WHEN THE INVISIBLE BECOMES VSIBLE: DECONSTRUCTING STIGMA
AND CHANGING IDENTIY BY EXPLORING THE LIVED
EXPERIENCE OF THOSE WITH
MULTIPLE SCLEROSIS

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ABSTRACT

This paper examines the lived experience of multiple sclerosis (MS) through the lens of stigma. Stigma is a social phenomenon through which people who are deemed outside the norm, due to either behavior or appearance, become vulnerable to being discredited or ostracized. The case of MS is interesting, because while it eventually manifests in distinct outward physical signs, individuals with the disease often live for years without outward symptoms, meaning that their stigma-inducing qualities are latent, but not yet seen. Pre-symptomatic individuals, in attempting to manage the inevitable stigma, must balance the risks and benefits of choosing whether to pass or reveal. The seismic physiologic shifts MS flares cause result in changes to both an individual's physical and social capabilities, thus affecting individual's roles and subsequent emotional well-being, which can be further impacted by social stigmatization. As a result of physical limitations, individuals with MS experience stigma in the form of employment discrimination, co-worker misunderstandings, and familial over or under attention to their illness. These factors only exacerbate the emotional despondence these individuals experience from a loss in their identity. By looking at the literature on stigma formation, management of invisible social identities, and the stigma of MS, an appreciation for the lived experience of MS can be gained. Such an appreciation can hopefully lead to methods to prevent the marginalization of such groups and foster supportive measures and education that helps deconstruct the stigma.

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TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Multiple sclerosis (MS) is a chronic progressive disease that inflicts damage upon individuals in a very slow and often sporadic pattern. The disease of MS is an autoimmune phenomenon in which the body's immune system attacks and destroys myelin, the protective sheaths around nerve cells within the central nervous system. The condition primarily affects young women, and is classified as either chronic progressive, relapsing-progressive, or relapsing-remitting, depending on the rate of neurological decline. In chronic progressive, individuals experience a steady decline in function, while in relapsing disease there are bouts of neurologic illness with either relatively full recovery between attacks (relapsing-remitting) or partial deficits after a flare (relapsing-progressive). Due to the sporadic nature of myelin destruction, MS patients experience varied neurological symptoms that include: visual disturbances, coordination and balance issues, difficulties in speech and swallowing, loss of bladder and/or bowel control, slowed cognition, fatigue, neuropsychological disorders, permanent disability, and more (Miller, 1997; Vickers, 2010). These drastic neurological changes highlight not only the medical, clinical, and physical hurdles these individuals face but also the impact these disturbances have on a person's social wellbeing.

While MS is a medical phenomenon, the disease process of MS serves as a reflection on societal views on disease, chronic disease, the construction of self, and the body. The body, in particular, highlights the importance of our physical form in both the construction of identity and the social meaning and value being attached to bodily image.

The body is a powerful medium; it is both a physical and symbolic entity that is instrumental in forming the notion of 'me.' People utilize their body to both navigate the physical world around them and participate in social interactions. The establishment of identity is an active process in response to social stimuli within one's environment (Ragins, 2008). These interactions help corroborate self-identity as well as play an influential role in modifying bodily performance to ensure an accurate portrayal of self. When societal perceptions of one's identity differ from one's own definition of self, the body serves as the medium to correct and realign this mismatch (Grytten & Maseide, 2006). It is during times of illness and disability, though, that the body's role in the construction of identity is most evident. A disturbance to one's physical and mental capacity, such as during a flare of MS, restricts people from manipulating their bodily performance. With an ailing body's inability to rectify misinterpretations, an individual's identity is threatened due to the subsequent lack of reaffirmation of self in social settings. Thus, these individuals are then forced into new life roles, new bodily awareness, and new constructions of self (Vickers, 2010).

However, the lived experience of MS does more than just highlight the way in which the body serves to establish identity but more so uncovers societal prejudices and marginalization of ailing bodies. The view of disease-related changes as handicapping and lessening dichotomizes bodies into those that are valued and those that are not. This polarizing stance empowers those who are healthy, while disenfranchising those who are ill (Joachinn & Acorn, 2000). This unequal power dynamic devalues the lived experience of those with chronic conditions, and results in the internalization of the stigma, creating feelings of reduced self-worth. The degree to which individuals with an

illness are stigmatized, though, varies greatly according to the level of disease visibility (Clair, Beatty, & Maclean, 2005; Rao, et al., 2009). Neurological disorders, like MS, demonstrate a unique situation in which early signs of the disease are/can be/remain invisible for long periods of time. However, due to the progressive nature of the illness, hidden symptoms eventually become visible, inviting stigmatization (Rao, et al., 2009).

The unpredictable and progressive nature of MS creates stress for these individuals as these drastic neurological changes inflict permanent damages to a person's physical, mental, and social well-being that destabilizes their understanding of self. For individuals with MS, the struggle they also face is choosing to pass or reveal their invisible, but also stigmatizing identity. The dilemma arises from the knowledge that eventually their invisible condition will soon become visible, and so they must balance and reconcile an ever-changing identity with the fear of being stigmatized. This unique disease experience leads us to consider the challenging interplay between the phenomenology of disease management, disclosure, visibility, social interaction, identity, and stigma. Through this paper, I will explore and clarify further: (1) the role, construction, and influence of stigma on chronic disease and identity, (2) the reasons, strategies, and consequences of managing invisible social identities, and (3) the effect of disclosure over the MS time course in empowering or disqualifying individuals' management over stigma and their disease identity. By answering these questions, I will hope to provide further understanding into the lived experience of MS and the interplay between the medical, clinical, and social during the reconstruction of self.

CHAPTER 2

THE CONSTRUCTION AND DEFINING OF STIGMA

Stigma plays an instrumental role in the lived experience of those with an illness. Due to its power to reinforce social norms, stigma disenfranchises and marginalizes those with perceived deviant attributes. In society, the term stigma is frequently used in public discourse in reference to deviation from prevalent or valued norms (Grytten & Maseide, 2005). According to Goffman (1963), stigma refers to "the situation of the individual who is disqualified from full social acceptance" through the process of negative social meaning being attached to individuals and behaviors. He described stigma as being composed of three parts: physical deformities, character blemishes, and tribal qualities, such as race or religion (Goffman, 1963). These qualities, however, only consider the physical aspects contributing to stigma and failed to account for the ways in which these stigmatizing attributes influenced interpersonal relationships. To understand this better, Jones *et al* (1984) divided stigma into six dimensions to better understand the interpersonal impact and the power stigma has in marginalizing individuals. These six dimensions include: concealability, course, strain, aestheticism, cause, and peril.

The first quality, *concealability,* describes the degree to which a condition is hidden or visible. This dimension is the most important because the degree of disease visibility not only influences negative social reaction but also influences stigma formation in each of the following dimensions. The second dimension focuses on *course*, or the way in which a disorder changes over time. The third dimension, *strain*, describes how noticeable stigmatizing attributes create tension in interpersonal relationships. The

fourth dimension, *aestheticism,* looks at the extent to which a condition affects the appearance of a person. *Cause*, the fifth quality, looks at whether a defect is congenital or acquired. And then finally the sixth dimension, *peril*, focuses on the dangers associated with a stigmatizing attribute (Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984).

By looking at these six dimensions, it becomes apparent how all six are instrumental and interrelated in stigma formation and social interaction. Those afflicted with MS exemplify how these six principles of stigma interact to influence and impact interpersonal relationships. In the disease process, or more specifically when observing individuals suffering with MS, the more visible their illness features become the more they are stigmatized (Joachinn & Acorn, 2000). With time, further MS-related changes cause deviations from the norm that strain and distance interpersonal relationships. These actions subsequently expose ailing individuals to the threat of social isolation and/or physical harm.

The above example demonstrates the importance of bodily appearance and the way in which the six elements of stigma interact during times of disease-change to impact interpersonal relationships. The power, though, that comes from stigma arises from the deeper sociological meanings implicitly conveyed through these social interactions. As defined earlier, stigma is the act of attributing negative perceptions to individuals or behaviors deemed outside of the norm (Goffman, 1974). The consequence of these actions permits marginalization of individuals by labeling differences as foreign, undesirable, and lesser (Grytten & Maseide, 2005). This view dichotomizes people into those who are valued and those who are not.

Additionally, the power of stigma comes from its ability to discredit individuals (Goffman, 1963). An individual may be discredited or discreditable based on the visibility of their stigmatizing condition. Those with observable signs of difference are discredited and perceived as "damaged goods" (Joachinn & Acorn, 2000). The result of this view enables discriminatory practices and generates hyper-awareness among stigmatized individuals to perceived stereotypes. As a consequence, stigmatized individuals begin to internalize this stigma, leading to a decreased sense of self through lowered self-esteem, depression, anxiety, and social isolation (Rao, et al., 2009). However, when signs of a stigma are not yet visible to others, the individual is discreditable, but has not yet been discredited. For these individuals, the stress they experience is centered on the risk and embarrassment of being caught, and subsequently being subjected to the same fate as those with visible, discredited defects (Joachinn & Acorn, 2000).

Individuals with MS straddle this stigma phenomenon of being both discredited and discreditable. The nature of the disease initially produces invisible symptoms that mark an individual as discreditable but has not yet been discredited. However, as the disease progresses, the MS-related changes become more visible and thus the person is now discredited and marginalized due to their disease-related differences. While the act of discrediting isolates these individuals and results in reduced self-esteem and depression, the stress of living with the invisible symptoms of MS also generates social isolation and internal strife due to identity dissonance and fears of being discovered. As a result, the experience of others with invisible social identities provides some insight into the inner turmoil those with less obvious MS symptoms experience.

CHAPTER 3

INVISIBLE SOCIAL IDENTITIES AND THE RISK OF STIGMA

Individuals' with invisible social identities ability to pass as normal but also risk

stigma, should they be discovered, poses this interesting yet challenging conundrum.

Due to the social cost for these individuals, they struggle and have to think strategically

about whether, when, how, or if at all they should reveal their difference (Clair, Beatty, &

Maclean, 2005). These individuals have various options, each with unknown

consequences. They can: continue to pass as normal and continue as they are; pass as

normal and be discovered, risking embarrassment and possible stigmatization; divulge

their condition and be ostracized; or reveal their invisible social identity and be accepted.

The numerous scenarios, uncertain possible outcomes, and potential lack of control in the

disclosure process generates and amplifies fears and anxieties surrounding their

stigmatizing identity (Ragins, 2008).

In each social interaction, these individuals reflect, weigh, and judge the decision

to divulge or not divulge their invisible condition. Each choice reflects this fine balance

between wanting to prevent social rejection versus avoiding being seen as manipulative

(Ragins, 2008). This psychologically and emotionally taxing ordeal often leads to self-

inflicted social isolation due to fear of discovery as well as strain of managing various

pseudo-identities (Clair, Beatty, & Maclean, 2005). Thus, the decision to disclose relies

heavily on an individual's ability to judge others and the environmental context.

This latter experience and dilemma is what most people with chronic progressive

diseases like MS confront. The unique situation they experience is that early portions of

their chronic disease are invisible; however, as explained in the stigma model, symptoms of their illness soon are no longer concealable, thus inviting stigma formation. The predicament these individuals face is whether to keep their identity invisible or risk disclosing the truth about their identity. The danger in either situation is having their secret exposed or being rejected if they disclose. As a result, individuals with MS, like those with invisible social identities, must delicately balance the risks and benefits and the decision to pass or reveal, based upon the larger social context.

CHAPTER 4

STRATEGIES IN MANAGING INVISIBLE SOCIAL IDENTITIES:

TO PASS OR REVEAL

Individuals who are weighing whether to pass or reveal their potentially

stigmatizing identities have various tactics at their disposal as they make this decision. In

passing, those with invisible stigmatizing identities use one of the three following tactics

– fabrication, concealment, or discretion – in order to appear normal. *Fabrication* occurs

when an individual deliberately falsifies information about himself/herself in order to

construct a new, socially accepted identity. The second tactic, *concealment*, involves

individuals actively preventing others from obtaining further personal information. And

finally, *discretion* is the process by which individuals avoid inquiries related to invisible

identities by evading opportunities and shirking personal questions. No matter which

tactic is used, the act of passing requires the person to adopt different personas, which

may create internal turmoil (Clair, Beatty, & Maclean, 2005).

Alternatively, in the act of revealing, individuals have at their disposal tactics of

signaling, normalizing, and differentiating, in order to elucidate otherwise unrecognizable

identities. In *signaling*, individuals straddle the act of going fully public versus also

remaining somewhat private about their invisible identity. Through the use of ambiguous

language, specific conversational topics, and various symbols or nonverbal cues, these

individuals partially disclose their invisible social identity. An example is the use of

rainbow bumper stickers, which can signal that one is either gay or one is heterosexual

but supports gay rights. Depending on the social context, an individual may choose to

use a more or less well known signal to reveal an invisible stigmatizing social identity. In either case, signaling provides an interim step in the disclosure process by allowing individuals the ability to safely assess the social context without the inherent risk present in explicitly revealing.

The second approach, *normalizing*, attempts to make a difference seem commonplace. An individual may acknowledge his/her difference but demonstrates that this alteration has little or no impact on his/her ability to live a 'normal' life. If executed appropriately, this disclosure process allows for the acknowledgement of an invisible social identity while also minimizing significant stigma. The final tactic for those interested in revealing is *differentiating*. In this process, individuals highlight how their invisible social identity differentiates them from others. These individuals seek to demonstrate how their identity is equally as valid through efforts that attempt to change individual, group, and institutional perceptions on the stigmatizing condition. This process allows stigmatized persons to reclaim and redefine their invisible social identity while also transforming marginalized differences into equally respected dissimilarities (Clair, Beatty, & Maclean, 2005).

The antecedents to passing and/or revealing, though, circle back to the earlier mentioned notion that disclosure relies heavily on an individual's ability to judge specific social situations. By looking at the contextual, interpersonal, and individual factors that make up one's social experience, these interrelated characteristics determine whether, when, and how a person will choose to pass or reveal his/her invisible identity. The first factor, one's contextual condition, is further subdivided into the organizational climates, industry and professional environments, and legal protections that influence a person's

choice to disclose. The organizational context examines the way in which institutions harbor an atmosphere of inclusivity through embedded cultural and policy practices (Ragins, 2008). Supportive and affirming workplace environments are associated with greater disclosure because of an atmosphere that genuinely fosters and protects individual differences. These actions include implementation of nondiscriminatory practices, transparency of decision-making processes, and presence of other "out" individuals (Clair, Beatty, & Maclean, 2005; Ragins, 2008).

Organizations that exceed minimal compliance standards and truly enforce discrimination-free environments experience more individuals revealing their invisible identities (Clair, Beatty, & Maclean, 2005; Ragins, 2008). The reason is that these efforts signal to employees a truly welcoming and supportive workplace environment. This is in contrast to institutions with non-discriminatory policies that are only loosely enforced. Individuals view these policies as only symbolic in nature, consequently discouraging disclosure of invisible identities because of continued and perceived threat of stigmatization (Clair, Beatty, & Maclean, 2005). Additionally, transparency in the decision making process of hiring and promotions greatly influences a person's decision to reveal. Organizations that provide feedback regarding hiring/promotional practices with decisions grounded in meritocracy foster better disclosure amongst those with invisible identities. The reason is that fears centered on financial discrimination due to an invisible stigmatizing attribute are removed. Finally, the presence of other "out" individuals within an organization, especially if they did not suffer any negative consequences, not only demonstrates the inclusivity of a workplace environment but also helps facilitate disclosure amongst other individuals (Clair, Beatty, & Maclean, 2005).

Industrial and professional norms also set the context in which people may feel pressure to tailor their behavior in order to pass or reveal. In organizations situated in industries where passing for "normal" is implicitly or explicitly encouraged, people are less likely to reveal in order to avoid the stigma and discrimination which bars them from obtaining equal cultural, socio-economic, and recreational advantages (Conyers & Kennedy, 1963). An example of such attitudes was the military's former "Don't ask, don't tell" policy that encouraged normalcy among its homosexual servicemen through implicit, explicit, and occupational repercussions if these behaviors were violated (Herek, 1996). On the other hand, revealing may be encouraged in occupations, such as human services, where one's work relies on honest and open discourse in order to foster trusting relationships (Halmos, 1970). Finally the legal context also influences a person's choice to pass or reveal. Legislation at the local, state, or federal level protecting the rights as well as preventing the discrimination and violence against individuals with an invisible social identity favors revealing amongst these individuals (Ragins & Cornwall, 2001).

The second factor, or interpersonal relationships, also influences the decision to reveal or pass. The presence of other "out" individuals, as mentioned earlier, helps facilitate the disclosure process through guidance. More than that, though, these relationships provide a sense of inclusion through shared experiences, affirmations, and acceptance. The benefit of being part of these groups is that it counteracts stress, social rejection, and isolation experienced as a consequence of stigma. The sense of cohesion and increased self-esteem these relationships provide thus helps to embolden individuals to disclose their invisible social identity (Ragins, 2008).

Additionally, the assistance of ally relationships provides a unique and important form of support in the disclosure of a stigmatized identity. Ally individuals are those who do not have a stigmatizing condition but consciously and deliberately advocate for the rights of those who do. These individuals often include family members, friends, and coworkers. The ally relationship helps facilitate the disclosure process through two means of support. The first is social support in which their influence and power, being part of the 'normal' group, shields stigmatized individuals from the negative consequences of disclosure. The second is ally groups positive reaction and support of stigmatized individuals, which creates a sense of trust and security that lessens fears and encourages disclosure to others (Ragins, 2008). These interpersonal relationships demonstrate that the power of such experiences comes from the inherent trust, security, acceptance, and strength in such interactions. These qualities, thus, help foster disclosure behavior.

The final social factor instrumental in the choice to pass or reveal is individual personality traits. This characteristic evaluates people's propensity towards risk taking, self-monitoring, and personal motives in the overall decision to disclose. Individuals who are less risk averse are more likely to reveal a stigmatizing attribute, while those who are more cautious will attempt to pass as normal. Relatedly, self-monitors are those who regulate, observe, and control how well they are fulfilling social expectations. High self-monitors often behave in ways to fit within socially accepted norms, while low self-monitors are less concerned with social appropriateness and tend to act in ways more "true to themselves" (Kilduff & Day, 1994). Finally, personal motive plays a tremendous influence in disclosure. While motives to hide an invisible social identity may be done to

avoid stigmatization, the management of pseudo-identities often creates internal strife and turmoil. These individuals eventually disclose as a therapeutic means to dispel negative feelings that accompany secrecy (Clair, Beatty, & Maclean, 2005). In any case, the choice to pass or reveal is not only linked to an individual's identity and goals of self-presentation but is also nestled within the larger context of interpersonal relationships and organizational policies, practices, and cultures.

Consequences To Passing Or Revealing Invisible Social Identities

As with any decision, there are inherent risks in the process of passing or revealing. The perils of choosing to pass can occur at both the individual and interpersonal levels. The act of concealing, as mentioned earlier, often leads to psychological strain from guilt and feeling like a fraud (Clair, Beatty, & Maclean, 2005). The anxiety and stress, as a result, come from the varying degrees of different identities presented across a life domain that create a state of identity disconnect (Ragins, 2008). At the interpersonal level, in order to keep a difference hidden, a passer may isolate himself/herself from colleagues, potentially leading to strained coworker relationships, limited networking opportunities, and social isolation. Additionally, this active process, in maintaining secrecy, can often strain interpersonal relationships at home. A partner's forced role in participating in the concealment of an invisible identity through limited social engagement and lying, stress partner relationships due to the shared social isolation. This situation generates feelings of resentment and hate that subsequently ruin relationships (Clair, Beatty, & Maclean, 2005).

14

In the process of revealing, the consequences are relatively more apparent with risks of stigmatization, prejudice, discrimination, and possible harm. As discussed above, though, a person must weigh the risks and benefits within the setting of the larger social context. A person must determine whether the psychological relief and identity cohesion achieved by revealing outweigh the costs of stigmatization.

CHAPTER 5

THE MULTIPLE SCLEROSIS IDENTITY

The disease of multiple sclerosis, with its varied presentation, unpredictability, and progressive neurological decline, place individuals in the dilemma of whether to pass or reveal in a situation where the invisibility of their disease will soon become visible. Along with this internal strife, though, these individuals experience destabilization of their identity with every random flare that occurs, requiring these individuals to make constant adjustments to their personal, social, and work lives. The only given in the MS identity, though, is the shift these people undergo from their healthy lives into their new roles as diseased individuals. This process, described by Vickers (2010), is known as the Illness Onset Status Passage, which entails the initial transition these individuals experience in the disease course.

In interviews conducted by Vickers (2010), many respondents expressed that they attributed their initial symptoms to trivial and seemingly harmless issues. One person stated that even though she was having difficulty walking, because no one else noticed it, she believed that nothing could actually be wrong with her (Vickers, 2010). This statement highlights this desire to remain normal and ignore signs of early disease because acknowledging a change threatens one's identity built around notions of health and wellbeing. It is only when individuals begin to experience unexplained and destabilizing bodily changes can they no longer ignore the symptoms of disease-related change. One young woman in her twenties describes how literally overnight she began to have trouble speaking and experienced some nocturnal incontinence (Vickers, 2010).

Another lady related that: "It was hard for me to speak. I needed to have two people help me go to the doctor…I was very incapacitated and scared" (Vickers, 2010). These seismic shifts in bodily function frighten individuals not only because of the drastic physiological changes but also because of the actual threat to their healthy identity. Individuals begin to realize the shift in health status they are experiencing and learn, for the first time, the irreversibility, involuntariness, and undesirability of such a shift in health status. The shift is one in which these individuals lose power both over themselves and their standing in society as they enter a social group seen as less desirable, devalued, and stigmatizable.

The change in identity individuals with MS experience not only centers on this shift from healthy to unhealthy physical and identity status but also involves changes in family and occupational life. At home, the effects of MS impact both the individual and others within the home. For many individuals, part of their identity is built around family interactions and their role within the house. The consequence of MS often hinders individuals from fulfilling their normal role within the home as fatigue or total disability prevents them from fully participating in parenting or caregiver activities. Additionally, complete disability forces individuals to rely on others for daily functions such as bathing, changing, and eating. The loss of independence and responsibility within the home due to MS leads to feelings of sadness, embarrassment, guilt, anger and depression (Halper, 2007). These feelings stem from the loss of identity these individuals experience as their independence and role as caregiver are stripped away from them due to the disease. The loss of identity is only exacerbated by the cyclical effect the disease has on family members. Due to their disease-related limitations, the responsibilities

individuals once had in the home are now shifted onto others within the home. These role changes, along with dealing with the sporadic MS flares, often place stress on the other family members who are forced to do more within the home. These increased stressors not only breed feelings of resentment, anger, and guilt but also increase partner burnout as one individual attempts to juggle all of the responsibilities (Halper, 2007). The changes in family dynamics only worsen feelings of guilt for individuals with the disease as they despair at the loss of their original role and identity.

Additionally, the physical and cognitive changes associated with MS also affect an individual's identity as it relates to their job and occupation. The visual, motor, and cognitive impairments affect an individual's ability to carry out specific tasks and thus jeopardize their employment status, financial stability, and identity. Many women with MS often choose to hide their diagnosis of MS at work due to concerns about job loss and disability benefits; however, tied into this sentiment are feelings related to loss of self if they should have to stop working (Dyck & Jongbloed, 2000). As one woman describes, "I could not have talked about leaving work without breaking down completely. Because my whole being was built around what I was doing." Another woman describes how she wanted to stay at work because "I have a feeling that it's much more about me than it is about them…I mean most of my life I was the one who had a lot of energy" (Dyck & Jongbloed, 2000). Both quotations highlight a sense of self and identity felt by being employed as the work gives individuals a sense of purpose, self-worth, and accomplishment. The assault on identity comes when these individuals are unable to perform their occupational skills as before due to the limitations of their MS. Interestingly, in interviews conducted by Dyck & Jongbloed (2000), while some women

18

choose to hide their MS diagnosis to maintain employment, others, depending on the workplace culture, found greater relief in revealing their MS identity. In these instances, employers who were more open to supporting workplace arrangements for these women resulted in more women disclosing their MS diagnosis. The result of such actions allowed these women to maintain employment for longer (Dyck & Jongbloed, 2000). The benefit of such practices is it increases self-esteem and promotes better health outcome for these individuals through greater feelings of self-worth, independence, and positivity.

During the MS process, individuals experience threats to their identity as they are shifted into new life roles centered now on a view from a diseased rather than a healthy perspective. This new role affects individuals' identity inside and outside of the home as caregiver duties are shifted, family dynamics affected, and occupational responsibilities left uncertain. However, intertwined within this changing identity is the fear and threat of being discredited by stigma and whether to pass or reveal their stigmatizing MS condition.

CHAPTER 6

THE STIGMA OF MULTIPLE SCLEROSIS

As with any stigmatizing attribute, the goal of stigma is to discredit and marginalize a group of individuals deemed as other. For those with MS, the perceived stigma often centers on means that attempt to disqualify an individual. And while at times these can be done through discriminatory practices, seemingly friendly gestures can become patronizing and reinforce MS stereotypes and stigma. For the individual with MS, they must decide whether to pass or reveal their identity; this decision, as discussed earlier, is imbedded within the social context and relies on the perceived risk versus benefit of the situation.

The workplace remains an area of high stress for those with MS. The fear stems from either being discovered or revealing their MS identity and being fired or prevented from future employment, due to discriminatory-related practices. Even in instances where revealing leads to employers making workplace modifications, individuals with MS still risk workplace ostracism due to coworkers viewing their situation as preferential treatment (Dyck & Jongbloed, 2000; Grytten & Maseide, 2005). As one woman told her coworker, "What is expressed is not always what is felt," when referring to her MS symptoms (Grytten & Maseide, 2005). This quotation highlights this double-edged sword those with stigmatizing conditions like MS experience. They risk stigma and social isolation either way, whether they choose to reveal and are accepted or reveal/pass and are rejected. This rejection or fear of discrimination fosters self-isolation, leading to depression and reduced health-related quality of life (Halper, 2007; Jones, et al, 1984).

In other situations, outside of the office, individuals with MS sometimes reveal their condition indirectly by exaggerating one of their disabilities for a social benefit. One individual mentioned how "Using the crutches felt good" because it prevented bartenders or bouncers from questioning his sobriety (Grytten & Maseide, 2005). In these instances, the crutches are an indirect symbol of this person's MS. The use of crutches signals to others that the person's abnormal gait is due to some medical cause rather than something like public intoxication. Thus, the use of assistive devices or anything that indirectly reveals one's underlying MS is often employed in order to avoid and alleviate perceived stigma associated with another, non-medical, socially taboo cause.

Finally, the stigma of MS can also be experienced even when no discriminatory or prejudicial acts are occurring. Often times it is family members' overemphasis on the disease or underemphasizing the illness that further propagates feelings of isolation. For one individual whose family overemphasized his MS, he describes, "When I am together with [my family] I feel more ill" (Grytten & Maseide, 2006). The importance of this quotation is it demonstrates that despite the well-intentioned involvement of family members, the overindulgence leaves the person with MS as feeling less valued, as being held less accountable, and as having no responsibilities. This indirect stigma leads to individuals feeling more 'ill.' For these individuals, such actions erode away at their identity because such practices imply that these individuals are less capable. In a similar fashion, underemphasizing an individual's MS also propagates feelings of stigma. For individuals with MS, comments such as "Ann has MS, but she seems to function so well" sound more like "you look so good, so MS must be insignificant" (Grytten & Maseide,

2006). The use of minimizing language to describe an individual's MS creates a notion of not being taken seriously. In the same way that overemphasis reduces identity, so too does a lack of full acknowledgement of the disease. The unacknowledged MS role is associated with a feeling of being 'other-ized' because the ignoring of the illness only reinforces stigma by indirectly implying that there is something abnormal about the person. While individuals with MS may attempt to normalize their condition in an attempt to reveal their illness, the action of others to normalize the situation actually has the opposite and undesirable consequence.

CHAPTER 7

PREVENTING MARGINALIZATION FOR THE

MULTPLE SCLEROSIS INDIVIDUAL

The sporadic nature of MS threatens an individual's emotional well-being due to changes in their identity. The physical and mental changes affect an individual's prior roles at home and at work, and stigma formation from co-workers and family cast doubts on an individual's capabilities. One consequence of such actions is emotional despondence due to a loss in self-esteem, independence, and identity. These responses only feed back and are exacerbated by MS flares, decreasing these individuals overall quality of life and slipping them further into emotional despair (Halper, 2007). By understanding the role changes these individuals experience and the stigma experienced through both direct and indirect means, we hope to address the appropriate emotional and social factors necessary to support this vulnerable group. In order to make these changes, though, healthcare providers, family members, employers, and those with MS all need to be educated on not only the medical and physical changes of the disease but also the social impacts.

As healthcare providers, a focus on the emotional well-being and understanding of the social changes the MS patient is experiencing should also be evaluated, in addition to the medical illness. By understanding these issues, a physician can help by providing emotional counseling, instructions on adaptive techniques, and education to family and the individual himself/herself on how to prevent stigma formation. In providing adaptive technique instructions, the physician can demonstrate or provide physical/occupational

therapy that allows the MS individual to make adaptive changes. These modifications would allow the individual to better manage some of the physical limitations of their disease and thus maintain their independence.

Additionally, teaching family ways to support the patient without being overbearing or underemphasizing the individual's illness would help the emotional well-being of the patient. These actions would help reduce perceived stigma as over/underemphasizing the disease makes the patient feel lesser (Grytten & Maseide, 2006). The changes seen by modifying family behavior would, again, help preserve and protect the patient's independence thus fostering greater self-esteem and positivity. Family should also be educated on not overburdening themselves and find other lines of support when they do feel overwhelmed with household duties. These techniques, as well as providing family members with emotional counseling, would be beneficial in preventing partner burn out and feelings of resentment (Halper, 2007). By addressing the emotional needs of family members, negativity within the household can be prevented and thus reducing negative emotions that only further reduce the quality of life for those with MS.

Finally, individuals with MS should learn how to educate their employers and co-workers about their disease, and employers and co-workers need to educate themselves about the condition of MS. By being well informed, employers may make adaptive changes to these individuals' occupation so they may remain employed longer and maintain their independence. In a similar fashion, with co-workers being well informed about the disease, they may not see these adaptive changes as preferential treatment. This knowledge would hopefully reduce co-worker discrimination and stigma within the

workplace environment. It is through a proper understanding of the MS experience that methods can be implemented to educate individuals. Through education we can help to deconstruct the MS stigma and implement adaptive changes that foster the independence of these individuals, helping to decrease the vulnerability of this group of individuals and increase their overall quality of life.

CHAPTER 8

DISCUSSION/CONCLUSION

The disease process of MS provides an interesting view into the interplay between chronic disease, visibility, stigma formation, and identity. The sporadic course of the disease and the progressive transition from symptom invisibility to visibility place individuals with MS in the dilemma of when or if at all to reveal their identity. As discussed, stigma formation is largely based on how visible disfiguring attributes negatively impact social interaction. The power from stigma comes from its ability to marginalize a group of people deemed outside of the norm, barring these individuals access to the same social freedoms as others. For individuals with MS, the acute change in social status going from the healthy group to unhealthy group is destabilizing to both their identity and fear of being discredited. These individuals now possess a quality deemed lesser and discreditable. Like others with invisible social identities, individuals with MS, during periods of disease quiescence, struggle with whether to pass or reveal their condition. The choice largely hinges on the greater social context, revealing more in settings that are more supportive. But unlike other invisible social identities, the unpredictability of MS flares place greater burden on these individuals.

For those with MS, their identity is in constant flux. After each attack, individuals are forced into new, and often lesser, roles at home, work, and other social settings. The psychological and emotional effects these changes place on the individual and his/her family affects self-esteem and reduces overall quality of life. These feelings often result in social isolation, worsening symptoms of depression. Furthermore, feelings

of self-worth are further reduced by stigma through workplace discrimination or through overemphasis/underemphasis of the disease – actions that further marginalize an individual's identity. This process results in a cyclic nature of emotional despair during a period when these individuals are already most vulnerable.

The lived experience of the MS patient is complex at its core, made more so considering the combination of the medical, clinical, and social all impacting the person's health. However, it is only by understanding how social barriers, such as stigma, also influence the wellbeing of those with MS can we truly address these individuals' needs. By gaining insight into the lived experience of those with MS, an approach that deconstructs stigma while working to foster greater support for those with MS will help prevent the social isolation and emotional turmoil these individuals experience. The destabilization of their identity and loss of prior abilities is a large factor in these individuals' withdrawal from society and spiral into depression, sadness, and decreased self-esteem. Methods that aim to help these individuals make adaptive changes along with teaching family members and other caregivers how to support the individual without overburdening, overemphasizing, or over normalizing the disease will increase positivity. By making these changes and being more aware of the lived experience of those with MS, the goal is to not only deconstruct the stigma but also increase these individuals quality of life by helping to maintain, foster, and preserve these individuals' independence.

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