

MeSsy identities: an ethnographic exploration of a multiple sclerosis support group

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ABSTRACT

The following is an ethnographic study of a multiple sclerosis (MS) support group. This study underscores the importance of access to counternarratives for individuals with chronic illness and disabilities through organizational structures such as support groups. This work can help those with disabilities/chronic diseases, such as MS, because it provides a space for discussing the communicative forces that shape individual experiences of living with disability and chronic illness. Thus, this study seeks to understand how pharmaceutical representatives' and doctors' grand medical narratives influence the communication of MS support group attendees and their construction/performance of self. This study shows that participation in support groups provides a space to renegotiate identity in which new forms of self can develop external to the dominant discourse. The support group becomes a space where counternarratives of empowerment develop in the face of master narratives.

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Introduction

Multiple sclerosis (MS) is a chronic autoimmune disease that attacks the central nervous system and is diagnosed in approximately one million Americans and 2.5 million people worldwide (Olsson et al., 2008; Hoops, 2008). MS is an incurable chronic illness and has garnered attention through celebrity cases such as Selma Blair, Montel Williams, Christina Applegate, Jamie-Lynn Sigler, and Jack Osbourne. Although medication now readily exists on the market to delay onset, symptoms such as visual loss, cognitive impairment, lack of coordination, fatigue, and diminished ability to walk are still prominent among patients (Olsson et al., 2008).

MS is discussed and defined in disability studies literature as both a chronic illness and disability (Berger, 2013; Wendell, 2001). Since it is generally misdiagnosed multiple times before a patient receives a final diagnosis, the arduous (mis)diagnosis process and final verdict generate a sense of uncertainty, accompanied by much strife and misunderstanding by those living through the experience and those outside the experience (Hoops, 2008). A person's ambiguous experience with MS can trigger feelings of despair, confusion, and increased depression (Eeltink & Duffy, 2004, p. 284). In the wake of this, MSers¹ often seek social support.

Literature on MS acknowledges that one of the most significant issues patients with MS face is constructing identity in relation to those who are non-disabled (Hoops, 2008; Lenchuk & Swain, 2010; Riessman, 2003). With this, the MS identity transcends the individual and thus relies on the collective (Hoops, 2008, p.85). Over the past few decades, illness-focused support groups have multiplied due to their ability to create relationships,

¹ MSer is an "in-vivo, native language" (Lindlof & Taylor, 2011, p. 250) term used by attendees to refer to themselves as a collective. This term is used frequently throughout this study to refer to members of the MS community.

provide access to resources, and provide an outlet to cope for those living with chronic illness (Coreil et al., 2004). These support groups provide a space for those whose identity becomes inherently tied up in their illness to renegotiate identity so that new forms of self can develop external to dominant discourse and norms (Hoops, 2008; Shadden & Agan, 2004).

Introduction to the Bapcock MS Support Group

Deirdra arrives a little after ten. She rides up in her shimmering blue and silver motor scooter and zooms into the room, situating herself at the front table. The Bapcock MS support group meets the first Thursday of every month at the Bapcock Baptist church. The event is in a newly renovated “adult Bible study” room, covered with crosses over all doorways and a painting of Jesus Christ, who has been staring me down since I arrived. The tables in the room are set up in a rectangle, providing enough space around the perimeter for wheelchair and scooter accessibility. Deirdra’s motor scooter takes up most of the area around her, so she sits alone at the front table. She is the leader and primary facilitator of the support group. When she enters the room, she immediately exclaims, “What is this? All these people!” Maryanne, the first member of the support group I meet, provides Deirdra a royal introduction as she whizzes in and introduces me to her, “Alyse, this is Deirdra.”

The group took a two-month hiatus during the summer months, and many members expressed that they had missed the regular Thursday meetings. The members chit-chat and embrace with hugs until Deirdra finally settles them down. Her first order of business is to introduce me to the group. She immediately asks, “Alyse, why don’t you tell us your tie?” By “tie,” she means my connection to the MS community, and I become tense and self-conscious. My composed demeanor changes as I realize I will not merely be observing. I became linked to the group from the get-go. I explain that my mother and late grandmother suffer/ed from MS and that, given my intimate familial connection to the community, I am interested in observing the group and learning more about the communication that occurs in an MS support group. I hear the crowd reacting as I speak. I glance around the room and realize they are directing nods of approval at me. I have clearly said something right because I feel immediate acceptance which never wavers during my time with the group. As the meeting seems to wind down, Deirdra announces that we will continue the meeting at a restaurant across the street where we will hear a presentation from the pharmaceutical company, Betaseron.

The Bapcock MS group is located in Southern California and is part of a regional chapter of the Multiple Sclerosis Society. The Multiple Sclerosis Society is a national association that promotes empowerment and educational resources for people diagnosed with MS. The organization’s resources help patients with the disease’s emotional, physical, and social implications. Although the Bapcock group prioritizes membership to those with MS, caregivers and other interested parties are welcome to attend with permission from current group members. In addition to the monthly meeting, group members often attend luncheons immediately after each session at the church. This particular luncheon occurs at a local restaurant, Kegs, within blocks of the Bapcock Baptist church and is paid for entirely by a rotating array of pharmaceutical companies, with the expectation that they will provide presentations on MS-specific drugs to members.

Though the Bapcock MS support group allows portions of meeting time and most of the luncheon time for doctors and pharmaceutical representatives to give presentations about drugs, I no-

ticed a pattern throughout my ethnographic observations and interviews with members of the Bapcock MS support group. There is a particular relationship between the members and the pharmaceutical representatives that I began to observe, and it became clear that the cultural identity constructed among the members of the Bapcock MS group is established in opposition to the discourse of the pharmaceutical representatives. In this study, I explore how the grand medical narratives of pharmaceutical representatives and doctors, which pose a rhetoric of “normalcy,” influence the communication of MS support group attendees and their construction/performance of self.

Models and materials for understanding disability and narrative

As a discipline, disability studies works to address the social barriers that perpetuate negative stereotypes of people with disabilities (PWD) and to gain equity for PWD. Disability studies is concerned with the embodiment of difference and reframe disability as a “byproduct of social, environmental, and biological forces” (UIC Department of Disability and Human Development, 2015) or something that is constructed, rather innate. The goal of communication scholars studying disability is to focus on how PWD’s lived physical and material experiences are constituted through communicative and discursive actions and policies.

Disability studies scholars, such as Davis (2006), encourage us to rethink and create alternate readings of the disabled body, compelling those with and without disabilities to understand the world through the point of view of the disabled experience. This disability studies consciousness “is a lens through which ideas, individuals, and relationships are newly viewed” (Katzenstein, 1987, p. 8).

Master medical narratives

A master or grand narrative is a totalizing narrative that provides universal order to lived experiences (Lyotard, 1984). Meta- or master narratives are woven into society’s fabric and constitutive of the dominant discourse about disability. Narrative scholars argue that all social structures can be conceived as narrative threads of this broad discursive form (Harter et al., 2006; Tracy, 2004). I understand narrative as contributing to the conceptualization and “lived sociocultural and political context which individuals [with illness and disability] continually (re)create and perform” (Harter et al., 2006, p. 5). Langellier (2009) believes that “When we make and do stories, we ‘make do’ with what is available, legible, intelligible” (p. 153). Master narratives become what we “make do” with, creating overarching norms, while inadvertently ignoring local and diverse experiences and stories.

The medical model of disability is a master narrative that reduces disability to impairment and calls for medical treatment to normalize patients (Grue, 2011). *Impairment* is “the physiological loss of physical, sensory, or cognitive function” (Berger, 2013, p. 145). In contrast, *disability* is “the inability to perform a personal or socially necessary task because of impairment or the societal reaction to it” (Berger, 2013, p. 145). The medical model is a response to the stigmatizing mistreatment of PWD, an attempt to humanize the experience of PWD and provide a definitive medical diagnosis. Though the medical model was established and is practiced with no ill intentions ultimately, it still frames PWD as social burdens or outcasts. Using referential language such as “handicapped,” the medical model of disability becomes a prominent

model used to describe, define, and label PWD based solely on impairment.

When we assign only medical meanings to a disability, we lose sight of the person behind the disability. By pathologizing and medicalizing disability, we wind up focusing solely on individual medical concerns instead of the social conditions that have created disenfranchisement for PWD (Linton, 2006). For instance, doctors treat incontinence, a significant symptom of MS, through prescription drugs. This treatment is crucial, since incontinence causes urinary tract infections and can lead to further systemic infections or even death. When we focus solely on individual medical concerns, though, we often forget to address social barriers such as inaccessible or handicapped accessible bathrooms, which are an essential part of being able to relieve oneself quickly. Thus, the medical model alone becomes a significant setback for the disability community.

In the Babcock support group context, the pharmaceutical representatives' and doctors' accounts or presentations can be defined as grand medical stories or "metanarratives" (Corker & French, 1999, p. 50). The doctors and pharmaceutical representatives are specifically influenced by the medical model of disability and narrate a master story that possesses the ability to influence identity construction and perceived social norms of those with disabilities (Thorne et al., 2004). As such, the discursive formulation and enactment of identity among members of the disability community are critically impacted by the dominant medical metanarrative. I contextualize the Babcock MS support group within the broader scope of the master narrative as I seek to understand how the medical model of disability and meta-narrative of pharmaceutical representatives/doctors can constrain or enable the members of the Babcock MS support group and with that, counter the medical master narratives.

Counter narratives of disability

In the wake of the medical narrative, one of the intentions of developing "a consciousness of disability issues" is to destabilize the hegemonic force of "normal and institute alternative ways of thinking about the abnormal" (Davis, 2006, p. 15.) Patient-oriented counternarratives subvert prevailing dominant narratives. The term "counternarrative" is used "to describe a cluster of histories, anecdotes, and other fragments woven together to disrupt stories of domination" and replace an oppressed identity with one that elicits respect (Harter et al., 2006, p. 6). A counternarrative compels scholars to explore the conditions that create disenfranchisement and create space to challenge such conditions. In response to the silencing of bodies and voices, the counternarrative emerges to help better understand humans as "storylivers" rather than storytellers (Allison, 1994; Park-Fuller, 1995). As such, this narrative paradigm helps conceptualize how MS shapes communicative exchanges among support group members. It is essential to establish and study narratives that empower rather than oppress identity formation, especially for those living with chronic illness/disability. Thus, understanding chronic illness and disability as a community, co-constructed through narrative, opens an empowering space for persons with disabilities to live and communicate authentically (Coopman, 2003).

The most widely adopted counternarrative to the master medical narrative in disability studies is the social model of disability. This model "posits that it is not an individual's impairment, but the socially imposed barriers—the inaccessible buildings, limited modes of transportation/ communication, prejudicial attitudes—that construct disability as a subordinate social status and a deval-

ued life experience" (Berger, 2013, p. 27). In contrast to the medical model, the social model focuses on the construction of disability in communication, language, and discourse. As with the medical model of disability, the social model also receives criticism, since, according to Siebers (2008), "the medical model pays too much attention to embodiment, whereas the social model in its purest form leaves the body out of the picture altogether" (p. 25). In other words, the disability and illness experience cannot solely be described as a social or medical experience. Both experiences influence and inform each other.

As a result, numerous scholars have continued to develop and build onto these important models to elucidate notions of disability through cultural, economic, political, and materialist frames. One such development—the cultural model of disability—combines arguments from both the social and medical models of disability in order to disrupt dominant narratives of chronic illness and disability. The cultural model:

Recognizes disability as a site of phenomenological value that...does not hide the degree to which social obstacles and biological capacities may impinge upon our lives, but rather suggests that the result of those differences come to bear significantly on the ways disabled people experience their environments and their bodies" (Snyder & Mitchell, 2006, p. 6).

This framework provides an all-encompassing portrayal of disability by accounting for the individual, social, biological, and cultural perspectives. Jarman et al. (2017) define this approach to disability as a "sociocultural approach" (p. 276), focusing on communication and the communication produced in relationships.

By situating my work within the cultural model of disability, this study provides a more holistic view of chronic illness and the counternarratives derived from this support group. The cultural model of disability allows me to mark "disability as a site of resistance and a source of cultural agency" (Snyder & Mitchell, 2006, p. 10) and incorporate both the medical and social narratives of the members of the Babcock support group's experiences. The cultural model guides and informs this study by permitting a redefinition and reshaping of chronic illness and disability as both a product of social disablement and biological forces. As such, it is appropriate to approach the MS support group from this "emancipatory paradigm" (Barnes et al., 2002, p. 245) in order to reveal and challenge oppressive social barriers and norms and "facilitate the empowerment of disabled people" (Barnes et al., 2002, p. 245).

The MS Babcock support group members respond to pharmaceutical representatives throughout this study through the counternarratives they create, which are informed by the cultural model of disability. Within the Babcock support group, the counternarrative acts as a site of resistance (Eeltink & Duffy, 2004; Hoops, 2008; Lenchuk & Swain, 2010).

Materials and Methods

My mother and paternal grandmother both lived with MS my entire life. The disease is an integral part of my upbringing and, thus, the impetus for my interest in observing the MS support group. For this study, I draw on twenty hours of participant observation fieldwork and informant interviews (Lindlof & Taylor, 2011). I entered the field as an observer-as-participant (Lindlof & Taylor, 2011) since my primary motive was to observe group

members, with infrequent participation as my secondary motive. According to Dwight Conquergood (1991), “Participant-observation fieldwork privileges the body as a site of knowing [and honors an] embodied practice” (p. 180). Given the overtly embodied effects and experience of MS, this qualitative approach was the most appropriate means of exploring members’ communication in the Bapcock MS support group (Hoops, 2008; Yorkston et al., 2001).

I learned about the Bapcock support group through the MS regional chapter’s monthly newsletter. After contacting several sites, Deirdra, from the Bapcock support group, was the first leader to contact me back. After speaking on the phone, Deirdra enthusiastically granted me access to the site, becoming the gatekeeper to the support group. The Bapcock support group consists of approximately 20 to 30 members, and monthly attendance ranges from 15-20 members. There is an even balance of males and females, ranging between 40-70 years old. There is varied socioeconomic representation in the group. For example, some group members express no need to apply for permanent disability, whereas others’ sole means of income is from government-assigned permanent disability.

The group meets the first Thursday of every month at the Bapcock Baptist Church in downtown Bapcock. After meeting at the church, the group reconvenes at a restaurant across the street for a luncheon that typically consists of PowerPoint presentations by doctors and pharmaceutical representatives discussing medications for MS. The luncheons generally last around two to three hours. The field notes from my observations of the group feature thick description (Geertz, 1973) and the fieldnotes resulted in 70 pages of typed single-spaced fieldnotes.

During my time in the field, I was allowed to conduct on-site, informal “ethnographic interviews” (Lindlof & Taylor, 2011, p.176). This access enabled me to establish themes and critical questions that arose from *emic* or emergent data collected during participant observation. The informal ethnographic interviews gave way to six structured informant interviews (Lindlof & Taylor, 2011, p.177). I conducted these interviews at various locales, but mainly at coffee shops and several informants’ houses.² Interviews were audiotaped and lasted 45 minutes to nearly two hours. Each audiotape was transcribed and yielded nearly 65 pages of single-spaced transcripts. Ultimately, to ensure anonymity, all audio recordings were deleted once interviews were conducted and rescribed, and the names of all participants, nonparticipants, locations and groups were replaced with pseudonyms. In addition, all participants signed informed consent forms. Ultimately though, IRB determined that by CUNY HRPP procedures, the research protocol for this project met the criteria for IRB Exemption.

Using an interview guide, types of informant interview questions included motive, grand tour, developing rapport, and emergent idea questions (Lindlof & Taylor, 2011). My focus on narrative theory informed my interview questions, since I desired to hear my participants’ stories and, thus, formulated my questions around storytelling/narrative. When I asked questions from my guide, I typically began with building rapport first, questions about the MS support group second, and the individual’s experience with multiple sclerosis last.

² Most interviews were not conducted at participants’ homes due to safety issues after my safety was compromised during an interview at a male informant’s home. From then on, interviews were conducted in public settings.

My analysis began with a line-by-line “open-coding” (Lindlof & Taylor, 2011, p. 250) process, which utilized the “grounded theory” (Charmaz, 2001, p. 35) approach. Grounded theory creates intimate connections between data and the categories by which data is coded. I categorized my data first through *emic*, “in vivo” (Lindlof & Taylor, 2011, p. 250) codes which emerged directly from participants’ language, as well as interpretive codes based on analysis. This process generated two strong categories. These categories were the master medical narratives and narratives of counter-hegemonic resistance.

In what follows, I present my findings and discussion in three sections. First, I detail the master narratives told and perpetuated in the support group by members and pharmaceutical representatives/visiting the group. Second, I elaborate on the counter-narratives of resistance produced by group members. Last, I conclude by exploring what these counter-narratives do for disability studies and the resistance to socially prescribed norms.

Results

Master narratives

Doctors know all

We are ushered out of the Bapcock Baptist Church and drive to the restaurant. Kegs is in the heart of downtown Bapcock, an affluent Southern California community. Upon arrival at the main entrance of the establishment, which is a significant walking distance from the parking lot, we are crammed into the small waiting area. Most members of the group are in a wheelchair or use a walking device, so we stand out among the ostensibly non-disabled servers. The room starts to heat up, our bodies are tightly cramped in the waiting area. I notice that our presence elicits confused stares from the wait staff. They stand erect and gaze at us with wide eyes and tense faces. Many attendees do not seem to notice—or at least choose not to notice—the stares directed toward them before we are ushered into the dining room.

Dr. Y stands above everyone else at the front of the room. He is dressed in a purple Oxford shirt, gray trousers, and hair that matches his pants. My inner public speaking instructor catches his monotonous tone from the start. The presentation begins by describing how MSers should “empower” themselves through medication to cure the symptoms that, as he proclaims, “you ‘MS people’ have.” His degrading language and flat tone were only surpassed the following week at our support group meeting when I met doctor number two.

It is my second day with the support group at the Bapcock Baptist Church, and I instantly notice a change in scenery. Deirdra no longer occupies the front of the room, but a rather, lanky man donning a black suit stands in her place. As I enter the room, I ingest the fragrance of freshly brewed hazelnut coffee and pastries. Breakfast is provided this morning. Deirdra still starts the meeting, but situates herself at a table among the rest of the group. She welcomes everyone, introduces new members, and then “turns the floor” to Dr. X.

Dr. X, awkwardly overdressed for the occasion, informs the group that he will introduce an exciting new drug, Amphil. The medication is theoretically supposed to improve patients’ walking abilities. As his presentation progresses, I notice the air-conditioning in the room keeps turning on and off. It makes a hissing noise and causes a fuss each time it wakes up, with group members becoming distracted and not focusing on the presentation at hand.

Dr. X. grows noticeably irritated by the sound and the members' subsequent reactions, so another pharmaceutical representative who accompanied Dr. X. that day turns off the air conditioning. As the room becomes progressively warmer, Dr. X inadvertently ignores that heat and a warm climate harm MSers' health. Thus, the battle over the air conditioner begins. Maryanne gets out of her seat and moves to the central air. She turns it back on.

After Dr. X has spoken for a substantial amount of time, a group member asks about Amphil's side effects. Rather than elaborate on the very valid question, Dr. X curtly responds, "We will cover that later. Any other relevant questions?" Dr. X. never returns to that question. Instead, he continues to market the drug to the group. After his lack of engagement and terse remarks, the group members become increasingly restless and pass pastries and orange juice around, even though the doctor is still speaking. It becomes clear that by interacting with one another and ignoring his "lead," the members refuse to let him take charge of their meeting. I do not recall the last 15 minutes of Dr. X's presentation, since we were all stuffing our faces with Danish rolls and bagels and starting side conversations. Some may perceive this defiance as rude, but it looked like resistance from my seat.

"I won the lottery:" The commodification of identity

Sherry and I share a penchant for academia. A former department chair at a private southern California university, Sherry acknowledges our similar life trajectories. We sit at her kitchen table, nestled in a beautiful hillside. I hand her the IRB consent form and go through my routine instructions, "Please note that you have the right to leave any question unanswered..." but as I run through my memorized script, I notice her hand shaking while she tries to sign her name on the form. This hand is all too familiar to me. It is my mother's hand. Their handwriting, to me, is nearly identical and illegible. One of the many symptoms of MS is the degradation of motor skills. My mother lost her ability to write us birthday cards, let alone her name, and Sherry has, too. I am yet again reminded of my corporeality in this scene. As I vigorously write down my observations or notes during interviews, I quickly forget that the sheer ability to write a sentence easily places my body in a different position than my participants.

After speaking for a while, our interview reached a hot-button topic I had been itching to discuss with her, "The lottery." Sherry starts:

Well, back in 1993, Betaseron was put on the market as the first drug that slowed the progression of MS. It was tough to manufacture, and they did not have sufficient doses for all the people that required it. So, your neurologist would put your name in the lottery. I didn't even know anything about it. I had been following and researching the drug, but when I got a call from Dr. Y, he said, "You won the lottery!" I said, "What? What does that mean?" He said, "You are one of the people whose name was selected to get the first dose of Betaseron." And that is what winning the lottery meant, and that was a big deal because 300,000 people in the country had the disease, and there were only enough doses for 100,000 people.

I was all too familiar with this story of the lottery. A similar story had been passed down to me by my mom, who, similar to Sherry, had been selected as a "lottery winner" and gained access

to a potentially life-changing drug. As there is no cure for MS, those diagnosed rely on medication to slow the progression of the disease, making Betaseron's competition for their drug ethically and morally questionable. Betaseron's perceived abuse of power through the lottery becomes central to the rest of our interview.

This theme of the pharmaceutical industry's control and authority over the bodies of MSers is elaborated further when Sherry continues:

When I was first diagnosed, I knew what I had. It was either MS or a brain tumor. [When I went to the] doctor, she started to cry. She said, "I do not know how to tell you this. I've never had to tell a patient something like this before." And so, I took her hand and said, "Honey, it's okay. I understand. I've read the report, and I know what MS is. It's Okay." "Well, I'm going to send you to our neurologist," [she said]. I said, "That's fine." So, we went to the neurologist the next day, and we had questions, but he kept backing away and literally backed into the corner of the room. Finally, he blurted out, "Stop asking me questions. For all I know, you could bring her in two years in a wheelchair, drooling. I don't know what the course is!" And my brain sort of shut down for several months after that.

Pharmaceutical companies and doctors constrained Sherry's performance of self and ability to process her disease and identity through their rhetoric and actions. Her reply, "My brain sort of shut down," signals a clear, visceral response to the doctor's diagnosis and reaction to the disease. Thus, master narratives such as these reinforced and reiterated by Sherry's doctor, instigating feelings of marginalization for Sherry and shared among other support group members.

"Mindless, dumb sheep"

Polly and I sit outside a small coffee house on the corner of Rita and Route 94. I sip on my cup of coffee—dark roast with a splash of whole milk—while she opts for purified water. Polly attends the support group meetings because her daughter has MS. She starts immediately, "Ever heard the terminology dumb sheep?" I assure her I have never heard of this term before. She continues: "It's a conditioning of the mind...the mentality of thoughtless or mindless decisions. [It is when people] don't have to hunt for options or education. [It is a] mindless conditioning." The "mindless, dumb sheep" Penny refers to are the members of the Bapcock support group, the members of which have MS. She continues:

When I heard that woman in the support group say, "Are you an MSer?" I wanted to puke. They have clothed themselves in an identity of MS. I held my tongue. It's like a person who says I'm a diabetic. You're not. You're a human being with a confused pancreas. You're not a diabetic. These people have clothed themselves in the identity, "I'm an MSer." I was choking on tongue meat when I heard that. Unfortunately, it's a sense of belonging from a sick dynamic and a "Let's identify ourselves from this negative aspect and fuel that instead of the positive!" perspective.

Polly is undoubtedly not a vicious woman. Neither is Dr. X or Dr. Y from the pharmaceutical presentations. They are people,

like me, intimately linked to MS or just simply doing their job. Polly, in particular, is a parent who likely feels caught in the liminal space between disability and non-disability while trying to make sense of her daughter's identity. With few representations of this, she and many other parents are left to their own devices to navigate these uncharted waters.

However, the medical narratives she and the many doctors we have witnessed perpetuate are messages that can potentially force those with MS to alter their self-perception. Medical colonization is when medicine tries to subjugate the body and one becomes "a spectator to their own drama, which means that they lose themselves" (Davis, 2006, p. 5). It is within these meta-narratives told by the pharmaceutical representatives, doctors, and even friends and family members, that MSers begin to lose agency, as they become "spectators" of their life dramas and are forced to perform a sense of "normalcy" for others, rather than others adapting to alternative "norms" or ways of being in the world.

Counter narratives of resistance

"We come for the food"

Maryanne, her husband Drake, and I sit in a booth separated from the main dining area. Penny's, a staple chain diner in Southern California, smells of freshly baked goods and ammonia cleaning supplies. However, that specific aroma of food seems appropriate, given its constant presence during support group meetings. Maryanne was the first member I met at the Bapcock support group. At 60 years old, she dyes her hair strikingly blonde and reminds me of my grandmother, with some added feist. At first glance, as is often the case with MS, one would overlook Maryanne's physical disability. However, when she walks through the aisles of the diner, her left leg drags ever so slightly behind her.

By the time our conversation makes its way to the discussion of pharmaceutical-hosted luncheons, Maryanne's sass is raring:

What is it they say? "You feed 'em, and they will come?" Yeah, yeah, because these luncheons are always in nice places. If they're not, people won't come. I'm going to one at Don's. Ahh, I wish I had known and gotten you a seat beforehand! And then, one on November first at the Suites, and that's very nice. Oh, and they even have one at the B.B. Club. Oh, and the E. V. Country Club. You know which ones are the nice ones and which ones... Eh, you want to go to the nice ones.

Her attitude toward the luncheons is the first I have heard from support group attendees, but it eventually becomes reinforced by other group members during my interview process. Jack, the group co-leader, states, "We try to help each other out. And being on social security, we can't afford a lot of stuff, and the places we go to I couldn't afford otherwise! So yeah, we go for the food!" It is clear that even though they do not necessarily see these representatives as inherently bad individuals, they also see past their motivations and, as such, have their own agendas.

Pearl reiterates these same sentiments when she states:

Yeah, because the one doctor I heard at the beginning [of one of the luncheons], it's almost like, golly, what is he saying? [...] The pharmaceutical industry is very much about selling its products. It is a powerful financial entity. I believe the money behind the pharmaceutical industry

is what drives this country. It's what drives the economy of the country.

All of these statements contribute to an overall narrative of autonomy and resistance, i.e., resistance to the metanarratives of pharmaceutical representatives and doctors. MS attendees re-appropriate the medical master narratives and gain agency by working within the system. They acknowledge that the pharmaceutical companies pay for these luncheons, but luncheons come with strings attached—presentations they would not otherwise be interested in sitting through. So, they counter this by exploiting the companies for their gratuitously expensive and elaborate events. They redefine the meaning of medicine and pharmaceutical-sponsored luncheons to exploit the profit-driven strategies of pharmaceutical companies while creating community and group identity among themselves.

My interview with Maryanne continues with a discussion about the support group. I ask her, "For someone who has never been to a Bapcock support group meeting, how would you describe it to them?" She responds:

Uplifting. I love the information that's given and the information that's shared. People are not afraid to talk about things and are caring. Everybody seems to care about each other. It helps me. Stay positive no matter what gets you down. Keep that positive bubble around you. I feel so welcomed by the group. Everyone here has a paradigm of coherence. No one feels left out because we are inclusive.

Maryanne and the rest of the Bapcock MS support group provide a unified counternarrative, which may strengthen their individual and communal identities. Their performance of selves within the support group is enabled because of the creation of a community they all acknowledge and cherish, an identity often glossed over by the doctors and pharmaceutical representatives who approach group members from the perspective of the medical model of disability.

Maryanne continues, "I'm just so glad you came to our support group. See, we love sharing because no one wants to listen to us. Otherwise, they don't know what we're talking about [when it comes to MS]." Dennis, another member of the support group, echoes these sentiments when he shares that his friends and family could not understand the disease. They would tell him, "You don't look like anything is wrong with you." Therefore, the support group became something fun for Dennis and a break from some of the harsh realities of the disease.

These counternarratives allow the Bapcock support group members to carve out a space for themselves beyond the master narratives of the pharmaceutical representatives and doctors. In doing so, they create counternarratives of resistance that allow for the subversion of dominant discourse and the potential for broader social change within the disability studies community (Corker & French, 1999).

My "hearty" discovery

During our interview, Maryanne and I found ourselves off track. As our conversation got off topic, we relished our Type A personalities, which brought us both stress-induced palpitations. We could not believe our similarities and began laughing at ourselves, much to the dismay of those around us. Our laughter caught the attention of others, which elicited uncomfortable stares,

but neither of us cared as we proceeded to talk for nearly another 30 minutes about our experiences.

At that moment, I realized what I had been missing as a researcher. As we relayed stories back and forth, we shared a commonality. My identity was no longer constrained. I was not Alyse, the researcher. I broke character. I broke my performance as a researcher. Maryanne permitted me to be myself with her, which I realized at that moment is what the support group and “MSer” identity provide for the attendees—space outside the social norms they are bombarded with every day, a haven to be who they are.

Discussion and Conclusions

The force that narrative plays in the lives of MSers is undeniable. Through participant observation fieldwork and informant interviews, it became clear to me that members create a community based on their “disequilibrating and discordant identities” (Hoops, 2008, p.102). For instance, many members come from various socioeconomic backgrounds and varied hobbies/interests, yet they found refuge and acceptance in the support group community despite this. Importantly, this community becomes a space where members can authentically perform and share their identities. What remains is a cultural identity fortified by counternarratives that undermine the medical meta-narratives.

Doctors and pharmaceutical representatives who attended many of the support group meetings and luncheons to provide presentations on MS-specific drugs were influenced by the medical model of disability. They narrated a master narrative, which perpetuated the notion that the MSers could be reduced to a set of symptoms that should be fixed without accounting for the complexity of their character and identities. Undoubtedly, this could easily influence support group attendees, yet what I observed emerging is a counternarrative of resistance, one in which support group attendees acknowledge the master narrative intentions of the doctors and pharmaceutical representatives and counter this by blatantly resisting those intentions while taking advantage of the luncheons hosted for them.

This study underscores the importance of access to counternarratives through organizational structures such as support groups. This type of work can help those with physical disabilities and chronic illnesses, such as MS, because “the incorporation of communicative disability studies perspectives can [create] a critical framework for discussing the forces that shape the individual accounts of disability and illness” (Garden, 2010, p. 74). Counternarratives function as a space for historically marginalized people to find a voice. Support groups act as a space for participants to find a voice while constructing a safe space to challenge hegemonic norms.

It is important to remember that the constituting force of communication is crucial to this study. Communication is central to this project because it is through communication that the Bapcock MS support group members can create, reshape, and negotiate their identities in their relationship with MS and one another. Through the shared space they have co-constructed together and through their communicative actions, the Bapcock MS support group members create a site of resistance within which they can flourish.

As my meeting with Maryanne ended, she and I exchanged phone numbers to ensure we kept in contact. It was in her closing remarks that she reiterated the true importance of support groups:

You and I understand each other, and that’s one of the big things about MS that you have over a lot of people. You know about it, number one, but you’ve had it in the family, and I’ll tell you, unless you have it in the family, it’s really hard to understand. You know, it’s like sometimes, Deirdra will talk about having a pity party, and we’ll cry a couple of times a month, and we’re over it. You do stuff like that, and no one will understand. They don’t understand. It’s like telling you not to stress out. To tell your heart to stop having heart palpitations. It’s the same with the MS. What’s worse is that people don’t even ask. They just don’t want to know. You have more understanding of MS because of your mom. Let me tell you, Alyse. You are part of the group now!

For Maryanne, this support group gave her a voice. Research pertaining to support groups and, specifically, the communication that occurs within them can continue to help highlight the voices of individuals such as Maryanne. It should be noted that this is, of course, one support group’s experience and, as such, I would encourage future researchers to explore how different support group spaces and different relationships within those spaces may manifest differently from my experience with the Bapcock support group.

At the time of this study, in-person support group meetings were the primary meeting modality. Since the pandemic, online support groups have flourished due to the shift in virtual spaces. This alternative space provides another area for inquiry, though uniquely different from this study, as it primarily allows those with chronic illness and disability to access meetings from home without the added mobility barrier. Yet, the embodied nature of the meeting that I was able to witness is no longer present. Further research would be needed to understand how counternarratives manifest and function in such spaces without the corporeality of the in-person support group meetings and luncheons I encountered during my observations.

Ultimately, in the wake of this research journey, I challenge communication and disability scholars to continue revealing these counternarratives of resistance to create a space for those like Maryanne and all the participants of the Bapcock MS support group who deserve to be heard.

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