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From Beasts to Faulty Wiring: Metaphorical Images of Multiple Sclerosis as described by women

«De bestias a instalaciones eléctricas defectuosas»: imágenes metafóricas de esclerosis múltiple descrita por mujeres

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Abstract: Multiple sclerosis (MS) is a disease affecting the brain and the spinal cord, in which the immune system attacks the myelin that protects nerve fibres, thus causing permanent damage resulting in various types of disabilities. As a (to date) incurable disease, the experience of the patient becomes central in coping with the many symptoms, especially in the way it is communicated, not only to treating physicians, but also to society at large. Over the last years MS, which a century ago seemed to affect women and men alike, has shown an increasing prevalence in the female to male ratio, both in small cohorts (Kotzamani et al., 2012; Krökki et al. 2011), and worldwide (Sellner et al., 2011). In view of this tendency, the study of MS has begun to include a gender approach, focusing on the potential explanatory factors, but also on the specific circumstances affecting women (Jobin et al., 2010). In our paper, drawing from a sample extracted from online testimonials, an analysis will be carried out of the various metaphorical imagery used by women to explain their symptoms to doctors, relatives, and society at large. Following the traditional classification by Lakoff and Johnson (1980: 14), we shall explore the framings used, which may lead to positive or negative experiences of the disease and may have an empowering potential when patients «fight» MS in the general framework of managing the condition.

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Key words: multiple sclerosis, health communication, health metaphor, women and disease.

RESUMEN: La esclerosis múltiple (EM) es una enfermedad que afecta al cerebro y a la médula espinal, en la que el sistema inmunológico ataca la mielina que protege las fibras nerviosas, provocando daños permanentes que derivan en diversos tipos de discapacidades. Como enfermedad (hasta la fecha) incurable, la experiencia del/de la paciente es fundamental para afrontar los numerosos síntomas, especialmente en la forma en que se comunica, no solo a los médicos, sino también a la sociedad en general. En los últimos años, la EM, que hace un siglo parecía afectar tanto a mujeres como a hombres, ha mostrado una prevalencia creciente en la proporción entre mujeres y hombres, tanto en cohortes pequeñas (Kotzamani et al., 2012; Krökki et al. 2011), como a nivel mundial (Sellner et al., 2011). Ante esta tendencia, el estudio de la EM ha comenzado a incluir un enfoque de género, centrándose en los potenciales factores explicativos, pero también en las circunstancias específicas que afectan a las mujeres (Jobin et al., 2010). En nuestro artículo, a partir de una muestra extraída de testimonios en línea, se realizará un análisis de las diversas imágenes metafóricas utilizadas por las mujeres para explicar sus síntomas a médicos, familiares y a la sociedad en general. Siguiendo la clasificación tradicional de Lakoff y Johnson (1980: 14), exploraremos los marcos utilizados, que pueden conducir a experiencias positivas o negativas de la enfermedad y pueden tener un potencial empoderante cuando las pacientes «luchan» contra la EM en el marco general del manejo de su enfermedad.

Palabras clave: esclerosis múltiple, comunicación para la salud, metáfora en salud, mujeres y enfermedad.

1. MULTIPLE SCLEROSIS AND ITS PREVALENCE

Multiple sclerosis (MS) is a chronic disease of the central nervous system that often causes disability, affecting around 2 million people worldwide (WHO, 2023). It occurs when the immune system attacks the protective sheath (myelin) of nerve fibres, which causes communication problems between the brain and the rest of the body. Although the symptoms greatly vary depending on the location and the severity of the nerve damage in the central nervous system, some common symptoms include weakness in limbs, tingling, sensation of electric shocks, vision problems, fatigue, and depression. In more serious cases it may also cause more severe problems, ranging from muscle spasms to bladder/bowel challenges, and cognitive and mood problems. Also, the consequences for the patients are limitations on their daily life, often including physical and financial insecurity (De Judicibus & McCabe, 2009). The symptoms are often unpredictable and may appear and disappear, to such an extent that people with MS may have long remission periods with no new symptoms.

MS is seldom fatal in itself, although there is increased mortality in MS patients compared to the general population due to other comorbidities and also MS-related suicide (Manouchehrinia et al., 2016), and it is also a chronic disease with no cure as of today. In spite of the non-fatality in itself, MS is often accompanied by other problems that can affect the patients' quality of life, such as infections or cardiovascular disease. Also, MS causes pain, discomfort, and inconvenience, but it is very seldom that the patient suffers severe disability. What is problematic, however, is the variability of the disease from person to person, which makes it difficult to predict if the condition will improve or worsen.

An added component of MS is that, although it is technically not a disease exclusive to women, it does have greater prevalence among women, which can at time reach 3:1 ratios (see, for instance, Wallin et al., 2019), which, most importantly, has changed from 1:1 a century ago (Ebers, 2008), and might be due to biological, genetic and environmental factors (Jobin et al., 2010, Kotzamani et al., 2012, Sellner et al., 2011). Also, MS particularly affects women insofar as women with any disability are a disadvantaged sector in the workplace, with higher unemployment rates and higher poverty rates, even including lower retirement pensions when calculated on the basis of years of full-time employment (Dyck & Jongbloed, 2000).

In our study, we shall explore the metaphors used by female patients to describe their disease, and more specifically, how they allow them to convey their feelings and how, through the use of metaphor, the patients build a self-empowering image. This will be done through a study of MS-related metaphors used in patient videos.

2. MULTIPLE SCLEROSIS AND COMMUNICATION

> The hardest part about having MS is not being able to explain how you feel. (Antonia)[2]

In general, some symptoms of diseases are not easy to communicate. Unlike symptoms marked by abnormalities in the body, which may be observed objectively, by means of blood tests, X-ray or MRI scans, symptoms associated to feelings, such as tiredness, tingling, numbness, and especially pain, are not easy to express: a patient who is too tired to walk, or who is ailed with such pain that they cannot sleep, cannot properly convey such sensations. Although medical science has developed a number of tools for patients to express the severity of pain, e.g. from «mild» to «excruciating», such tools are not without their problems (Dijkers, 2010). Also, this makes them subject to potential accusations of malingering (more below), even though there are widely used scales and instruments used to detect the exaggeration of symptoms by patients (see Lace et al., 2021). In the case of MS, there is general agreement in the literature that communication between the patient and their doctors is basic, initially to decide among treatment options and ensure adherence to treatment (Street et al., 2009), but most importantly, for the patient to manage MS itself (Heesen et al., 2007).

However, a generally underexplored area, in addition to patient-doctor communication, is communication between patients and their peers, or simply between the patient and society at large. This type of communication has been probably less explored because it apparently has no direct consequences on the way diseases or conditions are treated, since it is «telling the doctor» that really matters. However, it is also important, because this communication affects the perception of the patient by others,

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[2] Throughout the paper, the quotations from testimonials from MS patients will be followed by the patient's name between brackets; in the case of patients whose names are not mentioned, they will appear as FP (Female Patient)1, FP2., etc. Bold type in the examples is used to emphasize the relevant language in each case.

and therefore the patient's construction as an individual, and it may also happen that the healing process (or the coping process, for incurable diseases) is also impacted by these perceptions. Unlike some of the «traditional» diseases like cancer, where patients have widespread social recognition, the invisible diseases, like MS itself, are poorly understood by the medical community and by the general public (Miller, 1997). This would explain, for example, the importance of social support and community integration for MS patients (see Kratz et al., 2016). However, «support group» does not necessarily mean «widespread social recognition», which is why social media are used in order not only to support patients, which would be the role of discussion groups, but also to gain societal involvement.

Concerning MS, communication problems seem to affect the diagnosis of the disease itself. For a start, even in the initial stages, many participants in studies report that they struggled to obtain correct diagnoses and found it difficult to communicate with their doctors (Thompson et al., 2022). This also affected perception by non-experts surrounding the patients, especially given the unpredictability and invisibility of symptoms, such as pain, fatigue, and cognitive impairment. In fact, many studies describe patients not being believed by their families (Haubrick et al., 2021: 39, Parker et al., 2021), although deliberate deception in symptom reporting is seldom the case, even when financial gain is involved (see Bass & Wade, 2018).

The use of language is especially relevant because, with MS and other «not visible» diseases, communication is particularly important to patients. According to some studies, the «invisible» symptoms may be just as important to the patient's self-perception of health as the visible ones (Green et al., 2017). In fact, «lack of visibility» (both literal and metaphorical, based on SEEING IS UNDERSTANDING) is present in a great many of the testimonials:

> But with other issues that are out there like MS, other mental health issues, PTSD, **you can't see it**. And just because you **can't see** that there's a problem does not mean that there isn't one there. (Tracey)

In fact, one common story (widely reported in the literature; see, for instance, Haubrick et al., 2021) is that in which patients' behaviour or actions are misinterpreted because of this lack of visibility or because the symptoms are not there at a particular moment:

> I've got a service dog, so people didn't look at me so weird when I was stumbling. You know, I have a dog; **I am disabled, not drunk**. (Chloe)

> The hardest part about having MS is not being able to explain how you feel. I wish I could write I have MS somewhere on my body because **people are so judgmental when they can't see my invisible symptoms** – just because I'm not in a wheelchair doesn't mean it's not hard for me to walk every day.
> After I was diagnosed with MS, I got a handicap pass. One day, I was with one of my friends and I actually felt really good because although I had a little bit of a limp, I wasn't using a cane that day.
> I pulled into a handicap spot and the parking attendant looked at me and said, '**You're obviously lying. You're not handicapped**.' (Antonia)

As may be seen in this last example, visibility and social perception are problematic, especially with relapsing-remitting MS (Miller, 1997: 291), where the patient may have episodes of neurological illness, but appears to recover between those attacks (although there are residual deficits). There are plenty of examples of this:

> **Visible and invisible** symptoms come and go. It's hard to explain to your friends that last weekend you could do something, but this weekend you can't. Just because I can ride my horse one day, doesn't mean I'll be able to ride next week. (Antonia)
>
> And I want to help bring awareness, especially people who have relaxing, remitting MS and are in my position, **who may not always look like they have a disability**, but still go through some other suffering on a daily basis. (Charlotte)
>
> And I felt like **the doctor didn't believe me**. And that was a big thing. Uh. And it made me feel so unconfident. And I, I didn't like that. I didn't like how it took that empowerment away from me. (Jessie)

In the case of women, the function of this type of communication is especially relevant since, in order to become empowered patients, women must overcome the initial discrimination that makes them second-rate patients. In fact, Wendell (1996: 124) reported abundant cases in which women were misdiagnosed, the symptoms being attributed to their being «neurotic» or having the «housewife» syndrome, which leads to negative self-perceptions by the patients themselves. In fact, there are many cases of women being misdiagnosed or having their symptoms dismissed by clinicians more often than men (see, for instance, Newman-Toker et al., 2014; or Thompson & Blake, 2020), or simply being accused of exaggerating (Springer-Sullivan, 2005). In some instances, studies have shown that women with pain are more likely to be recommended psychological treatment, whereas men are more likely to be recommended analgesics (Schäfer et al., 2016). Some studies have reported women feeling greater stigma (Haubrick et al., 2021: 39). The problem becomes greater when the person with MS belongs to any non-majority group, which results in further alienation:

> … the disease seemed to **affect older, white women. I was young, black and felt like a unicorn** for having MS. (Victoria)

For women, who are assigned the role of carers for their children and for their parents, MS is a further source of anxiety (Parton et al., 2018):

> **My daughter** seeing me, erm, suffering. That for me is the worst part, my husband seeing it as well. But my daughter's still quite young and she doesn't understand. And seeing it affecting her and the way she thinks about me is the lowest. **I feel guilty for how it's affected her first years of life**. (Charlotte)
>
> My daughter was only six months old. I go to the park and. See all these moms playing with their kids on the structures and I didn't have the energy for it. **And I beat myself up thinking. I should be out there. I should be alongside my**

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> **child** and playing and throwing them up in the air and doing all these things and it couldn't. (Clarissa)

> And how **was I gonna be a parent to them** and not feel my leg? And what did this mean? And it was just all these scary emotions at once. (Sarah)

Nevertheless, in two of these women, the mention of the extra reason for anxiety is counteracted in their narratives by the fact that they have been able to overcome the alienation by precisely using it as a driving force for their management of the disease. The mothers mention the strength they derive, whereas the Afro-American woman has created a specific support group for Black women with MS:

> I find **strength** in being a mother. (Clarissa)

> I think **having MS and being a mother, I really value the small, everyday things in life that maybe people tend to take for granted**. (Sarah)

> I started We Are ILL as an awareness campaign on social media and an online support group to **help others feel less «rare.»** We Are ILL is now an organization with a support group that has grown tremendously. **Black women** can search for us and think, «I see myself». (Victoria)

Concerning the use of metaphor in health communication, there is abundant work by linguists and clinicians on the use of metaphor in doctor-patient communication, especially in diagnosis (Hanne, 2015), and even in MS (Duval, 1984). More specifically, Munday et al. (2022) have studied the expression of pain through metaphors which include physical attack, sharp objects, temperature, electricity or insects, and have pointed out the need for further study on the use of metaphor, especially as it concerns the adjustment to chronic pain. However, there appears to be scarce analysis of the use of metaphor in patient-society and patient-patient communication, a phenomenon which has been made possible by the Internet and social media (see, for instance, Patel et al., 2015, and especially Semino et al., 2015). Thus, one of the most salient changes from the traditional small-sized support group is the advent of social media (podcasts, YouTube channels, or non-profit-making websites). These tools have allowed people with chronic diseases to connect and share their experiences with others. This is not only helpful to others experiencing similar situations, but most importantly, it is aimed at changing the way society conceptualizes chronic diseases and those who have them, or, most importantly, for the patients themselves through the genre known as «personal illness narrative» (Bock, 2013). In other words, this has created a new communication channel, beyond the doctor-patient and patient-peer communication: patient and society.

This is important for three reasons: (1) the adjustment by patients themselves to chronic illnesses (as studied by Radley, 2002), which is part of the patient's self-perception; (2) the peer information provided to other patients, which can find support in the experience of others, and (3) most importantly, the perception of the patient by the whole of society, especially in the case of not-so-visible illnesses. As will be seen in the examples, although some of the metaphors used might contribute to increasing anxiety and shame in other contexts (as pointed out by Demjén & Semino, 2016: 387), in this case most of the figurative scenarios have an empowering nature and are used often in a multimodal manner as a way to show how the patient conceptualises and manages the disease.

3. METHODOLOGY

For our study, a total of 22 video testimonials (11,220 words) of female MS patients were downloaded from various sources, including YouTube, but also websites of MS support organizations, such as MSSupport (US), The Multiple Sclerosis Trust (UK) o OnetoOneEU[3], then transcribed using text-to-speech software (Speechnotes) and individually checked for possible errors. A qualitative analysis was performed in order to identify the metaphors used in the patients' descriptions, qualitative analyses being often found in literature on pain management (see a review in Stewart & Ryan, 2019) because of their ability to capture the patient's experience in context (Yorkston et al., 2001: 127).

The metaphors were selected using the MIP method (Pragglejaz Group, 2007). Since our analysis concerns MS metaphors, we disregarded instances of figurative language not related to MS, which yielded a total of 79 metaphorical expressions. Once the metaphors were manually selected, we classified them according to their source domains. In our case, we shall base our classification on the «classical» three-tiered taxonomy by Lakoff and Johnson (1980: 14) of ontological metaphors, structural metaphors and orientational metaphors, since it is our belief that it offers relevant insights on the effects of metaphors towards the conceptualization of the world of MS.

In the following section, we shall be looking at the most salient metaphors used in MS-related communication. In order to see the metaphorical associations through the effects achieved, we have subdivided the ontological metaphors into «living beings» and «object» metaphors, but also grouped together structural and orientational metaphors, as follows:

1. Metaphors of living beings (e.g. MS IS A LIVING BEING)
2. Object metaphors (e.g. MS IS AN OBJECT WITH PHYSICAL PROPERTIES, or THE BODY IS A CONTAINER)
3. Structural metaphors (movement and position metaphors, fight metaphors, e.g. MS IS A BATTLE, MS IS A PHYSICAL BLOW)

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[3] In the selection of testimonials, it was decided to rule out any source which could be affected by interests other than the communication of the disease, lest it should affect the spontaneity of the language used. As a result, we ignored not only videos by celebrities, but also videos which appeared to be testimonials but were actually marketing instruments for hospitals and clinics. In the case of OnetoOneEU, although it appears to be funded by a pharmaceutical company, the videos do not seem to contain any sales effort, and were thus considered acceptable.

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4. ANALYSIS AND DISCUSSION

4.1. METAPHORS OF LIVING BEINGS

4.1.1. Metaphors of living beings in general

Animated metaphors, where objects and events are compared to living beings and their behaviour, allow patients to achieve a more vivid description, for example, of symptoms, which are portrayed through the behaviour of animated beings (and therefore being easier to describe, «falling asleep» being more easily perceived than «numbness»). Here, the patient's legs become a self-standing entity:

> When my legs started randomly **falling asleep** and making it difficult for me to take the stairs… (Victoria)

The notion of «beinh asleep» may also apply to MS as a whole, meaning «not showing any symptoms»:

> It just felt **like it was asleep** and then it would just last for days and days and go away and you know, and then it started travelling. (Jennifer)

In the following example, MS is portrayed as a wild animal, sharing the features of power and, above all, unpredictability in the suffering caused. However, the potential helplessness conveyed is counteracted by «the patient is [also] a beast», which ties in with the fight metaphors (see the relevant section for a very similar example on «aggressiveness») and builds a highly empowered image:

> It [MS]'s **a beast. But so am I.** (Jessica)

In the following example, the image of alienation is conveyed through that of a unicorn (which is a rare animal, but also a *non-existent* one, which ties in with the stigma and disbelief we saw in earlier sections). The metaphor conveys the unique nature of the patient's experience, but also the fact that she is as isolated and alone as the solitary unicorn:

> … the disease seemed to a**ffect older, white women. I was young, black and felt like a unicorn** for having MS. (Victoria)

4.1.2. Metaphors of human beings

A further extension of the «X is a living being» metaphor is «X is a human being», whereby it is possible to attribute human qualities (thinking, speaking, acting in an intentional manner) to non-human target domains; this is conducive to better conceptualization, because human beings find it easier to understand objects and processes if they compare them to themselves. For instance, the body may acquire human-like qualities, and the symptoms become a form of communication between the body (which becomes a humanized agent) and the patient:

> I try to be really aware of what **my body is telling me** and not like overexert myself. (Sarah)

> Living with this illness, you have a **relationship with your body** where you're always learning. (Victoria)

However, human qualities are not necessarily positive, especially when MS is seen as a thinking being. Sometimes the disease has its own ability to think (and therefore becomes unpredictable and uncontrollable), but it also refuses to express itself clearly so that it can be managed properly:

> MS is something that **has a mind of its own.** (Selina)

> MS **does not discriminate**, and it's not specific. It **doesn't say**, 'Here's your disease and here's what's going to happen to you'. (Antonia)

Probably the most impacting scenarios are those related to the patient's fears, where popular culture provides two powerful images which may act as a common reference for potential audiences: the revenge movie (MS may strike at any time, is cruel and ruthless and will not rest until it reaches its target) and the boogeyman (MS is, like the mythical creature scaring children, unstoppable and inevitable):

> Not knowing when you're gonna have a relapse, or what that relapse might do, **is like living in one of those revenge movies**. You don't know how or when, but someday **this boogeyman is coming for you.** (Ardra)

Sometimes negative actions by human beings are exploited, MS being portrayed as an act of deprivation and even theft: when MS IS A THIEF, it is a destructive and invasive force, but also an unfair one:

> Multiple sclerosis **has taken the sight of one of my eyes**, so that it's also incredibly difficult to get depth perception correctly. (LydiaEmily)

> this disease **steals** the very things that make her feel like a person. (Yvette)

In these examples where MS steals or takes something, the difference between a positive and a negative outlook may be seen in whether the sentence is positive or negative. Whereas in one of the examples above the deprivation is undermining the patient's identity, in other cases the patient can successfully resist the deprivation:

> You are who you are, and MS **can't take that away from you**. (Clarissa)

Even in the case where the testimonial specifically mentions that MS has succeeded, the positive outlook by the patient stresses that her personality and self-perception remain unaltered and the «theft» will not take place («I am a painter, and I will continue to do it in spite of MS»), and does so at the very end of her testimonial so that the message remains and the theft metaphor does not undermine the patient's self-empowerment:

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> MS, uh, **won't take that from me**. It may have taken my sight and my hands and my legs, but it can't have that. **That's mine, you know**. (LydiaEmily)

A variation on the theft metaphor is that where MS attempts to prevent the patient from speaking (out), thus depriving the person of language as one of the most important tools, but the patient is able to overcome the problem (again, the metaphor appears in the final sentence at the end of the video, which leaves the audience with a powerful image of the patient):

> MS **tries to silence me**, but I won't let it. (Kim)

Nevertheless, MS can be a positive agent, allowing patients to improve their life experience. One of the frequent metaphors is «MS is a teacher» (some other testimonials mention «a learning curve», but they refer to the symptoms, and the learning process is a literal one). When identified with a teacher, MS is depicted as a positive force which, by requiring people to overcome difficulties and adapt to changes, builds resilience and brings out the best in the patient, whose self-perception is improved by learning:

> But MS is also a **great teacher**. (Chloe)

> MS has **taught me** that you don't know what someone is going through. (Antonia)

4.2. OBJECT METAPHORS

In addition to the «impact» metaphors we will see below regarding diagnosis, the act of receiving a diagnosis is at times paradoxically portrayed as «relief», since the worry is described as a physical burden:

> I was actually quite pleased and **relieved** to find out because all these strange things were happening to me. (FP4)

The container metaphor (THE BODY IS A CONTAINER) appears, especially when the patients' desire to manage the disease is restricted by a body with (small) physical boundaries:

> MS is getting worse. The anxiety is getting harder to deal with and **I'm still just stuck in this little body**. (FP1)

In the following example, «physical strength/energy» is viewed in terms of money, and therefore the amount of energy available to the patient is seen as a «budget», which implies that the speaker's energy is limited, and the patient must be careful and selective:

> And that just means that that gives me **energy in my budget** to lift and lay and to perform for as long as I need to perform. (Charlotte)

Finally, there is a specific category of metaphors, which at first sight could be termed as «unusual», in the sense that they only occur in one testimonial, and therefore cannot be said to generally apply to MS. However, a closer look at those images reveals that all of them are related to the patient herself and her personal, unique experience, which, according to Semino (2008: 178), may be due to the patient not feeling comfortable with the existent metaphorical frameworks and preferring to create her own. This would seem to be confirmed by the fact that, in our sample, the two testimonials containing these «unusual metaphors» do not resort to any of the prevailing illness metaphors described in the literature (e.g. fighting), and they focus, both visually (when showing the patient) and linguistically on the woman's experience. For example, Jessica, a «painter» and a «dancer» (note that the self-describing label is relevant here) chooses to depict her body as a canvas or a form of expression:

> My body is the **art piece**. My body is the expression. (Jessica).

Another patient, Tracey, is a veteran (she is shown in military uniform), but she chooses to present herself as «Veteran. Wife». In spite of the fact that one could expect the fight/war scenario to appear, she deliberately separates MS from any type of war experience («As a veteran, I have a few friends of mine who have actually had injuries that you could see»). Rather, it is the second feature she chooses to elaborate on. Married to an electrician, she compares MS to faulty wiring in an extended metaphor which portrays the irregularity of MS symptoms and the confusion they produce on the patient (which connects to the problematic perception by others, since the patient «seems to be ok» at a given moment):

> My wife is an electrician, and I don't know if you've ever seen like uh like wires like electrical wires, and when you strip the wires, eh, so basically what **MS does, it strips the wires**. So I like always saying if **you're in a in a room you turn on the light switch. The light switch is supposed to like just put on a regular light. It's either gonna turn on the dishwasher, it's gonna turn on the light. In upstairs bathroom it might be delayed. For like maybe anywhere from 5 minutes to three hours or nothing might happen. You don't know. And every time you basically hit that switch, something could be different. Sometimes it might come on, but that's basically like with that mess**. (Tracey)

In all these cases, these metaphors are important because they relate to the way the patient wishes to be perceived by others as a person with MS and specific traits either arising from the disease or being maintained *in spite of* MS. In this way, the figurative scenario is crucial to the patient's empowered image, helping towards her own resilience and the message conveyed.

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4.3. STRUCTURAL METAPHORS

4.3.1. Movement and position metaphors

Movement and journey metaphors, as a usual concept in everyday life, are frequently applied to disease-related concepts (although, quite interestingly, the journey scenario does not appear in any of our testimonials). For instance, in relapsing-remitting MS, appearance and disappearance of symptoms is equated to movement, with even a humanized verb of «travelling» to indicate symptoms appearing in different parts of the body:

> Visible and invisible symptoms **come and go**. (Antonia)
>
> So I waited a week. To see if it would **go away**. (Jessie)
>
> It just felt like it was asleep and then it would just last for days and days and **go away** and you know, and then it started **travelling**. (Jennifer)

A specific variety is the «blow» or «impact» metaphor, also present in everyday language, in which consequences are equated to physical force or a blow, at times to such an extent that the patient has to literally prepare for an impact («brace», using the same verb as for airline passengers before an emergency landing):

> She forgets to slow down and remember the **impact** that MS is having on her own body. (Yvette)
>
> I was like it was **quite a shock to find that out** while lying in hospital bed and I was in the gown and everything. (Paula)
>
> He just casually said oh it's MS as if it was nothing and it was like **a big smack in the face** really because it wasn't what I expected at all. (FP3)
>
> Looking back, the moment of diagnosis is crucial. No one tells you that you need **to brace yourself** to become an informed patient. (Victoria)

Although as lexicalized as blows and impacts, the concept of «bad things are a force of nature» is worth noting, especially to describe the effect of the diagnosis upon the patient (similar to the «shock» in one of the previous examples) leading to depression (see, for instance, Kaviani & Hamedi, 2011). While for some patients it is a relief (because they fear a worse diagnosis, such as a brain tumour), for most patients receiving the diagnosis is very frequently equated to extreme forms of physical destruction, implying loss of hope. The use of «devastation» implies complete loss of structures and resources (which is a potentially dangerous and self-harming metaphor, since complete destruction makes recovery logically impossible):

> When I was diagnosed with MS I felt pretty **devastated**. (Charlotte)

The patient's feelings are also expressed through the traditional framing of «Up is happy, down is unhappy» associated to mental issues, visually portraying states of mind in terms of physical position, either in general, or as in the second example, which combines feelings of depression and guilt because of the role assigned to women as carers:

> And I just, I was so depressed, and I was **so down,** and I was just so angry. (Jessie)

> Then be able to come home and cook dinner. Um, and still have enough energy. For me, that's a **highest high, the lowest** is probably my daughter seeing me, erm, suffering. (Charlotte)

Similarly, passivity is portrayed visually: while figuratively those in a corner do not participate, the use of the phrase in a negative sentence implies that the speaker leaves the corner and takes on an active role:

> I'm not the type of person to **sit in the corner** and feel sorry for myself. (Jennifer)

Since progress and life itself are equated to movement, «progress» is good, whereas slowing down or stopping stand for difficulties:

> MS **does not stop me. I don't plan on letting it stop me.** I feel as though I have a long life to live, and I have a lot of things and to accomplished. And MS is not gonna **get in the way of that**. (Selina)

> I think I haven't let MS **stop me**. Occasionally it **slows me down** a little bit, but **it hasn't stopped me**. (Elsa)

> A real opportunity in life. Not something's gonna **set me back**. (Paula)

Another structural metaphor is that where «Medicine is a sporting activity», and therefore images arise helping to describe the doctor-patient relationship, and also connects to the «fight» metaphors we shall see below:

> You have to be knowledgeable so you and your doctor can **work as a team**. (Victoria)

4.3.2. Aggression and fight metaphors

As pointed out by Sontag (1979, 1988), war and fighting are among the most usual metaphors in the description of illness (even found in academic literature titles not concerned with figurative language, which often resort to words like «struggle», «battle» or «fight»), where the patient is a fighter and disease management is conceptualized as a battle.

The fight starts with an «attack», that is, MS «attacking» the patient (again, «attack» being lexicalized as a «sudden manifestation of», as «an asthma attack» or a «heart attack»). Multiple sclerosis is an initial act of aggression, sometimes literal (stabbing being perceived as a specifically vicious form of assault):

> It’s this **stabbing feeling** of these jagged edges just coursing through your entire body. (FP2)
>
> It’s a little ironic that my MS is as **aggressive** as I am. (FP2)
>
> Because MS is **brutal**. (Chloe)

Once the act of aggression has taken place, the patient has to «fight back», by being «aggressive» herself (similar to the «MS is a beast. But so am I» we saw earlier):

> How does it affect your body? What can I do to like **beat it**? (Paula)
>
> **Struggle** with tremors. Double vision. Brain fog and chronic pain. (FP2)

Unlike the metaphors used in diseases where the outcome may be fatal, the «fight» metaphor may be less problematic, and actually becomes a tool for self-management. Persons with MS portray themselves as fighters, and any tools or strategy they develop make them «enabled warriors»:

> What it hasn’t been able to do is damage her **fighting** spirit. (Yvette)
>
> We just have to remind ourselves that we are **warriors.** (FP2)
>
> I made all these sheets and things, sent them out to the people in my **Enabled Warriors** group on Facebook. (Jessie)

5. CONCLUSIONS

Language plays various major roles in the experience of patients when expressing their symptoms and the way they manage the disease. First and foremost, it allows them to express their symptoms. As seen in the review of the literature and in the testimonials, many patients, in addition to the suffering of the MS itself, have to cope with lack of understanding, first by their doctors, but also by their friends and family. In this respect, the way patients express their experience (especially women, often misunderstood, misdiagnosed or simply not believed) may be crucial in avoiding the extra ingredient of disbelief and lack of understanding, given the importance of social support for the patients’ experience of the disease and their self-esteem.

However, the communication does not only take place with external addressees. In the examples analysed, we have seen how patients with the illness, as a personal, subjective experience, resort to metaphor in order to communicate with others, but also in order to shape their own experience and, ultimately, their identity. This is especially true of chronic diseases, like MS, where the lack of cure means that the condition will become part of the patients themselves, and therefore must be conceptually incorporated in the way the patients see themselves and how they are seen from the outside. In general, a difference can be made between the metaphors related to the symptoms, which necessarily must be negative, and the framings used by patients allowing them to manage and cope, such as, for instance, fight metaphors (devoid of their dangerous potential in fatal diseases) or learning metaphors, expressing resilience by allowing the patient to «look on the bright side» of multiple sclerosis. In some cases, the metaphor provides the patient's narrative with cohesion, by appearing a number of times in the testimonial, usually linked to the imagery and the self-description of the patient.

Concerning further avenues for research, we are aware that this is just but a small contribution to the study of figurative language and communication in MS. It is our belief that, given the importance for MS patients of friend, family and societal support, especially for women, more research should be conducted about patients' perceptions of the disease. This could include studies in a diversity of cultures and languages, in order to measure how cultural and linguistic factors may influence the expression of the disease. Also, an unexplored aspect in our analysis is the interrelations and the affordances between the medium and the metaphor: as we mentioned earlier, some of the testimonials contain only one metaphorical expression, but it is strategically placed at the very end of the video, providing a closure effect, and also leaving the audience with a positive message counteracting any negative aspects described (metaphorically or non-metaphorically). Similarly, a multimodal analysis might deal with the possibilities of the visual medium, for example, patients mentioning that things become «out of reach» and the video showing household objects floating in the air, or a patient who says she is unable to move, and the video shows her legs becoming wrapped in concrete. It is our hope that such further explorations will create a better understanding of women's experiences with MS and with chronic diseases in general.

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