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Julian, Knoff Ims

“Living in Liminality” The lived experience of fatigue in French patients with Multiple Sclerosis.

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| Author | Julian Knoff Ims |
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| Instructors | Tricia Cleland Silva Oliver Thomson |
| <p>The purpose of this study was to explore the lived experience of fatigue in French patients with Multiple Sclerosis (MS)</p> <p>Methods: An exploratory qualitative approach was used. Patients with Multiple Sclerosis were invited to participate in an in-depth interview to describe their lived experience of fatigue and five people were purposefully sampled. The interview transcripts were analysed using Reflexive Thematic Analysis by one researcher that produced the themes.</p> <p>Results: Qualitative data showcased how fatigue affected many aspects of their daily lives, their sense of identity and the social impact of living with an invisible symptom. Participants described that the constant adaptation to fatigue and the lack of understanding from others was a source of secondary fatigue. One overarching theme (OT) and four themes describe different aspects of the experience of fatigue in MS: (OT) Living in Liminality, (1) Fatigue as an entity, (2) The daily Grind, (3) Visible vs Invisible,(4) Identity. Conclusion: Fatigue in MS has a profound impact on many aspects linked to daily life but also social and other identity aspects. People with invisible symptoms might find themselves socially marginalized, and it can increase suffering. Healthcare professionals could be mindful and acknowledge these aspects as well as the fatigue and help to reduce the negative impact of living in liminality and enhance person-centred care. Further research into these aspects and how to support and help patients navigate uncertainty and fatigue is needed.</p> | |
| Keywords | Multiple sclerosis, fatigue, invisible disability, lived experience, liminality |

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1 Introduction

Multiple Sclerosis (MS) is an auto-immune, neurodegenerative disease. The immune system (IS) attacks the protective myelin sheath around the nerves of the central nervous system (CNS). Worldwide 2,8 million people are touched (Walton et al. 2020: 1817.) In 2010 it was the second cause of handicap among young people (Koch-Henriksen & Sørensen 2010). MS has a wide range of symptoms; their presentation is unique to each person. Symptoms range from motor troubles and dysregulation of the autonomous nervous system to sensory and cognitive problems. (Rezapour et al 2017: 1.)

It is a disease that I know intimately as my mother was diagnosed 40 years ago, and I have grown up seeing how it affects her. This led me to write my Bachelor's thesis on the possible impact of Osteopathy on the quality of life of patients with MS in 2018. This thesis will focus on the lived experience of multiple sclerosis-related fatigue (MSRF).

Fatigue is a commonly reported symptom considered present in 18,2-97% of cases depending on the studies (Oliva Ramirez, Keenan, Kalau, Worthington, Cohen & Singh 2021: 11). It is often present from early in the onset of the disease. It can profoundly impact the quality of life (QoL) (Göksel Karatepe et al., 2011.) The fact that its prevalence is reported so heterogeneously highlights that it is a complex phenomenon with a multi-causal etiology that is difficult to measure and treat. There is no pharmacological cure to date; some molecules might alleviate fatigue but are deemed unsatisfactory. Current best practices are multimodal and include fatigue management, educational therapy, and adapted physical exercise. MSRF is considered an invisible disability, often misunderstood by society and its impact is under-evaluated by medical professionals (Ayache & Chalah, 2017: 157; Johnson 2008: 75-76.)

This study aims to explore the experience of MSRF, to give space and allow the people living with this phenomenon to describe their lived experience, to help to bridge the gap and improve person-centred care. I, for one, have often misunderstood and failed to consider wholly the impact of MSRF on my mother and the lives of patients I see in the clinic. This leads us to the research question: How do people who live with MS describe how they experience fatigue? To gather detailed contextualized descriptions of the lived experience, an exploratory qualitative study seems the most appropriate.

2 Theoretical background

We will briefly look at MSRF and treatment options from a biomedical point of view to give context before moving on to research on the lived experience of fatigue, how it can impact identity and how its invisible and changing nature has many consequences, including in societal interactions. The style of this theoretical background is one of “making an argument model” rather than “filling the gap.” This means that its aim is a situated, contextualized review of the literature rather than an exhaustive account. This choice is made for coherency with qualitative methodology and the chosen method of Reflexive Thematic Analysis (RTA). Braun and Clark argue that the “filling the gap” model that is so prevalently used in research and some of its underlying presumptions can be problematic within a qualitative research paradigm (Braun & Clarke 2022:120.)

2.1 MS-related fatigue

“Normal” fatigue is hard to define since it is a subjective experience with a wide range of definitions between fields and within healthcare. Fatigue can be conceptualized as a temporary unpleasant subjective sensation that reduces both mental and physical capacities brought on by exertion, and that cedes with rest (Ream & Richardson 1996: 521.) MSRF can be distinguished from normal fatigue in healthy individuals in its severity and frequency, by a more prolonged duration and absence of recovery after rest, as well as by its impact on activities of daily life. It has more akin to exhaustion than tiredness (Newton, Griffith & Soundy 2020: 307.) In addition, MSRF has been defined as cognitive and motor troubles, which can be brought on by both physical and mental activity and are reversible in nature. MSRF can be divided into primary and secondary fatigue. A definition of primary fatigue is fatigue due to direct damage to the CNS. Secondary fatigue is associated with the symptoms and consequences of MS. This secondary fatigue responds better to treatment. (Johnson 2008: 72.)

A systematic literature review of MSRF in adults found that, depending on the studies, between 18,2% to 97% of MS patients complain of sensations of fatigue, exhaustion, tiredness, and a general lack of energy, which was not present before the onset of the disease. When controlling for higher quality studies through sample size >300 and use of validated questionnaires specific to fatigue, the prevalence ranged from 36,5-78% (Oliva Ramirez et al 2021:11.) One could understand through this wide range and disparity of results the difficulty and complexity of measuring the prevalence of MSRF encountered by researchers. 28-40% consider fatigue the most impacting symptom of their

illness. It is associated with poorer employment outcomes and a negative impact on QoL (Fisk, Pontefract, Ritvo, Archibald & Murray 1994: 9; Oliva Ramirez et al. 2021: 12.) In addition to the physical symptoms, many MS patients also complain of mental fatigue, which manifests as difficulty thinking or concentrating (Greim, Benecke & Zettl 2007: 63). Debouverie et al. (2009) describe the impact further with MSRF leading to changes in perceptions, affecting one's sense of self, mental activity, and emotional life. It can be a source of guilt and loss of self-confidence.

2.2 MSRF Treatment options

A brief overview to understand the current treatment options. This symptom is one of the least understood in MS, leaving clinicians with few options to offer patients and the common jargon used, is to help manage rather than treat fatigue. While clinical trials have demonstrated some benefits associated with medication, physical activity and cognitive-behaviour therapy benefits are limited. The experiences described in a narrative review indicate that there is no one-size-fits-all solution for fatigue. (Ayache & Chalah 2017: 157; Newton et al 2020: 307.) Helping patients with challenges relating to social support and disclosure has been identified as a potentially important dimension to be incorporated. (Skerrett & Moss-Morris 2006; Strober 2018; Foote, Piazza, Holcombe, Paul & Daffin 1990.) Apps helping self-manage MS symptoms, including fatigue, is a novel approach that is becoming increasingly popular, but few have been evaluated (Marziniak et al 2018).

No clear underlying mechanistic theory has been able to explain MSRF, current theories revolve around neuro-inflammation and cytokine influences (Matter & Kuppaswamy 2017: 240; Ayache, Serratrice, Abi Lahoud & Chalah 2022: 3; Miller & Soundy 2017). However, this lack of a precise mechanism is not uncommon in complex symptoms such as fatigue or pain. This adds to the difficulties of understanding, measuring, and treating MSRF from a biomedical point of view. The poor understanding of MSRF renders clinical management complicated, and clinicians generally underestimate the impact of the patient's experience of MSRF, this can reduce the quality of care (Newton et al. 2020: 307.)

2.3 The lived experience of fatigue and MS

Person-centred care is a key concept in health care, especially in the care of chronic illnesses and symptoms. It can be defined as care that is responsive and respectful to individual patients' needs, preferences, and values, using that patient's values to guide clinical decisions (Goodwin 2016; Tyreman 2018.) How can we provide good quality person-centred care without knowing the patient's experience and perceptions? There is a large gap between the biomedical descriptions and markers of MS and the lived experience. In the eloquent words of Kay Toombs, the biomedical description of MS captures little, if anything, of her actual experience of bodily disorder:

I do not experience the lesion(s) in my brain. Indeed, I do not even experience my disorder as a matter of abnormal reflexes. Rather, my illness is the impossibility of taking a walk around the bloc, of climbing the stairs to reach the second floor in my house, or of carrying a cup of coffee from the kitchen to the den. (Toombs 1995: 10)

There is a paucity of qualitative research on the lived experience of persons with MSRF, but they bring interesting insights into this complex daily life. The lived experience of fatigue among adolescents with MS and their caregivers underlined the difficulties and challenges, both practical and emotional, created by the uncertain and uncontrollable nature of the fatigue. Caregivers and adolescents had different worries, with parents expressing concern about the adolescent's future and well-being. In contrast, the adolescents themselves were more concerned with the difficulties of daily life and with the implications of disclosure or non-disclosure of their fatigue to teachers and peers. Fatigue impacted their mood at times and participants emphasized the need for better guidance in fatigue management. This study shows how fatigue affects not only the ill but also their entourage. (Carroll, Chalder, Hemingway, Heyman & Moss-Morris 2016.)

MSRF is also an invisible symptom. Its invisible nature renders it particularly distressing and brings along complex challenges around diagnosis and legitimacy, but also through living with hidden needs. Invisibility was conceptualized as the discrepancy between the internal experience of symptoms and external observation by persons with MS. The nature of these symptoms was found to pose a dilemma; the choice of remaining unseen or disclosing their diagnosis and remaining seen. This dilemma is not unique to MSRF but is shared amongst other invisible symptoms and disabilities. (Lingsom 2008; Göksel Karatepe et al. 2011.) People with MS reported concealing their diagnosis both professionally and socially for a variety of reasons, but mainly due to the uncertainty of how people would respond, to escape stigma, maintain a sense of identity, and not be seen as disabled or different (Desborough et al 2020.)

A thematic synthesis about the experience of fatigue in patients MS found that there were physical, social, and cognitive challenges in patients' experiences of fatigue, but also found individual strategies to alleviate and help manage fatigue. They highlight an interplay of several multi-dimensional factors that render the diagnostics, measurement, and treatment of MSRF complex. Firstly, the unclear pathogenesis and the fatigue experience of MS patients differ from that of the healthy population. In addition, objective physical signs do not correlate to subjective experience. Finally, two of the most utilized scales that measure fatigue (Modified Fatigue Impact Scale and Fatigue Severity Scale) have been found to be unresponsive and lack sensitivity to changes in fatigue levels of in people with MS (Newton et al. 2020.)

The following studies in a strict do not focus exclusively on MSRF. Even though MSRF is the focus of this thesis, I would argue that it is reductionist to reduce the lived experience to only one symptom, as it cannot be separated from the rest of the MS experience. To give a better understanding of what is to live with MSRF, we will zoom out it an attempt to succinctly contextualize it within a larger scope of disability and identity questions on an individual and societal level.

Identity and the sense of self are impacted in chronic illnesses and perhaps even more so in a degenerative condition such as MS. The diagnosis, evolving process and changing handicap cause a loss of habitual roles, loss of self, a change in personal narrative and a reconstruction of a different identity. Guilt and shame were often expressed in relation to changes in the ability to provide for families due to a loss of employment or income. Supportive environments at work or influenced if people with MS remained professionally active. (Toombs 1995; Desborough et al. 2020b; Strickland, Worth & Kennedy 2017.)

Within identity questions, liminality is a growing concept in the field of disability studies, but also within healthcare research. (Brown, Huszar & Chapman 2017; Honkasalo 2010; García-Santesmases & Sanmiquel-Molinero 2022a.) It originated with ethnologist Van Geenep and focused on rites of passage and detailed three periods involved: A preliminary separation phase that begins with a transition. A liminal phase characterized by a rupture of identity and sense of self, but also uncertainty, an ambiguous illness trajectory and loss of social connectedness and future. The liminal phase is followed by a post-liminal phase and the reconstruction of a new identity or being (Gibbons, Ross, Bevans & Inouye 2014.)

The concept of liminality has been applied primarily to MS patients during diagnosis to frame the difficulties around identity and uncertainty around the evolution of the disease, leading to social and identity troubles that increase the suffering (Strickland et al. 2017; Barrett 1995.) The final post-liminal phase is characterized by a new role in society and re-aggregated personal identity, but since MS is a degenerative disease, I would argue that the symptoms and disease continue to evolve, and the persons must adapt and reconstruct not only their personal narrative but also their position and role in society multiple times. This, coupled with the invisible nature of fatigue, complexifies the liminal process. The invisibly disabled hold a social position betwixt and between, and if not reintegrated, this can become a permanent liminality(García-Santesmases & Sanmiquel-Molinero 2022b; Brown et al. 2017.)

From a more societal angle, the chronically ill or disabled have trouble finding their place in society Ableism can be defined as prejudice, discrimination, stereotyping and social oppression toward the disabled (Bogart & Dunn 2019). From this point of view, people with chronic illness or disabilities risk becoming marginalized, possibly with people either shunning society or feeling shunned, especially in ableist societies constructed for and by the abled leading to the systemic discrimination of the disabled society (Toombs 1995; Lutz & Bowers 2005; Bogart & Dunn 2019; Friedman & Owen 2017.) The disabled feel a loss of value, and belonging, whilst subjected to micro or macro aggression, leading to further alienation and a vicious circle. (Bradford, Young, Whitechurch, Burbury & Pearson 2023; Olkin, Hayward, Abbene & VanHeel 2019.)

This concludes the theoretical background, situating the study in relevant research and concepts from a biomedical perspective, progressing to a lived experience and finally zooming out and looking briefly at living in an ableist society with an invisible disability. These concepts and the lack of qualitative studies on the lived experience of MSRF lay the land for why an exploratory qualitative study into the lived experience of patients living with MSRF in France is relevant. A better understanding of the lived experience of MSRF could enhance person-centred care and support for these patients.

3 Methodology

In this section, we will start by giving a broad definition of qualitative research before moving on to the specific methodology, paradigm, and method used in this thesis.

Qualitative research is an overarching term encompassing various methodologies and methods that are evolving, unsurprisingly it is then sometimes difficult to define. (Aspers & Corte 2019). A contemporary definition of qualitative research is:

Qualitative research is a form of social inquiry that focuses on the way people make sense of their experiences and the world in which they live (Holloway & Galvin 2017: 3)

Qualitative research is often defined in comparison to quantitative research in the literature, this dichotomy can be problematic since it creates an either-or. They are based on different assumptions around truth and knowledge and are used to answer different research questions. For explorations of lived experience and sense-making qualitative approach is most suited in contrast to the prevalence or prognostics of a certain illness or efficacy of a drug a quantitative approach is considered the most appropriate (Mumba & Alici 2018.)

In this thesis, I have chosen a Big Q methodology, which means using a qualitative paradigm with a qualitative method Reflexive Thematic Analysis (RTA). For the sake of clarity and transparency, and in accordance with good reporting practices for RTA, we will briefly outline the paradigm of this research project in the next paragraph (Braun & Clarke 2022: 157)

This project is based on certain theoretical assumptions about the nature of reality and around knowledge that affects it. Critical Realism is the chosen paradigm. In simple terms, we assume that there is an objective reality out there but that we cannot be sure, and we all view it through our own lenses and context (mind-dependant knowledge). In this paradigm, we treat language as experiential, as a good vehicle for communicating our subjective perception of reality and our truths. The goal of a critical realist RTA is to provide a compelling and coherent interpretation of the data grounded in the participants' accounts of situated realities. It is the most used paradigm within published RTA work (Braun & Clarke 2022: 169.)

I have used the COREQ checklist (COREQ (COnsolidated criteria for REporting Qualitative research) Checklist n.d.) loosely while writing this thesis. Mainly to ensure that the information required for good reporting of qualitative research is present. 31 out of 32 items on the COREQ checklist were present in this report. In accordance with the guidelines, the checklist relevant to this research project can be found in **Appendix 1**. In addition, I used specific recommendations for quality practice and reporting for RTA (Braun & Clarke 2023: 8).

3.1 Participant selection

Participants were recruited from my private practice as an osteopath in Toulouse, France. They were contacted by phone or personally invited to participate after briefly describing the study. The participants were then purposefully sampled. I sampled people with MS, suffering from fatigue. They were chosen for their ability and willingness to express themselves in French, the richness of their lived experience and the variety of forms of MS and the intensity of fatigue. These criteria were chosen to paint a rich and varied picture of fatigue across different forms of MS, living situations, and clinical presentations.

3.1.1 Ethics

This research project was conducted according to Metropolia's rules and guidelines for research, which means compliance with Global Data Protection Rights (GDPR) and Finnish National Board on Research Integrity. Informed and willing consent was given and signed before the interview. The participant consent form and participant information sheet can be found in **Appendix 2**. Participants were given a code P1-P5, and some details were, if necessary, altered in the final report to protect as well as possible anonymity. The data gathered will be stored on a password-protected external hard drive for 5 years before being deleted, as specified in the participant information sheet.

To reduce ethical conflict, participants were only invited once to avoid coercion, and only one informant was an active patient during the interview time. No participants refused. The dual role of researcher and healthcare professional can induce a power imbalance and confusion of roles, to address this, a conversation about the different roles was had before the interviews to "even the playing field" and diminish the possible

power imbalance. Interviews and participating in research might provoke emotional distress in participants, to minimize this risk, the researcher had contact information for MS patient support groups available and the possibility of speaking with a psychologist if it felt necessary (Holloway & Galvin 2017.)

3.2 Data collection

Data was collected through one in-depth interview per participant, conducted in the participant's home or at the researcher's private practice between July and December 2022. One interview was conducted over Zoom rather than in person due to scheduling constraints and limitations due to fatigue. Interviews were done in a 1 on 1 setting, by the author, and interviews lasted between 45 minutes to 1h30.

There was an interview guide that can be found in **Appendix 3**. It was developed by the researcher, inspired, and adapted from interview guides from studies with a similar methodology on the same subject (Carroll et al. 2016) and in discussion with supervisors. No prototyping was done. The questions evolved throughout the process, building on data and impressions from previous interviews. For example, after the second interview, specific questions on interactions with medical professionals were added.

Interviews were audio-recorded using a phone and then transcribed verbatim using an online service AI (happy scribe) that respects GRDP norms¹. This was due to time constraints and wanting to free up time for analysis. All the transcriptions were corrected while listening to the audio recording. Interviews and transcriptions were in French, while coding was done in English. After interviews with four participants, a sense of sufficiency started to arise, and after a fifth interview, the recruitment was stopped. In RTA the notion of data saturation is considered post-positivist, and the notion of sufficiency is more fitting (Braun & Clarke 2021: 211-212). No participants stopped or dropped out during the study. The transcripts were not returned for correction by the participants.

¹ <https://www.happyscribe.com/privacy>

3.3 Data analysis

The chosen approach was Reflexive Thematic Analysis (RTA) (Braun & Clarke 2022: 6-9). It was chosen because it allows the construction of themes from rich, complex data and uses the researcher's subjectivity as a tool. It allowed building upon the established relationship with the participants, treating it as an interesting starting point that needed to be reflected upon rather than a bias that needed to be controlled. It can be used with different analytical approaches. (Braun & Clarke 2022: 122) I was the sole coder and chose an inductive "data-driven" approach in accordance with the original intent to explore the lived experience of MSRF, but also the goal of producing an account anchored in the data. This is not to say that data speaks for itself because it is an inductive analysis, it is still very much generated by the researcher and the process.

A growing body of clear-conscience literature on performing RTA exists, and as I was more familiar with quantitative methodologies, this was part of the choice. Qualitative research and methods can be a confusing, complex landscape, with many theoretically loaded concepts and sometimes unclear boundaries. The number of times my supervisors have told me to be careful or conscious of using certain words attached to big concepts! Just within the term Thematic Analysis, there is a plethora of approaches; a family of sorts with a paradigm continuum ranging from post-positivism to interpretivism. This can lead to methodological confusion even for the experienced researcher, not to mention difficulties of consensus on reporting and what is considered good practice (Braun & Clarke 2020: 345-346.) Braun and Clark have published and written extensively about the methodology. Their very situated and contextualized map or adventure guide allowed me to navigate the qualitative landscape and try to avoid some of the pitfalls. All of this with the intent to create as high a quality work of research as possible with the capacities and limitations of my multiple roles and context that I will explicit further in the next paragraph. The wish to do quality work was grounded in the desire to do "justice" to the participants' experience.

To enhance transparency, it is important to briefly outline my position as a researcher and who I am. The researcher's subjectivity is used as a tool in RTA, and I have chosen Critical Realism as a paradigm where knowledge is considered contextual and mind-dependent (Braun & Clarke 2022: 14.) Professionally, I am primarily an osteopathic clinician, a part-time educator at the school I trained at in France. I am currently a remote last year master's student at Metropolia in Finland. I have a background in the sports/arts as a former professional ballet dancer in Europe. I come from a position of

privilege: a white western, cis-gender male, but I have experienced uncomfortable situations in society due to my sexual orientation and non-stereotypical career choice as a male ballet dancer. In relation to MS, my mother has the illness, and I have some insight into what it is to live with the disease through being her son. It is for this reason that I work clinically with MS patients as an osteopath and have been trained in educational therapy for MS but have not worked within the field. My bachelor thesis, as mentioned in the introduction, was on the effect of Osteopathy on the QoL of people with MS. You can find more details on my assumptions and views before starting the interviews in an excerpt from my reflexive research diary. The diary was used throughout the process to reflect upon my role as a researcher, the methodology interview process, and the analysis of the qualitative dataset. The excerpt can be found in **Appendix 4**

In RTA, they describe a 6-step process of data analysis. However, this is not a strictly linear process but a dynamic, recursive process where one can circle back between steps as needed (Braun & Clarke 2006: 11-12.)

3.3.1 Familiarization

I corrected the transcriptions and listened to the audio recordings multiple times. During that time, I wrote notes and noticed connections and nuances to get an intimate feel of the data. Some of this process was tricky since listening to the audio was emotionally challenging for me, more so than during the interviews. This challenge fueled me to reflect upon my role as a researcher, but also that of a clinician working with MS and the son of a person suffering from MS. Letting the data get under the skin during the data collection phase allowed the process to evolve and lent an organic quality to the interviews, the next building upon the others.

3.3.2 Coding

The first cycle of coding was done on paper. I needed to feel the data. The first round was mostly explicit/semantic coding, this was also coherent with the research questions of how participants describe their lived experience of MSRF. The second cycle was done in Microsoft Word with the comments function to be able to export the codes later. I coded each interview, manually extracting and organizing the codes in an Excel file. A third cycle felt necessary before going on to the next step. The 3rd cycle was coded in a different order as recommended by Braun and Clark (Braun & Clarke 2022: 71). The 3rd

cycle gave a deeper understanding and some more implicit codes. Ex. Us vs them. Us the sick, the misunderstood, vs them, the normal/healthy. I ended up with several hundreds of individually coded labels.

| Transcript | Code when there is a plus it is 2 or more codes |
|--|---|
| You have to do things to overcome this and have little tips. | I have to do something to fight this |
| Yes, it is a protection that I made for myself. Before, I was not like that at all. But suddenly, as there is the judgment of people from behind and we don't want to show ourselves to the people around us | Withdrawal a protection from judgment + past me |
| you don't want to talk, you don't want to give details, you refocus on yourself, you isolate yourself. There is a lot of isolation.Y | Just focus on yourself + isolation |
| You see the cortisol test for example, with blood tests, urination tests, saliva tests that I did repeatedly over several days at different times to see precisely when the fatigue is arrived. It's exactly 12:00. I gave it my all in the morning and after all after 12 p.m. until 7 p.m. You see, I am in a total descent, so there, that's a really good picture. It's very representative. There, we can put in boxes, for example and say Yes, fatigue. | Visible proof + living half time |
| I continue to be what I am, what I was, no what I am. Yes that is it..what I am | what I was + what I am +identity conflict |
| Especially when people see you, they don't understand your fatigue because. Normal people in quotes do not understand that in fact, inside, we are not seen, we are empty, there is nothing like my feeling of sinking in our body. Not me anyway, that's my feeling. For me, I speak, for me, I have the feeling of no longer being there | People dont understand + Contrast visible /invisible +Conflict lived experience/seen experience |
| I struggle trying to discuss or in understanding because of everything. I prefer to be alone, but suddenly, it puts me a little more on the sidelines. | What I need marginalizes me even more + Fighting to discuss and explain |

Figure 1. Examples of coding

3.3.3 Searching for themes

From the Excel file, the codes were transferred to an online whiteboard. At first, grouping and clustering codes, while also merging codes that seemed too similar. This was an active process of crafting and meaning-making and not trying to uncover the hidden themes in the data. Braun & Clarke (2022: 78.) use the metaphor of a sculptor, which adds nuances such as skill, tools, knowledge, and personal positioning, as well as the natural limits of the data to the process. The first five tentative themes that emerged were: "The big picture" "Daily grind" "Visible vs Invisible" "Identity" "Fatigue as an entity".

3.3.4 Reviewing, naming, and defining themes

In this step, I start to link the themes to findings in the literature, essentially stepping away from a purely inductive to a slightly more abductive approach. For the lived experience of disability, the work of Toombs (1995) resonated strongly. Literature supports a large amount of the findings from the data, even across other complex fatigue conditions such as CFS as well as chronic pain. (Bradford et al. 2023; Hovey 2023.) Visible

vs Invisible, Identity questions, the daily grind, uncertainty, and constant adaptation are all aspects that can be found in the literature. This strengthened my impression that having spent a long time in the previous steps had created relevant themes. I was even surprised at how well certain findings echoed other conditions.

This step made me think and reflect more about themes and powered the analytical process. I struggled with the feeling that sometimes themes were too thin, reporting only one dimension or facet, or too removed from the data (Braun and Clarke, 2022: 99). Reflecting upon how to balance creating richer complex themes, highlighting diverse aspects of the data/story, while resisting the trap of overanalyzing and too many subdivisions. This process led to more defined and developed themes: “Big picture” felt too thin, lacking a clear core concept, but some aspects were incorporated into the other themes Adaptation grew from a sub-theme to an overarching theme since it was present in all the themes. Illustrating how omnipresent adaptation is in every aspect of the experience. Themes were shown to participants for validation and feedback. A more artistic thematic map than in the results can be found in **Appendix 5**

3.3.5 Writing Up

During this phase, the process changed to full abductive. Going from the themes to the literature, and from the literature to the themes, and then grounding it in the data. It was changing up until the end. The overarching theme changed from Adaptation to Living in Liminality, allowing for deeper, more complex analysis and articulation of the themes and incorporating a previous OT candidate that didn't make the cut but still felt important “Same same but different.” As I was writing, the analysis evolved and deepened. The core themes did not change, but how they were articulated and what points were important did. The literature added rhythm and changed where the emphasis lay like reading a song text without the notes and then listening to the song. The words might be the same, but overall, it is a very different experience. It was quite destabilizing how it kept changing until the very end

4 RESULTS

Four themes were generated and refined through the analysis process: “Fatigue as a multi-faceted entity” (1) “The Daily Grind” (2) “Visible vs Invisible” (3) “Identity” (4) Together they tell the story of how MSRF is a chronic invisible disability, that effect identity and how this changes the interactions with society. The overarching theme “Living in Liminality” provides context and highlights how adaptation and liminal processes are ever-present in the lived experience of MSRF.



Figure 2. Thematic map of themes.

Braun and Clark advocate for a merging of the results and discussion section in qualitative research under the common term Analysis (Braun & Clarke 2022: 131). For the sake of the practicalities of reporting standards for Master thesis work at Metropolia, we will maintain the separation. However, the reader is invited to consider them as a whole. To avoid analytical repetition and enhance the reading experience, I will first develop the themes with a more illustrative use of the data in the results section. Then in the discussions section, we will look at how the themes relate to current research literature and concepts with a more analytical use of the data. Participant characteristics can be found in **Appendix 6**

4.1 Overarching theme: Living in Liminality

Living in liminality gathers the four other themes. People with MSRF experience multiple liminal processes on different levels. Identity theme encompasses the loss and reconstruction of one's sense of self when living with MS. Visible vs Invisible, people suffering from MSRF find themselves in an in-between social position, not belonging to one nor the other group, choosing to pass sometimes, making them a liminal being that falls between two categories, like a mythical creature. The theme Fatigue, a multi-faceted entity, contains a shorter-term liminal process. The uncertain and mercurial nature of MSRF demands a constant adaptation, coupled with the degenerative evolution of MS and the fact that MSRF is a medically unexplained symptom, creating a state of sustained liminality. This constant adaptation affects daily life and links to the theme of The Daily Grind. On all these levels, they adapt, finding themselves in transition. Prolonged liminality may increase suffering and fatigue in addition to the MSRF. Rest can also be seen as a liminal space, on the couch, in their bubble, away from the world, these are places where they can recharge.

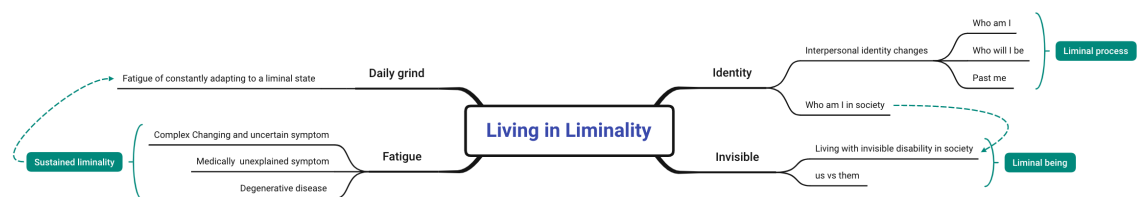


Figure 3 Illustrating the interactions of overarching theme “Living in Liminality” with the core themes

4.2 Fatigue a multi-faceted entity

MSRF is not lived as a simple tiredness but as a fatigue that is multifaceted and changing. It has a presence and weight, it takes up a lot of space in the participants' lives, and it modifies their interactions with the world. Like an entity that you share your life with:

I see it [the fatigue] as my evil twin (participant 2)

Participants would describe different kinds of fatigue: mental, physical, pathological, nervous fatigue, MS fatigue, global fatigue, social fatigue, and emotional fatigue, sometimes just being tired of being tired.

There is a physical fatigue, a mental fatigue (...) a global fatigue...they all depend on each other (participant 3) My fatigue is more of a muscular one, I am not tired (...), but I never wake up feeling rested (participant 1)

Participants could identify a qualitative difference between pathological MS fatigue and "normal" fatigue. Its random, sudden, and invasive nature incapacitates them at various times, causing them to be unable to act or express themselves. Often perception was left intact, but they experience an incapacity to act.

You want to do it, but you cannot. Even getting a cup of tea is impossible (participant 5) It is like I am empty inside (...) I know what I want to say or do, but there is a short circuit (participant 2)

I find myself speaking to someone I do not know, and suddenly, I cannot express myself anymore. The words come out all wrong (participant 3)

Participants might actively engage in physical outdoor activities to feel "normal" fatigue. It was considered pleasant

At least I know why I am tired (participant 4)

When in these states of fatigue, all participants mentioned that social interactions (even with close family or partners) were near impossible, considered too energy costly, and even described as painful. All participants spoke the exact same words at some point

Leave me alone! (participant 1) I don't want to speak to anyone (participant 3) Alone on my couch is the best place for me then (participant 4)

The triggers, when identifiable, were very diverse in nature. They could be due to stress, emotions, physical fatigue, heat, sun, too much sensory information, infection, conflict, mental activity, time of day, and cognitive or physical load. Sometimes there was no reason, it struck like lightning from a clear sky.

The sun in my worst enemy (participant 3) Stress and emotions tire me quickly (...) it's like an overheated (participant 4)

This pathological fatigue requires immediate rest, there is no buffer. All the participants had, at various points in time, continued pushing past limits, but this came at great cost. In the long-term, they avoid whenever they can to push through since it comes at such a significant cost afterwards, exponentially increasing the time of rest needed.

If I accumulate fatigue like a normal person during the week and rest during the weekend, it is the entire weekend I need to rest (...), not just a couple of hours (participant 2)

The constant presence of such mercurial fatigue has a heavy impact on quality of life and obliges participants to make choices between life and work, social or practical.

4.3 The daily grind

Living with this fatigue daily is a challenge. Much time and effort are spent on diminishing the burden of fatigue and other symptoms. It takes various forms; trying to maintain the status quo, increase the quality of life, regain capacity or adapt to the recent loss of function. A participant used the image of a tiny box where you try to fit everything; this box is, of course, changing in size depending on daily form, often shrinking but rarely extending.

You are constantly making choices and calculating how much you can fit in the box. Should I do this, or will it be too much (...) what else do I need to do today? (participant 3)

This process leads to a hyper-awareness of their surroundings and schedule. Such as the terrain, the temperature, and the time of day. Most plan around their fatigue to be able to live as normally as possible, a trial-and-error process of learning from experience.

This disease kills all spontaneity (participant 3)

If I know that I have work, I will schedule social events another day (participant 5)

Self-management is important in chronic illnesses, but little information seems to come from medical professionals, participants found information through the internet and from people with the same disease as well as support groups.

We do these webinars for us, for other sick ones (...) it is a lot of work, but it is worth it (participant 4)

Many are figuring out what works for them, through others with MS or patient associations.

We exchange tips [with a college with MS] (participant 2)

Alternative medicine and practices are often used in addition to physiotherapy and dietary changes. However, trying to slow the effects of MS takes a lot of effort and time

I am exhausted when I am done with physiotherapy; I need to stay on the waiting room couch for 30 min after the session (participant 1)

Several participants mentioned "*living half time*" needing to evaluate the cost of even mundane daily tasks, daily upkeep, and the need to rest after taking a shower or getting dressed.

After 14h I am done (participant 2) I often nap after getting dressed and showered (...) I am exhausted (participant 3)

The inner circle of friends and family are the ones that notice this daily grind and suffer the consequences of the limitation of possibilities.

Distant friends one can reschedule, but not your partner (participant 5)
For you, this is nothing, but for me to empty the dishwasher might be all I can do in a day (...) my partner does not always understand this (participant 3)

4.4 Visible vs Invisible

There is a contrast between visible and invisible symptoms of MS, with fatigue being in the latter category. A “real” handicap is a visible one.

People think MS, and they see a wheelchair. That is not the case (participant 2). I NEED that handicapped parking spot!! but sometimes I have to justify myself to people who accuse me of faking it (participant 5)

This can have tangible consequences, such as delayed diagnostics and treatments.

It was my doctor that showed me that my fatigue was actually my disease progressing. I didn't understand that it was because of the MS (participant 5)

Visible, physical handicaps are easier to evaluate and might get a permanent handicap card or more help faster.

My friend with MS had some temporary motor troubles and got a permanent handicap card right away (...) She is fine now. While I still struggle with crippling fatigue and have to reapply every year (participant 5)

The invisibility can lead to feelings of not being seen or understood.

Covid was a good period for me, we were all in the same boat. People understood what I live every day (participant 1)

This invisibility can lead to misunderstandings, and the resulting micro-aggressions have emotional consequences that are difficult to deal with, resulting in a withdrawal from society.

I'd much rather spend my energy walking in nature (...) there is too much I need to adapt to in town (participant 2), They think I am like them and do not understand that I need more rest (participant 4)

Within chronic diseases and disabilities and especially invisible disabilities, people are prone to social marginalization and liminality. Feeling misunderstood, not belonging, and so withdrawing from society. This can be considered a societal problem, but among the participants, there were different opinions where the burden to bridge the gap lies

I am so tired of people not seeing me (...) projecting their own fears and worries upon me" (participant 1) It is normal that they don't understand we need to educate them. (participant 4)

At the same time, visible symptoms are not better to deal with, several participants even mentioned that I prefer having invisible symptoms to visible ones. Allowing them to pass, but then also judged and misunderstood when they were different suddenly. There was a tension between not wanting to stand out and needing special attention sometimes. When they are seen, however, the pitfall is that they are seen as their handicap.

Don't they see that I need to sit? I see it for them! (participant 2). I am not this disease. This is not who I am (participant 1)

There exists a dilemma of disclosing or concealing one's impairments. Choosing to present without the impairment of fatigue essentially passing as "normal".

If I am sitting no one can see that I have MS (participant 1)

There are several reasons for wanting to pass and fit in, partly but not only to avoid microaggression and societal judgments. Even within the family and the inner circle, participants are sometimes met with disbelief. Are you doing the best you can?

My partner is patient, but sometimes one thinks I don't do things out of laziness or lack of motivation (participant 3)

In contrast to the skepticism that can come from the family, betimes participants are blind to the fatigue themselves. It is their close ones that notice the fatigue and alert them.

My husband sees it [the fatigue] on my face and takes the necessary actions to protect me (...) alerting our friends and me so I do not have to. (participant 4)

4.5 Identity

MSRF affects the sense of self and identity. Participants expressed engaging in meaning-making around past, present and future selves.

I am a healthcare worker, I help people, but I cannot work as one anymore. How do you think that makes me feel (participant 4)

When your current life contains nothing of what you loved doing, it can bring about a loss of identity and increase the suffering

I used to be the dancing mum, the one full of energy and life, I feel bad for my daughter that has to see me like this (participant 1)

Sense of identity can also be a trait of character, a force that helps with handling the difficulty of living with MS.

I am someone that doesn't give up. someone positive, but it is not always easy (participant 2)

In other cases, there is less of a difference between their former self and new self, allowing for a more harmonious transition

I was never someone that spoke a lot, so it didn't change much for my friends that sometimes I just sit quietly when I am tired (...) They understand (participant 3)

MSRF and living with this disease can also cause them to develop other aspects of their personality

I have learned to develop boundaries, to think I needed this disease to be able to (participant 1)

The loss of a professional identity forces them to adapt and live beyond a professional self.

I am more than just a healthcare worker; it has allowed me to spend so much time with my family. I do so much else than just working now (participant 4)

Participants develop character traits and inner strength to help navigate the disease. Most of these adaptations to enhance resilience are seen as positive

I used to be quite shy, but I have learnt to take advantage of the fact that I stand out. When you are in a wheelchair, people notice you (...) It is up to you what you do with it (participant 3) It has forced me to develop an inner strength. I find myself on a spiritual path now (participant 1). I was never good at saying no (...) to think of myself. That has changed now. I have to, but it is a good thing. (participant 5)

With a loss of ability and when work was no longer possible, some participants questioned their value or found new ways to create value. Shifting from work towards a passion or channelling their will to make a difference into associative actions. And through these diverse activities finding a new purpose.

I would like to find something creative that I can do, I used to love my job! I want to find a purpose (participant 1) The best thing I did was to stop working. Now I get to do what I love every day (participant 3) I found ways to help people, which is who I am. I cannot do my old job, but I created a business and do community work (participant 4)

Those still employed are willing to sacrifice a lot and schedule their life around work. Illustrating how important being an active participant in society can be for a sense of value and identity. They are sacrificing more personal and social aspects to maintain a work identity.

I go to bed at 21h30 every day, it's not fun, but otherwise, I can't function at work (participant 2)

There is great uncertainty about the future in participants with a recurrent remittent form. Often fearing the next evolution, the next debilitating attack. This is contrasted with a surety in the progressive forms where there is a steady, more or less hasty, but unavoidable decline. It can be compared to ageing on steroids, planning for a future with less capacity

We live with the Damocles Sword above our head (participant 2) Plan while you still can, while you are still capable of doing more (participant 3) The disease catches up with you (...) there is a before and an after (...)you have to see life differently, you have to redefine your limits, your capabilities, to know and try to recognize your limits (participant 4)

There is a divide between them and us. Us: the sick, the different, the invisible, the misunderstood, the unique. Them: the normal ones, not sick, the able, the ones who judge, the ones who do not see us. The divide highlights the difference and can create a sense of tension between the groups, but also foster a sense of solidarity with the group us:

We are all different. MS the disease with a thousand faces. (participant 2)
 We help each other, exchange tips. It would be great if we had a place, we could do this (participant 2) There are people [with MS] that are sicker than me, that are worse off. I am lucky, I do all this for them (participant 4)
 They do not understand me (...) they think about what they would need if they had this disease....not what I need (participant 1)

In contact with others, the gaze of the other can be difficult and add to the burden or be painful when they fail to see them. In this intersection between the groups and under the gaze of the other, limitations and disabilities might become more apparent.

They do not see us. It is not that hard...it is common sense (participant 2)
 They project their own fears upon me, it exhausts me. I just want to be left alone (participant 1) It doesn't help when people say get up and move, I am the first person when tired that would like to not be tired and do more (...) but if can't...I can't and that's all (participant 5) When I walk in the street, grandmas walk past me, but when I sit, no one can tell (participant 1)

5 DISCUSSIONS

In this section, we will discuss more in-depth certain themes, and look at how they relate to the relevant literature before moving on to a reflexive part.

5.1 Theme discussions

5.1.1 Fatigue a multifaceted entity and The Daily Grind

In this theme, fatigue is an entity: with body and weight in an attempt to illustrate how much space it takes up in the participant's lives and its impact. Its characteristics are mercurial and multi-faceted fatigue symptoms ranging from physical to mental, to emotional. What was clear for all the participants was that there was a qualitative difference between normal and pathological fatigue. Fatigue triggers were very diverse when identifiable, as was not always the case. Participants seemed to know themselves well and had gathered intimate knowledge about themselves through trial and error. The coping mechanisms and recovery strategies were more homogenous, with mostly immediate rest and withdrawal from social interactions, that were rendered impossible or very energy costly.

This theme mirrors strongly similar research done on MSRF experience of adolescents but also other chronic illnesses with fatigue such as CFS, fibromyalgia, and cancer-related fatigue. The lived experience of pathological fatigue described in research is similar despite independent origins with a large individual variation. This leads me to think that despite the heterogeneity of individual manifestations, there might be a commonality within the lived experience of fatigue. (Primdahl, Hegelund, Lorenzen, Loeppenthin, Dures & Esbensen 2019.) There is to date little qualitative literature on the lived experience of MSRF, but this phenomenon has been better explored from a qualitative point of view for CFS and cancer-related fatigue. The findings echoed and mirrored this study's results but added nuances such as race and socioeconomic status that were absent in this master thesis. People living with CFS felt disabled, dismissed, and invisible. Fatigue triggers and fatigue management were found to be heterogeneous and individual. However, the debilitating effects on social interactions, economics and sense of self were found to be in part due to its invisibility. Clinicians could look at the lived

experience of fatigue from these fields and assess the transferability and applicability to inform person centered care. (Roberts 2018; Walford et al. 1993; Bradford et al. 2023; Jaime-Lara, Koons, Matura, Hodgson & Riegel 2020.)

How we name things are important for how we understand them. The word fatigue does not manage to illustrate the enormity of this symptom and how it affects people. (Toombs 1992). Even this study does not do it justice. I have been close to someone with MS my entire life and spent the last year immersed in their stories of lived experience, and I still don't get it. It is like heartbreak; you don't truly understand it until you've lived it. However, maybe we can better communicate what it is through a rebranding of sorts to inform the public. The medical jargon of fatigue might do them a disservice since this fatigue has very little in common with what we live. In France, fatigue is the word used for normal tiredness. Would we understand slightly better if we used MS Burn Out, MS exhaustion when discussing it? Or maybe it's its own word altogether?

The daily grind tries to capture the challenges of daily living with MSRF. Showcasing how the participants are constantly adapting to the fatigue and coping with a loss of function or just working hard to maintain the status quo. It requires tough choices, a great deal of planning and prioritizing rest, and therapeutic activities such as physiotherapy, alternative treatments, and exercise. Some research mirrors similar experiences in people living with chronic pain and with disabilities (Hovey 2023.) The cognitive and physical burden of this daily grind can be classified as secondary fatigue. Targeting this secondary fatigue is a key approach to increase quality of life. Apps and therapeutic educational programs aim to do just that, and it is a beginning. (Oliva Ramirez et al. 2021; Ayache & Chalah 2017.)

5.1.2 Visible vs Invisible and Identity

MSRF is an invisible symptom, and this changes the nature of how other people, both the inner circle of family and friends and society, perceive the symptom. The invisibility complexifies the lived experience of MSRF and increases the burden. It also has tangible consequences, such as the socio-economic consequences of being classified as more able, getting less support than needed and being judged differently than other disabilities. Physical and visible handicaps are much easier to understand and quantify. The

Extended Disability Status Scale (EDSS), the most widely used scale to evaluate the loss of function for MS patients, has been criticized for being too focused on physical disability (Kamudoni et al. 2021; Newton et al. 2020.)

With invisibility comes the dilemma of disclosure. Within the scientific literature, this phenomenon has been studied. Participants have an active choice of revealing their disability and being seen mainly as their handicap or not disclosing and passing as able but at the expense of personal integrity and the peril of their capacities being overestimated. The ensuing cognitive dissonance and the phenomena of passing itself have consequences for mental health and quality of life. (Lingsom 2008.) Interestingly participants, while acknowledging the complications that come with an invisible symptom, all agreed that they prefer an invisible symptom to an invisible one. Sometimes using props such as a cane or their handicap card allowed them to signal that they were different when desired. In the literature, women seem particularly prone to suffer microaggression with visible and invisible disabilities (Olkin et al. 2019).

The consequences and stigma of living with an invisible symptom or disability is not unique to MS or MSRF. Many commonalities exist in the literature around chronic pain, fibromyalgia, CFS, and mental health troubles. (Green, Romei, Benjamin & Natelson 1999; Dickson, Knussen & Flowers 2007.) There are some powerful debates around the stigma and suffering of people with both visible and invisible disabilities in society, that also at how or who should bridge the gap, but it seems that implementation into practice is lagging. Because of the limitations of a master thesis, we will not be taking this discussion further, but a lot of fascinating research has been within the vast field of disability studies. (Dickson et al. 2007; Friedman & Owen 2017; Cieza, Sabariego, Bickenbach & Chatterji 2018.)

The Identity theme explored the identity questions around MSRF, and how it affects their identity and links closely to the theme Visible vs Invisible. Identity is a complex construct and being diagnosed as well as living with MS can disrupt our biographical self (Navon & Morag 2004; Mozo-Dutton, Simpson & Boot 2012; Strickland et al 2017.) The concept of liminality, which we will discuss more in-depth during the discussion around the overarching theme Living in Liminality, conceptualizes well the journey of constructing a new identity after being diagnosed with MS or any major illness. Studies have applied this phenomenon around the time of diagnosis. Still, in a degenerative disease such as MS and in people suffering from invisible symptoms such as MSRF, it

can become permanent or sustained and a source of emotional distress as well as secondary fatigue. (García-Santesmases & Sanmiquel-Molinero 2022b)

The tension between who I was, and who I am can have a profound impact on their quality of life and the lived experience. Sometimes the former personality matches the current situation and symptoms better and facilitates acceptance and integration of the diagnosis. Other times there is a clash between these two, increasing suffering greatly. This ties into other studies around MS, but with this aspect, we also find common characteristics within other degenerative and chronic illnesses as well as disabilities (Bradford et al. 2023; Barker, Lincoln & Hunt 2018; Irvine, Davidson, Hoy & Lowe-Strong 2009; Dickson, Knussen & Flowers 2008)

Participants described engaging in meaning-making around what gave them value today and found new roles and ways to create this: being a mother, practicing with passion a sport that fits their abilities, helping others or changing professions to be able to continue to work. The invisible nature of MSRF plays a role in this identity quest as we construct part of our identity through society (Barker et al. 2018). Studies have explored the effect of living with an invisible disability in society and how this often complexifies identity issues and hinders the construction of a new personal narrative, and people with invisible symptoms or disabilities find themselves as neither or in a position of betwixt and between in society (Honkasalo 2010; Brown et al. 2017.) Social marginalization with the negative consequences that entails often ensues. Increasing the gap between us, the disabled or sick and them, the normal or able. Disability studies have developed some fascinating perspectives on this and looked at questions around with whom the burden lies to bridge the gap. This debate was echoed by participants in the study, some expressing that it was up to them, the sick, to explain what is unseen and misunderstood, and others expecting more from society (Jackson 2005; De Carvalho et al. 2011.) Will not take this debate further here, because the field is theoretically dense and the limitations of the master thesis project, but this could be explored more in further research.

5.1.3 Living in Liminality

Liminality is a growing concept in social studies, the field of disability but also around terminal illnesses (Blows, Bird, Seymour & Cox 2012; Navon & Morag 2004; Frommer

2005.) Studies have applied this framework of rites of passage, and detailed three periods involved: a separation phase, a rupture of identity and sense of self, followed by reconstruction of a new identity. In essence, a pre-liminal phase, liminal and post-liminal state. It is typically used to describe the time around diagnosis, but it can become a permanent or sustained liminality (García-Santesmases & Sanmiquel-Molinero 2022b; Brown et al . 2017.) Liminality is ordinarily a temporary, transitory state governed by a lot of uncertainty and invisibility as the person reconstructs their identity. Within the field of architecture, a liminal space would be a space one cannot live in that takes you from one place to another, such as a hallway, an elevator, or a waiting room. Spaces we normally don't notice as we pass from one place to another. In more mainstream literature, there is a word for the unease we might feel as we pass through these spaces, liminal anxiety. It is a passage, from one state to another, a transformation, an adaptation. However, what happens when people get stuck in this state? Prolonged liminality has been correlated to poorer mental health and feelings of otherness and stigma (Jackson 2005; Warner & Gabe 2010.) Liminal beings also exist, mythological creatures that are neither this nor that, for example. This is a powerful metaphor for people living with MSRF. Liminal personae that transgress social norms, structures, and roles. (Wels, Waal, Spiegel & Kamsteeg 2015.) In the case of MSRF they look the same but have different, often hidden needs that they can choose to disclose or hide.

The world collectively involuntarily found itself in a liminal state during the 2020 pandemic. Covid showcased how we do not react equally to prolonged uncertainty. Some people handled it better, while others found it more difficult. It also highlighted socio-economic-cultural differences in how well we coped. It was often the most vulnerable that were affected the strongest (Naylor, Burke & Holman 2020; Banwell, Williamson, Batterham, Leach, LaBond, Calear, Olsen, Philips, Zhao, Doan & Walsh 2023; Careless 2023; Jamjoom 2022; Wayland 2021.)

The "original" liminal process of loss of identity and reconstructing it, is temporary, however since invisible disabilities are not easily integrated, it leads to an us and them, a person in society caught in betwixt and between. One could speculate that any major changes to a personal ability demand an adaptation and engages a change in the personal narrative and sensemaking process around identity as described by Steven Tyerman through his experience with prostatic cancer (Tyerman 2018). MSRF is exactly that complex and changing people suffering from MSRF don't know how they will wake

up. They just know that they will wake up tired, but not to what extent, not how. The recurrent remittent form of MS has people living with uncertainty constantly, will I have another attack, when will it be, will I recover fully or partially, is this who I am now? What will tomorrow bring? With these arguments, I would propose that they Live in Liminality. This constant adaptation and being stuck in a transitory phase have emotional consequences, engender secondary fatigue, increases stigma, and affects mental health poorly in addition to the challenges of having MS.

5.2 Future research

This section will be dedicated to thinking forward, opening possibilities for future research around MSRF, but also the implications for the osteopathic field clinically, theoretically, and educationally.

The poor understanding of MSRF renders clinical management complicated, and clinicians generally underestimate the impact of the patient's experience of MSRF, which can reduce the quality of care (Newton et al. 2020). The lack of clear underlying mechanistic theory for MSRF, adds to the difficulties of understanding, measuring, and treating MSRF from a biomedical point of view. Given the relative lack of qualitative research, I would argue for a more qualitative experiential exploration of this phenomenon in future research, to capture the patient's perspective and lived experience. This could help inform person-centred care and improve the quality of care.

To provide patient-centred care, we need patient-centred research. In disability research, there is a strong notion of nothing about us without us (Johnson, K. 2009). To respect this and enhance the quality of studies, I would propose co-constructing the research design and process with patients. This could help construct the research design in such a way as to have optimal impact and relevance in terms of patients' needs. Participatory Research Partnership is an interesting framework, developed within the field of rehabilitation, but that could have a greater scope (Sipari, Vänskä, Lehtonen, Helenius, Väisänen & Harra 2022)

In regards to MS and MSRF further research on the aspect of liminality and identity could be interesting. How can clinicians, support this process in MSRF or for people with MS in general? Studies centred around new modules of educational therapy focused on the identity aspect, with workshops designed to help navigate uncertainty and tools for

sensemaking around identity and reconstructing personal narratives, could be an avenue to explore to reduce fatigue, suffering and improve quality of life. Collaborative Story Craft has been used in an organizational setting but could perhaps be used in this context as well (Cleland Silva & Fonseca Silva 2022).

On the subject of osteopathy to improve quality of life in patients with MSRF. One promising but underpowered pilot study compared Osteopathic manual therapy (OMT) to educational therapy, the current gold standard in managing MSRF, showed positive results for OMT in fatigue reduction. (Cordano et al. 2018). This could be an avenue to explore, both through larger scale, more robust quantitative studies but also qualitative studies using interviews rather than questionnaires to evaluate the impact, given some research highlighting the low reliability of validated questionnaires to pick up variations in MSRF (Newton et al. 2020)

Research possibilities in the field of osteopathy: In alignment with the current research and emerging integrative hypothesis and fra(Esteves, Cerritelli, Kim & Friston 2022)Cerritelli, Kim & Friston 2022), further research could explore MSRF, but also other complex medically unexplained symptoms such as chronic fatigue syndrome (CFS), chronic pain, and fibromyalgia from an Enactive perspective, using mixed or qualitative methods. In addition, research from this point of view around chronic conditions in general with osteopathy as an add-on to current treatments, could improve multi-disciplinary person-centred care. Tyerman states that loss of agency and suffering, be it through pain, loss of ability, or an illness, can be lived as a perturbation of the personal narrative. I would argue that this can be seen as a lower volume, transitory liminal process. Esteves et al. (2022) already propose viewing a manual therapy session as a therapeutic ritual, where through the therapeutic alliance and the dyad patient-practitioner, new ecological niches and possibilities for action are created. The ritual of consulting an osteopath could be seen as a facilitator of the liminal process, and future research could explore these possibilities. Helping to anchor these models clinically and open other views and possibilities for manual therapy.

More research is needed into the social dimension of living with chronic invisible symptoms, medically unexplained symptoms, and disabilities to improve osteopathic person-centred care for patients in these circumstances. Currently, there is a lack of knowledge, I would propose collaborative research with researchers from the field of social sciences

to better our understanding of patients 'needs and social context. This could have educational implications, improving understanding and teaching around the bio-psycho-social aspect of care of patients in these circumstances, as well as improving clinical care.

5.3 Reflexivity

5.3.1 Reflections on themes

Some themes are stronger than others and more linked to each other. Invisibility and identity were strongly linked. So was the fatigue theme and daily grind, these could perhaps have been merged into a larger theme: living with fatigue, for example. However, given the invisible nature of fatigue and our constant tendency to miss judge the huge impact it has and the place it takes up in the lived experience of people living with MS, it felt important to keep them as separate themes. In this way, they are more visible and take up more place, as it does in their lives. It was a way of materializing the immaterial and rendering explicit the implicit. Maintaining the separation also marks a clearer distinction symbolically of primary (MS fatigue) and secondary fatigue (due to consequences of the MSRF). It thus highlights the daily struggles of these courageous people.

Reflections upon the process and choices.

I made a choice to stop after five participants due to a strong sense of sufficiency, but it also meant that other voices were not heard, perhaps that suffered differently or more from MSRF. However, this also meant that the qualitative data set was of a manageable scale for a master's thesis. A too-large dataset and being overwhelmed by the quantity of data can be a danger for junior researchers.

I spent a considerable time coding and generating theme's part. Choosing to do a 3rd round of coding to be sure and have more implicit codes. Theme generation also took time. The upside is that I felt like I had solid themes, when I dove into the scientific literature, I was surprised at how well they reflected many of the themes and through the literature, I understood why certain aspects just felt important. That being said, I should

have started writing earlier. I underestimated how much the analysis would evolve during the writing process and how long it would take. The shift to an abductive process going between the data, themes and scientific literature while writing deepened the analysis. The downside is that I had less time to write the report and the story of the themes. I fear this has affected the quality of how their story is told and hence understood, despite setting aside more time for writing in my schedule.

My intimate connection with the subject means that I care in so many ways. It created a great deal of discomfort for me. This was surprising because working clinically with persons with MS is not as emotionally taxing for me. However, I realized as I wrote up the process and read through my research diary that this discomfort and its challenges pushed me to reflect more upon my multiple roles and if I was “doing justice” to the participant’s experience. Creating a glitch that forced me to stop and reflect rather than plod on. Initially, this reflection was quite affective and centered on me and as the project continued, it evolved into a deeper analytical thought process on MS and what it meant to live with it in society and what it meant for me as an able person doing research about them.

The writing up was difficult and time-consuming. You think you have understood, but then realize that it is a superficial understanding. Time management and academic writing are two major areas of improvement for me that I have identified through this project and taken steps to better. I navigated 3 different professional roles while writing this thesis and failed to initially allocate enough time for the final stage and then set aside more time. This meant a very labour-intensive period, with insufficient time to let it sit and return to it.

Another aspect is that I relied heavily upon Braun and Clark’s literature on how to do RTA. This was a great help, as this was my first qualitative research project. However, my lack of greater knowledge and actual experience in the field meant that I didn’t think so critically about their writing, my attitude was more trusting them as experts. This has probably influenced the project, and I am mindful of it.

5.3.2 Reflections upon surprises and exceptions

A collection of voices: In Norway, there are two official languages, one being New Norwegian, it is a synthesis and reworking of the multitude of dialects spoken throughout

the country compiled by a linguist. He strived to capture the essence of how we speak in contrast to the Bokmål heavily influenced by Danish, but at the same time, New Norwegian does not exactly portray any of the dialects. It is the same with these Themes. This work is based on a collection of voices, bringing them together, but there is a richness and heterogeneity to each of these stories that have been transformed into a collective and told through my voice. It was sometimes difficult to capture the disparity, but I tried to express variety with my choice of quotes from the data set. To this sense, I would like to briefly highlight a sub-group. Those that have had the disease around 20 years seemed to be coping better, despite having a higher handicap. Reading through the transcripts again towards the end, there were differences in their attitude towards identity and society, perhaps they are in a post-liminal phase? One participant was in a wheelchair and expressed less trouble with the invisibility and identity aspect and was the person that gave the impression of suffering the least from some of the societal and identity aspects highlighted through the themes.

An aspect that struck me as different from the literature was that participants had little to say about interactions with the medical world. Quite happy, in contrast with many other pieces of scientific literature on MS, but also other chronic illnesses. This could be because the study took place in Toulouse, and Toulouse has one of the most prestigious MS centers in France with a pluri-disciplinary approach that gathers a lot of diverse competencies. Or just simply that it was less problematic for these individuals?

5.3.3 My own liminal process

As this research project is coming to an end, I realize it was my own liminal process in transitional space and time. Time and space carved out between all my different roles to work on it, for example, at night when my partner was sleeping, and I was having analytical waves of “insight” or coming together. I got into the habit of having my notebook by the bed. On a more symbolic level, this was also identity work at a time when I transition from being a clinician and junior teacher into a more senior teacher and integrating some research projects as a junior and carving out some of those skills needed for the future and putting some of my past to rest. The qualitative process pushed me into some quite uncomfortable corners and helped me become more comfortable with uncertainty while highlighting areas that yet need to be worked on. The immersion into all the data and information had me feeling like a jar filled to the brim, about to burst at

times, but it has enlarged my understanding and compassion for those in society that live with invisible disabilities. This immersive process has also been cathartic work, the privilege of being trusted with such powerful lived experiences of MS and listening to such courageous individuals has given me a new understanding of what it is to live with MS, and I see my mother's journey with MS through different eyes and listen with more compassionate ears. It has also made me more mindful of societal inequality and what we do not see.

6 CONCLUSIONS

MSRF affects multiple bio-psycho-social dimensions of being. This invisible, misunderstood symptom has a profound impact not only on daily life but also on aspects of identity, and this influence can increase suffering, adding to fatigue. This exploratory qualitative study used RTA to generate four themes that highlight these different aspects: (1) Fatigue as a multifaceted entity, (2) The Daily Grind, (3) Visible vs Invisible, (4) Identity, and the overarching theme Living in Liminality.

People living with MSRF could be living in multiple processes of transition or liminality. A long-term process on an identity level, reconstructing a new sense of self after the diagnosis. Shorter term, navigating the constant adaptations to MSRF consequences on daily life, as well as the evolution of the illness and the symptoms. The high uncertainty, constant adaptation and invisibility could be a source of fatigue and mental stress in addition to the pathology burden, further exacerbating the lived experience of fatigue and suffering. More research is needed into how we can give space and support this sense-making process and perhaps give people living with MSRF tools to navigate or better tolerate the liminal process.

Liminality as a concept could offer some interesting perspectives for future research within the field of osteopathy and manual therapy. The recent (En)active ecological framework puts emphasis on personal narrative and embodied lived experiences. The treatment session is seen as a ritualistic, collaborative sense-making process. In addition, osteopaths often see patients with medically unexplained symptoms, chronic pain and illness. Is not the loss of agency, pain and suffering a more gentle volume liminal process? Treatment can be seen as a ritualistic process that helps to navigate uncertainty through the help of an “expert,” both in the sense of the neuroscientific concept of active inference and lived experience.

Living with MSRF is complex, and there is no quick fix. Secondary fatigue and other sources of suffering could be alleviated. Collaborating in multi-disciplinary teams to offer individually tailored person-centred treatment plans. To enhance person-centered

care, healthcare professionals could be aware of the social context of living with invisible disabilities. We could perhaps acknowledge this tremendous amount of work that goes on “under the surface” and be mindful of it, seeing what is so often missed. We could be careful not to add to the burden with too many exercises, diagnostic labels, or “helpful” suggestions on how they should do it. They are already doing their best. An open discussion exploring together different options and giving information if the patient wants it. They already get many tips and tricks from other people with MS. The disease tends to isolate and fatigue, perhaps facilitating the creation of and communication around already existing communities of practice of sorts, where they can learn from each other, both online and physically, could be beneficial. Several participants expressed their wish for this during the study.

In disability research, there is a strong statement of “Not about us without us”, and even in qualitative research, where participants have a lot to say and influence, they could be rendered more active participants. They could provide information and guidance gathered from lived experience as well as other perspectives. I suggest utilizing this body of knowledge that the patients have and including them in further research on MSRF and fatigue management, this seems to already be the case in more recent research. Further research could follow participatory research models such as Participatory Research Partnerships.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist. n.d.

COREQ (CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH) CHECKLIST

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|--|----------|--|----------------------|
| Domain 1: Research team and reflexivity | | | |
| <i>Personal characteristics</i> | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | 10 |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | 11 |
| Occupation | 3 | What was their occupation at the time of the study? | 11 |
| Gender | 4 | Was the researcher male or female? | 11 |
| Experience and training | 5 | What experience or training did the researcher have? | 12 |
| <i>Relationship with participants</i> | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | 9 |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | |
| Interviewer characteristics | 8 | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 12 |
| Domain 2: Study design | | | |
| <i>Theoretical framework</i> | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 11 |
| <i>Participant selection</i> | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 9 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | 9 |
| Sample size | 12 | How many participants were in the study? | 10 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | 10 |
| <i>Setting</i> | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | 10 |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | 10 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | 62 |
| <i>Data collection</i> | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 10 |
| Repeat interviews | 18 | Were repeat interviews carried out? If yes, how many? | 10 |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | 10 |
| Field notes | 20 | Were field notes made during and/or after the interview or focus group? | 12 |
| Duration | 21 | What was the duration of the interviews or focus group? | 10 |
| Data saturation | 22 | Was data saturation discussed? | 10 |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | 10 |

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|--|----------|--|----------------------|
| | | correction? | |
| Domain 3: analysis and findings | | | |
| <i>Data analysis</i> | | | |
| Number of data coders | 24 | How many data coders coded the data? | 11 |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | 13 |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | 11 |
| Software | 27 | What software, if applicable, was used to manage the data? | 12 +13 |
| Participant checking | 28 | Did participants provide feedback on the findings? | 14 |
| <i>Reporting</i> | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 16-23 |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | 16-24 |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | 15 |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | 33 |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

PARTICIPANT CONSENT FORM

Title of the study: The experience of fatigue by patients with MS, a qualitative study.

Location of the study: Metropolia University of Applied Sciences, Masters in Osteopathy, performed by Julian Ims, Supervisor Tricia Cleland Silva.

I have been invited to participate in the above research study. The purpose of the research is to give voice to the complex phenomenon of MSRF, how it is perceived and lived by patients.

I have read and understood the written participant information sheet. The information sheet has provided me sufficient information about above study, the purpose and execution of the study, about my rights as well as about the benefits and risks involved in it. I have had the opportunity to ask questions about the study and have had these answered satisfactorily.

I have had sufficient information of the collection, processing and transfer/disclosure of my personal data during the study and the Privacy Notice has been available.

I have not been pressurized or persuaded into participation.

I have had enough time to consider my participation in the study.

I understand that my participation is entirely voluntary and that I am free to withdraw my consent at any time, without giving any reason. I am aware that if I withdraw from the study or withdraw my consent, any data collected from me before my withdrawal can be included as part of the research data.

By signing this form I confirm that I voluntarily consent to participate in this study.

If the legal basis of processing personal data within this study is a consent granted by the data subject, by signing I grant the consent for process my personal data. I have right to withdraw the consent regarding processing of personal data as described in the Privacy Notice.

Date

Signature of Participant

The original consent signed by the participant and a copy of the participant information sheet will be kept in the records of the researcher. Participant information sheet, privacy notice and a copy of the signed consent will be given to the participant.

PARTICIPANT INFORMATION SHEET

Study title: The lived experience of fatigue by patients with Multiple Sclerosis (MS), a qualitative study.

Invitation to participate in a research study

We'd like to invite You to take part in our research study, where we conduct interviews to learn about what it is like to live with fatigue due to MS. It takes place between 2022/23 in Toulouse, France. Participants are purposefully chosen.

Voluntary nature of participation

The participation in this study is entirely voluntary. You can withdraw from the study at any time without giving any reason and without there being any negative consequences. If You withdraw from the study or withdraw Your consent, any data collected from You before the withdrawal can be included as part of the research data.

Purpose of the study

The aim of this study is to give a better understanding of the lived experience of fatigue from MS. It is a complex phenomenon and little qualitative research has been done so far. It might hopefully be used to better inform health care professionals and others of what it is like.

Who is organizing and funding the research?

No financing. Personal master thesis.

What will the participation involve?

- How long will the participant be involved: 6 months.
- How long will the research study last: 2022/23
- How often will the participants meet the researcher : One or more interviews
- How long will the meetings with the researcher/s be : 1 hour-1,5 hours
- What exactly will happen: Interview, and a verification session.
- What is the research method used : Qualitative method. Interviews and analysis.
- Where is the research taking place: Toulouse, France.

Possible benefits of taking part

There could be benefits to voicing one's narrative and participating in a study,

Possible disadvantages and risks of taking part

Some emotional and psychological discomfort could arise during the interviews. If needed there is a psychologist that can offer support or a support group.

Financial information

Participation in this study will involve no cost to ou. You will receive no payment for Your participation.



Participant Information Sheet

Informing about the research results

Results and a summary will be made available in a verification session. This is the Master Thesis of Julian Ims. You can receive an electronic copy of the thesis upon completion if wished for.

Termination of the study

The researcher(s) conducting the study can also terminate the study if it is deemed imprudent to continue.

Further information

Further information related to the study can be requested from the researcher/person in charge of the study.

Contact details of the researchers

Researcher / Student : Julian Ims
Tel. number: +33658278445
Email: julian.knoff.ims@gmail.com

Person in charge of the study / Supervisor
Name: Tricia Cleland Silva
Helsinki Metropolia University of Applied Sciences / Business Health Management
Email:

Appendix to the Participant Information Sheet: A Privacy Notice for Scientific Research

Within this study, Your personal data will be processed according to the European Union General Data Protection Regulation (679/2016) and current national regulation. The processing of personal data will be described in the following items.

Types of personal data that will be collected

There is no statutory or contractual requirement to provide Your personal data, participation is entirely voluntary.

Personal data protection principles

Stored on a hard drive, audio files are transcribed using a third party (Happy Scribe). User Id and anonymization.

The data that is to be processed in the information systems have been protected using the following:

user ID password user registration access control (physical location)

For what purpose will personal data be processed?

The aim of this study is to give a better understanding of the lived experience of fatigue from MS. It is a complex phenomenon and little qualitative research has been done so far. It might hopefully be used to better inform healthcare professionals and others of what it is like.

Legal basis of processing personal data

If the legal basis is consent granted by the data subject, You have the right to withdraw the consent at any time as described in this Privacy Notice.

Nature and duration of the research (how long will the personal data be processed):

One-time research Follow-up research

Duration of the research:

= time frame needed for collecting and analyzing the data and for the publication of the study (plus three years for possible reclamations about the research results and time needed to respond to them).

What happens to the personal data after the research has ended?

How the personal data will be processed after the research has ended:

- Any research materials containing personal data will be destroyed
 Any research materials containing personal data will be archived
 without identifiers
 with identifiers

Where the materials will be archived and for how long: 5 years

Data transfer outside of research registry:

Audio files from interviews are transcribed by a third-party organization. Happy Scribe.

Possible transfer of personal data outside the EU or the EEA:

Your data will not be transferred outside of the EU or the EEA.

Your rights as a data subject

Because Your personal data will be used in this study, You will be registered to study registry. Your rights as a data subject are the following

- Right to obtain information on the processing of personal data
- Right of access
- Right to rectification
- Right to restriction of processing
- Notification obligation regarding rectification of personal data or restriction of processing
- Right to object to the processing
- Right not to be subject to a decision based solely on automated processing

- Right to notify the Data Protection Ombudsman if you suspect that an organization or individual is processing personal data in violation of data protection regulations.

You can exercise your rights by contacting the data controller of the study.

- Right to obtain information on the processing of personal data
- Right of access
- Right to rectification
- Right to erasure (right to be forgotten)
- Right to withdraw the consent regarding processing of personal data
- Right to restriction of processing
- Notification obligation regarding rectification or erasure of personal data or restriction of processing
- Right to data portability
- The data subject can allow automated decision-making (including profiling) with his or her specific consent
- Right to notify the Data Protection Ombudsman if you suspect that an organization or individual is processing personal data in violation of data protection regulations.

If the purposes for which a controller processes personal data do not or do no longer require the identification of a data subject by the controller, the controller shall not be obliged to maintain, acquire or process additional information in order to identify the data subject for the sole purpose of complying with this Regulation. If the controller cannot identify the data subject the rights of access, rectification, erasure, notification obligation and data portability shall not apply except if the data subject provides additional information enabling his or her identification.

You can exercise your rights by contacting the data controller of the study.

Personal data collected in this study will not be used for automated decision-making

In scientific research, the processing of personal data is never used in any decisions concerning the participants of the research.

Pseudonymisation and anonymisation

All information collected from you will be handled confidentially and according to the legislation. Individual participants will be given a code, and the data will be stored in a coded form in the research files. Results will be analyzed and presented in a coded, aggregate form. Individuals can not be identified without a code key. A code key, which can be used to identify individual research participants and their responses, will be stored in a secure location and the data will not be given to people outside the research group. The final research results will be reported in aggregate form and it will be impossible to identify individual participants. Research registry will be stored in France for (05) years, after which it will be destroyed.

Interview guide thesis

Could you please tell me about your experience of fatigue and MS. What is your story?

Could you tell me more about this? An event that illustrates it?

Mirroring, and validating to get more information about a subject

If we imagine that this interview is a megaphone, what would you like people to know?

Are there any solutions/helps you have found?
Could you describe them?

How would you describe your fatigue?

Has there been an evolution how you deal with the fatigue?

Added Interview 2: How does it affect/manifest in your social life? Interactions with society?

Added Interview 3 how do you feel the medical world understands your fatigue? Is there anything you would like them to know and/or change?

Anything else you would like to tell?

Any questions I haven't asked but should?

Follow up questions:

- Could you tell me more
- How did that make you feel
- What did you do then?
- Anything else?

Reflexive Research journal

Date: 18/06/22

As I prepare to conduct the first interview and as recommended by Braun and Clark, I will reflect upon my assumptions and starting point around MSRF. My main experience of fatigue in MS patients comes from my mother. For a long time, I did not understand it. I became aware of this aspect of MS through patients, and it helped me be less judgmental of my mother, as I stopped putting pressure on her when I thought she was stalling or procrastinating, but it was actually fatigue. This approach has improved our relationship greatly. In patients, I give it more space now.

I assume that fatigue from MS, is somehow worse than fatigue in other diseases and that these misunderstood symptoms create problems in interactions with healthcare professionals. This is what I see clinically. They are mainly left to their own as doctors cannot offer much help. I humbly recognize my own misunderstandings around fatigue and think that if someone that has a close relative. that has conducted one thesis on MS and worked with MS patients clinically, needed so much time to understand others both personally and professionally underestimate fatigue. This is one of the main reasons for conducting this research, I would like to explore how osteopathy could possibly help later, but since there is so little knowledge from their perspective, the first step will be to give voice to them.

I think this concludes this reflective writing. Otherwise, I am full of doubt and hope to be "a la hauteur" as we say in French, of this challenge to give voice to these brave people who go through so much. I am outside of my comfort zone as I deep dive into qualitative research, but also excited to see what this methodology can bring.

Appendix 5

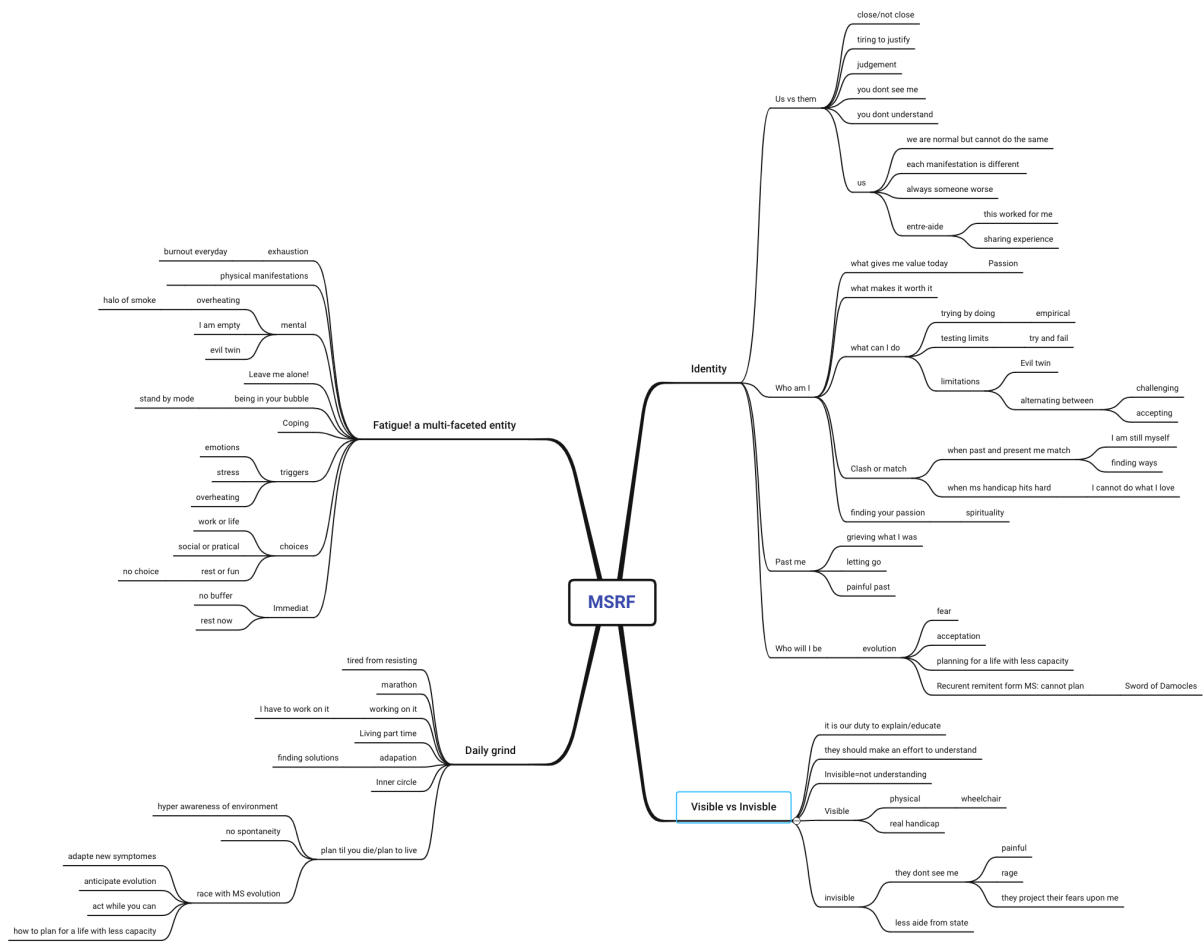


Table 1

| Patient characteristics | Participants (n=5) | |
|-------------------------------------|---------------------------|-----|
| Gender | | |
| Male | 1 | 20% |
| Female | 4 | 80% |
| MS type | | |
| Recurrent Remittent | 4 | 80% |
| Primary progressive | 1 | 20% |
| Age (years) | | |
| Average | 50,2 | |
| Range | 42-57 | |
| Time since diagnosis (years) | | |
| <10 years | 3 | 60% |
| <20 years | 1 | 20% |
| >20 years | 1 | 20% |
| Average | 13,1 | |
| Employment status | | |
| Working | 2 | 40% |
| Not working/retired | 2 | 40% |
| Other | 1 | 20% |