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How Memory Affects Sense of Self: Stories of Traumatic Brain Injury

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How does memory affect sense of self? For traumatic brain injury (TBI) survivors, memory has a large impact on sense of self. Some cannot remember who they were before the injury and have to rely on others' memories or photographs to reinvent their sense of self. Others can remember who they were before the accident, but feel they are vastly different than their old self. How do TBI survivors negotiate reconstructing identities and sense of self when memories play a disconnecting role? Through this process, storytelling can help survivors recreate a sense of self that is more continuous and also empower them in educating others about their experience and decreasing stigma.

Introduction

When you think about who you are, do you think about all the things you do? Do you think about the people that you love, or the feelings you have experienced in your life? For most of us, these ideas guide us in thinking about our sense of self. For many traumatic brain injury (TBI) survivors, thinking about who they are may be more of a comparative question. They compare who they used to be before injury, what they used to do, or how they used to feel, with their lives now, life after their "second birthday," as one survivor I interviewed called the day of her injury. Many survivors don't know whether to think of themselves in terms of before or after injury, when many times these two time frames seem very incongruent. Loss of self is commonly described "in relation to pre- to post-injury comparison, loss of self in the eyes of others, and discontinuity of identity through lost or disrupted memories"(Dewar and Fergus 2007:603).

Many survivors wonder if they will ever make their way back to their "old self" or if they are going to be forever different. Jennings explains this journey as an act of "reminding." He explains this concept,

First, I mean reminding in the ordinary sense of recalling to mind something that has been forgotten. In TBI rehabilitation, the person's memory of past

activities is (to some extent) restored. But it is also ‘re-minding’ in the more radical sense of reconstructing the subject, the person. Is this the reconstruction of the person who was, or the fashioning of a new person who has never been? A false dichotomy surely, but how are we to describe what lies between? (Jennings 2006:30)

Medical ethicist William May (1991) asserts that memory both creates continuity with the past while distancing the present from the past. When survivors have memories of the past, the juxtaposition of old memories and current life situation creates uncertainty in self. Through forming and telling their own stories, survivors can explore how they can recreate sense of self in the midst of memories of contrasting life experiences before and after injury.

Doing fieldwork among the Asheville TBI community

To get to know the local TBI community in Asheville, I started attending a monthly support group meeting of the Brian Injury Association of North Carolina (BIANC) as well as weekly visiting Hinds Feet Farm, a new brain injury day program. I learned about TBI through neuropsychology and anthropology classes, and had met a few survivors at a summer camp, but didn’t know any local survivors, so I was really excited to meet with the local group.

Driving over to my first brain injury support group meeting, I was nervous about how the night would turn out and if people would think it was weird that I was coming even though I didn’t have a TBI. But right when I walked in the door, I felt so welcomed. Everyone was so real, honest, funny, and relaxed; you couldn’t help but feel at home. There were five TBI survivors there, along with four of their moms. Everyone had so much to share. People would ask each other, “with your injury, did taste change? And smell?” They were so curious about the subtleties of the differences in their injuries. Karen, an outreach coordinator with BIANC, says that a lot of people with TBI miss the social interaction they used to have. Chances to get together might be limited for some of these people, but the support group seems to be providing a great way to interact with others and also a way to find empathy in shared experiences.

My experience at the Hinds’ Feet Farms day program was a little different. When I came during some free time in the afternoon hours, people were finishing up lunch and playing cards or doing artwork. Unlike the support group meeting, there were no moms there and the people “in charge” (as in the director or physical therapist) were in and out of the room, which might lead the participants to feel more free in their conversations with me. They asked me why I was there, and I told them I was a student studying sociology who was interested in TBI. They all responded pretty much the same way, “Oh, you are here to see if TBI people are retarded or crazy,” something I did not hear at all at the support group meeting. I thought this was an interesting response. Of course, I didn’t really know what to say, except “no. . . you know that is not why I am here.” They seemed like they were kidding, but I had to wonder if they really were.

I wonder if these responses are pointing to an underlying notion, that these brain injury survivors at the day program think people really do see them as crazy now. Some of the people there couldn't walk very well, talked really slow, needed help playing simple card games, and had trouble finding words they wanted to say. Maybe they, the people who answered in this way, feel self-conscious about how other people see them now, after their brain injury. Would frequent interactions with people who are uncomfortable talking to you because you talk really slow finally influence you to think of yourself as slow and "retarded"? The stigma with which others view them would certainly have an effect. One survivor I interviewed talked about how people are scared of what they don't know, afraid of what's different, and spoke of how this affected how she interacted with people and how she came to view herself through the eyes of others. Charles Horton Cooley, a symbolic interactionist sociologist, describes this phenomenon of seeing yourself reflected through the judgments of others in social interactions (in Wallace and Wolf 1995).

When I met Drew at Hinds' Feet Farm, he came up to me and introduced himself; he said he hadn't seen me before. At one point in our conversation, Drew said, "Disabled? Look at me, I am not disabled," as he did a rap dance move. He said that he has a lot of skill in social interaction. He questioned what "disabled" even really means, which is a question many disability scholars ask. Robert Murphy, a quadriplegic professor, tells a story about receiving the census and encountering a question asking how many disabled people were living in his household. He answered "none," as he is a professor and earns a living, something that seems to be things that "abled" people do (Murphy 1990).

In addition to attending the support group and day program, I interviewed many people whom I met through these activities, and a few more with other survivors who interviewees connected me with. I interviewed ten people, including eight TBI survivors and two moms, four females and six males. These people were of various ages and had their injuries in various ways, such as car wrecks, bike accidents, and falls. It will be important to remember that I interviewed survivors who are members of social networks¹ and will have very different experiences and perspectives than survivors who are isolated in their homes. This might skew these survivors' stories and views to be more optimistic and hopeful than those who are isolated practical means of socializing with people.

During my conversation with Angela, a TBI survivor who I'll introduce later, she noted that she was saying "survivor" and not "victim." I want to follow her lead by using "survivor," which is more empowering and positive than "victim" which sounds like something to be pitied. We see this when advertisements and fundraising campaigns use words like "killer disease, life ebbing away, before it's too late" describing the need to help people with different forms of disability (Johnson 2005). These words imply that disability is bad, disgusting, and

1 I met these survivors precisely because of the social networks they were a part of, such as the support group, day program, or other more informal personal connections with the brain injury community.

something with which you could never have a fulfilling life. Phrases like “confined” to a wheelchair or “save” the people “stricken” with this form of disability perform the same function.

I began my research with the intention of studying people with TBI, as I had heard of groups which are organized around this group specifically. The medical field categorizes brain injuries into either Traumatic Brain Injury, meaning an external force caused the injury, or Acquired Brain Injury (ABI), which involves something internal, such as stroke or brain tumor. As I got deeper into my research, I found there was no fundamental difference between the experiences of TBI and ABI. Michael Paul Mason, a brain injury case manager and author explains it best,

Every brain injury involves trauma, and every brain injury is by some means acquired, but the terms are disparate in medicine... Outside of hospital walls, however, an injured brain is always traumatic, always a TBI. (Mason 2008:70)

Brain injuries are often recorded in medical records as an insult to the brain, insult meaning assault, but implying that the survivor has been “wronged, offended, somehow made less as a result of his injury” (Mason 2008:71). Many survivors may experience these feelings that “insult” implies, feeling degraded or reduced, but at the same time they have the ability to be free of the negative thoughts, thinking instead, “they are not insulted; they are transformed. They are not disabled, but challenged” (Mason 2008:72) In this opposite, positive way of viewing TBI, survivors can lead a life full of love, joy, and variety.

I have come to value storytelling and the empowerment that comes with telling your story and having it heard. Throughout this process of interviewing, I have been excited about giving these survivors space in which to tell their stories. They all seemed eager for this opportunity, for many of the people I interviewed find importance in brain injury advocacy. They feel that with the understanding that comes with advocacy, perceived stigmas are lessened and change can be made.

Barbara A. Hogan, a professor of Sociology, Criminology, and Human Services at Chestnut Hill College, writes about how narrative therapy can help TBI survivors. She says,

In narrative therapies, people are encouraged to name their own problems and to participate in therapy as authors who write/ tell stories rather than solely as “patients” about whom reports are written. They engage with therapists in a process of co-authoring new narratives characterized by themes of their capacities for agency (power, achievement) and communion (interdependence, care) (Hogan 1999:22).

Hogan shares one story about co-authoring a book with a TBI survivor Jeff. While Hogan can’t answer Jeff’s questions about why he is alive, she can validate the questioner. She can be a witness to Jeff’s journey, legitimating, validating, and understanding his experience. She says Jeff “has the potential to claim an identity

as an author not just of a book but an author of his own life from which he has felt quite alienated” (Hogan 1999:24) He wants the people who he shares his story with to be a part of a “mutual process” of education about health, identity, and rehabilitation can mean for TBI survivors.

Psychologists McAdams, Josselson, and Lieblich, in their book “Identity and Story: Creating Self in Narrative,” explore how the construction of a self-defining life story can be a critical part of exploring identity questions such as “who am I?” and “How do I fit into the world?” They continue,

Internalized and evolving life stories—what we call narrative identities—function to organize and make more or less coherent a whole life, a life that otherwise might feel fragmented and diffuse” (McAdams, Joesselson, and Lieblich 2006:5)

When TBI survivors feel like their identity is disconnected between life before and life after injury, stories may not only help educate others about their experiences, but help themselves construct a more continuous image of identity throughout their lives. Psychology professors and writers of “*Storied Lives: The Cultural Politics of Self-Understanding*” believe that the stories people tell of themselves are remarkable for the explicit scenes and stories that are shared, but also for the production of the stories themselves.

How individuals recount their histories—what they emphasize and omit, their stance as protagonists or victims, the relationship the story establishes between teller and audience—all shape what individuals can claim of their own lives. Personal stories are not merely a way of telling someone (or oneself) about one’s life; they are the means by which identities may be fashioned. It is this formative—and sometimes deformative—power of stories that makes them important. (Ochberg and Rosenwald 1992:1)

Through stories, survivors can defeat negative perceptions of the “insult” to their brain and create empowering, hopeful, and fulfilling life narratives.

I have the chance to put these many stories together into a more powerful unified story, which is a great advocacy opportunity. I am nervous though about how I have represented these people and their experiences. Images I paint, words I choose to include or leave out, and how I analyze these words will affect how readers see these people and think about brain injury. I want to try to use the voices of survivors as much as possible to really make it their stories.

Trying to Remember

For some survivors, their brain injuries were not immediately obvious. Some may have had a car wreck and walked away from it thinking they just had a few bruises, though a few weeks later they may notice symptoms, like a numb arm, memory issues, or differences in emotions. At this point, they may go to the doctor

and find out they had a TBI. But many of the survivors I interviewed were in a coma for some period of time after their injury, from a few weeks to many months. Waking up from a coma is not a sudden occurrence, but a long process of slowly making sense of your environment, of where you are, why you are there. This is when survivors slowly begin to look around, try to move their body parts, start rehabilitation therapies which involve learning how to swallow, talk, walk, and think. This is also when survivors try to remember their lives and figure out who they are.

“remembering my life by how other people remember me:” on not remembering. Angela was the vice president of a big PR firm in New York City. She had recently married Rich, the love of her life, who was also a vice president of another company. She was in the middle of planning a \$200,000 event and didn’t feel like going to a Yankees game, but her friends convinced her to go. She was driving home from the game with her husband when their car was hit by a USPS truck. Rich died instantly. Angela was left with many injuries, including a left frontal hemorrhage, a right parietal contusion, many fractures including ribs and her C1 vertebrae, the most serious of the injuries. She told me if C1 fracture isn’t stabilized within five minutes, you die or become completely paralyzed. But because she was in New York City, she was air lifted to the hospital and stabilized within five minutes, something Angela refers to as the first of many miracles.

When Angela woke from her coma, she didn’t know what had happened. After a few months she started to piece things together and started asking about her husband. Her family had to tell her that her husband had died instantly in the car wreck. She couldn’t remember who she was before the accident. She didn’t know how far she would recover. She didn’t know if she would be able to walk or have a job again.

I first heard Angela speak about her experience at a TBI panel at UNC Asheville. I recently reconnected with her at a brain injury support group meeting, where we decided to meet again for an interview. The following week, Angela and I walked into a beautiful coffee shop in downtown Hendersonville full of wonderful fragrances of coffee and scones. We sat sipping our hot teas and continued the energetic conversation we were having ever since we met up an hour earlier at her home. Looking around at the antique furniture and fancy mirrors that filled the café, Angela describes remembering who she was through other people’s memories,

I don’t know how accurate that is. It’s really scary to think about. But I’m remembering my life by how other people remember me. But fortunately it’s pretty good memories. Apparently I was very nice, I was a good mentor. I mean when I first came to NC, I was being reminded ‘oh you mentored kids you volunteered all the time.’ I was like ‘really? Golly, I was a pretty good person, am a pretty good person. That’s a terrible. I quickly broke that habit of referring to myself in the past tense because I *am* a good person. I *am* a volunteer. It was a bad habit that I got into, but I broke that habit (Interviews with TBI survivors, 2009).

Angela acknowledges the strange experience of relying on others to create a sense of self. She doesn't know if this is a reliable way to find out about herself, but apart from reading her old journals and looking at old pictures, she doesn't have many other options. She jokes about telling one of her friends that this would be a good time to tell her she did some extraordinary thing, like climb Mt. Everest, because Angela would have to believe it. She also talks about herself in past tense then immediately corrects herself to use present tense. She has a disconnected sense of self which she is slowly but very intentionally trying to make continuous.

Just as she doesn't remember herself, Angela doesn't remember her husband Rich. She remembers how they met through how it's been recounted to her, though she says she does remember pieces of it. She stumbled upon an online photo journal of their life together, which she has carefully poured over, trying with all her might to remember him. She has viewed Rich as her guardian angel throughout her recovery process, even though she doesn't remember him. She talks to him all the time, praying to him, talking to God through him. She remembers him through photographs but doesn't remember

Things like what side of the bed did he sleep on, what was his favorite meal, what did he love most about me. I actually don't remember much about when we met, how did we meet, where was our first date. That's the stuff that I'm praying that will come back when he thinks I'm ready, when Rich thinks that my recovery is coming far enough, because I think Rich knows that a recovery would be harder and slower if I had a broken heart, and so when he thinks I'm ready, I'll remember (Interviews with TBI survivors, 2009).

Angela is grateful for the ways she has of remembering him, but mourns the loss of the personal information she alone used to know about Rich. Angela refers to her guardian angel Rich's keeping these memories away from her as the "brain's unique and powerful ability to protect itself and to heal (Interviews with TBI survivors, 2009)" When Rich thinks she is ready, she will remember.

How do you create a new sense of self if you don't remember who you used to be, or roles you used to play, such as wife and lover? Michael Paul Mason says "Most of what we consider essential depends on memory. We carry a host of suppositions about what it means to be human, but without access to our memories, our notions surrounding identity begin to crumble" (Mason 2008:47). How does Angela begin to put together an integrated picture of who she is? She would wonder "if you asked my friends 'how am I the same or different?' what they'd say, I really don't know. Am I more short tempered, more irrational? These are things that cross my mind all the time" (Interviews with TBI survivors, 2009). She clearly thinks about how she might have changed since the accident, but to be optimistic and hopeful, she doesn't want to think about it too much.

"kind of woke up in bed:" the process of remembering. Drew and I had been talking about doing an interview for a few weeks. Finally we decided to meet up at a Jamaican place downtown for dinner. I had picked it because I thought it

would be a quiet place to have an interview, my first formal recorded interview this semester. We get there, and we are the only people in the entire restaurant. Our waiter's only customers, we are getting his full undivided attention. And in between our interactions with the waiter, it is just too quiet for an interview. So I eat my calooloo as Drew eats his ribs, jerk sauce everywhere. We decide to have the interview after dinner.

We walk around downtown looking for a quiet place and we just can't find one that suits us. I suggest driving to UNC Asheville and finding a quiet room in the student union. Of course when we get there, the whole place is packed, students everywhere, not a single free room. Living off campus, I forget that other people still do live on campus, and actually hang out at the student union. Yet we roam around the building and finally decide to sit on some couches in the open and have the interview. I am wondering if I have been stalling this whole time. But here we sit.

I start off very vague and general, "tell me about your injury, this is your space, to say whatever it is you need to say" and after a bit of back and forth, the ball finally starts rolling. Drew described his injury, falling off a fifteen foot retaining wall, being in a coma for two months, and finally waking up. He just "kind of woke up in bed and it's not like I didn't really have any questions because, I mean, I was like an infant so you don't really have a question, like 'why am I here?' because I was kind of born again and what not" (Interviews with TBI survivors, 2009). He says you're not going to say anything about it because you don't know anything else. Only with time was he able to form questions to make sense of his being in the hospital.

Angela's doctor told her many survivors might not remember events that happened in what is called an amnesiac window, a period one year before the accident and one year after. Diane Chamberlain, a nurse and critical care studies lecturer, led a study which found that survivors "relied heavily on their carers for recovery narrative expression. The carer was used to transform and reflect narratives in a sometimes desperate relationship bound by complex trust and interdependence" (Chamberlain 2006:413-414) Drew depended on his family to tell him what happened during the period he couldn't, and still can't, remember. I asked him about how he was treated in the hospitals and rehabs, and he can just tell me what has been told to him.

Remembering and Negotiating the Differences

As we have seen, recovering memories from the past can be a process. For some TBI survivors, certain, or even all, long term memories don't come back. But for most, long term memory stays intact while short term memory is weakened. Feminist philosopher and brain injury survivor Kate Lindemann says that for these survivors with good long term memory,, "Childhood holiday celebrations, teenage adventures, and former professional triumphs can still be recalled as vividly as ever, and they often present a stark contrast to one's present situation"(Lindemann 2001:110) Having memories of the past and realizing how different these memories

are from the current moment can be very troubling to a TBI survivor. Who are you, if you used to define yourself by something that you no longer have, something you've lost, or something you have now rejected? How do you negotiate sense of self with such critical differences in identity?

“you were always such a happy little boy:” memories of moods and personality. While at work on June 28, 2006, Frank was walking down the halls of the television news broadcasting studio, lost consciousness, and fell. He has no recollection of the event. Seven days later he was able to listen and digest what happened and why he was in the hospital. He learned he had a subdural hematoma, meaning a piece of bone inside his skull, above his left ear, splintered out and clipped an artery inside his head, causing extensive internal bleeding. He says he is literally lucky to be alive, thanks to the speed at which he was taken to a hospital and operated on.

Like Angela, I first heard Frank speak at the TBI panel at UNC Asheville, and it was through Angela that I connected with him again. Frank and I decided to meet to have an interview. Frank enters the library, tall in his Grateful Dead sweatshirt and coordinating Grateful Dead T-shirt underneath. We walk downstairs to have our interview.

Frank tells me he hasn't had any physical impairments from his injury, but has had experienced immense emotional changes. After his injury, Frank was diagnosed with bipolar disorder. With this, he is now either really manic or depressed, never in the middle. When he is manic, he is “sometimes way too energetic and chatty” (Interviews with TBI survivors, 2009). On this day at the library, he tells me he was probably on the manic side, because he was pretty chatty, and brought water with him because he thought he would be chatty and knew his throat would get dry. This was good on this day, since we were having a conversation about TBI, though other times, his mania can be way too much. In reflecting about his depressive times, he says,

I'm really not happy anymore. Like I said, at the depressive times, nothing is funny. I don't want to watch any kind of movie. I don't want to read anything. Nothing is funny. And what I've noticed is that I can be amused now, when I'm not depressed, I can be amused. So I can read a joke or look at a cartoon in the *New Yorker* and start to laugh. Or I can watch a comedy on TV or movie and laugh at moments, but I'm not happy, I'm humored. Happiness went away, and what I need to try to do at some point, or I'm hoping it just does itself, is for happiness to come back. Because like Jean [his sister] says, 'you were always such a happy little boy.' And I turned into being a happy adult. And this thing that happened in June of '06 has taken the happiness away (Interviews with TBI survivors, 2009).

Frank shows real remorse in this loss of happiness in his life, something that used to define who he was.

Ten years ago, Dora was a college student at home on break when she got into a car wreck. She doesn't know what happened. She was going through a curve near

her house, something happened, and her car did a 180. The side of her car hit a tree, and the car “crumpled in around it” (Interviews with TBI survivors, 2009). She was airlifted to the hospital and was in a coma for fifteen days. She stayed at the hospital for four weeks and then spent another five weeks in a different hospital for in patient therapy. She learned that in the wreck, she had gotten brain shears. The doctors explained to her that brains are like jello, and skulls are like bowls. So when you knock a bowl of jello into a wall, it jiggles and slits are created throughout the jello. Her skull didn’t break but her brain was agitated and sheared, bruised in a couple different areas. All the slits had to reroute and the doctors told her parents that Dora would never be the same person from then on², that things might be similar, but that she would need 50% help with everything forever.

I first met Dora at the brain injury support group meeting. We met the next week at Earthfare and sat at a small table in the café. To start off our conversation, I asked Dora, a beautiful, soft spoken, Southern woman in her thirties, to tell me about herself. The very first thing she tells me is:

Before the accident, I was very outgoing. I was very. . . I was a happy person. I had problems just like anybody else, I was generally happy and I was fun. I was really fun to be around. I was jokin’, I mean I was shy to a degree but I was really a lot funner I think (Interviews with TBI survivors, 2009).

This reflection must hold such significant weight for Dora since this was the very first thing she tells me and also a theme she keeps referring to throughout the interview. She could have started off by telling me about who she is now or by describing her accident, but no, she tells me about who she was before. Later, she says, “I didn’t have a personality, it was gone. I remember I was this fun person, I don’t know what to do to get that back” (Interviews with TBI survivors, 2009). Another phrase she uses a lot was “it’s tough.” It’s tough trying to get your personality back. It’s tough not knowing how far to expect to recover. It’s tough to have people be afraid to interact with you because they don’t understand TBI. Dora says, “it bothers you, here you are a different person, but you’re the same person, you look the same...” (Interviews with TBI survivors, 2009).

Dora says it is “hard to get back in the swing of things, back socially where you were, it’s just tough, because you’re trying to figure out who you are now” (Interviews with TBI survivors, 2009). After her injury, she didn’t have much to say to her friends. When her friends would call her on the phone, they “wouldn’t get very far,” Dora would just “sit there.” She said this is when her friends began the three way calls. This way, “at least they could talk to each other when I was on

2 Many of my participants have mentioned doctors telling them or their families that they would not get much better or that they wouldn’t be themselves ever again. Dora thinks doctors might do this because they don’t want to give false hope, since every brain injury survivor is different and recovers differently and to different functioning levels. However, some participants feel that doctors should do a better job of encouraging and fostering hope.

the phone. Because I wouldn't talk much. And I still don't talk much" (Interviews with TBI survivors, 2009). Dora clearly had many friends who knew her as this fun person, and she has had to recreate her sense of self, through the looking glass. Her friends put her on three way because she does not talk, and that is reflected back to her, and she uses the information to change the way she sees herself, as a less talkative, less fun person.

In remembering their former selves as happy or fun people, there is a sense of regret or sorrow at the loss of these pieces of themselves. Both Frank and Dora seem desperate to find their ways back to being fun or being happy.

"because I was very tied to what I did:" memories of activities of daily living. One day while he was mountain biking, Joe, a very enthusiastic, optimistic, engaging man, flipped over his handlebars and had a mild traumatic brain injury. Luckily, he was wearing a helmet, so his injury wasn't worse. He found a brain injury day program to attend in New England, and finally got to go back to school for therapeutic recreation. He has recently moved to Asheville to work part time at the new day program for brain injury survivors called Hinds Feet Farms. We met at the library to talk about his experience with brain injury.

Joe used to train with other cyclists on the coasts of New Hampshire. The cyclist in front, the leader, has to put the most energy in, and the rest in back work off the leaders' energy and don't have to work as hard. Leaders rotate so everyone shares the energy load. The first time he practiced with this group again after his injury, he describes being the leader as they crossed over a bridge. He looked down from the bridge and saw a seal, which amazed him, and caused him to lose his speed. When the group stopped for a rest, all the guys asked him what happened on the bridge, implicitly referring to the time in which he lost speed. With excitement, Joe told his friends, "I saw a seal and it was the neatest thing!" (Interviews with TBI survivors, 2009). They immediately started "whopping" him with their hats and scolding him for slowing down. He realized,

Oh my God, racing is more important than the seal. Ha, and honestly before my injury I would have never noticed the seal there. But I started to realize, okay, I'm viewing the world differently and so I would like to be appreciated for the way I view the world instead of stomped on because I saw something that I felt good about. (Interviews with TBI survivors, 2009)

So Joe stepped down from the competitive activities that used to be so central to his life before. With this decision, "a lot of old friends became old gone friends" since they no longer had mutual interests.

After his injury, he feels that he has become not only less competitive, but more understanding, compassionate, and patient. He says that "most of us men" don't get it, but that women have more of "a flexibility, an understanding, a way of listening," all of which are benefits in his opinion. He feels that male TBI survivors have more of these listening, compassionate qualities, qualities that he truly values. These traits produce a community of acceptance, support, and cooperation instead

of individualized competition. He says, “For the most part in our country, you’re number one, stand alone. Do it yourself. That’s our culture although that becomes a very difficult scenario to play out successfully with the brain injury population.” He thinks that a healthier society would be one with a more “collective consciousness” idea, a phrase he emphasized throughout our conversation.

Frank has also experienced dramatic changes in his daily activities since his injury. Frank spent his entire career in broadcast television. He started in 1979 and says he knows nothing else. Most of his passion and energy was focused at work, where he has played many roles over the years, including reporter, anchor, and news director. He thrived in that fast paced, short deadline, high pressure workplace, the same factors that can challenge a TBI survivor. He says these factors can bring “a certain craziness, if you will, to what I did for a living, but there was no depression in my life. To a certain extent, I wouldn’t call it mania, but it’s a manic job anyway.” For Frank, his job was

This thing that I had that drove the financial part of my life, as well as, you know, what you referred to as identity. That’s a good way to put it, because I was very tied to what I did. I had a family and friends and a social life which I liked but that was really just Saturday and Sunday. Monday through Friday it was just go, go, go, this is what I do, this is how I live (Interviews with TBI survivors, 2009).

Like Joe, Frank expressed struggle in identity due to difference of daily life and activities. For Joe, we see this with athletic activities; for Frank, it is his work. Now with his TBI and bipolar diagnosis, Frank does not consider himself a reliable employee. He says, “with the mania and the depression, I’m pretty unpredictable, its not like I have any choice really. And when you’re like that, I have serious doubts about what I’d be able to offer to an employer.” On days when he is depressed, he does not want to talk to anyone or do anything. He struggles about what he would do on these days if he were employed, knowing he shouldn’t call in sick because he isn’t physically ill, but wonders about what an alternative would be. To be fair to potential employers, Frank says he has to understand that he really can’t make that kind of commitment. Even in a more manic mood, he might be flying all over the place, like a whirlwind, or have filtering issues, something common to many TBI survivors, which could cause confrontational problems in the workplace.

Frank has tried to go back to work twice since his injury. The first time everyone around him (family, friends, coworkers) did not think it was a good idea. But he insisted, so they let him try, and he quickly realized that they were right, he was not ready for work. He said he was “trying and trying and it just got to be too much” and so he had to ask for more time. When he came back for a second try, he was again unsuccessful. On top of this, he thinks news stations don’t want fifty three year olds, but the “completely inverse reality”—they’re looking for thirty five year old people. Frank also thinks and that it would be “difficult, perhaps unattainable, perhaps impossible” to retrain now. He isn’t trying to “wah wah wah, cry or anything” (Interviews with TBI survivors, 2009) but really questions his

ability to work, either in his own field or another.

For Joe and Frank, these activities were crucial to their identities. Being outdoors, physically active, and competitive were a large part of Joe's life. Frank's work was the master status of his life before his injury, something that defined him and energized him. In Chamberlain's study, "Men frequently commented about employment and how their identity was well-established in what they did for work. Employment difficulties seemed to affect their self-esteem and hinder their ability to recover" (Chamberlain 2006:413). With Joe's change in priorities and activities, and Frank's loss of being able to work, how can these individuals reconstruct or re-imagine their sense of selves to include these differences?

Reconstructing a Sense of Self

"my brain is *that* impaired:" cognitive differences. Kate Lindemann illustrates the struggle to find a sense of self with a changing way of thinking and processing information about the world. She describes a fifty year old woman who used to be a highly verbal thinker, but who, now after a stroke, cannot think in words anymore. How does she find a sense of self now? Lindemann elaborates,

The person with adult-onset brain injury, however, has had an identity that included certain styles of thought, certain ways of processing information that are now flawed or missing. She may learn coping skills for these deficits or she may abandon tasks that are no longer possible, but she also deals with the fact that her 'own mind is now like a stranger' (Lindemann 2001:110).

Angela, like most TBI survivors, went to many kinds of therapy as a part of her rehabilitation program. She went to a physical therapist, occupational therapist, and speech therapist. She really admires her speech therapist, who Angela thinks had the hardest job, basically to help Angela "use her brain again." The therapist helped Angela with her attention, focus, and cognition. Angela told me, "you can't imagine what it's like to not be able to use your brain. When you use it your whole life. I couldn't use it" (Interviews with TBI survivors, 2009).

Angela illustrates her issues with short term memory with an example. One day she called someone and was put on hold, so while she waited she checked a few emails on her laptop. While reading an email, Angela realized,

Oh my God, I'm on the phone! I couldn't remember who I was on the phone with, what we were talking about, I had no idea. And that was when I realized, this is terrifying. My brain is that impaired. I have that much work ahead of me (Interviews with TBI survivors, 2009).

Unlike most survivors, Angela also went to a developmental psychologist as a part of her therapies. Most survivors don't get much official help in learning how to navigate social situations, they have to find ways to practice social skills on their

own, like through support groups. After her injury, Angela says she was being treated like a child because she was “very much behaving like one.” She used to be a very social person, as any VP of a PR firm would be. But now she had trouble walking into a room full of people and knowing what to do. She didn’t know how to turn the focus away from her in a conversation. So her developmental psychologist would help her come up with strategies for these situations and help her start to think like she used to.

Bryce, a passionate brain injury survivor and advocate, also speaks about differences in cognition. He views his pre-injury self and his post-injury self as very different people. Since his injury, he has experienced drastic differences in his decision making, having to negotiate between the two selves, asking each what they want to do. Bryce shared the story of his experience with the Story Corps project, explaining it as:

Every time I approach a decision to make, I have before-car-wreck-adrenaline-junkie-Bryce and then I have the more reasonable, let’s-figure-it-out-Bryce. And every time I make a decision I have to have a committee hearing. My favorite analogy is: I’m out at a swimming hole and I ask myself, ‘What do you want to do, pre-car-wreck-Bryce?’ “Well I want to go to the top of that waterfall and dive from the top of that rock.’ “What do you wanna do post-car-wreck Bryce?’ “I’m happy sunbathing on the beach.’ “And I have to mediate between the two sides of myself, so I go halfway up the rock and jump in feet first. It’s not that this isn’t something that everyone goes through. It just seems that much more dramatic to me. On top of the patience that I have with myself, I accrue the debt of patience or lack of patience from society (Story Corps 2009).

Bryce also now has issues with short term memory and sequential thinking. Kate Lindemann speaks to the troubles survivors have with storing new memories. She asks how someone can create “a new sense of when new experiences are not codified and stored?” She continues, “If I can only remember myself pre-trauma and have little memory of what I have done post-trauma, how do I reconstruct an identity?”(Lindeman 2001:110).

Short term memory issues are common to many TBI survivors. After I met Drew, we decided that we would go contra dancing together. A carload of my friends and I picked him up and we drove to Warren Wilson College for the dance. In the car, everyone introduced themselves to Drew, and within minutes, he kept having trouble remembering names. Everyone laughed like it was funny, but fifteen minutes later, as we were parking, after a whole car ride of name games, he still could not remember any of the names. During the dance, he asked me my name again. He had called me for a ride, so I had assumed he would remember my name, but this made me realize the full extent of his short term memory problems.

Drew says forgetfulness is his biggest downfall. Memory loss inflicts a devastating blow to a survivor’s “sense of continuous identity, severely limiting his ability to articulate a stable narrative account of himself”(Eakin 2001:120). People

have expectations of you remembering names after a certain point, and if you don't remember, you must be lazy or not interested in the person enough to remember a name. For a social person like Drew, how does this affect sense of self?

the “sticky situation:” the (in)visibility of TBI. For some survivors, TBI is a noticeable disability. Survivors may walk slowly, talk slowly, have scars from their surgeries, or have double vision which might cause their eyes to go in different directions. For some, these features stay with the survivor for long periods of time, maybe for the rest of their lives. For other survivors, with time and therapies, these features slowly disappear, and their TBI becomes an invisible disability. Chamberlain describes this invisibility of TBI and how it affects survivors' sense of self,

TBI disability was integral to their being (and self). One of the difficulties encountered with constructing reality was the invisible nature of TBI disability. The construction of the recovering self required reflection and comparison with what resembled being normal, yet subsisting with an invisible disability made that process exigent (Chamberlain 2006:414).

Dora struggles with the invisibility of her disability. Most of Dora's friends say that she is the same person from before her car wreck. She looks the same, which made it hard for them to fully understand how she had changed. Only Dora and her mom, who has been with her truly throughout the entire process, really understand the change. When she got back to college, she would try to hang out with her friends just like she used to, and she would notice how different she was. She says,

My friends had a hard time. Still my friends will say, there's nothing wrong with you, you're exactly the same, there's nothing wrong with you, you might've had a brain injury but you are the exact same person. Well, no I'm not. And it is so hard. Some of my friends still don't get that, some of my friends still think I am the same person (Interviews with TBI survivors, 2009).

Frank's disability is also invisible and like Dora, his friends don't see any difference after his injury. The people he is closest to, his wife, sister, and daughter, see the differences clearly, subtle differences that sometimes Frank himself doesn't necessarily notice. But in general, Frank is very aware of the striking differences he experiences every day. He says,

Traumatic brain injury is a really sticky situation, especially my situation. Because, once again, you know, people look at me, and it's like 'wow, he's in good shape. Physically, he looks terrific, and he can talk, and you know all that other stuff (Interviews with TBI survivors, 2009).

Not only do friends, coworkers, and other acquaintances not notice his disability, insurance companies don't recognize it either. He says if he was in a wheelchair or had fallen off a ladder and hurt his back, his disability would be more definable.

Frank says that insurance companies in general don't like to pay on those disabilities that aren't obvious. Because of this, he has had to fight to prove his disability by having interviews and tests from doctors and hiring an attorney to put together case law appeals. He is happy he isn't in a wheelchair, but he does have a disability. And at a time when he is trying to figure out who he is and how he has changed, he has to battle this system of bureaucracy that doesn't help with his stress, anxiety, and general well being.

The effect of the apparent invisibility of both Frank and Dora's disability make it hard for others to understand the full affects of their experiences with TBI. Frank has had a lot of problems fighting insurance companies due to this very reason.

"I'm gonna be fun again:" reimagining self. In Chamberlain's study, "Twenty six of the fifty nine informants presented themselves as being on their way back to their old selves 'before injury'" (Chamberlain 2006:413). Many survivors are told they will never get back to where they used to be, they'll never be their old selves again. Many crave to be back to their old selves though they don't know how reasonable it is to hope for it. Many have to reconstruct a new identity, one that combines aspects of their self, old and new.

Being a TBI survivor has become a critical part of Frank's identity. He describes how he is reminded of this every morning when he wakes up,

Every day since that day in June when I got my where-with-all back I have woken up in the morning and the first thing I think is 'I'm a TBI survivor.' Every morning that's the first thing you think and it bugs the hell out of you. I want to wake up one morning and think of something else. But I can't. My guess at this point, more than three years later, is that I never will. And that might not sound like a big deal to some people but it bugs the hell out of you. It's not where you want to start the day. Where I would start the day before, like normal people, with hope, with excitement, 'hey it's Saturday!' Everyday's the same to me. Seven days a week. A week. A month. Everyday's the same (Interviews with TBI survivors, 2009).

He wishes this wasn't so, but this is clearly a critical part of his identity. Before his injury, he took his moments of waking up for granted. Now with his TBI, that is all he can think of. Work must have been something he thought about upon waking most days of the week. Now he doesn't know whether he will be able to go back to work, and it is frustrating. He is going to have to reframe his identity around something new if his life continues not to include work and this is going to be something he will have trouble with since his previous self revolved around what he did for a living.

Drew says that after his injury, he is probably 75% a different person, "I've changed a great deal but I still have some of the characteristics, I am still me! I am still Drew!" (Interviews with TBI survivors, 2009). He explains,

I got like four heads running around. Four Drew's. I believe that I am very variable in a lot of ways but this head, maybe a couple of these heads, sort of feel like I want to get up and do something in this world... (Interviews with TBI survivors, 2009).

Drew feels inconsistent, sometimes optimistic about making a name for himself and changing the world, and sometimes not. He describes being diagnosed with bipolar disorder, going on different medications which cause him not feeling in control of himself, jumpy, and unsure about everything. How can he reconstruct his sense of self when he feels so variable? He is trying to get of meds which he attributes many of these feelings of inconsistency and variability, but he will still have to negotiate the question of "who am I?"

Dora feels the same inconsistencies that Drew talks about. She expresses this struggle with self well,

I still can't figure out how to get to be the same way as I was, or the same kind of personality, or the same, I can't figure it out, but I'm gonna get there someday. I'll never be the same person again, but I'm gonna be fun again! I'm gonna, I don't know. I'm still there, I'm just trying to figure it out (Interviews with TBI survivors, 2009).

Dora's hesitations and uncertainties highlight her journey, a journey so many survivors travel, to figure out how to move on from here, how to move towards her old self, even though that might not mean returning to her old self completely.

Conclusion

Traumatic Brain Injury Survivors have to reimagine sense of self. After their injury, they may not have memory of their earlier lives, who they were, or events in the amnesiac window. Some will never recover these memories, but most survivors will, and they have to manage incorporating memories which emphasize the sometimes extreme differences in self before and after injury. These memories may include activities they have lost or rejected. They may include traits and moods that are missing or changed now, or different ways of thinking. People in the survivors' lives may or may not see any difference in the survivor before and after injury, which may cause lack of understanding of survivors' full experience and journey of self.

Through narrative and the story telling process, survivors experience a form of therapy, a way of reforming and reimagining their identities. As the narrative psychologists say, "We are all storytellers, and we are the stories we tell" (McAdams, Josselson, and Lieblich 2006:3). Survivors take the old memories and new experiences and form them into a cohesive life story which they can claim. Their sense of self can begin to feel connected, not disjointed, and with it, survivors can create a fulfilling life.

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