A Balancing Act: How Women with a Hidden Disability Perform Femininity

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Abstract:

The word “disability” carries strong cultural and social symbolic meaning. The impact of these meanings is entrenched in the storied experiences of either embracing or repelling “disability” as a self-characteristic. Persons with a “hidden disability,” one that is unapparent to the unknowing observer, make daily decisions about when, where, why, and how to disclose and adopt the disability identity or to “pass” and give society the impression of able-bodiedness. These decisions are heavily influenced by the bodily and social performance expectations of a given gender. Such gender expectations have reverberating effects on self-concept, relationships, and the way one interacts with the world. This study used a narrative research methodology to understand the identity processes of four women ranging in age from 21 to 46 years who have a hidden disability. Victoria has Juvenile Rheumatoid Arthritis; Angela has Epilepsy, Mary has Mitochondrial Myopathy, and Rosalina has Celiac Disease. In this essay, I also reflect on my own experiences as a woman with a hidden disability, Muscular Dystrophy. Through these personal, emotional, and insightful self-narratives, each woman relays the complexity of self-disclosure and disability identity.

> *All the world’s a stage, And all the men and women merely players: They have their exits and their entrances; And one man in his time plays many parts.* William Shakespeare, *As You Like It* (1600)

Introduction *Hidden Disability*

1 A “hidden disability” is one that is unapparent to outside observers except by disclosure or unusual circumstances. While persons with hidden disabilities are afforded a sense of anonymity, they must contend with different challenges, including learning strategic self-disclosure and impression management; when to disclose and make disability visible and when to “pass” and give society the impression of able-bodiedness. The choice, to be or not to be disabled, has important implications for the way we conceptualize disability, and the concept of identity as a whole. Gendered social expectations impact these decisions on a constant basis.

2 This paper uses a narrative research approach to understand women’s personal identification (or lack thereof) with being “disabled” and the impact of womanhood on this identity process. I will focus on the self-narratives of four women, ranging in age from 21 to 46 years, who have a hidden disability. Victoria has Juvenile Rheumatoid Arthritis; Angela has Epilepsy; Mary has Mitochondrial Myopathy, and Rosalina has Celiac Disease. In this essay, I also reflect on my own experiences as a woman with a hidden disability, Muscular Dystrophy. *Narrative Research Methodology*

3 Through a face-to-face two-hour tape-recorded guided conversation with Victoria, Angela, Mary, and Rosalina, I solicited the unfolding of each woman's "story" prompted by the question, "Tell me about what your life has been like living with (specific condition), from the beginning." Each woman had the opportunity to respond to the presentation of data, joining with me in the construction of the results, enabling a sense of 'co-ownership' of the research. In this process, the participants and I together embraced the discovery of the experience of hidden disability.

4 A narrative research methodology is used to present the results. Using *narrative construction,* I assemble the elements of a participant's descriptions into a single vivid narrative to draw the reader into the individual's lived experience as an alternative reality (Barone and Eisner; Polkinghorne). This data presentation is meant to enable 'empathetic witnessing' of a different kind of life to inspire a dialogue between the reader and the text, invoking an understanding of why and how a person acts as he or she does (Barone and Eisner; Coulter; Docherty and McColl).

5 While narrative construction is used to emphasize unique differences across cases, *analysis of narratives* is used to generalize to the overall experience of hidden disability. Analysis of narratives illuminates universal features of participants' stories, breaking the participants' overall narrative into paradigmatic categories, allowing for common themes to emerge across the collected stories (Polkinghorne). By reading the interview transcripts over and over, *key linkages,* common themes and ideas, emerged (Charmaz and Mitchell; Erikson). These key linkages were then grouped with others as part of an overarching concept, leading to the construction of categories of central significance (Erikson; Polkinghorne). This overall process, in effect, brings order and consistency to the data by classifying sections according to their commonalities (Polkinghorne).

Narrative Construction

6 Mary gripped her mug of tea in one hand, the stair railing in the other and eased her way down three small steps. She sunk into a lawn chair, its tattered material sinking with her weight. The sky was a mixture of pinks and oranges, as the sun slowly disappeared. A lone cactus stuck out of the ground, disrupting the flat horizon. It leaned slightly to the left, its arms extending upward as if ready to fight its impending doom brought on by men, materials, and machines.

7 Her mind shifted back to her day at work. It always took a cup of tea and deep breathing to relax her mind before night descended and it was time to fall asleep and start all

over again. The most unsettling aspect of waking up was not knowing whether her body would work the way she instructed it to, or if it would fail her when she least expects, embarrassing her in front of her coworkers. Today was a perfect example of that dreaded humiliation. As she recalled it, the rancid feeling in her stomach returned.

8 That afternoon, Mary had skipped lunch break. The constantly ringing phone had to be answered and insurance claims had to be dealt with. The day had seemed especially busy and if she let the calls go to voicemail, she knew she would be more overwhelmed later. Around four o'clock, her stomach growled an unhappy reminder that it missed a meal. She should have known better than to skip a meal in the first place, especially in the midst of a demanding day. By now, Mary knew that if her body didn't get the nutrition it needed when it needed it, it would rebel.

9 On her way to the kitchen, a young coworker stopped her to ask if she took care of a call he'd forwarded to her. She hadn't yet, but she didn't want to explain this to him, because she could feel *it* coming on. She knew she had to get to the kitchen, to the lunch sack waiting in the refrigerator. She threw a brisk answer at him as she moved. Oh no! She realized it right away … her tongue hadn't quite formed the words properly and her words came out slurred. With a mocking, but intrigued look on his face, he followed behind her. Consciously Mary formed each word in her mind before verbalizing it. Slowly, meticulously, she made every effort to enunciate each syllable, hoping to make him think he had imagined it.

10 "You're slurring, Mary! Did you knock a few back over lunch?" His laughter bounced off the walls. Mary could feel her face burning with embarrassment. She tried to laugh with him, "I'm so tired, I can't even think or talk straight!" But, his arrogant eyes narrowed, seeing right through her forced laugh. Escape to the bathroom, she instructed herself, but her legs wobbled and she stumbled. Of all times for her leg weakness to kick in! This instigated more heckling, louder and more obnoxious, drawing the attention of several people she supervised. She felt her credibility slipping away. In a rush of emotion and defensiveness, she almost blurted 'it' out into the air like a quest for legitimacy. But the voice in her mind reminded her, '*Bathroom*!' and she escaped.

11 Now looking back on it, she felt thankful she hadn't reacted in emotion sharing with this insensitive coworker such a private aspect of her life. After years of doctors in long white coats peering over spectacles with clipboards in hand, transition questions from physical to emotional, concluding with a possible diagnosis of Depression and Somatization of symptoms, she had nearly given in to believing that it must be all in her head. Mary had gone years without the security of a label, despite countless blood draws, strength tests, and muscle

biopsies. When the diagnosis finally came, it was bittersweet. Mi-to-chon-dri-al My-o-path-y. The doctor sounded it out with a glint of pride as if coming up with a stickler for a spelling bee.

12 Mitochondrial Myopathy! A form of Muscular Dystrophy. These words on a piece of paper, in black and white, were proof that it was not all in her head. She felt like shouting from rooftops, “I have a name.” Her teachings in Judaism engrained in her the concept of Yahweh—if you can name it you own it. This is why the Jewish people tried to get God to give them His name. If they knew His name, they could control Him. And that’s why God responded, “No, my name is Yahweh, I am who I am.” Mary felt like because she could name her condition, she could own it and exert a little more control over it.

13 Gradually, however, control was slipping through her fingertips. Her move to the southwestern desert coincided with her body revealing her diagnosis more and more frequently without her permission. When it began affecting her work relationships, Mary sought out a new neurologist for answers. Armed with a thick file of paperwork, Mary explained, “It’s getting worse. I am slurring my speech, and I’ve never had such severe muscle cramping like I’ve had in the past year. My legs go numb all the way up to the thigh, every other day. I have to crawl around my apartment.”

14 Looking at her barely covered by a paper-thin cloth, the doctor said matter-of-factly, “Well,” looking down at the chart to find her name, “Mary. At least you’re not in a wheelchair.”

15 A breeze was picking up and Mary pulled her sweater closer, shuddering with exasperation at this memory. The chorus of howling coyotes rose with the darkness. But at least they had each other, Mary thought with jealousy. Last week, Mary had mustered up the courage to seek out the monthly support group run by the Muscular Dystrophy Association. She had felt excited, desperate even, for the possibility of meeting someone whom she can relate to, whom she can learn from, whom she can confide in and conspire with.

16 As soon as she walked into the room and saw several overbearing black electric wheelchairs and heard loud whirring machines, she’d concluded that she’d made a mistake. One man used his lips to move a stick which propelled his wheelchair towards her.

17 “Welcome,” she thought he said. “Come in.”

18 She pulled a folding chair over to this lopsided circle. “I’m Mary,” she introduced herself, “I have Mitochondrial Myopathy. I came tonight to meet other people with MD.”

19 They looked her up and down, appraising every curve of her body that implied muscle lay beneath, as if evidence of an outright lie. The man, speaking on behalf of the group repeated himself, "Well … welcome."

20 In the hour that followed, no one spoke about anything Mary could relate to. The group shared the challenges of feeding tubes, breathing tubes, IV needles, inaccessible buildings, and personal care attendants. They discussed their week, each person describing the experience of confronting and clashing with ableist stereotypes and oppressive attitudes. Mary looked around blankly. They were trying to get others to understand and recognize all the things they *can* do as people with disabilities. She was trying to get people believe that she had a disability and to recognize the things she could not do. During the bathroom break, Mary grabbed her cloth bag and made for the door.

21 The light of the moon reflected off her now empty mug. She gazed out over the vast emptiness. Alone, she thought. I'm alone in this one.

Analysis of Narratives

Feminized Disability Identity

22 The body is a symbolic and cultural bearer of value (Edwards and Imrie). It is a tool that communicates the junction of both gender and ability. Persons with a hidden disability differ from nondisabled persons because they are often intimately aware of their bodily performance (Corbin). Similarly, 'doing gender' is an unconscious process for most (Butler, *Gender Trouble*; "Gender as Performance"; Brickell). In the United States, as well as many other parts of the world, gender norms and expectations exist in all social situations, dictating how men and women are supposed to look, behave, and what they are supposed to be able to do: how they are supposed to perform (Butler, *Gender Trouble*; Wilson). The expectations for a gendered performance becomes ingrained in us from the moment we are wrapped in a pink or a blue blanket and cooed at that we are 'pretty' or 'handsome.' A masculine person should embody strength, rationality, self-reliance, determination, and perseverance (Robertson; Shuttleworth). Women, on the other hand, are expected to embody beauty, nurturance, dependence, compassion, and vulnerability.

Self-Concept and Disability

23 Goffman coined the term dramaturgy to describe the performance that two people engage in when interacting with each other. It is during this dramaturgical performance that an 'actor' manages the impression of the 'audience' (real or imaginary) by asserting and

emphasizing certain qualities and downplaying or hiding others, both verbally and nonverbally (Riessman). Humans seek to perform in ways that will promote a favorable impression of themselves (Brickell). The self-concept is consequently affected by what we do in our performance (Herek).

24 The self-concept is a person's self-perceptions formed through experience with and interpretations of one's environment (Bracken). The development of a self-concept is a continuous process, constantly changing to integrate experiences and feelings (Charmaz and Paterniti). A self-concept is negatively affected by shame (Matthews). Shame is a painful emotion involving the negative evaluation of the global self resulting from the perception that one's self or one's presentation to others has not met with one's personal expectations. At the core of shame there is the belief that oneself is bad, deficient, defective, inadequate, and unworthy (S. Taylor; Dickerson), which occurs in response to a discrepancy between one's actual self and one's ideal self, or when one fears being negatively evaluated by others (Bracken).

25 One is most vulnerable to shame when s/he is exposed as inadequate or defective, when feeling rejected or weak, when his/her situation is out of control, or when an uncontrollable and/or undesirable characteristic is made salient, for example, when a symptom of a hidden disability occurs publicly (Matthews; Dickerson). When this happens, the individual might respond with an overpowering desire escape the social situation or to hide to conceal the 'defective' self from social scrutiny (Dickerson).

26 Perceived skeptical attitudes and doubtful comments from members of the support system reinforce fears of a 'discredible' self (Davis; Matthews). When a person has a disability that is not apparent, or when acute symptoms are present one day and few or none are present the next, members of his/her support system often unknowingly minimize the experience or give an impression that the condition is not believable. Many family members and friends openly question the reality and severity of the disability (Charmaz and Paterniti; Matthews). Mary explains her experience with this within her support circle: "I still get the same type of response from even family and friends. 'Ooh you don't look that bad.' 'You go hiking with me, you can't be that bad.'"

27 When interactions with authority figures regarding the disability are met with hostility and resistance, one might feel as though he or she is personally disliked because of the disability claim. Victoria explains feeling targeted and publicly humiliated when her requested accommodations were flat-out denied by a teacher that she perceived as spiteful:

I went through a remission at about age 12 or 13. My body developed, I grew, and I wasn't as small and skinny and sickly-looking as I had been before. Coming out of remission caused a lot of problems, I think, because I looked like everybody else. I wanted to look like everybody else. I wanted to put makeup on, and I wanted to do my hair. I liked to keep myself looking nice. But because I did that, I think the teachers looked at me like, "There's nothing wrong with you." The teachers were really mean to me. It started in middle school.

28 Health professionals react differently to people with hidden disabilities than to those with visible disabilities (Charmaz and Paterniti; Davis). Service providers might react with disbelief, lack of knowledge about how the disability presents itself, and overall lack of responsiveness, treatment planning, and service referral (Taylor and Eisele; R. Taylor). Mary describes her experience:

> I feel guilt, because when I do tell someone about it, I feel like they don't believe me. I feel like, oh, it's not that bad. That's what doctors have told me. "Oh, it's not that bad. At least you're not in a wheelchair." … I feel like I should have my lab results or my biopsy results with me and say "here, see, look, its right there." … Even with doctors I feel like I need proof because I look too good … I've gone through hell because of it … Doctors looking at me like there's nothing wrong with me. … I mean, I felt like saying to him, are you going to pay more attention to me and help me once I get into a wheelchair?

29 Even strangers express dissatisfaction with stares, frowns, silent disapproval, and outright verbal questioning when persons with hidden disabilities access special accommodations (S. Taylor). Persons with hidden disabilities then face the additional burden of explaining or proving to others why they need a particular service, which can, in itself, be a shame-producing experience (Matthews). Simply the fear of having to do so keeps Mary from accessing necessary accommodations:

> I've never used (accommodations) even when I need to use them … because I didn't know what to say to people. I even got the parking permit (application), and I was going to ask the doctor to fill it out, and I thought people are going to look at me and say, "She's not disabled. She's using somebody else's permit." I just never did it because I never wanted to deal with people saying anything to me. There's that 'different' again. I mean, that's my issue that I need to work on, but I'm getting this close to asking the doctor to fill it out. Because when I feel that bad, I would like to able to park closer so I don't have to expend as much energy. I thought about it, and thought I wouldn't use it if I wasn't feeling bad, so I wouldn't feel guilty. Here I am saying, 'Oh no, I'm just going to use it when I get bad.' Instead of using it preventatively. But then I think people will say, "She hikes, she does some exercise, why is she using this disability permit?" I don't feel like going into a whole explanation.
>
> I mean, even in the grocery store, I was almost stumbling, and my muscles were cramping stiff, and I probably could have used one of those wheelchair carts they have, but I didn't use it. I just looked at it … (I thought to myself) 'Oh, I don't need

> that. Nobody's going to believe that I need that. I can still walk. I might be stumbling but I can still walk.' Instead of thinking, 'this will help me to not expend any more energy and help me recover faster.'

30 Persons with a hidden disability may feel under constant surveillance when utilizing necessary accommodations (Samuels). An individual may feel self-consciously 'on' at all times (Goffman). Victoria describes this experience:

> My handicap (placard) hangs. And when people see my car, I'm always thinking, "Oh my gosh, what are they thinking right now?" And I'm always thinking, "They probably don't think it's me." Someone will come up and say, "Why do you guys have a handicap (placard)? What's that about?" It's hard because people will look at me and not think that something's wrong. I think that's the hardest part … having people looking at me and not thinking that there's anything wrong.

Gendered Disability 'Performance'

31 Each bodily and social performance is shaped by, and even confined to, the cultural values, norms and expectations of the particular situation. Such gender expectations have significant consequences for the bodily performance of persons with a hidden disability. Women with disabilities are expected to maintain a dramaturgical performance that embodies vulnerability, inferiority, and dependence (Asch and Fine). While these societal notions stand in stark contrast to ideals of masculinity, they epitomize femininity (Garland-Thomson). Women are supposed to be submissive, sensitive, romantically appealing, and dependent, while appearing healthy, due to the social value placed on their bodily appearance and nurturing role (Abrams; Asch and Fine; Johnston and Sinclair; Vickers). Understanding the pervading emphasis on exterior appearance and beauty and on the importance of the ability to disguise bodily limitations will allow insight into why women may be likely to conceal a hidden disability (Stone).

32 The long-standing feminist movement against a patriarchal society rages against women being taught that their individual worth is based on how closely and how favorably their bodily appearance comes to desirable objects (Mairs; Stone). While standards for appearance significantly affect women, ironically it is the stereotype of femininity that allows for certain coping mechanisms for women with a hidden disability. There is more societal acceptance for them to access the resources necessary to adapt to their conditions. Therefore, they show greater resiliency (Charmaz). Angela describes how being female and knowing that society accepts her dependence upon others allows her to request the help she needs:

> I would prefer not to have seizures by myself, and (with epilepsy) you have to depend on someone. Someone has to help me. It's scary to have a seizure by myself. Because usually when I have a seizure they have to turn me on my side. So if I had it by myself, who's going to turn me on my side? I'm going to choke on my throw up or my

> blood and I might suffocate. It bothers me that I have to be dependent, but it doesn't bother me asking for help when I need it. I could see a guy being more embarrassed to ask for help and to be like, "I'm epileptic."

33 Women are socialized into developing a high level of understanding of the intricacies of human relationships (Abrams; Greenhalgh). They tend to place more importance on social interaction with others, and they seek out the opportunity to lean on and learn from others when coping with life's hardships (Abrams; Petronio, Martin, and Littlefield). Rosalina believes this is the cause for the gender discrepancy in her support group:

> It seems to me the guys have a lot more trouble staying on (the diet) than girls. Even our support groups are maybe seventy-five percent women. I think it's because it's a lot easier for women to bond and talk about ways they've found to make a bread that comes out lighter and exchange recipes. It becomes a therapeutical woman's world type of thing, of how to make gluten-free things or order online products and making those and baking those. Men don't really go out of their way to learn how to make special recipes or share recipes with anyone. That's been a huge thing of the diet; finding the foods and finding gluten-free things. Men are more, "Leave me my steak and my potatoes and hold the bread." Also, I think the men consider the women weaker than them, like, about stomach pains or anything that's wrong. With them, they'll get sick, but they're not going to be telling anyone else about it—they're just going to try to keep it to themselves. Men don't want to be admitting weakness. The women are a lot more open with how sick they were and how it affects them.

34 Women's self-esteem is gained through their connection to others (Abrams). Thus, accessing peer-support contributes to both positive identity development and resilient coping skills. A woman's success, however, still hinges on her ability to conform to the societal standards of appearance. In today's society, the dominant ideal for a women's appearance is to have a body that is as thin as possible. Victoria describes that it was this very preference in the female body that allowed her to escape the social ridicule a male with the same condition faced:

> Being thin and being little, because of the arthritis— being skinny isn't a factor when you're female, but it's probably definitely a factor when you're male … I know a kid that gets beat up because he is so small because arthritis stunts your growth. They see him, and they put him in the lockers. They beat him up and he has to deal with a whole other set of challenges that I would never have thought of. So he left school early and got his GED because he couldn't deal with all the ridicule.

35 Women with unapparent conditions may find themselves suspended between their day-to-day experiences and the ideals of feminism (Sherr Klein). Some aspects of patriarchy benefit their daily coping; other aspects remain oppressive. Displaying less than perfect elegance, poise, and bodily integrity, women with disabilities are frequently rejected by both mainstream patriarchy and the feminist movement (Asch and Fine). Feminism is preoccupied

with projecting an image of autonomy, strength, and competence; an image that women with disabilities do not embody. Meanwhile, other 'feminine' roles, like motherhood, are called into question for women with disabilities (Sheldon). Powerful economic, social, and cultural forces reduce the autonomy of women with visible and hidden disabilities of all forms to become mothers and for women to give birth to a baby with a disability (Sherry). Victoria describes such a confrontation:

> I told one guy (about my condition), and he told me I shouldn't reproduce. I was in high school. "You shouldn't reproduce," he said. He was a friend. And I was just like, "Really?" Now it bothers me. I feel like calling him and telling him what I think. But then I was just like, "Hmm."

36 Women with disabilities are counseled away from motherhood, routinely persuaded that their own health will be jeopardized, or that the baby might inherit the 'problem,' or that their own impairments will keep them from being a good mother (Edwards and Imrie; Sheldon). I can relate to many females with disabilities who are confronted at a very young age about how to prevent the birth of a child like ourselves. I was still a child, only twelve years old, when I heard the first of many warnings, "When it is time to think about starting a family, I strongly suggest…." Procreation was the furthest thing from my mind, but the medical model was becoming etched in my psyche: prevention of more disability at all costs.

Conclusion

37 Ultimately, women with unapparent disabilities are juxtaposed between influential societal ideals of what it means to be a woman and the feminist call to resent and resist such oppressive standards. Some standards are entirely out of reach, while others assist and abate their daily struggle, presenting these women with a complex paradox.

38 When I 'discovered' feminism, I remember feeling enlightened, empowered, liberated. The more feminist literature I became immersed in, the more it became engrained in me that anything but complete independence and autonomy goes against the tenets of feminism: "I can do it myself. I am a woman, hear me roar!" This idea made me hate the ways that I am not independent; it made me feel guilty for the ways I have used my femininity to my advantage in soliciting help. When I became involved in disability studies, I learned that I am not alone in the observation that feminism neglects women with disabilities, as we are perceived to embody stereotypically feminine qualities (Sherr Klein; Sheldon; Fine and Asch). Prolific in the literature are accusations against the feminist movement for undermining the struggle of women with disabilities in pursuit of advancing power and potency (Fine and Asch; Morris; Garland-Thomson). My definition of independence changed

when I read George Bernard Shaw's quote (1916) posted on a Society for Disability Studies listserv email: "Independence? That's middle class blasphemy. We are all dependent on one another, every soul of us on Earth." It was an epiphany for me. I *can* ask someone to lift my carry-on into the storage compartment in an airplane, or to unscrew the cap off my water bottle, or to open a heavy door, without batting my eyes and raising the pitch of my voice. I can be an *inter*dependent woman, a feminist, *and* I have physical limitations. I can be weak in body without being weak in spirit. I, like many women with a hidden disability, am learning how to live in paradox.

39 Women with hidden disabilities learn to transform their identity and needs depending on the situational context. With a foot in both the nondisabled and the disability worlds, they both belong to both and fit completely into neither. The hidden disability is framed differently minute to minute as it is integrated into the individual identity as a "flexible continuum of responses that folds back on itself in various directions in response to myriad of internal and external factors" (Olney and Kim 4). By better understanding the commonalities and differences present in the individual experience of hidden disability, women with hidden disabilities and their support system may benefit from hearing a story they can relate to, become empowered for healthy preservation of self, and they might receive the message that, although it may feel like it, they are not alone in this limbo between the nondisabled and disabled worlds.

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