# "I was the 'Energizer Bunny' and now I'm the turtle'The effect of fatigue on the identity of people living with multiple sclerosis

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# "I was the 'Energizer Bunny' and now I'm the turtle":
# The effect of fatigue on the identity of people living with multiple sclerosis

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**Abstract**: Issues of identity among people with fatigue from multiple sclerosis were explored. Participants experienced changes in self-perception and struggled with not seeing themselves as busy and active as before MS. Some described a mourning process which led to resolution of a new identity. The findings have implications for health educators.

Multiple sclerosis (MS) is a chronic, progressive neurological disorder that affects approximately 2.3 million people worldwide (National Multiple Sclerosis Society, 2014) and 400,000 individuals in the United States (Trullman, 2013) Fatigue is one of the most common and most disabling symptoms of MS. Although researchers have investigated how MS, in general, affects individuals' spiritual lives (Irvine, Davidson, Hoy, & Lowe-Strong, 2009), masculine identity (Reissman, 2003) and sexual self-identity (Kralik, Koch, & Eastwood, 2003), the investigation of how the MS symptom of fatigue affects the identity of individuals living with MS has not been explored. Because disease management concerns the whole person, the investigation of how fatigue affects identity could broaden the identity development and chronic illness literature

## Literature Review
Identity theory posits that a person's sense of self is comprised of many identities that make a stable self (Stryker & Burke, 2000)). Hence, a chronic illness can affect other identities. Illnesses such as multiple sclerosis can be highly disruptive and life altering. When people experience such illnesses, their attempts to reorient themselves can be viewed as an effort to reconstruct their life histories (Williams, 1984). Narratives help people with illnesses "repair the damage that illness has done to the ill person's sense of where she is in life, and where she may be going" (Frank, 1995, p. 53). Arthur Frank proposed three types of illness narratives. The first type is *restitution*, which involves the person wanting to be healthy again. The restitution narrative is common in people who are newly diagnosed with an illness but less common among people with chronic illnesses. The *chaos* narrative is the opposite of the restitution narrative. A person with a chaos narrative believes that their life will never get better. Finally, those with a *quest* narrative accept their illness and seek to use it to gain something out of their experience.
Articles that address the effect of multiple sclerosis on identity are few. (Reissman, 2003) re-analyzed the narratives of two men living with MS through the lens of masculinity and how each man portrayed masculinity in light of illness. Other researchers conducted a focus group and discovered that many participants discontinued paid employment, were more dependent on caregivers, valued life more, and reported increased spirituality which was a resolution to the

identity crisis (Irvine et al., 2009). A third study examined the sexual self-identity of women living with MS (Kralik et al., 2003).

## Purpose and Methods

The purpose of this study was to explore how fatigue affected identity from the perspectives of people with MS. A qualitative case study (Yin, 2009) was used because it provided a "richly descriptive" (Merriam, 2009, p. 16) understanding of how one group of individuals undergoing a six week fatigue management program interpreted and understood their experiences. Potential participants were recruited through MS support groups and flyers. Criterion sampling was used to select participants. Participants had to: (1) be diagnosed with MS; (2) be age 18 or older; (3) reside in Illinois where the group leader was licensed as an occupational therapists; (4) participate in a program and interviews that were conducted in English; (5) attend at least five of six sessions of the fatigue management program; (6) have MS fatigue that was severe enough to be appropriate for the program as judged by a score of four on the *Fatigue Severity Scale* (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989); and (7) score 12 or higher on the *Blessed Orientation, Memory, and Concentration Test* (Katzman et al., 1983), to rule out more than mild cognitive impairment.

Seven respondents participated in this study. Individuals participated in in-depth pre-and post- group interviews conducted by the first author and at least 5 of 6 teleconference group sessions led by an occupational therapist, all of which were recorded and transcribed. Participants ranged in age from 27 to 64 years with five of the seven participants being 50 years old or older. All participants were White females with the exception of one African American male. All of the participants were unemployed or retired when interviewed.

The qualitative management software, NVivo 9 was used to manage the data. The constant comparative method was used to derive themes including using open and axial coding. (Glaser & Strauss, 1967). Methods of trustworthiness used included peer review, triangulation through multiple methods of data collection, adequate engagement in data collection, an audit trail, and thick, rich description for transferability.

## Findings

Participants changed how they performed daily activities, which changed self-perception. They struggled with not seeing themselves as busy and active as they had been prior to diagnosis. Some participants described a mourning process which led to a resolution of a new identity. Discussion in the fatigue management group helped individuals re-conceptualize their situations.

### Identity and Activity Performance

The participants' views of fatigue and its impact on their lives had an influence on their identities. Most often, they described how fatigue caused them to change the way they went about some of the daily activities that made up their life roles and sense of identity. For example, Debra, who taught adults, discussed her identity by describing activities that she needed to change as a result of MS fatigue:

> Back then, I was a multi-tasker, you know, Type A personality. I just went – didn't stop. So I know even now with my teaching, I did teach three classes pretty much straight in a row, but you will see me sitting now, and I never used to sit.

In this quote, Debra describes a modification to an activity due to fatigue, specifically a change in her physical position when teaching, from standing to sitting. This change, which she perceived as a slowing down of the way she use to go about teaching, is in contrast to her sense that she used to be a person who "didn't stop," a "multi-tasker" and a "Type A personality." These kinds of modifications to everyday activities were very frustrating to Debra:

> [The most frustrating part of living with fatigue is] being a Type A personality who multi-tasked, who always had everything done, whose desk never had anything on it. Things were like a hot potato for me, to get things done. Even when I was teaching – I teach college now but I taught high school, middle school, elementary up until 12 years ago. I would be teaching all day, taking one or two classes at the same time in the evenings or weekends, and I would be exercising anywhere between three to four hours…I had the nickname of "the Energizer Bunny." And so now I'm the turtle.

In this quote, Debra talks about giving up part of her identity – that of being a person who was always busy and accomplished many things. Her change in identity was related to the speed in which she was able to move. Before MS, she was able to move quickly, like an Energizer Bunny, and accomplish many things. With MS, Debra was slowed down, like a turtle, and accomplished less.

*Balance between sameness and difference.* Participants discussed how they struggled with issues of being the same or different. Linda discussed her guilt about asking for help from her children. She said, "I just want to be the same person they [Linda's daughters] remember me as six years ago instead of five." Group participants challenged Linda's desire to be the same person that she was five years ago. , Barbara said:

> You're trying to show them that you are the same mom, but really you're not the same mom. And by not sharing your issues with them, how are they to understand you are fatigued? You're not sharing that with them. All they see is Mom is up there at the stove, doing her thing, just like she always has. You're not communicating.

By the end of her participation in the fatigue management program, Linda reported feeling differently about her identity as a mother, and felt less guilty about receiving assistance from her children. She credited the other group participants who challenged her for this change in thinking.

*Mourning loss of active self.* Many of the participants struggled with the conflict between perceptions of past and current self. Some seemed to have undergone a mourning of their past identity which led to a resolution of a new identity.Karen explained:

> I mourn those things.  I mourn it like a death, you know.  I mourn
> that part of me that could finish that project, but I can't right

now...It's hard to do, but I just try to embrace the person that I am
now.

## Occurrence of Chaos and Restitution Narratives

The restitution narrative did not emerge as a guiding narrative for the participants, which is consistent with Frank's (1995) finding that the restitution narrative is not often the dominating narrative of people with chronic illness. There were some suggestions of the chaos narrative, a narrative which is characterized by hopelessness, loss of control, vulnerability, and futility (Frank, 1995). For example, Debra stated that fatigue disrupted her life. She said:

> I have all these things that I want to get done that day. But then
> they don't happen. And you would see lots of stuff started and I
> have these piles of things to do. And so I feel very scattered.

Though the participants shared their challenges with MS, the majority appeared to have a quest narrative. Quest narratives "meet suffering head on" (Frank, 1995, p. 115) and people with quest narratives accept their illnesses and see something to be gained from the experience. Although they may have wished that they were not ill, these participants accepted that they had MS and tried to make the best of their situations. Respondents' participation in the fatigue management program itself suggests that they were "searching for alternative ways of being ill" (p. 117), which is a feature of the quest narrative. They frequently talked about wanting to gain new knowledge and skills related to MS. For example, Karen said about managing fatigue, "I'm always a person who believes there is more to learn and more to know…always a way to tweak something and make it just better, even if you are doing the right thing."

The framework of restitution, chaos, and quest narratives is important when considering learning with a chronic illness. People with a restitution narrative seek to be healthy again. The desire is for the illness to go away, so there is not an impetus for learning to live well in the presence of an illness. People with a chaos narrative lack optimism that things will get better, so they may not seek out illness-related learning opportunities because they may not anticipate any benefit. The quest narrative, however, is the ideal foundation for learning when living with a chronic illness. People with quest narratives have accepted their illness and they want to gain something from the experience; that is, they want to use their illness as an opportunity to learn and develop.

## Conclusions and Implications

Perceptions of multiple sclerosis, fatigue, fatigue management and identity are closely connected. MS fatigue affected participants' activity performance part of themselves in a three step process: (1) Fatigue caused changes in everyday activities; (2) This change affected individuals' efficacy with their life roles and (3) Alteration in a sense of achievement affected one's overall sense of self. While this research confirms other studies that explored the effect of MS on identity in that change occurs (e.g. Irvine et al., 2009), this study contributes to the literature because it examined how one symptom – fatigue -- affected the "activity" identity, and it confirmed Frank's (1998) conceptualization of narratives for individuals living with chronic illness.

Findings have implications for health educators working with people with MS. First, recognizing MS clients' different identities (e.g. grandmother, volunteer) may help MS educators strategize as to how clients should spend their energy. Second, recognizing that grief is an important part of coming to terms with a chronic illness is also important for health educators to

address. Third, encouraging interaction between MS education group members is important as this social interaction helps individuals grapple with new identities.

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