery was scheduled for after Jenni’s Sweet 16 party. What a fun party! I think we all made sure to have a good time; to drink, to dance, to eat, like nothing was happening. And we did.

The day of the surgery, the waiting area was filled with our family. My mother, mother-in-law, Uncle Larry, Aunt Eunice, Uncle Mark, and Aunt Natalie, were all there. My friend Michelle came at lunch time. She left, the family stayed and Ben came. The surgery took hours. Dr. Goodwin came out and walked directly over to me. He put his hand on my shoulder, looked me

straight in the eye and said, “We got it and we got it before it went into the brain.” That was when I realized they were concerned that the cancer had gone into his brain. I hadn’t thought about that before that moment.

He looked rough. He really looked rough; face all swollen and bandaged. I took pictures of him with a Polaroid camera to show the girls, before I brought him home. It didn’t help. Samantha screamed and cried when she saw him. I had gone to the grocery store with my mother before she got home and got a terrible, crying phone call from my frightened child. I should have waited to go to the store until I knew she was ok. That he was ok. He was shook up at that. They both were.

How many reconstructive surgeries were there? I lost count at 12. It might have been 14 or more, even. Dr. Davis would do something, it wouldn’t take, would have to be re-done. The titanium melted after the radiation. The Teflon-like substance got infected; the bone got infected. It was so tough on Brian. But he just did what he had to do. You learn a lot about people going through something like this. You learn strength. You learn weakness from those who run, or cannot look you in the face. You learn there are people in your life that will stay in your life and those that will not. You learn about being there for each other, no matter what. I think Brian is the only one of us who sees scars when he looks at himself. We just see him.

Jenni: Nothing Could Touch Him. Except Cancer.

I was 15 when my world came crashing down around me. My father, the rock and head of my family, was diagnosed with cancer.

I couldn’t believe this. My father couldn’t be sick. He was in great shape, weighing nearly the same as he did in high school (a fact he proudly shared often). He was active, coaching my little sister’s softball teams and playing with us in the pool on hot summer days. He was strong and stern. While my mother took care of the day-to-day problems, the major ones were saved for Dad. “Don’t make me tell Dad” was a common, and effective, scare tactic growing up. Nothing could touch him. Except cancer.

Looking back, I can’t believe we didn’t notice it sooner. My father had a growth on his nose that made his nose look even larger than normal. My dad had a prominent schnoz, which he ‘kindly’ passed on to me, but this bump made it look bigger. It grew slowly, taking months before I finally noticed something was ‘off.’ When I look at pictures from that time, I am shocked at how large the protrusion actually was. I remember little of the events that took place before my father was diagnosed. The day he and my mother told us the news was one of the worst days of my life. They were calm and answered our questions, but I went numb. Cancer. *It’s a death sentence, isn’t it? Is my father going to die?* Although my parents reassured us they had caught it early, I wasn’t so sure. After all, I thought he was healthy. Strong. He could beat anything. But could he beat this?

He decided to wait until after my Sweet Sixteen party to have his surgery. I was worried the cancer would cause greater damage, but he insisted the month or so wouldn't make a big difference. My party was amazing. Our months of planning paid off. My family can really throw a party. We danced, ate great food, and enjoyed being together. I danced with my dad and was more grateful for him than I had been in the past. That night, I forgot about his illness and enjoyed my family.

He never let his illness define him. It's one of the things I am most proud of. He lived his life as if he wasn't sick, having several surgeries to remove the cancer and repair his nose. He hated having his picture taken, but he wasn't afraid to ground us if we acted out. He lost the nose we shared, along with cartilage and bone from his ear and rib, but he wouldn't hesitate to help me study for an exam. The hardest part was when he had the balloon.

To use his own facial skin, the doctors inserted a balloon under his skin. Every so often the doctors would blow up the balloon slightly too slowly stretch the skin. It was then cut, twisted, and used to cover his new nose. The human body and medical science is truly amazing. Before this surgery, however, he had a balloon of skin protruding from his face. I thought it was cool, the way doctors could manipulate your body to help heal itself, but it made him self-conscious. I don't blame him. I don't know how I would feel walking around with a huge lump on my head. People looked at us strangely. I hated them. "Don't you know," I would silently scream. "Don't you understand what he's going through!?" I despised their shocked looks and wary demeanor. *How dare they be disrespectful? He looks funny, but he's still my dad. He's still a person.*

He went through hell. His nose was completely removed. My mother took a picture to show us what he'd look like when he came home, but it didn't prepare us. He looked different. He was different. He was no longer my powerful dad, the guy who couldn't be touched. His reconstructed nose deteriorated under the radiation treatment, and he had several more nose reconstruction surgeries. His face still carries those scars. I don't notice them now. I'm so used to them, I'm shocked when someone brings it up. If I look at him in the mirror, I notice them and it surprises me. I have to remind myself what happened. He looks different, but he's still my dad. Now I think he has a greater appreciation for life and family. I know I do.

My father has been cancer-free since 2003. Beating this disease has brought my family closer. My father is still the head of our family, but I have a newfound respect for my mother. She held us together at our worst. She never allowed us to give up hope that my father would be okay, that this disease would go away and we'd still be us. As a wife now, I cannot imagine the pain and suffering she went through, trying to stay positive in the face of that obstacle, not allowing herself to imagine the worst case scenario. She is the reason we are still a family today.

When I think of my life, my father's disease is one of the most powerful experiences I've gone through. It completely changed my life. It changed my

relationship with my family. At 15, I became an adult. My parents and younger sister leaned on me for support. I felt I had to be strong for them all, and internalized much of what I was feeling and thinking. I strove to stay positive for my sister's sake, and my mom's sanity and my dad's emotional well-being. I turned to friends to help me shoulder the burden, but no one really understands if they haven't been through it. I thought I was losing my father, and no one could know what that was like. A typical teen, I believed no one could possibly understand my experiences, and often turned away from supportive friends, turning into myself for strength. I lied to family, telling them I was okay when I wasn't. I didn't want to worry my mother, or upset my sister. It was my job to be strong, to be the rock, so Mom could take care of Dad and Sam could survive. At 10, she was so young and I didn't want her to be in pain. "I can handle it," I'd say to myself. "I have to be strong."

That strength and that experience have helped shape who I am and what I believe. I am a strong, independent woman and I believe time is too short, and we should always let those around us know we love them. I still tend to retreat into myself when struggles arise, but I know I will survive them, as my father survived. As my family survived.

Sam: My strong daddy was broken.

At 10 years old, all I cared about was playing in the neighborhood after school, practicing softball and annoying my older sister. Like lots of kids, a skinned knee was the worst part of my day. That was all true until the day I found out my dad had cancer.

For starters, my father and I were very close during my childhood. Being a daddy's girl, I looked up to him for direction and assurance. He was the one I ran to for help with school projects and the one who endlessly coached me in softball. This strong, talented man was everything I could ever hope for in a dad. Nothing would or could ever happen to him, right? Wrong.

It's hard to say I remember the exact words my parents spoke, or where we were sitting when the conversation took place. I barely remember the beginning of this life changing event, really. A 10 year old girl doesn't understand the magnitude of any situation unless it's about a boy knocking on the door asking if she wants to play with all the other kids in the neighborhood. I can't explain what I was thinking when my parents told me about my dad being diagnosed with cancer, but I do remember not understanding what it meant. All I cared about was if my dad was going to live or die.

For a short time after being diagnosed and before his first surgery, my dad was able to work and go on with life as it was, knowing there was something deadly inside him. His strength and positive outlook is the only thing I can remember and I'm so thankful for that memory. I don't think I can bear how scared he must have been, nor do I think I realized how traumatic this situation was for him. My father was now facing the greatest hardship of his life and I was too young and naive to understand any of it.

My mother showed me strength that I admired then, and possess as a woman today. She so flawlessly picked up the pieces while my dad was sick, making decisions for the family and dealing with his sickness by taking no prisoners. She did so much research, went to every doctor's appointment, even threatened a few people if they didn't do what she asked, but all for the sake of her beloved, and her family. I barely remember her crying in front of me, but I do know that her and my dad both answered any questions we had and kept us quite involved in what was happening with doctors' appointments and surgeries. I remember being very attentive to how my dad was feeling, and always cozying up to him to look at his new nose. My mom encouraged me to do this and to make sure I always asked questions. It was not an uncomfortable topic for us to address, however it was definitely upsetting to watch everything unfold in front of you, no matter how much you understand it.

Having an older sister who protects you from everything she can is really something amazing. I can bring myself back to the age of 10, when I did nothing but drive her crazy. However, when my dad was diagnosed with cancer, she stepped up and talked to me a lot about what was going on. My sister, Jen and I would cry a lot. I remember after my parents would give us updates we would become emotional, and Jen always held my hand through. She always spoke with me about our dad and his diagnosis. We had an open forum in the house, where any questions were allowed. If I was too scared to ask, I approached Jen. I've always wondered what it must have been like to truly understand and know what the diagnosis meant, and that my dad's life was truly in danger.

There is one day that I will never forget in my life and it brings tears to my eyes every time I bring myself back to that day. I can close my eyes and see myself skipping and running home from school. My grandparents were at my house, and I was looking forward to seeing them, as well as my dad. He had just had surgery and was finally going to be home. I remember turning the front door knob, letting myself inside, expecting my family to be there when I arrived. I called out but no one answered. I let myself into my parent's bedroom to visit my dad and walked into the room completely taken aback. He was lying in bed, with bandages all over his face, covered in bruises. My strong daddy was broken. I can vaguely remember the yelp that escaped from my mouth, tears streaming down my face and quickly running out of the room. Looking back, this must have been crushing for my dad. It breaks my heart to look back and see that because I know that there is nothing in the world he wants more than to protect me from pain, not cause it.

My dad didn't feel well for quite some time considering the size of the tumor and the surgeries he went through. I'm so thankful to have family and friends that were able to support us through that awful time. I remember the only time in my life that our Passover Seder was not held at home and my dad wasn't running it. During the year my father was sick, my sister and I spent the holiday at a family members house. I remember being uncomfortable in the fact that this was all of our holiday, but MY dad runs the Seder. It was sad to

me that we couldn't celebrate the holiday together, in the same fashion we always had. It was times like these that made me realize how sick he really was, missing important events that my dad never would have missed if cancer was in his control.

We don't speak much about my father's illness or the effects that it has had on our family. I can tell you that thinking about it brings tears to my eyes that I always become upset remembering the time I heard how serious my father's diagnosis was. I almost wish I was older when it happened, so I could have handled it better. But, I guess I should be happy I barely remember, because what a scary and awful time it was.

With this piece, I want to be sure to say something to my family. You are all absolutely amazing for standing so strongly through this horrific process and that dad, your illness didn't make you weak; it showed all the strength you were made of. My sister and I used to write papers in school about our hero, our dad. We started writing things down and connecting your illness to you being a hero not because your life was at risk, but because you dealt with it in such a heroic way. Your illness did not define you, the way you fought back did, and THAT is why you are still my hero today.

Findings

The purpose of this study was to investigate my family's experience with my father's cancer. Analysis of our narratives reveals some interesting findings. The overarching themes that emerged were disbelief, unreliable memories, wanting to forge ahead, and a strong family.

Disbelief.

One theme prevalent in all our stories was disbelief. Most of us felt a similar sense of disbelief when we found out my father's diagnosis. My father described his experience as "numbing" and "simply hard to believe." He could not believe he was sick, especially because he "was in pretty good shape physically" and had not had any major medical problems. My mother also exhibited disbelief, when she cursed the situation and questioned how she would tell her children. "What was I going to do with this information?" Her disbelief was connected to how my sister and I would react to the news. I also experienced disbelief with my father's diagnosis, "I couldn't believe this. My father couldn't be sick." My father was so healthy; the idea of him being ill was difficult to accept. The feeling of disbelief was pervasive in our stories.

Unreliable memories.

Another theme that emerged from our stories was of unreliable memories. Each of us had gaping holes in our memory. My father did not remember the date of his surgery, "I don't remember the date but I do remember the World Series was on." My mother could not recall how she told my sister and me about Dad's diagnosis. She wrote, "Interestingly, I don't remember how we told the girls...But I don't remember." She also did not remember the exact number of surgeries he had, "How many reconstructive surgeries were there?" My sister experienced the biggest lack of memories, probably due to her young age when the illness occurred. She wrote, "It's hard to say I remember the exact words my parents spoke,

or where we were sitting when the conversation took place. I barely remember the beginning of this life changing event, really.” She wished she could have been older to better deal with it, but then realized she was lucky to not have so many bad memories. “But, I guess I should be happy I barely remember, because what scary and awful time it was.” The theme of unreliable or missing memories was common, and caused us to have different stories.

Wanting to forge ahead.

A common theme from our stories was our desire to forge ahead and continue life with as little disruption as possible. My father insisted on pushing back his surgery until after my Sweet Sixteen party:

At that point I really wasn't sure what lie ahead for me but my family was what mattered most and I was going to that Sweet Sixteen looking like the same dad I had always been...whether they agreed or not!

He consciously “made a point to try not to allow the illness to change” his life. He was determined to stay the same person he was, with the same goals and ambitions.

My mother, too, wanted life to change little for us. She hid her crying from us so we would not know how bad things were, “...going into my closet late the night after I brought him home from the biopsy surgery and cried.” My sister echoes this, “I barely remember her crying in front of me...” Her focus became on making our day-to-day lives as normal as possible:

I was much more concerned that the girls have as normal a time during whatever we were going to go through...I made sure Samantha got to practices and games and tried to get to as many as I could.

By focusing on our daily lives, my mother built a sense of normalcy that was consistent throughout my father's illness.

My sister and I noticed how our parents fought to keep our lives normal. My father “lived his life as if he wasn't sick...but he wasn't afraid to ground us if we acted out.” I learned from that and internalized it. I did my part by helping out. “I strove to stay positive for my sister's sake, my mom's sanity and my dad's emotional well-being.” I felt it was my job to help lead the family, “It was my job to be strong, to be the rock...” I became another caretaker for my sister, in an effort to help her come through this event unharmed. She remembers, “...she stepped up and talked to me a lot about what was going on...Jen always held my hand through.” By being there for her, I was able to get through the experience. It was like we had an unspoken rule, just bow your head, deflect the blows, and get through it. By living our lives and being there for each other, we were able to do that.

A strong family.

Through our stories, we all agree the result of this experience is a stronger family. My sister and I always thought of our father as strong, though this event solidified that even more. I describe my father as “the rock, the head of our family.” My sister wrote:

...dad, your illness didn't make you weak, it showed all the strength you were made of. My sister and I used to write papers in school about our hero, our

dad...Your illness did not define you, the way you fought back did, and THAT is why you are still my hero today.

Though we all admire my father for his strength, he feels he is strong because of us. "...they are my reason for being, they are MY rock...it's easy to be fearless when you are as lucky a man as I am." My father found his strength in us. We found strength in him.

My mother found strength in the situation. "You learn strength. You learn weakness from those who run, or cannot look you in the face...You learn about being there for each other, no matter what." The experience itself showed my mother her strength and the strength in others. My sister and I recognized her strength. I wrote:

...I have a newfound respect for my mother. She held us together at our worst. She never allowed us to give up hope that my father would be okay, that this disease would go away and we'd still be us....She is the reason we are still a family today.

My sister echoes my sentiments:

My mother showed me strength that I admired then, and possess as a woman today. She so flawlessly picked up the pieces while my dad was sick, making decisions for the family and dealing with his sickness by taking no prisoners.

The experience helped us see the strength in each other. As I wrote, "That strength and that experience have helped shape who I am and what I believe...I know I will survive them [struggles], as my father survived. As my family survived."

We each viewed the experience in similar ways, though our lack of memories and perspectives allowed us to tell unique aspects of the same event. Our stories differed mainly in the details leading up to my father's diagnosis, and our individual memories of how we coped with the disease.

Writing narratives gave us an opportunity to give a voice to our varied experience. Narratives can function as "medicine for the ill person" (Anderson & Martin, 2009, p. 135). The same is true for family members of the afflicted. Writing about my interpretations of my father's illness helped me further heal. The act of writing was a catharsis, allowing me to re-examine feelings and emotions I had locked away, and opened us all up to talk about what happened, drawing us closer as a family. "Chronic illness...usually changes the very foundation of our lives because the illness creates a new and qualitatively different life conditions" (p. 52). This is sort of true. My father's cancer did change our lives, and really make us appreciate every day, but our life conditions did not drastically change, mostly due to my parents' determination to keep our everyday life normal.

Conclusions

Narrative is a way of reasoning, a way to use what we know to tell about our world (Anderson & Martin, 2009). Our narratives were of the same phenomenon, but we each took different paths in writing them. Dad was concerned about participating, about what others would think and the pain of reliving this event. Mom was focused on what everyone else wrote and experienced. Sam was very concerned about getting it 'right.' I was worried about getting everyone on board, and how writing this would affect us both individually and as a family. I did not want anyone to hurt, but thought our story was an important one to tell.

My dad, the least emotional of us all, told the least emotional story. His narrative is full of facts and events, and lacks much about what he felt as he experienced cancer. His concern was getting the story out, and telling us what happened and when, not what he was thinking and feeling as it was happening. Cancer survivors often feel stigmatized, and avoidance of fully disclosing their story helps them deal with this (Anderson & Martin, 2009). My father has been around women all his life, and detaches himself from his emotions. Perhaps this is societal; the man is not supposed to show emotion. This does not mean my dad is not a loving, caring person. He is, and he shows affection for us constantly. He does not, however, tell us how he feels about things, how his feelings affect his life. I contemplated digging deeper with his story, asking him to rewrite it with more emotions, but in the end, I decided against it. This is his story, and I was uncomfortable asking him to change it.

The female stories, the ones from my mom, sister, and me, are full of emotion and feelings, which is fitting if you know us. We have no problem expressing how we feel and are emotional beings. I think some of this is societal, how we were raised. Perhaps some is biological. Whatever the cause, our stories mirror our personalities. We are emotional, and so are our narratives.

It is interesting how different my sister's and my stories are. We experienced the exact same phenomenon, in the exact same role as the daughter of a cancer survivor, but in different ways. As the older sister and eldest child, I took it upon myself to become caretaker. I assumed this role with little pressure from my mother. I just knew she would be so busy with Dad, and I would need to "step up" and be strong for my family. When my mom read my narrative, she apologized. "I never meant for you to feel you had to take on that responsibility." Looking back, I realized I had made myself take on the added pressure. I reassured her it was not her, it was me. I created this situation in my mind that everyone needed me to be an adult. Perhaps that was somewhat true, but not to the extent I thought at the time. My sister, on the other hand, had a different experience to tell. She didn't remember much, and compensated by including more of her feelings than actual events. My story has more chronological facts to it, while hers focuses more on how she dealt with the situation.

My father, the afflicted, experienced something quite different than any of us. My mom's story of her struggle to survive while raising us differs from my sister's and my narratives of trying to get on with our lives after realizing our father was not impervious to disaster.

Our stories are similar as well. This one event drastically changed our lives and the way we viewed my father and each other. We saw each other step up and assume a difficult role in trying to get on with our lives. We see our family as stronger and closer. We have more respect for each other after going through this together. I thought it was fascinating how we each ended our story the same way: with a message to each other. My father said we were his rocks and got him through his illness. My mother discussed how we look past my father's scars and see him because we love him. I talk about our strength as survivors, and my sister sends a message directly to Dad, telling him of her admiration and love for his refusal to allow his illness to define him. We ended our stories with a message of love, appreciation, and awe.

Utilizing narrative allowed us to tell our experiences of what happened, to reconstruct what happened and give meaning to this life-changing event (Hydén, 1997). For me, it also served as a catharsis, a way to heal more (Anderson & Martin, 2009). I gained more respect for my family after learning their interpretations of my father's illness and I think this brought us closer together.

As in any study, there are limitations. I sought to share my family's story of our struggle with cancer in the most trustworthy way possible, by allowing them to write their

own narratives. However, these narratives are based on memories. “When individuals talk about their experiences with illness they rely on what psychologists have called autobiographical memory” which “can be thought of as guidelines for perceiving, organizing, interpreting, representing, making inferences about, and acting in the world” (Garro, 1994, p. 776). These narratives are what happened as we see them now. Our “personal complexities” have infiltrated what actually occurred (Anderson & Martin, 2009, p. 141). However, “the primary goal of narratives seems to be to communicate and negotiate the world of illness” (Hydén, 1997, p. 63). Narratives are not about truth, but about how we perceive the truth. Anderson and Martin (2009) declare, “We can learn best about illness through narrative” (p. 141). This narrative allowed us all a voice in a life-changing event. Further studies should look more deeply at the experiences of family members of cancer survivors, and how they construct meaning from this event. This article may benefit other cancer survivors and their families, as well as doctors, nurses, and anyone else connected to the care of cancer sufferers. Perhaps by hearing our voices we can better understand how victims and their families negotiate this illness.

References

- Anderson, J. O., & Martin, P. G. (2003). Narratives and healing: Exploring one family's stories of cancer survivorship. *Health Communication, 15*(2), 133-143.
- Garro, L. C. (1994). Narrative representations of chronic illness experience: Cultural models of illness, mind, and body in stories concerning the temporomandibular joint (TMJ). *Social Science and Medicine, 38*(6), 775-788.
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Alpine.
- Hydén, L. (1997). Illness and narrative. *Sociology of Health and Illness, 19*(1), 48-69.
- Patton, M. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Rodriguez, A. (2002). Redefining our understanding of narrative. *The Qualitative Report, 7*(1). Retrieved from <http://www.nova.edu/ssss/QR/QR7-1/rodriguez.html>.
- Salander, P. (2002). Bad news from the patient's perspective: An analysis of the written narratives of newly diagnosed cancer patients. *Social Science and Medicine, 55*, 721-732.
- Stake, R. (2005). Qualitative case studies. In N. Denzin & Y. Lincoln (Eds.). *The Sage handbook of qualitative research* (3rd ed, pp. 435-454). Thousand Oaks, CA: Sage Publications

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