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Illness, Identity, and the Redefinition of Self through Narrative

My Experience with Guillain-Barré Syndrome

By Adrian Wittenberg

Introduction

The mind and body are linked in an individual's self-identity. A disease—an abnormal biological condition—thus leads to illness, "[the] innately human experience of symptoms and suffering. . ." which includes the ways that "the sick person and members of the family or wider social network perceive, live with, and respond to symptoms and disability."[i] The change in self-identity for those experiencing illness can be palliative, or can exacerbate the illness, leading to a disassociation with a new, unrecognizable self. Either way, the individual must learn to proceed through life anew.

Self-identity is formed by recognizing one's own characteristics, as well as by interacting with society. Similarly, those who experience illness form a new self-identity based on their subjective experience of an objectively defined disease, as well as the response of their social network, family, medical professionals, and society at large. This self-identity may continually change throughout the course of the illness experience—from the onset of symptoms, through recovery, or through the perception of a fundamentally changed self.

This paper explores the interrelationship between illness and self-identity, utilizing both second-hand research, as well as my own affliction with Guillain-Barré Syndrome (GBS), a rare autoimmune neuropathy. In the following pages, I

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will address the five stages of illness as defined by Suchman's psychosocial model and explore both the similarities and differences experienced by patients during their illnesses.[ii] In particular, I will focus on the ways in which the illness experience disrupts the patient's self-identity, affecting the personal norms and knowledge that underlie one's self-concept and interactions in the world.

Guillain-Barré Syndrome

GBS is an autoimmune peripheral neuropathy, where the immune system attacks the conductive myelin sheath surrounding the nerves. As a result, the nerves cannot send signals to the various parts of the body and the patient experiences ascending—starting at the feet and rising in the body—muscle weakness and loss of muscle function. Severe cases can lead to respiratory failure and total paralysis. GBS typically becomes progressively worse, plateaus, and then resolves itself even without treatment.

One or two people in 100,000 are diagnosed with GBS each year. About 80 percent of all GBS patients fully recover.[iii] While 70 percent experience a full neurological recovery within a year, displaying basic functionality, close to a quarter of patients do not regain their pre-illness state of physical ability.[iv] Despite its rapid onset, recovery from GBS can take months, often requiring physical and occupational therapy, with residual effects that can last years. Recurrences of GBS are rare and can occur over decades. The chronic form of the condition, Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), is even rarer than GBS itself. The psychological effects of the experience can be "traumatic for many . . . reducing the patient to profound physical and psychological helplessness with little warning."[v]

Two weeks before my twenty-fifth birthday, I woke up to toes that were tingling and slightly numb. In the following days, the numbness and tingling spread through my feet; my fingertips also began to experience the same tingling and numbness. I became unsteady on my feet; my legs would give out unexpectedly. I needed to hold on to the walls as I moved around my house; climbing even a slight curb required someone's arm for support; ascending the stairs to my bedroom became a crucible. Within a week the numbness had spread through my legs and up my arms to the elbows. Even the cane I had begun to walk with was soon insufficient. Throughout this early stage of illness, I tried to conceal the severity of my condition at my new job.

I was in constant contact with my doctor by e-mail. She assured me my condition would improve, even speaking to neurologists on my behalf, claiming that my symptoms would soon dissipate, even after my third visit. The tests, however, revealed nothing.

During the course of my illness, I watched my body slowly wither. Each morning, I awoke, evaluated the changes to my body, and contemplated their impact on my future. My handwriting had become unrecognizable. I lost the ability to drive, then the ability to walk. As long as my doctors were powerless to diagnose, I too was powerless to classify myself within a defined illness narrative. Having received no explanation of the underlying cause of my illness, I was given no reason to hope for improvement.

I spent hours online trying to self-diagnose. The spectrum of possibilities ranged from a B-12 deficiency to multiple sclerosis. Guillain-Barré fell somewhere in the middle and was the best match to my symptoms. When I suggested this to my general practitioner, she was dismissive. Much later, at a follow-up appointment after my release from the hospital, she told me that I had been her first case of GBS since residency, and was shocked to read the results from my various neurological tests and exams.

On February 24, a month after my symptoms first appeared, I finally met with a neurologist. After two days of questioning and tests, the doctor told me I had a demyelinating neuropathy, Guillain-Barré Syndrome. My immune system was attacking my nerves. I needed to be admitted to the hospital as soon as possible.

There is power in naming, identifying and classifying an experience or affliction. Without these diagnoses, a feeling of powerlessness stems from both the lack of reason or cause for illness and in the lack of a validating response from either doctors or one's social network. A diagnosis of Guillain-Barré Syndrome, however, still leaves questions unanswered. The very classification of a "syndrome" (as opposed to a "disease") designates unknown causation.

In the hospital, I received daily infusions of intravenous immune-globulin, healthy anti-bodies to stop my body from attacking my nerves. I was released with a walker and a promise that I would feel better soon. Physical recovery took months; my strength and balance had to be built anew. I regained my motor and sensory functions. My sense of self, however, remained lost for over a year.

The Social Network

Edward Suchman delineates five stages of illness in his article "Stages of Illness and Medical Care."[vi] According to Suchman, the process of being ill follows particular social patterns. This normalizing analysis of illness behavior identifies benchmarks in the illness experience as it relates to seeking and accepting medical care. Suchman's analysis outlines how an individual is expected to behave during illness; when behavioral patterns deviate from these norms, society struggles to make allowances for those experiencing illness. This is in line with Kleinman's declaration that "there are normal ways to be ill"[vii] that operate within our cultural norms and expectations. In *The Man Who Mistook His Wife For a Hat*, Oliver Sacks describes the case of a woman whose illness results in no immediately apparent physical disfigurement, but nonetheless leaves her functionally deficient. The patient not only struggles with her physical condition, a medical oddity, but with society's reaction to her perception of herself as someone who is chronically ill. According to Sacks, "society lacks words, and sympathy, for such states. The lack of social support and sympathy is an additional trial: disabled, but with the nature of her disability not clear . . . she tends to be treated as a phony or a fool."[viii]

The responses to my illness—ranging from disbelief to pity—were as discouraging as the numbness throughout my body. When the symptoms of an illness are outwardly imperceptible, others tend to presume the patient to be well, have little compassion, and make few allowances. The way people with illness or disability are viewed, and the internalization of that view that many with illness may feel, is an internalization of social norms. Chronic illness is not viewed with understanding as part of the lifecycle, but rather as an interruption of a life. There is both an extreme visibility and invisibility of illness, as people with illness are viewed as social undesirables.

Suchman comments in his study that the behavior of the "sick individual is dictated by both social and medical considerations," more so than individual or personal considerations, and that "the pathways and routines established . . . appear to function quite smoothly."[ix] I utilize Suchman not as an accurate or all-encompassing model of the illness experience, but because it highlights the various facets of the illness experience and provides a framework from which the multitude of interactions that influence the course of illness can be addressed.

The initial stage is the experience of symptoms. In addition to the physical experience, Suchman also addresses the cognitive aspect of the "interpretation and derived meaning for the individual experiencing the symptoms, and the emotional response of fear or anxiety"[x] that accompanies both the physical and cognitive experience. Though Suchman does not address this directly, it is important to acknowledge the cognitive and emotional response of the individual throughout all stages of the illness experience, as these aspects often outlast the physical symptoms.

In the next stage, the individual assumes the sick role, seeking validation from family and friends and possibly a release from normal social obligations. The sick individual seeks diagnosis and treatment, both of which lend scientific legitimacy to their illness. In my own experience, the initial stage was prolonged, as my symptoms continued to worsen without the validation of a diagnosis. I stayed in limbo, unable to resume my normal activities, yet equally unable to progress through the 'normal' stages of illness as described by Suchman. Suchman details that the initial medical diagnosis "will set the stage for subsequent medical care . . . and progress towards health."[xi]

My ability to become a dependent-patient in the penultimate stage was delayed by my inability to meet with a neurologist, an experience that recast me through the stages with a new medical professional, weeks after first contacting my general practitioner, thus making my movement through Suchman's stages non-linear. According to Suchman, in this fourth stage, the patient often takes on the role of dependent with ambivalence, wishing to avoid complete surrender, but seeing it as the only means by which to regain health and return to a previous pre-illness role.

Upon being admitted to the hospital, I was distinctly ambivalent, not wanting to be so thoroughly immersed in my own illness experience, and doubting the viability of the proposed solution. During my stay, however, I gradually acclimated to the dependent-patient role, which was physically trying and emotionally unrelenting. In particular I felt as though my mental capabilities were being called into question, as everyone insisted I was getting better, in spite of the fact that nothing was actually changing. Here we see a dissociation between the patient's experience and the societal view that defines the experience on its own terms, actively setting the expectation of recovery and behavior without acknowledging or respecting the individual's experience.

The final stage, according to Suchman, is recovery and rehabilitation. At this point, society expects the patient to re-enter their previous role, fully recovered, with little to no acknowledgment of the illness (the other option being to adopt a new role as a chronically ill individual who will never recover). The expectation that a patient will simply resume his or her previous life both physiologically and psychologically is built on the assumption that the individual's sense of self is unchanged by his or her illness experience. It is the expectation of a return to society and thus normalcy that perhaps most distinctly demonstrates how illness isolates and labels patients as abnormal. Separate from society, from the whole, an identity is assigned based on a deficiency: being unwell or lacking the means to perform an expected social role. This prioritizes normalcy and conformity over acknowledging each individual experience of illness. Until recovery is seen as a second change, and not a return to normalcy after the initial change, illnesses will continue to be treated according to Suchman's narrative.

Illness and Self-Identity

We are quick to address the physical needs of someone who is sick, but reflection on their psychological wellbeing tends to come after the physical condition is resolved. Society focuses primarily on resolving the physical—in particular the visible—issues, while paying little attention to the possible severity and long-term effects of what the patient may feel. The physical challenges of my illness did require a withdrawal from standard social roles and expectations. According to Suchman, I would receive a grace period of inadequacy, after which I would be expected to eventually rehabilitate and re-socialize.

In light of illnesses such as GBS, MS, HIV, the medical establishment is beginning to admit to changes in both self-identity and social roles throughout and following the illness experience. I argue that an extreme illness experience alters one's identity so that there cannot be a simple return to one's former self through physical healing. Full recovery must also incorporate the acceptance of a change in identity affected by the illness experience, particularly ones which result in chronic conditions, or the possibility of relapse. The recovering patient must negotiate the concept of life as it was before the disease, as well as life now, with the continuing illness itself or with the experience of having been fundamentally altered.

Illness Narratives

Acute and chronic illnesses are differentiated by a life-changing experience and the enactment of life-changing conditions, respectively. With delayed diagnosis and no visible progress, I pictured my future self as one with chronic, debilitating illness. The illness experience is a disruption of the experience of continuity in one's own life. Illness constitutes a disruption in the individual's life and in his or her sense of identity. When that inner coherence is called into question, the illness experience serves to rupture one's self-identity, often irreparably, calling for the establishment of a new identity. The new identity can be described in terms of otherness—a new, unfamiliar self not yet integrated with the previous one. The result can be a feeling of living with someone whom one neither knows nor feels comfortable around. This disruption in identity can lead to a partial transformation of identity or to two completely disparate identities, neither of which is necessarily the pre-illness identity.

The development of new illness narratives can be therapeutic for patients. Such narratives allow the patient to "share the illness experience . . . and discuss possible interpretations of the illness."[xii] Online forums and support groups bring people together to reconstruct their lives by sharing their stories with a sympathetic, empathetic, and knowledgeable community. This is an example of redefining the self through illness narratives. Sharon Kilty describes how the speakers can "unravel the truth of their own experience of illness and begin to adjust to the person they have become."[xiii] Telling their stories gives people the opportunity to step outside of themselves and witness their changed identity, and through such dis-identification, see new possibilities emerge.

While sometimes associated with just chronic illness, narratives that revise personal identities and life histories in terms of the illness can be used to cope not just with the realization of illness, but also with the loss of one's previous identity in the wake of illness. Similar to a support group, non-judgmental acceptance of the personal experience grants validity to the subjective view in the story as it is told. There is immense benefit to sharing stories of illness with people who simply listen and acknowledge the individuals' experiences. Narratives are tools that enable people to live with the illness experience. While a disease may be remedied, the individual can never regain his or her pre-illness self. By revising his or her story, the patient may be better able to reconstruct a modified sense of self. In studying how patients with chronic illness often suffer from loss of identity, Pia Asbring details that biographical work is necessary to discover which aspects of the identity have been lost, which aspects remain, and which new aspects have been added, resulting in a redefinition of identity, or a partly new identity based on the changes brought on by illness.[xiv]

Though my prolonged experience made me view myself as someone with a chronic condition, a particular event—what Wally Karnilowicz terms a negative epiphany[xv]—forced me to come to terms with what my illness might mean for my future self, solidifying the severity of my condition and my emotional reaction to it. While driving to class, I was unable to recognize the brake pedal and crashed my car. As bad as this experience was, the thought that overwhelmed my consciousness was that I was getting worse. While immersed in the world of my illness, I experienced the ambiguity of not knowing the extent or duration of my experience and how it would affect the rest of my life. I saw myself in this feeble state, endlessly getting worse. My consciousness shifted into a new role with an imagined disability that outlasted the real condition. I began to come to terms with a new, imagined life that may have befallen me in a different condition. I envisioned myself in a new light and a role that society had not prescribed for me before, one of serious incapacity, a prematurely elderly person with a crumbling body, but without the long life experience that generally precedes old age.

Earlier that day, prior to the crash, I had listened to a piece on NPR about the photographer Sally Mann. Mann's recent work had focused on her husband of forty years, a lawyer and a blacksmith, who lived with muscular dystrophy for the previous fifteen years.[xvi] Each new piece of the interview related directly to my new state of illness. The distress and degradation of his body reflected my own; the difficulty going up stairs, the loss of muscle, and the sudden inability to do things that so recently were thoughtless movements all rang true. My body was withering; there was nothing I could do to stop it. The pity, resignation, and heart-rending sadness I had heard in his wife's voice were not only what I felt from others, but a reflection of how I felt about myself. The key difference was that he had love, acceptance, and resolve facing his vulnerability. That I experienced none of this only made me more distraught. While her husband spoke with a lightness that still evades my grasps, Mann spoke of a raw fear that penetrated me.

The body is the link between power and knowledge when it comes to the illness experience. The 'body politic' is profoundly personal. While Foucault says that power produces knowledge, the inverse is also true; the sense of disempowerment creates a unique perspective. Normally, the body is subjected to the rule of the mind. In my case, my body became subject to the power of the disease. Subsequently there is a parallel of the body attacking itself and the mind not recognizing the self. As my immune system no longer recognized my nerves, I no longer recognized my body. “Some such depersonalization or derealisation must always occur,” Sacks says, “when there are deep disturbances of body perception or body image.”[xvii] In recovery, I became completely detached from my previous identity and sense of self. This physical disruption translates into a disruption of identity and the resulting social displacement. Previous social norms no longer apply to the patient, but continue to apply to everybody else.

Conclusion

While modern medical treatment closely follows Suchman’s model, medical professionals are beginning to pay heed to the illness narratives of patients, who detail their experiences of illness to supplement the traditional treatment of disease. Illness narratives are now acknowledged as offering an unmatched window into subjective experience.[xviii] Illness narratives enable more effective care. This distinctly humanistic shift in perspective allows for acknowledgment of the non-physical aspects of the illness experience and gives credibility to the personal and subjective experiences of the individual. In telling their stories, the individuals have the power to shape their own reality.

Lacking a resolution for my own narrative, it was difficult to give meaning to my illness experience. In the early days of my illness, gathering information was my only form of power. It was my hope that through knowledge of what was happening to me, I could enact some form of control, or at least understanding. I was attempting to construct for myself a sort of illness identity. This co-existence with illness, in which it becomes linked to identity, creates psychological vulnerability and the loss of personal power. There is a loss of autonomy in the illness experience. One’s agency, the power to act within one’s subjectivity, is reduced. In addition, we fall victim to societal expectations of how we should be both acting and feeling. It is important to realize that there are multiple aspects to identity; disruption of one does not have to translate to abandonment of all. In the initial stages of my illness, my symptoms did not fit neatly into the categories as recognized by my physician, thus delaying my diagnosis. Similarly, my recovery was not recognized by traditional models, which expected me to return, rather than recover and renew. I not only had to diagnose my own illness, I also had to determine what it was that I had become, and what I wanted to be. In presenting my own narrative, I furthered my recovery, and reclaimed my lost power by assigning meaning to my experience.

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[ix] Suchman, 117.

[x] Suchman, 120.

[xi] Suchman, 121.

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