

My Quest through Chaos: My Narrative of Illness and Recovery

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Abstract:

Stories of people trying to figure out who they are following illness are both popular amongst readers and vital to the author's recovery. This article is an illness narrative and an exploration of illness, narrative, recovery, and critical disability studies. Using my own experience of having a massive stroke as an 18-year-old, the article considers narrative structures present in a series of journal entries, video diaries, letters, and blogs to reflect on the importance of narrative throughout my recovery. My story has evolved through the dominant narrative structures of the illness narrative as outlined by Frank (1995)—chaos, restitution, and quest. These narrative types display the relationship between narrative and culture, and emphasise the complexity of illness. Telling illness narratives is a valuable means of recovery when the body becomes what the individual never expected it would—damaged. Narrative is vital, as the ill persons work out their changing identity and position in the world of health, continuing when they are no longer ill, but remain marked by their experience. This article connects the (my) autobiographical to the social, political and cultural.

Writing testimony, to be sure, means that we tell our stories. But it also means that we no longer allow ourselves to be silenced or allow others to speak for our experience. Louise DeSalvo, *Writing as a Way of Healing* (216)

Stories of people trying to sort out who they are figure prominently on the landscape of postmodern times. Those who have been objects of others' reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own truth, in her own words. Arthur W. Frank, *The Wounded Storyteller* (xiii)

Introduction

1 Seriously ill people need to tell stories: to their doctors, to their family, to their friends, to themselves. This article is both an illness narrative and an exploration of illness, narrative, recovery and critical disability studies. Telling illness narratives is a valuable means of recovery when the body becomes what the individual never expected it would—damaged. Narrative is vital, as the ill person works out their changing identity, and position in the world of health, continuing when they are no longer ill, but remain marked by their experience.

2 Following the tradition of illness auto ethnographers (Frank, *The Wounded Storyteller*; Ettore; Rier), this article critically examines the role of narrative throughout recovery from serious illness or trauma by connecting the (my) autobiographical to the social, political and cultural. The paper is divided into six sections and explores three different narrative structures commonly adopted by people telling illness narratives and the way they are shaped by culture.

I begin by establishing illness narratives as a field of enquiry within critical disability studies and introduce my own experience with life threatening illness as the motivation for storytelling. The next three sections of the paper utilise Arthur Frank's chaos, restitution and quest illness narrative structures in conjunction with Joseph Campbell's hero's journey to argue recovery is a process of travelling through and returning to these modes of storytelling. Restitution desires the past and prevents recovery while chaos does not consider recovery. When the wounded storyteller arrives at the quest narrative and draws together chaos and restitution with a sense of purpose, recovery can be achieved. Although these narrative types are not the only structures available (cf. Couser), I introduce them here as an opportunity for reflexive self research. The focus then shifts to the recent emergence of illness narrative blogging to consider their cultural significance before exploring stigma and resistance to the telling of illness narratives and offering conclusions towards this end.

3 Although influenced by medical sociologists such as Arthur Frank and Elizabeth Ettorre, I write this article as a critical disability theorist seeking to refine the social model of disability in order to recognize the impact of impairment and illness on those who find benefit from a social understanding of disability. The social model of disability sees disability as the negative social reaction to impairment which has resulted in disempowerment and an inaccessible environment. This model has traditionally neglected to include people suffering from illness or debilitating impairments. I proceed alongside recent calls to broaden the scope of theorization to reflect on biology and the difficulties that result from illness and impairment and can't be blamed purely on a disabling society (Shakespeare 39).

4 Like Mitchell and Snyder (2), I choose to use the terminology "people with disability" throughout this paper rather than "disabled people" which is favoured by social modellers. Via this terminology I recognise disability as more than a medical problem yet acknowledge the body (including medicalized experiences) within my theorization of disability and social construction. Mitchell and Snyder's definition works well with Goffman's notes on stigma creation and encompasses people experiencing illness. By drawing on a series of journal entries, video diaries, letters, and blogs, my narrative and argument moves between and alongside the chronology of the catastrophic event which has motivated both my research and writing and personal perception of the world. While I have attempted to record months as accurately as possible, the exclusion of dates from some of the reflective material arises from the chaotic experience of my illness and recovery. I did not always record the date on which I wrote something, perhaps because a future was so out of sight and in many ways time did stand still.

Illness Narratives

5 Monday 24 March 1997 I had a massive stroke and my life depended on controversial surgery. Eventually my ability to walk would depend on exhaustive rehabilitation. I was 18 years old. I never expected such a thing would happen to me. Recovery seemed very long and required a total reworking of who I believed myself to be:

On Saturday it was exactly 10 years since I had a stroke and my life changed forever. And that day was the first 'anniversary' that I wasn't sad. I had a really awesome day. I read somewhere that you're more likely to have another stroke within 10 years of your first one, so I dunno if that's why I was feeling good or if it's cause I realise that my life 'changes forever' almost every year... (Unpublished Livejournal blog 26 March 2007)

6 According to Bonner and McKay, an illness narrative is most often autobiographical in nature and “recount[s] an individual’s experience with accident and disease, usually tracing the situation from onset through diagnosis, treatment and recovery” (156). Illness narratives allow damaged bodies a privileged means of recovery and a way to navigate the worlds of health and illness. People enter into narrative predominantly out of a desire for self-exploration, but also to help others going through a similar experience. Many note that in the process of telling their illness narrative they experienced healing and a renewed identity (see Sherr Klein; DeSalvo). Illness narratives adopt different structures but can usually be categorised as chaos, restitution or quest (Frank, *The Wounded Storyteller* 53).

7 The chaos narrative lacks reflection as recovery is not a recognisable possibility, while in the restitution narrative, a recovery of the self as it existed before the onset of illness is emphasised, and restoring health is the basis of the storyline. Finally, in the quest narrative, the illness is seen as a calling and recovery is dependent on acknowledging a changing world view and sense of self (DeSalvo 199). Combining these narrative structures documents and aids recovery. These narrative types move alongside each other as the story continually unfolds (Thomas-MacLean 1648).

8 I have used the documentary film medium twice to document my illness narrative. However, it was not until I had finished the second film that I felt I had personally gained something out of it, emerging as a changed person. During the making of the second film I described it as:

A story about Katie Ellis a 21 year old who after suffering a massive stroke at the age of 18 wants to find healing by turning her stroke into a documentary to gain insight enabling her to get on with her life as someone new. (With Both Hands Directors' Statement April 2000)

9 I wrote that the success of this aim would simply be in completing the documentary. However, I had already completed a documentary the previous year; if the success was simply in making the film, why was I not satisfied? I initially described this earlier film in these terms:

An 18-year-old girl has a severe stroke. She is not affected mentally but physically she is left totally paralysed on one side of her body. She is placed in a rehabilitation hospital with other stroke patients about three times her age. She feels no one else understands but internalises this feeling. At first she is very outwardly depressed and keeps to herself in the hospital and doesn't associate with the other patients but as time goes on and she improves she begins to rely more on the other patients than her friends. She has been told that she will never fully recover and that her arm and foot in particular will probably never actively function again. She knows that this is true but cannot admit it to other people let alone herself. (In Between Spaces Directors' Statement August 1999)

10 While at this stage I was beginning to address thoughts and feelings with detailed accounts, I don't appear to be writing about *my* personal experiences. Although both documentaries were about myself—and I had control over what went into each—there is an obvious difference in approach. I wrote about wanting to remake the film:

I wanted to tell my story not just to work out my changing identity but also to guide others. Restoring my health was the basis of the story line of a previous film I had made. While at first this story seemed cathartic, I needed to make a film where I linked my feeling with events in a detailed way. When I made this link a sense of purpose emerged. My struggle became an opportunity for journey. (With Both Hands Directors' Statement February 2001)

11 The need to turn these experiences of illness into stories is not uncommon: “people tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one's own map” (Frank, *The Wounded Storyteller* 17). I felt the need to tell my story:

I felt a responsibility for testimony, to give it voice, to share my story for use so that it was not wasted. The quest story changed my relationship with my pain. I preferred to use it rather than regret it. (With Both Hands Directors' Statement November 2000)

12 Using rather than regretting my illness involved giving voice to my experience via narrative and I began with the chaos narrative, perhaps the most uncomfortable and least heard of the three structures Frank describes.

Chaos Narratives

13 When serious physical illness or injury happen in a culture that takes health for granted, it is a shock that makes the body unfamiliar to the individual and thus brings about a total re-imagination of the 'self' (Nettelbeck 153). People often retell their stories by venting their feelings through the chaos narrative. In the chaos story illness stretches on forever as time has no sequence, and the writer does not associate with what s/he is writing. There is no future in sight. It is as though the story is being forced to go faster in order to catch the suffering in words (Frank, *The Wounded Storyteller* 102):

I'm trying desperately to be the girl I used to be but there was nothing wrong with her. She wasn't trapped in a body that doesn't work. Sometimes I think I did die and this is actually hell. I'm so scared I might not get better but how can I tell myself this, let alone other people? Is this really a life wasted? No one really understands what I'm going through, but how does feeling sorry for myself help? Now I'm living in a rehab hospital, depending on people I don't know to wash, dress, and toilet me. Sometimes it gets me down that everyone in this hospital is so much older than me. I'm only somewhat comforted when told that younger people have a higher chance of recovery, because I'm also constantly reminded how abnormal it is for an 18-year-old to have a stroke in the first place. I think about what I am missing out on, all the time. (Unpublished Journal April 1997)

14 In my chaos narrative, recovery is already deemed unachievable because I have no other way of thinking about myself in the world. My present self was so different to the past, that I was experiencing myself as an "other" (Rimmon-Kenan). I have no agency; other people "do" everything to and for me. I feel out of place, perhaps already dead, a wasted life. I'm unable to receive comfort. It's not comforting that younger people have a higher chance of recovery when I know younger have a lower chance of having a stroke in the first place, and it's already happened to me.

15 In the chaos narrative, I have dissociated from my body, abandoned identification with myself. Through a lack of reflection these stories take on an 'and then and then' structure:

I'm only 18, I didn't realise 18-year-olds could have strokes; I thought that only happened to 500-year-olds. When it happened I was talking on the phone to a friend. I started to develop a headache and apparently my voice became softer and I began slurring my words and just hung up. I then took two panadol and began throwing up violently. I began looking around my bedroom for something to throw up in, as I felt too weak to walk to the toilet. It was then that my mother and two sisters found me and tried to lift me but couldn't, my dad came home and told me to put my weight on my leg and I told him that it already was. I was then driven to hospital in an ambulance. (Unpublished Journal April 1997)

16 Seriously ill people need to tell stories: to their doctors, to their family, to their friends, to themselves. The story I was telling my friends in 1997 was a combination of the chaos and restitution narratives (explored in the next section). But as yet, it didn't have a purpose:

I can't move my left side. But my face has gone back to normal, but they had to shave half my head because part of my skull has been removed, as my brain was swelling too much and I would have died otherwise. I used to wish that I had just died, because I feel that my recovery is taking too long and that no one understood. But in reality, my doctors reckon that I'm getting better really fast. Well my arm is moving a bit more. I can basically move my thumb whenever I want but my fingers aren't back yet. My foot isn't either. And I'm really stressing about that. So yeah, I'm pissed off that this has happened to me. (Unpublished Letter May 1997)

This letter begins to link feelings with detail, but still demonstrates dissociation with myself. When this link is made “the ill person gradually realises a sense of purpose, [and] the idea that illness has been a journey emerges” (Frank, *The Wounded Storyteller* 117). This letter (which I never sent) reveals that I was not seeing a future for myself yet and was relying heavily on doctors' opinions, even to the point where I was discounting my own. I was having trouble admitting that I might never fully recover the parts of my body that were paralysed. Admitting the severity of my impairment to other people was worse because I felt an intense cultural pressure to tell a restitution narrative that would reassure everyone that I was, and would be, okay:

Constantly people ask me 'how are you?' How do I answer that? I can't move properly or much really but health wise I feel normal—not sick or anything like that. Also people wish me well for a speedy recovery. While this would be great a full recovery is what I hope for. (Unpublished Journal June 1997)

Restitution Narratives

17 In the restitution narrative, restoring health is the basis of the story line. They are like a paracetamol commercial—“yesterday I was healthy, today I'm sick and tomorrow I'll be healthy again” (Frank, *The Wounded Storyteller* 77). Our society welcomes restitution narratives, encourages them because we need to believe that medicine can cure everything. The restitution narrative is favoured by people who are ill because new identities, that acutely remind individuals of their difference, are resisted.

18 During the period of my physiotherapy treatment I stopped using my journal to vent and instead started documenting what I saw as important steps towards my recovery of becoming that girl I “used to be”:

11 April 1997 Started physio

17 April 1997 Walked with two physios

05 May 1997 Walked with one physio

20 May 1997 Walked alone

24 June 1997 Walked alone 20 minutes

13 July 1997 Didn't use wheelchair all weekend

21 March 2000 I am able (bodied). I am independent. There is nothing I can't achieve

Although documenting what I experienced, these short entries in no way explain what I was experiencing or what is really involved in learning to walk again. The only time I did venture further than just one sentence was the day I walked alone for the very first time and even then all I said was: *The feeling of euphoria I experienced at that moment is describable only by the smile that was my face.* (Unpublished Journal May 1997) These entries provide evidence for DeSalvo's argument that "the implication of the restitution narrative is that our bodies can be restored to what they were like before illness struck" (198). Although discounted by disability theorists (Barnes 23; Oliver 32), the restitution narrative is nevertheless crucial to recovery because it encourages people who are ill come to terms with the world of "health" and their place in it (Radley 98). Although initially resisted, following illness or injury, individuals must redefine themselves. By reworking the restitution narrative's claim that things can return to how they were before, the quest narrative acknowledges that everything has changed.

19 The restitution story is favoured by society because it provides reassurance in the myth of body stability. However, many people with illness and disability do not fit into a restitution narrative. Although I sought to believe in restorative health via the restitution narrative, ultimately I acknowledged that illness was an experience and identity that I needed to embrace and via the quest narrative I'm able to explore an alternative way of being (well).

Quest Narratives

20 The quest story allows the ill person to give testimony and reflect on their changing identity in a culture of health. Several years after my stroke I described having my stroke without adopting the chaos structure:

I was watching t.v., and also talking on the phone and then I started feeling dizzy. I wasn't mad at my friend who I was talking to or anything; it was a normal time, normal day. So I said to her I have to get off the phone because I feel really dizzy. [...] I ran up to my bedroom and started talking really funny and just threw up everywhere. Then I had this explosion in my head, a really bad headache, worse than I've ever had before. I didn't think this was as bad as it was. I just thought it was this really weird headache that I was having and didn't realise that I was having a stroke. But I realized something was going to be different, from that moment but I didn't really realise how and how badly. I was really confused the whole time and I went and took panadol as well. It was more the pain of having it, even though it's not supposed to hurt. That's crap, because it does. And vomiting, I don't know how normal that is but that's what happened to me. That might have had something to do with me choking on panadol. Because I thought I'll take panadol and be okay. (With Both Hands recorded on 15 August 2000)

About the same event, there are significant differences in the retelling. In my chaos narrative I described events leading up to the stroke without actually writing about the moment itself,

although I have always been able to remember it. In the later description, I also noted that I realised something was going to be different, without realising what would change. The quest had begun, as I was beginning to accept my stroke was a calling, that my life would take a new direction.

21 Throughout the writing of my own quest narrative I drew on several published examples of illness narratives dealing with stroke (Newborn; Berger; Sherr Klein) while rejecting others (Leaney; Veith). The authors that I followed conceptually saw their strokes as the first stage of the hero's journey as according to Joseph Campbell; departure. According to Campbell, all narratives adopt three main stages beginning with departure where the hero leaves the ordinary world to search for a solution or elixir. In all cases mentioned the call to departure is having a stroke. Before finding the elixir in the second stage (initiation) the hero encounters trials. In the illness narrative these trials take the form of suffering, and illness. The elixir, which the hero finds in the initiation stage, is in the form of knowledge gained. This basic narrative structure corresponds with Frank's framework for illness narrative as he ultimately suggests the "crucial test of a story might be the sort of person it shapes" (Frank, *The Wounded Storyteller* 157). The hero returns to the world transformed with new strength in the third stage. The hero of the illness narrative "returns as one who is no longer ill but remains marked by illness" (Frank, *The Wounded Storyteller* 118). The illness has changed the hero, given him/ her a new perspective. Healing brings about a new perspective (DeSalvo 3).

22 The quest narrative follows the three major stages of Joseph Campbell's description of the hero's journey; departure, initiation and return. My call to departure was having a stroke. My initiation was trials, in the form of suffering and illness, enabling me to gain knowledge (elixir):

Yeah I was amazed that I was doing this all by myself. Yeah I wasn't prepared for it and I remember thinking 1st time I walked I'm gunna be so happy and then when I actually did I didn't realise I was until towards the very end and if you see the smile on my face I think that's the only way I can possibly describe it there's no words. It's still an ongoing thing it's not like you walk one day and you walk forever you have to still work at it. (With Both Hands recorded on 15 August 2000)

23 In the third stage, the hero of the illness narrative "returns as one who is no longer ill but remains marked by illness" (Frank, *The Wounded Storyteller* 118). I returned in the third stage no longer ill but forever influenced by my trials. I was changed by illness, given a new perspective. The quest story changed my relationship with my pain. When I began this journey I couldn't understand why I was chosen to take it: *Why couldn't this have happened*

to a stronger person? Unpublished Journal May 1997 I now know that I am this “stronger person” I wrote about. I would not have chosen this way, and I often wonder how I travelled it, but I would never change it either:

It's a huge part of my life, it's everything to me—that this has happened to me and that I got through it and things are pretty normal and that I can pretty much live as I would have before. It's just, there is a weakness. You could say it's like this hasn't happened to me, but it has. That's what's made me who I am now, and I am grateful for that, I am happy for that. It changed how I felt about things. (With Both Hands recorded on 15 August 2000)

This entry demonstrates the importance of not choosing one narrative structure above another, but keeping all of them. All three types are clear in this entry. Restitution: when I claim that I can live as I would have been able to before. Chaos: when I continue to dissociate myself from my body “there is a weakness.” Quest: when I recognise the knowledge I have gained. These types of experience are different from the mainstream belief in health and body stability yet cannot be attributed wholly to a disabling society. In the next section, I explore the relevance of the social model of disability to my own changing identity and offer some reflections on how illness can expand the relevance of this model.

Illness Narratives and the Social Model of Disability

24 People who are seriously ill or who experience disability as a result of illness do not fit neatly into cultural and social theories, often being positioned as the real limitation from which to escape. For example, women, gay men and lesbians and indigenous people have historically experienced a medical pathologisation that has contributed to their social exclusion. Disability activists likewise refuse any association with illness, particularly within the social model of disability which argues that most, if not all, of the problems experienced by people with disability can be solved via social manipulation. Under the paradigm of the social model of disability, impairment becomes disability because society is structured for the able bodied majority (Oliver 22):

The more I read about the social model of disability, the more I began to question my own identity. I became absorbed in the debate as it ran through every aspect of my life, often seeping into practical aspects of my research. Why, for example, were the disability studies books placed on the top shelf of my university's library? Why wouldn't my university's insurance policy cover me for overseas research travel? Why did delivery trucks park in the disabled parking bays? These disabling situations that have been left up to me as an individual to deal with, have nothing to do with my impairment. Disability is an ideological reality. (Ellis, “You Look Normal to Me” 8 June 2004)

25 As a way to maintain political power, illness and the effects of impairment have been played down under this model of empowerment (Shakespeare and Watson 5). While this strategy was integral in raising the self esteem and political awareness of the disability community, this model requires a revision to allow for the inclusion of other groups experiencing social exclusion. As Shakespeare and Watson argue, “the denial of difference is as big a problem for disability studies [...] as it was for feminism” (11). They draw on the work of Linda Birke in feminist studies to suggest the body does affect the lives of people who have impairments and to deny this is to deny a huge part of the lived experience of these people. Illness and impairment are important aspects of the personal identity of many people with disability:

I cut my long hair pretty short [and] I feel like I've reclaimed myself and have stopped trying to chase the person I was when I was 18—before I had a stroke and was forced to shave my hair off for an operation. (Unpublished Livejournal blog 24 January 2006)

This short blog appears in my Livejournal alongside longer entries that document my social life, search for an academic job, publications strategy, teaching workload and pop culture quizzes which I describe as my “journey of self-discovery.” This blog entry acknowledges that long hair is a socially constructed marker of femininity, yet recognises the significant impact losing my hair had on my sense of self and the loss of control I felt at that moment. There is also much evidence throughout this blog that although I am no longer ill, I remain marked by my illness as Frank predicts happens to people who experience and recover from serious illness:

Yesterday I was reading an article that said people who drink lots of coffee are more likely to have heart attacks. This was not good news but I thought I'd be able to screen it out of my consciousness but then I kept reading and it went on to say coffee also increases levels of the stress hormone homocystine, which can lead to strokes. Considering I've had a very very high level of homocystine which did in fact lead to stroke I felt I should pay attention. My sister Amanda tells me that I already knew this—just chose to forget. Maybe I should get a homocystine check. So today I have had one cup of coffee and one decaf. I feel my productivity slipping in very extreme ways. (Unpublished Livejournal blog 13 March 2006)

26 Blogs are interactive online reverse chronological journals that allow authors to reflect on life and the events they experience. Unlike typical diaries or journals, blogs are characterised by community, and allow others to contribute to your experiences via comments. For Michael Keren, illness narrative blogs are one of the most important functions of this new form of communication because they allow sick people to share their day by day, hour by hour feelings while gaining and sharing information and emotional support (119).

Although the experience of stroke shapes my daily perceptions, my blog is not an illness narrative blog in the strictest sense of the definition. It does however allow me an outlet to express experiences that are usually silenced by both my culture which does not wish to be reminded of body instability, and my research area which discourages any association with the body. The blog format likewise generates chaos, restitution and quest narrative structures in the recording of my continuing experiences.

27 Bogs enable people an outlet, and illness narrative blogs which focus on the articulation of the experience of illness in order to understand it better and/ or provide support to others, have emerged as an important subgroup in the blogosphere. These online spaces hold significance for life writing as they allow suffers (or recovers) a way to recover a sense of agency while transforming the private into public (McCosker). Power imbalances and social constructions are de- and reconstructed within these narratives. Patients become the experts online in a massive power shift and people who never recover from their illness or who eventually die as a result receive as much agency as those fully realising the restitution narrative. Although blogging was not an option available to me in 1997, based on my short and sometimes, several times a day journal entries, I imagine I would have used it if it were. I use blogs now as a way to navigate my life and experiences within and outside my research and writing in critical disability studies.

28 For Rosemary Garland-Thompson conventional narrative genres usually conform to an image of bodily stability and perpetuate cultural fantasies of loss and relentless cure seeking rather than present stories “possible because of rather than in spite of disability” (114). She argues that by presenting disability within the context of community in particular, disability can structure a positive story. Illness narrative blogs as they are firmly embedded within community achieve Garland-Thompson’s vision while also allowing for the narrative structures examined earlier in this article. The potential for each of the three narrative structures to be present at any one time within a blog generates different narrative models within illness narrative.

29 The cultural implications of the intersection between the social model of disability and disability and illness blogging can be seen in the way they “move beyond the medical versus social divide of disability” (Goggin and Noonan 165). My blog from 2006 compared to my musings about the social model of disability in 2004 demonstrate that while I ascribe to the social model of disability, my illness narrative is continually unfolding, impacting on my personal identity.

30 Through a focus on the individual, illness narratives have been accused of medicalising the experience of disability by perpetuating damaging stereotypes (Barnes 23). The social model must also respond to the stereotypical aspects of life, disability and illness (Waine; Ellis, “Aww Factor”). Tom Shakespeare draws on these critiques to argue that the social model must engage with impairment because it is a “central and structuring part of the experience [of disability].” Impairment is not neutral and while it does lead to disadvantage it also “lead[s] to opportunities: for example, to experience the world in a different way” (43):

I went back to University the year after my stroke to study film and media and in my final unit two years later I stood up at the beginning of the semester and pitched a film about my having had a stroke a few years before. Most of my class mates had no idea, I had successfully passed. My class voted to make this film and I began my process of “coming out” by talking about what I had experienced rather than silencing myself. My passing had deprived people of experiencing the diversity of society although it took me a while to embrace my illness and to realize illness autobiography and honour in disease are possible because of other marginalized groups taking pride in their stigmatized identities. (Ellis, “I Premiered My First Film in an Inaccessible Cinema” 9 August 2009)

31 Despite the proliferation of ill bodies in Western mass media, illness makes us uncomfortable. Illness and people who are ill are stigmatized and used to make the rest of society feel less tenuous about their own body stability. This stigma is perpetuated via mainstream media through the saturation of restitution narratives and the silencing of chaos and the idea that quest establishes a different way of being well. Goffman distinguishes between the *normals* and those who possess a stigma and argues that those who have stigmas such as physical deformities are discriminated against by the normals because “we believe the person with the stigma is not quite human” (73). Although Goffman recognises that an ideology is created in regard to stigma to explain inferiority and rationalise fears about the stigmatised group, he places the stigma within the body.

32 Definitions of illness operate on an ideological level through stigma, and the hegemony of ‘health’ is maintained as long as illness is individualised. Illness is not just there; it is constructed by the boundaries of normality. The most popular illness narratives project a cultural narrative of loss and cure seeking—our society encourages narratives that have happy endings. For Susan Sontag, this is because everyone holds membership within both the world of the sick and that of the well and we rely on the promise of medicine to cure all diseases (1). New identities, that acutely remind individuals of their difference, are resisted and stigmatised by wider society.

33 When I was invited to give a client’s perspective on experiencing neurological disability to a group of physiotherapists completing a Graduate Diploma in Neurological

Rehabilitation at the University of Western Australia, I decided to share several of the journal entries discussed throughout this paper, while reflecting on the way society encourages certain types of stories while discouraging others in order to reinforce socially constructed power imbalances:

My brief was broad, I could discuss whatever I wanted to; however, as I was invited due to my personal experiences, success and knowledge, I felt some pressure to tell an 'inspirational' story. I decided instead to talk about how I have told my 'illness narrative' and how this can be used in stroke recovery, particularly in relation to negotiating a changing identity. What an interesting experience! I titled my piece "Testimony: Illness and narrative" and used excerpts from my journal to highlight the differing narrative structures a person adopts when writing through trauma. The students who were largely practicing physiotherapists had trouble relating to me as a person with knowledge and attempted to turn me into a patient again, offering me advice on my walking and pointing out the way my movement changed when I revisited particularly traumatic times in my illness and recovery. This was despite my telling them that I found it difficult to read some particularly chaotic and depressing journal entries. They wanted the power, but I refused to give it up. Their attempts to put me in that position of patient again made me realize the importance of telling my own story all over again. (Unpublished Journal 17 August 2006)

Retelling my illness narrative in this way from the perspective of someone who had recovered but remained marked by their illness was difficult for the students to comprehend, and they encouraged me to adopt the restitution narrative, to socially and medically shape my experience once again; to treat me as a body to be observed. My cultural and literary interpretations of my own experiences left them wanting as they continued to medicalise me and others like me.

Conclusion

34 Prominent sociologist C. Wright Mills maintains that admirable scholarly thinkers draw on their life in their intellectual work (195-96). I have attempted to do this throughout this paper in order to foreground the importance of narrative knowledge within both medical knowledge and critical disability activism.

35 Taking health for granted looms large in our culture, "one of our most tenacious cultural fantasies is a belief in body stability" (Garland-Thompson 114). When illness does occur we relentlessly strive for a happy ending, and the most popular narratives retell a story of loss and cure-seeking. Arguably, the act of writing this article could be seen as a (re)telling of my restitution narrative; however, the inclusion of chaos aspects disrupts the culturally shaped framework of illness and recovery.

36 The narrative of recovery invariably includes aspects of grief and yearning for the past. The three illness narrative types I have discussed in this article are not separate entities in the search for an essential self. They are postmodern stages through which one passes and returns. There is power in sharing, and using writing as a means to work through pain invites creativity and innovation (Jones and Brabazon). While this article has predominantly focused on older forms of media, new media, such as blogs and virtual reality are providing people recovering from serious illness the chance to use narrative as a way to reflect on their recovery (Pajtas 13).

37 As a process of recovery, illness narratives invariably incorporate the chaos, restitution and quest structures. These narrative types display the relationship between narrative and culture, and emphasise the complexity of illness (Thomas-MacLean 1648). Narrative is vital, as the ill persons work out their changing identity and position in the world of health, continuing when they are no longer ill, but remain marked by their experience:

My interest in disability is largely due to my own experience with disability. Following a stroke, I have for the last eleven years lived with weakness and spasticity in the left side of my body and epilepsy. [Eight years ago] I made a documentary about my rehabilitation from stroke. During this exercise I began to notice that many able-bodied people who had not had similar experiences to my own were “reassuring” me that I looked and seemed “normal.” (Disabling Diversity 18 May 2008)

Disability and illness are not straightforward and warrant further investigation. Writing this paper has allowed me to think reflexively on my own illness and how it continues to affect my life, including my ongoing research and writing.

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