



**Original citation:** Richardson, Emma and Motl, R.W. (2020) *The Experience and Meaning of Aging with Multiple Sclerosis: An Existential Phenomenological Approach*. Journal of Aging Studies, 54. Article no. 100872. ISSN 0890-4065. DOI: [10.1016/j.jaging.2020.100872](https://doi.org/10.1016/j.jaging.2020.100872)

**Permanent WRaP URL:** <https://eprints.worc.ac.uk/id/eprint/9760>

### **Copyright and reuse:**

The Worcester Research and Publications (WRaP) makes this work available open access under the following conditions. Copyright © and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable the material made available in WRaP has been checked for eligibility before being made available.

Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

### **Publisher's statement:**

This is an Accepted Manuscript of an article published by Elsevier in Journal of Aging Studies on 8 September 2020, available online: <https://www.sciencedirect.com/science/article/pii/S0890406520300426> © 2020 Elsevier. Licensed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International. <http://creativecommons.org/licenses/by-nc-nd/4.0/>

### **A note on versions:**

The version presented here may differ from the published version or, version of record, if you wish to cite this item you are advised to consult the publisher's version. Please see the 'permanent WRaP URL' above for details on accessing the published version and note that access may require a subscription.

**For more information, please contact [wrapteam@worc.ac.uk](mailto:wrapteam@worc.ac.uk)**

Highlights

- Aging with MS means different things to people.
- Increased age makes some people’s MS symptoms worse.
- MS symptoms makes the natural aging process worse for others.
- Some people believe they ‘age out’ of MS
- Having MS in earlier life makes aging easier for other people.

AGING IN MULTIPLE SCLEROSIS

**The Experience and Meaning of Aging with Multiple Sclerosis: An Existential Phenomenological Approach**

Emma V. Richardson, PhD<sup>a\*</sup> and Robert W. Motl, PhD<sup>b</sup>

<sup>a\*</sup>School of Sport and Exercise, College of Business, Psychology and Sport, University of Worcester, UK; e.richardson@worc.ac.uk

<sup>b</sup>School of Health Professions, University of Alabama at Birmingham, Birmingham, AL.

**Funding**

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Health Aging through LifeStyle (HALT) Research Center which was supported by the NMSS [grant number 000518032].

Running Head: AGING IN MULTIPLE SCLEROSIS

1 **The Experience and Meaning of Aging with Multiple Sclerosis: An Existential Phenomenological**  
2 **Approach**

3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18

**Objectives:** Over the past 3 decades there have been significant advances in the development of pharmaceutical and rehabilitative treatments for persons with multiple sclerosis (MS), such that life expectancy is continuing to increase. Whilst these advancements are exciting, there are also concerns and unknowns regarding what it is like to age with MS. The objectives of this research were to explore the lived experiences and meaning of aging in conjunction with having MS. **Methods:** Semi-structured interviews with 40 persons with MS over 60 years were conducted. Thereafter data were subject to an existential phenomenological analysis. **Results:** Four different ways were discussed with regards to embodied experiences of aging with MS: aging makes MS worse; MS makes aging worse; aging makes MS better; and MS makes aging better. **Discussion:** This research highlighted the complexity of aging with MS and the various of ways persons over 60 with MS experience and interpret this phenomenon.

Keywords: qualitative; phenomenology; multiple sclerosis; aging

19

20

21

# 21 **The Experience and Meaning of Aging with Multiple Sclerosis: An Existential Phenomenological** 22 **Approach**

## 23 **Introduction**

24 Over the past 3 decades, there have been significant advances in the development of  
25 pharmaceutical and rehabilitative treatments for persons with multiple sclerosis (MS). Such advances  
26 have, in part, shifted the life expectancy of persons with MS with a median increase of 7 years (Marrie et  
27 al., 2015). As such, there is now a ‘greying’ phenomenon within the global MS population characterized  
28 by a demographic shift in the median age of adults with MS (Wallin et al., 2019). This  
29 ‘greying’ of the MS population represents an emerging problem of aging while living with a chronic,  
30 disabling condition (Sanai et al., 2016). MS is caused when an immune mediated response attacks white  
31 and grey matter tissue in the central nervous system. The resulting damage in the brain, spinal cord, and  
32 optic nerves result in scars that cause numerous symptoms including, but not limited to, fatigue, pain,  
33 walking dysfunction, bladder and bowel dysfunction, cognitive impairment, functional deficits,  
34 depression and anxiety (Motl, 2010). The phenomenon of living with MS, of course, goes far beyond  
35 these symptoms. The chronicity of MS means that living with this illness is an ongoing process of  
36 negotiating one’s self-concept and self-identity as deterioration of mobility, function, cognition, sight  
37 and independence follows an uncertain course; negotiation of the self, relationships, roles, life purpose  
38 and meaning are continually assessed and amended (Reynolds and Prior, 2003). Though these symptoms  
39 are common across persons living with MS, there are two distinct disease courses. Relapsing remitting  
40 MS (RRMS) is the most common and is characterised by clearly defined relapses of new or increased  
41 symptoms followed by periods of partial or full remission. Progressive MS is less common and is  
42 characterised by a steady decline of worsening symptoms. RRMS often transitions into a progressive  
43 course of MS over time, with current rates of transition being 50% within 10 years and 90% of people

44 with RRMS transitioning to progressive MS within 25 years (NMSS, 2020). Aging thus plays a  
45 considerable role in the MS experience.

46 To date, we know very little about what it ‘means’ to age with MS. Research that has explored  
47 the phenomenon of aging with MS has reported worsening of physical function, cognitive impairment,  
48 medication complications, disease comorbidities, dependence, depression, bowel and bladder  
49 dysfunction, isolation, cumulative effects of other chronic conditions such as heart disease or diabetes,  
50 increased risk and incidence of falls, and decreased quality of life (Branco et al., 2019; Finlayson, 2002;  
51 Finlayson, 2004; Finlayson, Peterson, and Cho, 2006; Motl et al., 2018; Sanai et al., 2016; Solaro et al.,  
52 2015; Trojano et al., 2002). This problem is likely accentuated by older adults with MS having far fewer  
53 treatment options for managing disability progression and symptoms than younger adults with MS  
54 (Finlayson, VanDenend, and Hudson, 2004), as well as contending with the natural physical and  
55 cognitive decline that is associated with aging (Gullette, 2004).

56 The above research paints a stark picture of aging with MS, yet some researchers have reported  
57 positive features of this phenomena. There is tentative evidence that the inflammatory phase of MS can  
58 ‘burn out’ with increasing age such that people with MS experience a stability or plateau of MS  
59 symptoms (Hua et al., 2019). Qualitative explorations have also highlighted that early experiences of  
60 MS may better prepare persons for the ‘normal’ aging process compared with peers who do not have MS  
61 (Dilorenzo, Becker-Feigles, Halper, and Picone, 2008). Research further has suggested that older  
62 persons with MS may have enhanced resilience, and may better adjust to meet the physical and  
63 psychosocial changes associated with aging (Finlayson, 2002; Finlayson, Van Denend, and DalMonte,  
64 2005). Collectively, this past research presents aging with MS as a complex and nuanced experience that  
65 does not follow a set phenotype.

66           Importantly, the majority of research on aging with MS, particularly qualitative studies exploring  
67 lived experiences (Dilorenzo, Becker-Feigles, Halper, and Picone, 2008; Finlayson, 2002; Finlayson,  
68 Van Denend, and DalMonte, 2005) , was conducted over 10 years ago and does not necessary reflect the  
69 current pharmacological or therapeutic landscape now afforded to older adults with MS. For example,  
70 over the last 10 years the number of approved MS disease modifying therapies (DMTs) for RRMS has  
71 increased from 7 in 2010 (Binks and Dobson, 2015) to 20 in 2020 (NMSS, 2020). Moreover, the first  
72 approved DMT for treating progressive MS was released in 2019, and this has now increased to 3  
73 (Healthline, 2020) highlighting the advances that have been made over the last decade. Therapeutically,  
74 advancement have been made through the creation (Latimeur-Cheung et al., 2013), feasibility  
75 (Learmonth et al., 2017) and testing (Motl et al., 2019) of exercise guidelines to improve symptoms of  
76 MS. These advancements have shifted the life expectancy and landscape of persons aging with MS, and  
77 the meaning and experience of aging with MS may too have shifted. The time is ripe for a new  
78 contemporary exploration of the lived experiences and meaning of aging with MS that reflects this  
79 shifted landscape. The resulting knowledge will be a foundation for future lines of research, and can  
80 answer the call to place increasing emphasis on studying healthy-aging and wellness among persons  
81 living with MS (Motl et al., 2018). Studying healthy aging and wellness, however, requires establishing  
82 what aging with MS ‘means’ among persons experiencing this phenomena as a starting point. Such  
83 research can be conducted in a meaningful way using the qualitative tradition of phenomenology.

84           From the Greek ‘phainomenon’, phenomenology is the study of things as they present  
85 themselves and are perceived in consciousness; or ‘phenomena’ (Husserl, 1961). Phenomenology in a  
86 ‘modern’ sense, was spearheaded by Edmund Husserl to address what he perceived as the inadequacies  
87 of the objective ‘scientific’ method to appreciate the essence of human experience. Since Husserl,  
88 phenomenology has expanded to include a myriad of strands, interpretations, perspectives and traditions;



89 realist, constitutive, existentialist and hermeneutic (Embree and Mohanty, 1997). In this work, we use an  
90 existential phenomenological approach. The focus of existential phenomenology involves how the body  
91 is experienced and perceived through time and space, and how it is interrelated and mediated through  
92 actions with other people and the social environment (Merleau-Ponty, 1969). Existentialist  
93 phenomenology therefore places the body as a subject of culture, and world, body and consciousness are  
94 fundamentally intertwined, inter-related, and mutually influential and the self is culturally constituted  
95 (Merleau-Ponty, 1969). Accordingly, an existential phenomenological approach is a strong and robust  
96 method for exploring aging and MS, as both experiences (aging and MS) are inherently physical,  
97 embodied experiences, and are shaped through cultural understandings and perceptions. The exploration  
98 of these dual lived experiences through a corporeal frame, and how these are understood through social  
99 structures, embodiment and consciousness can bring a greater understanding of what it is to ‘age with  
100 MS’.

101         Though different strands exist, at it’s core essence, phenomenology seeks detailed, complex  
102 descriptions of subjective, human experience within context, and is shaped by 4 principles or  
103 cornerstones for individuals endeavouring to undertake phenomenologically inspired research. Derived  
104 from Husserlian phenomenology, these 4 cornerstones are description, epoché, essences, and  
105 intentionality. Description requires researchers to suspend as much as possible prior knowledge and  
106 assumptions of the thing being studied to ‘get at’ the phenomena itself. In so doing, we assert the core of  
107 the experience and its essential characteristics. To do this, researchers engage in epoché, Epoché, like  
108 the origin of phenomenology, is derived from the Greek meaning to ‘abstain’ or ‘to distance from’. In  
109 the phenomenological ‘method’, this requires us to separate or ‘bracket’ our taken for granted, (pre)  
110 assumptions of an experience in order to cut through layers of context to arrive at essential core essences  
111 and characteristics of a phenomenon. Intentionality refers to the concept that we are always conscious of

112 something, thus it is intentionally brought into focus. Following reducing the phenomenon to its ‘eidos’  
113 (core meanings) through description and epoché, the essence of a phenomena can be established. In this  
114 way, core meanings and taken for granted knowledge of an experience can be identified. Intentionality  
115 then allows us to direct our attention on a phenomena (e.g. aging with MS) to explain why different  
116 people perceive and experience the ‘same phenomena’ in completely different ways. These cornerstones  
117 shape the ‘method’ of phenomenological research, but in actuality these cornerstones represent a way of  
118 being and thinking about the data through a specific reflexive lens, rather than as a method in itself. We  
119 explain how we utilized these cornerstones in our research in the data analysis section.

120         The ‘phenomenology of MS’ has explored different aspects of this experience including  
121 receiving a diagnosis of MS (Strickland, Worth, and Kennedy, 2015), living with a diagnosis of MS  
122 (Finlay, 2003; Toombs 1995), changes in relationships (Strickland, Worth, and Kennedy, 2017), and  
123 dignity with MS (Ziakova et al., 2020). A phenomenology of aging with MS is required to complement  
124 this literature and expand phenomenology of MS through the lifespan. The exploration of aging through  
125 a phenomenological view has too provided important insights into the meaning of aging (Adams-Price,  
126 Harley and Hale, 1998), self-biography and the social self while aging (Starr, 1983), and embodied  
127 experiences of aging from the stand points of Beauvoir and Merleau-Ponty (Domingues and Freitas,  
128 2019). The background of phenomenological work in MS and aging purport the strengths of utilizing  
129 this tradition to explore aging with MS as an experience in itself. The current study explored the  
130 experience and meaning of aging with MS through an existential phenomenological lens. To provide  
131 some structure to this exploration, we posed the following questions:

132             What is it like to experience aging with MS?

133             How do persons over 60 with MS interpret aging?

134             What should future research target for optimizing quality of life among older persons with MS?



157 The inclusion criteria were (i) age of 60 years or older, (ii) confirmed diagnosis of MS, (iii) fluent in  
158 English, and (iv) willingness to take part in a recorded interview lasting between 1 and 2 hours.

159 Over 300 persons expressed interest in this qualitative study. To manage this amount of interest,  
160 we engaged in purposive sampling methods using criterion based (inclusion criteria stated above), and  
161 quota-based maximum variation techniques. Quota sampling seeks an equal representation from  
162 different areas (Robinson, 2014). This was adopted to ensure a cross-section of aging experiences in the  
163 United States (US) were equally represented from north, south, east and west. We sought 10 persons per  
164 region for an equal distribution and saturation of experiences in these areas. To do quota sampling, we  
165 created an extensive list of interested persons and asked these individuals to respond via e-mail with  
166 their age, state, MS disease duration, current MS typology if they would still like to participate. We then  
167 divided this list into north, south, east and west. To purposefully select participants, we then engaged in  
168 maximum variation sampling whereby within the inclusion criteria, a deliberate range of demographics  
169 were purposefully selected. Maximum variation ensured an extensive variety of age, locations and  
170 disease durations were represented in the data, and allowed for a robust and extensive cross-section of  
171 experiences that represented aging with MS. To do maximum variation sampling, we selected 10  
172 persons from the 4 areas (n=40) that were wide ranging regarding state, gender, disease duration and  
173 age. We adopted these particular sampling strategies to gain an appreciation of aging with MS from  
174 across the different cultural and geographic areas of the US, and ensure that participants could provide  
175 rich, detailed accounts of lived experiences (Smith and Sparkes, 2014).

176 To screen participants, the first author called interested persons, explained the study in more  
177 detail and conducted the phone screen. If participants did not meet the inclusion criteria or chose not to  
178 participate, the first author contacted another participant within that geographical area. This resulted in  
179 the inclusion of 40 participants from 33 states. Of the 40, 29 participants were female, and 11 were male.

180 Age ranged between 60 and 85 years with a mean age of 67.5 years. Disease duration of MS ranged  
181 between 3 and 55 years with a mean disease duration of 25 years. Nineteen participants had RRMS, 21  
182 had progressive MS. Eighteen were ambulatory, 17 used a walking aid, and 5 a wheelchair or  
183 powerchair. Thirty-three were retired, 5 were employed on a part time basis, and 2 on a full-time basis.

184 *Data Collection*

185 Data were collected through Internet based, face-to-face, semi-structured interviews. Online  
186 interviewing techniques were selected, in part, as it is the preferred method within the MS population as  
187 such techniques allow for representation of persons who may not otherwise be able to participate.  
188 Indeed, it has been posited that data can be richer as the participant has not expended excessive energy  
189 travelling to an in-person interview (Synnot, Hill, Summers, and Taylor, 2014). Though advantageous,  
190 limitations of using online methods included some difficulties with internet signal meaning breaks in  
191 interviews and flow, an inability to read non-verbal cues, and an inability to create as strong a rapport as  
192 is possible in person. Nevertheless, the utilization of internet-based interviewing strategies further  
193 enabled a wide geographic representation of aging with MS.

194 The semi-structured design was chosen as such an approach afforded participants and the first  
195 author the opportunity to cooperatively make meaning out of experience, focus on perceived areas of  
196 importance, and discuss unexpected phenomena that may not have been investigated using a more  
197 structured approach (Smith and Sparkes, 2016). The semi-structured interview guide was designed  
198 through discussion between the first and second author, engaging in aging and MS literature, and  
199 informed by focus groups with persons over 60 years of age with MS who attended the opening of the

200 [REDACTED].  
201 Participants gave verbal consent to being recorded before the interview began. Interviews ranged  
202 between 58 and 118 minutes with a mean interview length of 78 minutes. There was a total of 3,116

203 minutes (54.5 hours) of raw interview data. Participants received a \$50 gift card as a thank you for  
204 participating. Raw audio data were sent to an external transcription company immediately after the  
205 interview and this allowed for a written transcript within 24 hours of the interview conclusion.  
206 Thereafter, the transcript was changed to pseudonyms, and checked for accuracy against the original  
207 recording. Pseudonyms are used in the direct quotations in the results section.

208 *Data Analysis*

209 As noted in the introduction, there is no specific method to do phenomenology but instead a way  
210 to engage in a specific type of reflection about the human experience through (1) description, (2)  
211 epoché, (3) intentionality, and (4) essences. To do this kind of phenomenological analysis, there are 2  
212 methodological choices; employing phenomenology in the analysis of qualitative data, or employing  
213 qualitative research in phenomenological analysis (Ravn, 2016). We did the former, and followed the  
214 guide outlined by Ravn (2016).

215 The first phase of employing phenomenology in the analysis of qualitative data was to generate  
216 rich descriptions of lived experience. To do so, the first author engaged in the processes of epoché and  
217 description. Though bracketing and separating her assumptions completely was impossible, she reflected  
218 on her own beliefs of aging with MS and attempted to separate these as much as possible from her  
219 reading of the data. She did this by writing down her assumptions to be aware of her preconceived  
220 notions, and prepared herself before reading transcripts to be in a position of nativity where she actively  
221 sought taken for granted descriptions and experiences. When prepared, she engaged in description by  
222 reading and rereading transcripts, identifying points when participants described symptoms, changes,  
223 stories, and perceptions about MS, aging and/or aging with MS. She made a descriptive table for each  
224 participant that included descriptions of experiences and direct quotations supporting this description,

225 and a note of core meanings and essences for each person. In so doing, these descriptions and essences  
226 became the building blocks identifying different ways of aging with MS.

227         The second phase of employing phenomenology in the analysis of qualitative data was to  
228 conduct an exploratory analysis of data and transform description into meaning. The first author  
229 completed this stage by identifying the distinctive characteristics of aging with MS and began to craft  
230 groups that shared similar experiences. In so doing, she identified 4 key meanings or ‘ways’ participants  
231 perceived the phenomena of aging with MS: aging makes MS worse; MS makes aging worse, aging  
232 makes MS better, and MS makes aging better.

233         The third phase of analysis was to relate these 4 different meanings within the scientific  
234 literature. We did this through engaging in intentionality by assessing the situatedness of participants  
235 and exploring what shaped these different meanings of aging with MS. To do so, we analysed each  
236 meaning through theoretical frameworks of chronic illness and aging. We first analysed the data by  
237 interpreting how the experience of chronic illness influenced participants’ perceptions of what it was like  
238 to age with MS. Thereafter, we cast an aging lens by assessing how participants’ perception of aging  
239 influenced interpretations of what it was like to age with MS. The final report of these different  
240 meanings and how they related to scientific literature is presented in the results and discussion.

#### 241 *Rigor and Trustworthiness*

242         To ensure rigor and trustworthiness through the research process, we adopted a relativist  
243 approach. In other words, we chose quality standards that aligned to the purpose and method of the  
244 research (Burke, 2016; Gergen 2014), specifically how to rigorously do an existential phenomenological  
245 study. We therefore drew upon the ongoing ‘lists’ for quality and rigor first proposed by Smith and  
246 Caddick (2012) and the list proposed by Tracy (2010). First, we chose “worthy topic.” The worthy topic

247 criteria stipulate that the research must be timely, significant, interesting and relevant (Sparkes and  
248 Smith, 2013). We highlighted the worthiness of our topic through justification in the introduction  
249 regarding why a contemporary, phenomenological understanding of aging with MS is currently needed.  
250 Second, we chose the criteria of sincerity whereby the study is steeped in self-reflection about values,  
251 biases and presumptions of the researcher (Tracey, 2010). Considering the requirement to engage in  
252 epoché within phenomenology, worthy topic was appropriate and important to use. We engaged in  
253 sincerity throughout the process by reflecting on our presumptions about aging with MS and engaging in  
254 epoché exercises, outlined in the data analysis section. Third, throughout the analysis and data collection  
255 process we used member reflections to ensure that the meaning and experience of aging with MS  
256 constructed by the researcher was recognizable to participants in the study. Member reflections are an  
257 important process within phenomenology as the researcher attempts to reconstruct the reality of  
258 participants by creating a relatable and resonating representation of someone's lived experience (Grant,  
259 2012). Reflections were done through reflexive conversations with participants throughout the research  
260 process. Fourth, we sought to make a significant contribution to the literature. The criteria call for  
261 researchers to make a meaningful impact on our understanding of what is being researched theoretically,  
262 conceptually, practically or methodologically (Sparkes and Smith, 2013). We ensured we made a  
263 meaningful contribution by conceptualizing and theorizing aging with MS within aging and chronic  
264 illness frameworks, providing recommendations for practice and future research, and highlighting how  
265 existentially phenomenology can be used to illuminate the meaning of an experience not well  
266 understood. Our significant contribution to the literature is shown in the results and discussion, and  
267 concluding remarks sections.



268  
269  
270  
271  
272  
273  
274  
275  
276  
277  
278  
279  
280  
281  
282  
283  
284  
285  
286  
287  
288  
289  
290  
291  
292

### Results and Discussion

The phenomenon of aging with MS was extensive, complex and contrasting among participants.

Participants all discussed compounding effects of aging with MS, yet the cause-effect relationship differed regarding whether (i) aging made MS worse, (ii) MS made aging worse, (iii) aging made MS better, or (iv) MS made aging better. The results and discussion will be presented together in order to immediately conceptualize and theorize findings within wider literature, and address the first two questions of this study.

#### *Aging made my MS worse*

The majority of participants discussed the perception that the progression of age had markedly worsened already existing MS symptoms and brought about new symptoms. In particular, the effects of aging on MS that were deemed to impact quality of life and participation most were (i) decreased physical function and (ii) bladder dysfunction.

*Decreased physical function.* Participants deemed that a decrease in physical function (for many premature), was the result of age exacerbating symptoms including balance, strength and flexibility such that the ability to walk safely worsened:

When I was younger you really didn't notice a lot of difference between me and the next man but since I turned 60 there's been a rapid downturn physically. I've noticed that I've lost a lot of strength and stamina, and I find it hard to balance because my legs are so tight all the time. I definitely feel old. I don't look older, but I definitely feel older, physically, because I am not able to do a lot of things. I am not able to be as physical as I once was. And like I said earlier, when you are physical all your life, it's hard to put that down. It's almost like a kick in the face, that you can't do these things anymore. (John, 62, M, RRMS)

Physical dysfunction manifested in the requirement of walking aids, and the progression toward more advanced aids with continued aging:

293 It was all right until about 10 years ago, until about the time I retired in '95. It's gone downhill  
294 from there, slowly. I went from a cane to a walker to a wheelchair to a wheelchair and a walker,  
295 to now a specialty wheelchair. (Becky, 34, 68, F, SPMS)

296  
297 Research has highlighted that the aging process can exacerbate and worsen MS symptoms and  
298 can cause new symptoms (Sanai et al., 2016). Physical function is one of the most noticeable results of  
299 the aging effect as persons with MS experience embodied differences regarding fatigue, balance,  
300 spasticity, pain and flexibility that compromise the ability to walk safely (Silverman, Verrall, Alschuler,  
301 Smith, and Ehde, 2017). Compared to peers without MS, the necessity of a walking aid is more  
302 prevalent among persons with MS, and tends to occur at a younger age (Bishop et al., 2015). With a  
303 'greying' MS population, walking aid use is likely to increase (Silveira, Richardson, and Motl., 2019).  
304 With walking aids set to become a widely distributed experience, it is important to delve deeper into the  
305 meaning of physical function and the requirement of walking aids.

306 For some, walking aids meant infirmity and they fought to avoid using aids, opting instead for  
307 ill-balance and 'walking into walls':

308 I was wheelchair bound for 5 years when I was first diagnosed...I hope I never go in a  
309 wheelchair again, but I have trouble... Well, because of the lungs, I have trouble walking not to  
310 mention the MS. But the two together. I have difficulty walking and have difficulty with my  
311 balance. I'd rather walk into a wall than to the wheelchair. I do pretty well at not being too  
312 conspicuous. (Catherine, 79, F, SPMS)

313

314 Others, however, perceived walking aids meant participation and saving energy:

315 I changed from a cane to a walker. I have been amazed, absolutely amazed, how much less  
316 energy it takes for me to use the walker versus a cane. You never want to go that next step, and  
317 go from the cane to the walker, walker-wheelchair. You never want to do that. But I really have  
318 been totally surprised of how less energy it takes and I can do more of the things I love with the  
319 energy I save with a walker. (Joan, 67, F, progressive MS)

320

321 For these particular individuals, the value of walking diminished and the value of continued

322 participation increased; “You know, it's incredible how much value we place in certain things, like the  
323 ability to walk for example realized that once you're in that situation, it's no longer an issue” (Jennifer,  
324 67, F, progressive MS).

325         The contrasting meanings of the phenomena of physical dysfunction and the requirement of  
326 walking aids can be better interpreted through different lenses of analysis. Individuals for whom the  
327 phenomena meant infirmity may have seen physical dysfunction and walking aids through a chronic  
328 illness lens. A chronic illness interpretation of walking aids can highlight the social stigma of disability,  
329 particularly at a younger age, and the obvious difference between persons that are ‘well’ and those that  
330 are not by virtue of ambulating without assistance (Wendell, 1996). For example, a walking aid may be  
331 perceived as ‘being vulnerable and dependent’ (Brannstrom, Backman, and Fischer, 2003). Rather than a  
332 symbol of independence and empowerment (Wressle and Samuelsson, 2004), walking aids, wheelchairs  
333 or power chairs can be stigmatized (Goffman, 1963), and symbolic of ‘giving up’ (Iezzoni, 1993).

334         Individuals who perceived walking aids as ‘energy-savers’ that allowed participation may have  
335 viewed physical dysfunction through an aging lens. Aging lenses cast physical dysfunction as a natural  
336 progression that every individual will at some point experience (Gullette, 2004). The ‘normalcy’ of  
337 physical dysfunction at an older age therefore casts a different meaning of walking aids. For some older  
338 people, a walking aid is perceived as ‘being confident and independent’ (Brannstrom, Backman, and  
339 Fischer, 2003). For example, the adoption of a wheelchair or power chair may be perceived as a positive  
340 adaptation and maintaining control for continued participation (Finlayson and Van Denend, 2003).  
341 Further, with age, the value of ‘objective’ measures of walking mobility (i.e. steps taken, distance  
342 covered) are superseded by the ability to ambulate in general (Dilorenzo, et al., 2008; Finlayson, and  
343 Van Denend, 2003). The change in valuing walking unaided is a phenomenon further discussed in  
344 sociological perspectives of illness whereby modifications in one’s embodied experiences modifies

345 one's values (Carel, 2016). Thus, perceptions of physical dysfunction and walking age were interpreted  
346 differently by participants.

347 Within wider literature this can be further conceptualized. The phenomenon of becoming  
348 'enwheeled' has been discussed and reflects well within our findings. Literature highlights a continuum  
349 of becoming with objects (Papadimitrous, 2008) and becoming against them (Montforte, 2019). That is,  
350 work has highlighted a positive re-embodiment of self-concept with the addition of aids such that  
351 wheelchair use was perceived as an accomplishment with positive social and political consequences  
352 (Papadimitrou, 2008). Alternatively, the struggle of 'becoming enwheeled' (Montforte, 2019) has also  
353 been presented whereby a struggle of self-concept ensues as one recognizes the need for a walking aid  
354 conflating with one 'becoming' the aid. As such, akin to becoming 'enwheeled', the complex  
355 relationship persons aging with MS had with walking aids pushes these concepts further by showing  
356 how the addition of any walking aid (e.g. cane, crutch, walker, wheelchair scooter), not just a  
357 wheelchair, reflected this becoming with or becoming against continuum.

358 Bladder dysfunction. A key negative impact of aging on MS symptoms described by participants  
359 was bladder dysfunction. In particular, the increased prevalence and severity of urinary tract infections  
360 (UTIs):

361 After that 1999 diagnosis I was able to function fairly normally. I continued to work, and until  
362 2002 when I found that MS was affecting me too much to continue...It's just a long, slow  
363 decline. We're just dealing with it as best we can...what impedes me most is the constant UTIs.  
364 With the recurring UTI's I have been in and out of the hospital and rehab facilities a few times  
365 .... These seem to be taking the biggest toll and there's nothing I seem to be able to do to fight  
366 them off; they hit hard and they hit fast. (Don, 77, M, progressive MS)

367 Participants described the belief that aging impacted the immune response such that UTIs  
368 became very dangerous:

369 Last year was a very bad year physically. I had at least 10 UTI's and every time I ended up in the  
370 hospital. I'm not sure, I still have the UTI's but I haven't been back to the hospital since  
371 beginning of February so I don't know what is different, why it's not affecting me like it did last  
372 year, but I'm thankful I'm not back in the hospital. I moved here (care home) in January this year.  
373 Three times with the UTI's I almost died... At first I was just blowing it off, but my girlfriends  
374 wanted me to ask my doctor if I could have died and he said 'oh definitely'. If you had not been  
375 found and it just continued yes, you would have.' That was scary... We actually thought that  
376 Ocrevus may have been the reason I was having so many UTI's because it compromises the  
377 immune system, so I stopped using that. You know, when I talked to him (doctor) about it he  
378 said that that hasn't shown up with any of the research or any of the trials or anything. It was  
379 never mentioned, but it could so I quit (Ocrevus). I do have less UTI's now. I do not have as  
380 many. Who knows? Maybe it did. On the other, hand your immune system does weaken as you  
381 get older so it might be that. May it's that. Either way, having a lower immune system and being  
382 on immunosuppressants definitely doesn't help with UTIs. (Moira, 60, F, progressive MS)

383

384 For participants, the reduced immune response that comes with aging was perceived to cause  
385 more severe and numerous UTIs and was a further negative aging effect on MS symptoms. Bladder  
386 dysfunction has been noted in previous literature as one of the 'worst symptoms' of aging with MS  
387 (Ploughman et al., 2014). It may be a specific aging experience in MS as there is a significantly higher  
388 percentage of older persons with MS who experience UTI and bladder infections than younger persons  
389 with MS (Minden et al., 2004). UTIs are particularly dangerous in MS as these can trigger relapses  
390 (Metz, McGuinness, and Harris, 1998) and among older persons with MS may result in hospitalizations  
391 (Sanai et al., 2016). As persons with MS and older persons in general are two 'at-risks' group with  
392 regards to UTI's, it could be argued there is a double impact or double likelihood that an older person  
393 with MS will experience a severe UTI. Moreover, the fear of potential UTIs may result in older persons  
394 with MS experiencing increased anxiety, isolation, and overall compromised quality of life (Phe et al.,  
395 2015), as well as actual UTIs being a significant predictor for death in MS (Jick et al., 2015). The impact  
396 of aging may therefore have a detrimental effect on older people with MS health and quality of life through  
397 the risks carried by UTIs.

398

399 *MS made my aging worse*

400 Some participants perceived MS symptoms made the aging process worse. Specifically,  
401 participants deemed (i) physical degeneration and (ii) cognitive issues were mainly affected.

402 Physical degeneration: Participants described the general ‘wear and tear’ expected from older  
403 age. The participants further stated, however, that the progression of arthritis, osteoarthritis and other  
404 degenerative conditions were exacerbated and hastened by the presence of MS:

405 I had problems with my walking all the time, and with my balance... All of that walking, that I  
406 did try to compensate for the problem, especially in the left leg, has changed my gait so that I  
407 have terrible arthritis in both knees... That's when my MS started to kick in. With this arthritis in  
408 my knees it was already bad but in 2010 MS really stepped up and it was like the breakdown of  
409 the joints sped up twice as fast...I attribute that to the MS as the arthritis was progressing fairly  
410 standardly for a 70-year-old until 2010. (Dolly, 85, F, progressive MS)

411  
412 The presence of MS was deemed to make managing the age-related degeneration more difficult,  
413 ultimate compromising desired participation and quality of life:

414 I've got arthritis in my neck. I've got arthritis in my hands. I've got arthritis in my right knee...I  
415 got a torn rotator cuff. So, what has this got to do with the MS? Well, I'll tell you. It makes it  
416 harder and harder for me to exercise, or to get up and get around. So, with this torn rotator cuff,  
417 if I were a mobile person, I would put this arm in a sling and immobilize this, and just do the  
418 exercises they give me, which I do, for healing this. But I would keep this immobile. Well, I  
419 can't do that. I need this arm to lever myself in and out of my chair, in and out of the bed, in and  
420 out of the bathroom. So, this arm is actually, it's abused. When it should be quiet and stable, I  
421 have to have it. That's an example of how MS impacts my general health now when it didn't  
422 before. (Lisa, 69, F, progressive MS)

423  
424 Individuals with MS cannot escape the natural biological process of aging. The compounding  
425 effect of aging plus MS can mean that persons with MS have worse physical functioning compared to  
426 the older general population (Riazi et al., 2003) and are more likely to have mobility issues (Paltamaa et

427 al., 2006). Thus, the natural experience of aging may be worsened by additional complications resultant  
428 from MS that can compromise participation and quality of life.

429 For some participants whose MS symptoms at a younger age were stable, they are experiencing  
430 detrimental effects of MS only now. As participant 8 stated, MS is stopping her from addressing injuries  
431 she has from aging, and this impacts her general health now when it was not immediately present before.  
432 Thus, for some persons with MS, the ‘double impact’ of MS and aging differed; some people perceived  
433 aging accentuated MS (the first theme), but in this case, aging was seen as a natural process, but MS  
434 made it worse. Through a lens of chronic illness and embodiment, this experience can be described as  
435 ‘dysappearance to hyperappearance’ (Frank, 1996). To expand, though diagnosed with MS, living with  
436 MS ‘dys-appeared’ for some participants as it was not an everyday focus and did not significantly  
437 impact day-to-day function. With the combination of aging, however MS is now in ‘hyper-appearance’  
438 and something that is every present and in focus. Through time, age can completely change the  
439 embodied experience of persons with MS throughout the life-course.

440 Cognitive issues: Some participants deemed the addition of MS increased cognitive dysfunction  
441 already impacted by age:

442 I think that cognitive testing had shown a clear MS impact on working memory, so that has  
443 impact in, I notice that sometimes driving and decision making and word choice, and there was  
444 just no hunting for words for some of those things. (Frank, 60, M, progressive MS)

445

446 A real concern was that the combined effects of MS and aging on cognitive dysfunction may

447 mean older persons with MS are more at risk of dementia or Alzheimer’s:

448 I think, probably, my ultimate fear, or anyone's ultimate fear, is losing your mind, or dementia,  
449 or not being able to communicate or know who is sitting across the table from you. That worries  
450 me. With MS affecting my sleep and already having cognitive issues, I’m terrified all that  
451 together is going to make me more likely to get dementia. (Johanna, 62, F, RRMS)

452

453 Participants feared that MS as well as aging could mean increased likelihood of severe cognitive  
454 issues. Age related cognitive issues include the gradual decline of conceptual reasoning, memory, and  
455 processing speed (Harada, Love, and Triebel, 2014). MS related cognitive issues include slowed  
456 processing speed, impaired memory and episodic memory, and executive function (Bobhdz and Rao,  
457 2003; Chiarvalloti and DeLuca, 2008; Rao, Lea, Bernardn, and Unverzagt, 1991). Work on cognition  
458 across the lifespan concluded that there were meaningful cognitive differences between older persons  
459 with MS and those without (Bollaert et al., 2016), and some work does hypothesize that the combined  
460 effects of MS related and age-related cognition increased the risk of developing age-related  
461 neurodegenerative dementia (Roy et al., 2018).

462 Delving deeper into this experience, we suggest that the fear of increased cognitive impairment  
463 is strongly linked with losing ‘the self’. An individual’s fear of forgetting loved ones, forgetting  
464 themselves, and becoming reliant on others for self-care is a fear deeply embedded in the aging  
465 experience (French, Floyd, Wilkins, and Osato, 2012). A person who is experiencing cognitive  
466 impairment from two different sources (in this case aging and MS), may therefore embody a fear from  
467 two different standpoints, thereby increasing anxiety and stress regarding future selves. The fear of MS  
468 worsening age-related cognitive disfunction is therefore a fear of losing a sense of self and autonomy  
469 that may be more prevalent among older persons with MS than the general population.

470

471 *Aging made my MS better*

472 Contrary to the above embodied experiences of MS and aging, some participants perceived that  
473 aging made symptoms of MS better. Specifically, participants described aging improved MS through (i)  
474 improved physical function and (ii) normalizing cognitive issues.



475 Improved physical function: Participants who perceived aging made MS better stated they could  
476 objectively see improvements in function and participation compared to younger age:

477 I had really severe MS at onset. I was quadriplegic with my first episode. I was in the hospital. I  
478 went to every hospital to talk to all the specialists and ask them what's the prognosis. They said,  
479 "Terrible. Five to 10 years you're going to be bed-bound," which they were totally  
480 wrong...Compared to 10 or 15 years ago, I'm 1000% better...Honestly, waking up in the morning  
481 and being able to get out of bed, because for years I couldn't do that. My back muscles were too  
482 weak. I had to crab it sideways and I'd just fall of the bed and then try and get up. To just jump  
483 out of bed in the morning now, right there, that's heavenly right there. (Jack, 67, M, progressive  
484 MS)

485

486 Moreover, some participants believed MS had 'burned-out', and had successfully discontinued  
487 all DMTs for MS without relapse:

488 I was on Copaxone for over 20 years and I just was talking to my neurologist the past couple of  
489 years about that. You start reading it, 'it appears MS might burn out and doesn't make sense to  
490 stay on the treatments' and that was really my experience. I switched to the new MS specialist  
491 who said she did think I could stop the Copaxone so I stopped it in the spring. This past spring,  
492 she did an MRI and I will follow up but it seems to be going okay and I've certainly not  
493 experienced any relapses or feel worse; the opposite in fact. It's glorious not to have to do those  
494 shots so I really think I have 'aged-out' of MS is that's a thing. (Christy, 63, F, RRMS)

495

496 The pathology of aging with MS is not well understood. In this paper, we have highlighted the  
497 phenomenon of the 'double-impact' of aging and MS, but the above testimonies describe a phenomena  
498 of MS symptoms improving with age. For some participants, they experienced severe and rapid onset of  
499 symptoms and disability at the beginning of their MS journey. Many participants were diagnosed in the  
500 1970s and 1980s when there was little understanding of MS, no DMTs available, and few rehabilitation  
501 or therapeutic options. This meant a poor future prognosis for many, and the real fear of dying at a very  
502 young age. The successful progression of age and MS may therefore feel empowering for persons with  
503 MS as they are experiencing not only a counter narrative to what they were told about MS, but a counter

504 narrative to aging (Phoenix and Smith, 2011) whereby they perceive they are improving and in better  
505 health rather than declining.

506 For persons diagnosed at a young age, there is tentative evidence that they may ‘age-out’ of MS,  
507 perhaps because the inflammatory process, or immune system, decreases with age (Solana et al., 2012).  
508 As such, some people have been able to discontinue DMTs without consequences (Hua et al., 2019).  
509 This is a phenomenon that is not yet fully investigated and much work is required to better understand  
510 the possibility of MS ‘burn-out’, however these positive testimonies highlight that there may be  
511 elements of aging with MS that benefits persons with MS, and not all will experience a double impact.

512 Normalizing cognitive issues: In the previous section we described the fear participants had  
513 regarding combined impacts of MS and aging on cognitive dysfunction. However, other participants  
514 described the addition of age made them query whether cognitive issues were MS or what is to be  
515 expected of aging:

516 And that other parts of MS. Cognitive. I have some issues with cognitive. And the hard part is  
517 I'm getting older. So when I say I can't remember a word, people go, "Oh, I can't either.  
518 Everyone does when we get older." So is it my brain or is it my memory? I don't know. Getting  
519 older, again, starts crossing that line of, well that's just you, that's just getting older, or that's  
520 MS. And I'm in a quandary right now at this age as to what is and isn't my age, or isn't MS.  
521 (Ruth, 65, F, RRMS)

522  
523 Consequently, some individuals who had experienced cognitive deficits at a younger age,  
524 reported that aging changed the meaning of cognitive deficits into an experience to share and ‘laugh’ at  
525 with peers:

526 I have these brain fogs...They've gotten to where now, and it's funny...All my church friends are  
527 the same way. They just laugh and say, "Heh, I do it all the time too." I say, "No, I really do." I  
528 forget where I'm at in the middle of a sentence, you know? We all just have a big time. We laugh  
529 about a lot of things that I used to worry about. I didn't want to talk to people, because I would  
530 lose track of where I was at. (Sarah, 60, F, RRMS)

531

532           The compounding effects of MS and age-related cognitive impairment is not well-understood.  
533 Research proposes different hypothesis regarding the potential dual impact of these issues and the risk of  
534 dementia. Some posit the double source of cognitive impairment means older persons with MS are more  
535 at risk (discussed in the previous theme), but others posit this to be false. Indeed, work comparing motor  
536 and cognitive decline of persons with MS and persons without found motor decline was amplified by  
537 age, but cognitive impairments did not vary across the lifespan (Roy et al., 2017), and there is no more  
538 risk to persons with MS developing dementia than the general population (Branco et al., 2019).

539           It could be argued that among older people, cognitive decline is an ‘essence of aging’; it is  
540 expected. With the addition of an aging lens to interpret cognitive impairment, this experience becomes  
541 a ‘normal’ experience they can share with peers. This shared experience can enhance coping with these  
542 changes. Having a shared experience with relational others is a powerful tool for coping with potentially  
543 negative experiences (Richardson, Smith and Papatomas, 2017). Sharing and bonding over a difficult  
544 experience can promote feelings of understanding, acceptance and support (Caddick, Phoenix, and  
545 Smith, 2015) and bring people together from isolated selves into a shared consciousness. As cognitive  
546 issues are a shared experience among persons who are aging, older persons with MS may experience a  
547 new supportive network with peers that did not exist at a younger age.

548

549 *MS makes my aging better*

550           Finally, some participants perceived that experiencing a degenerative disease from a young age  
551 prepared them for the phenomena of aging. Such participants were better equipped to deal with this life  
552 transition:

553 I'd say one of the things about when you get old, and a lot of friends get very upset when all  
554 these little things happen, but I've been having all kinds of little things happen for years and right  
555 now I feel in my prime. MS when I was young was so, so much worse. Old age really isn't very  
556 different from just having MS. It's just, it's true. I notice it with my husband. These little things  
557 happen, "Oh dear." But we're so used to having little things happen that it's just not a big deal. I  
558 have a new neurologic thing that is happening with my eyes, which is very interesting, visually.  
559 And I assume it'll probably go away. It's not something, when I described it to a friend, she said,  
560 "Oh my god, how can you cope? Oh, this is terrible." And I'm just thinking, "Oh, well I was  
561 much worse when I was younger. Just another thing. It's just another thing." I've really never felt  
562 better, so there are certain positive aspects to MS as you age. (Joy, 79, F, RRMS)

563

564 Participants discussed the perception that peers had 'caught up' with them disability wise, and

565 therefore the participants were aging more successfully than peers:

566 Well, it's interesting because certainly I feel like in some ways I am now dealing with MS in the  
567 same way I deal with aging. Things are more challenging definitely. I sort of joke that I've been  
568 waiting my whole life for the other Baby Boomers to catch up with me. It's happening. It's  
569 interesting to see people that have enjoyed good health, how indigent they are when anything  
570 goes wrong. (Christy, 63, F, RRMS)

571

572 This study corroborates other qualitative works that have highlighted MS may prepare persons  
573 for older age as they experience a process that mirrors aging at a young age (Dilorenzo et al., 2008). The  
574 resilience that had to be built appears to translate to better adjustment and coping with new symptoms,  
575 be this the result of aging or MS (Finlayson, 2002; Finlayson, Van Denend, and DalMonte, 2005;  
576 Silverman, 2017). It may be that although persons with MS can experience more disability than persons  
577 their own age, they experience higher levels of acceptance, satisfaction and happiness than counterparts  
578 without MS.

579 Aging literature focuses on the underlying social, cultural, and individual processes that shape  
580 experiences of aging (Moody, 2008). For participants in this study, aging experiences were strongly  
581 intersected by past and present experiences of MS. For example, participants perceived they experienced

582 aging before their time. Now they are at an ‘acceptable’ age for these experiences, they perceive they are  
583 normal. Persons over 60 with MS may live a different biography to societal expectations of decline as  
584 they experience aging phenomena at a much younger age. When peers reach this same age, persons with  
585 MS become ‘normal’ through a lens of Western aging culture whereby physical and cognitive deficits  
586 are expected (Gullette, 2004). Experiences of ‘abnormal’ aging at a young age may however allow older  
587 persons with MS to age more successfully and could have a perceived higher quality of life than older  
588 persons without MS. As such, it may be that persons with MS reach a perceived peak life with older age  
589 relative to peers, highlighting real positivity for the future.

590

591

### **Concluding Remarks**

592 This contemporary work on aging and MS provides a foundation of new understanding of what it  
593 is like to age with MS and the various ways these phenomena were experienced. Utilizing an existential  
594 phenomenological tradition, and further analyzed through lenses of chronic illness and aging, this work  
595 provided multiple layers of interpretations regarding how older persons with MS may experience and  
596 interpret the intersection between aging and MS differently.

597 This research sought to answer 3 questions about aging and MS: 1) What is it like to experience  
598 aging with MS?; 2) How do persons over 60 with MS interpret aging?; 3) What does future research  
599 need to target to improve quality of life among older persons with MS? The results and discussion  
600 section addressed the first two questions. To summarize, we presented 4 ways that participants with MS  
601 interpreted aging with MS; aging makes me MS worse, MS makes aging worse; aging makes MS better;  
602 and MS makes aging better. We conceptualize this in Figure 1.

603

*[Figure 1 about here]*

604           Persons aging with MS therefore can experience these two embodied experiences in different  
605 ways; for some there is a decline and negative interaction between the two, while others perceive a peak  
606 of life and positive interactions. Depending on a person's biography, MS symptom experiences,  
607 perception of aging and MS expectations, and trajectory of MS, participants interpreted aging and MS  
608 differently. The intersection of aging and MS is therefore a complex and nuanced experience that means  
609 different things to different people, and can follow different trajectories.

610           A phenomenology of aging with MS compliments previous phenomenological works of the lived  
611 experiences of MS (Finlay, 2005; Strickland, Worth and Kennedy, 2015, 2016; Toombs, 1995). In  
612 particular, past works have described the renegotiation and reconstruction of the self upon diagnosis  
613 (Toombs, 1995) and the liminal self with MS as one transitions to reincorporating MS as part of the self  
614 (Strickland, Worth and Kennedy, 2017). Our findings regarding aging further this work by showing that,  
615 with age, there may be a threshold whereby another stage of transition occurs. That is, a reconstructing  
616 of the self through an aging lens such that (i) MS may no longer be part of self-concept (e.g. if persons  
617 perceive aging made MS better and they have 'aged out'), (ii) MS is merely part of self-concept but not  
618 the definite construct (e.g. if persons experience other age related deficits that are more problematic than  
619 MS), or (iii) age adds another element to one's biography such that one must renegotiate the self not  
620 only within a chronically ill body, but now an aging body. This is an important finding to consider  
621 regarding social and relational recommendations for supporting successful aging with MS. Taking the  
622 liminal self as a framework, there is a threshold by which persons newly diagnosed with MS seek  
623 information and support (Strickland, Worth and Kennedy, 2017). We posit there is another threshold  
624 among persons aging with MS whereby information and support for aging with MS is sought. Currently,  
625 however, this is lacking with persons aging with MS under-served and under supported by the research,  
626 health care providers, and other support networks. An important recommendation for the wider MS field

627 is to create a focused research effort investigating aging with MS, and to craft ways to share this  
628 information with those that require it. Further, specific support is required for this group, as we highlight  
629 various ways in which aging with MS can impact wellness that require social and relation support. This  
630 is as yet missing.

631 This work also highlights ways interventions around aging with MS can be crafted. Wellness and  
632 lifestyles interventions can be created around affirming narratives of aging with MS to amplify the  
633 possibility of experiencing wellness in older age. For example, amplifying that ‘MS makes aging better’  
634 if an individual engages in lifestyle strategies to enhance health and wellness, building up physical and  
635 cognitive reserves, and developing lifelong habits may help encourage people with MS to engage and  
636 maintain these activities from a younger age. Another intervention could focus on the narrative that  
637 ‘aging may help MS’ by providing testimonies or role models exhibiting this, thereby acting as a  
638 narrative map and aspirational self by amplifying positive narratives of aging. That being said, balance  
639 must be found regarding the possibility of a more negative aging experience. Interventions should also  
640 focus on coping strategies to support persons aging with MS that are experiencing a progressive  
641 deterioration to experience as high a quality of life as possible. Social and relational support networks  
642 are also required to ensure equitable opportunities for wellness among persons who experience a  
643 deterioration in function with age. These are but a few ways in which this empirical data can be used as  
644 a road map for future interventions.

645 The third question, was to determine what is required of future research with regards to aging  
646 with MS. While the current research is a good start, much more exploration must be done to better  
647 understand the experiences of aging with MS. First, further work is needed to explore why older persons  
648 with MS interpret aging in these various ways. Doing so can help identify potential influences that shape  
649 why people interpret aging differently, which can thereby enhance practice of ongoing management of

650 MS among older persons by specifying and individualizing plans according to past experiences and  
651 current perceptions.

652 Another recommendation for future research is to further explore the idea of ‘peaking’ regarding  
653 quality of life among older persons with MS. A key finding from this story was some participants  
654 perceiving they were experiencing their best life and were aging more successfully than peers without  
655 MS. Considering the call to explore successful aging, not only within MS but the population in general  
656 (Molton and Yorkston, 2017), future work should explore more deeply what is meant by successful  
657 aging, what wellness and quality of life mean to older persons with MS, what strategies they utilize to  
658 maintain successful aging, why they perceive they are aging more successfully. Such research can be  
659 used to better inform future wellness interventions that can improve quality of life among this group.

660 There has been some cross-sectional research conducted comparing physical and cognitive  
661 function between older persons with MS and healthy controls (Roy et al., 2017; Baird et al., 2019). This  
662 qualitative study further discussed comparisons participants made between themselves and peers. We  
663 touched upon this comparison, however, it would be beneficial to go deeper into these comparisons to  
664 establish what aspects of life are being compared, how persons with MS perceive they compare to peers  
665 in different ways, and why they come to different conclusions regarding these comparisons. This work  
666 would further contextualize aging with MS within the wider aging literature.

667 Also, we acknowledge that a limitation of our methodological choice of employing phenomenology  
668 in the analysis of qualitative data meant that we were reliant only on semi-structured interviews. Using  
669 only semi-structured interviews can be problematic as this method can ‘impose’ pre-supposed meanings  
670 on participants and, despite researchers best efforts to bracket presumptions, filter through to the  
671 questions asked (Allen-Collinson, 2016). Future research utilizing the phenomenological tradition to



672 explore aging and MS should combine interviews with participant observations in order for richer, more  
673 authentic descriptions to be constructed (Ravn, 2016).

674 To conclude, this is the first contemporary work on aging and MS that utilized an existential  
675 phenomenology framework to explore the intersection of aging and MS. We present 4 ways that persons  
676 over 60 with MS experienced and interpreted this experience, and recommendations for future research  
677 to move this area of study forward. By utilizing analytical lenses that highlight the two key embodied  
678 experiences of aging and MS, this allowed us to craft findings that appreciated both experiences as  
679 separate entities as well as assess the impact of both experiences together. We posit that the rigor of this  
680 work allows us to claim that these 4 different ways of aging with MS are generalizable in terms of  
681 naturalistic generalizability, transferability, and generativity (Smith, 2018). That is, people aging with  
682 MS may find their own experiences resonates with what we state such that lived realities are validated  
683 (naturalistic generalizability), people aging with or without other chronic illnesses may also find ‘their  
684 truth’ within the experiences depicted within aging with MS (transferability), and thereby be moved to  
685 act upon what they have read (generativity). Thus, we make contributions to the literature in aging and  
686 MS, and the wider literature of chronic illness and phenomenology of illness. This foundational work  
687 highlights the complexity and nuance of the experience of MS, and provides a fresh perspective  
688 regarding the current ‘greying’ of the MS population.

689

690

691

694

**Declaration of Conflicting Interests**

695

The authors declare no conflicts of interest.

696

696

**References**

- 697 Adams-Price, C. E., Henley, T. B., & Hale, M. (1998). Phenomenology and the meaning of aging for  
698 young and old adults. *The International Journal of Aging and Human Development*, 47(4),  
699 263-277.
- 700 Allen-Collinson, J. (2009). Sporting embodiment: Sports studies and the (continueing) promise of  
701 phenomenology. *Qualitative Research in Sport, Exercise, and Health*, 1(3), 279-296.
- 702 Allen. Collinson, J. (2011). Intention and epochē in tension: autophenomenography, bracketing and a  
703 novel approach to researching sporting embodiment. *Qualitative Research in Sport, Exercise  
704 and Health*, 3(1), 48-62.
- 705 Allen-Collinson, J. (2016) Phenomenology. In B. Smith, & A. C. Sparkes (Eds.), *Routledge Handbook  
706 of Qualitative Research in Sport and Exercise* (pp. 11-23). London: Routledge.
- 707 Baird, J. F., Cederberg, K. L., Sikes, E. M., Silveira, S. L., Jeng, B., Sasaki, J. E., ... & Motl, R. W.  
708 (2019). Physical activity and walking performance across the lifespan among adults with  
709 multiple sclerosis. *Multiple sclerosis and related disorders*, 35, 36-41.
- 710 Binks, S., & Dobson, R. (2015). Established, new and future disease modifying therapies for  
711 MS. *Progress in Neurology and Psychiatry*, 19(5), 27-35.
- 712 Bishop, M., Dennis, K. L., Bishop, L. A., Sheppard-Jones, K., Bishop, F., & Frain, M. (2015). The  
713 prevalence and nature of modified housing and assistive devices use among Americans with  
714 multiple sclerosis. *Journal of Vocational Rehabilitation*, 42(2), 153-165.
- 715 Bobholz, J. A., & Rao, S. M. (2003). Cognitive dysfunction in multiple sclerosis: a review of recent  
716 developments. *Current opinion in neurology*, 16(3), 283-288.

- 717 Bollaert, R. E., Balto, J. M., Sandroff, B. M., Chaparro, G., Hernandez, M. E., & Motl, R. W. (2017).  
 718 Preliminary evidence for the effects of aging and multiple sclerosis on cognitive performance:  
 719 an analysis based on effect size estimates. *Experimental Aging Research*, 43(4), 346-354.
- 720 Branco, M., Ruano, L., Portaccio, E., Goretti, B., Niccolai, C., Patti, F., ... & Roscio, M. (2019). Aging  
 721 with multiple sclerosis: prevalence and profile of cognitive impairment. *Neurological Sciences*,  
 722 40(8), 1651-1657.
- 723 Brännström, H., Bäckman, M., & Santamäki Fischer, R. (2013). Walking on the edge: meanings of  
 724 living in an ageing body and using a walker in everyday life—a phenomenological hermeneutic  
 725 study. *International Journal of Older People Nursing*, 8(2), 116-122.
- 726 Burke, S. (2016). Rethinking ‘validity’ and ‘trustworthiness’ in qualitative inquiry: How might we judge  
 727 the quality of qualitative research in sport and exercise sciences. In B. Smith, & A. C. Sparkes  
 728 (Eds.), *Routledge Handbook of Qualitative Research in Sport and Exercise* (pp. 330-339).  
 729 London: Routledge.
- 730 Caddick, N., Phoenix, C., & Smith, B. (2015). Collective stories and well-being: Using a  
 731 dialogical narrative approach to understand peer relationships among combat veterans  
 732 experiencing post-traumatic stress disorder. *Journal of Health Psychology*, 20(3), 286-299.
- 733 Carel, H. (2016). *Phenomenology of illness*. Oxford, UK: Oxford University Press.
- 734 Chiaravalloti, N. D., & DeLuca, J. (2008). Cognitive impairment in multiple sclerosis. *The Lancet*  
 735 *Neurology*, 7(12), 1139-1151.
- 736 Dilorenzo, T. A., Becker-Feigeles, J., Halper, J., & Picone, M. A. (2008). A qualitative investigation of

- 737 adaptation in older individuals with multiple sclerosis. *Disability and Rehabilitation*, 30(15),  
 738 1088-1097.
- 739 Domingues, R. D. C., & Freitas, J. D. L. (2019). The phenomenology of the body in aging: dialogues  
 740 between Beauvoir and Merleau-Ponty. *Revista Subjetividades*, 19(3), 1-13.
- 741 Embree, L. & Mohanty, J. N. (1997). Introduction. In L. Embree et al. (Eds), *Encyclopedia of*  
 742 *phenomenology* (pp. 1-10). Dordrecht: Kluwer Academic.
- 743 Finlay, L. (2003). The intertwining of body, self and world: a phenomenological study of living with  
 744 recently-diagnosed multiple sclerosis. *Journal of Phenomenological Psychology* 34, 157–178.
- 745 Finlayson, M. (2002). Health and social profile of older adults with MS: findings from three  
 746 studies. *International Journal of MS Care*, 4(3), 139-151.
- 747 Finlayson, M. (2004). Concerns about the future among older adults with multiple sclerosis. *The*  
 748 *American Journal of Occupational Therapy*, 58(1), 54-63.
- 749 Finlayson, M. L., Peterson, E. W., & Cho, C. C. (2006). Risk factors for falling among people aged 45  
 750 to 90 years with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 87(9),  
 751 1274-1279.
- 752 Finlayson, M., & Van Denend, T. (2003). Experiencing the loss of mobility: perspectives of older adults  
 753 with MS. *Disability and Rehabilitation*, 25(20), 1168-1180.
- 754 Finlayson, M., Van Denend, T., & DalMonte, J. (2005). Older adults' perspectives on the positive and  
 755 negative aspects of living with multiple sclerosis. *British Journal of Occupational*  
 756 *Therapy*, 68(3), 117-124.
- 757 Finlayson, M., Van Denend, T., & Hudson, E. (2004). Aging with multiple sclerosis. *Journal of*

- 758 Neuroscience Nursing, 36(5), 245.
- 759 Frank, A. W. (1996). From disappearance to hyperappearance: Sliding boundaries of illness and  
760 bodies. *Theory & Psychology*, 6(4), 733-760.
- 761 French, S. L., Floyd, M., Wilkins, S., & Osato, S. (2012). The fear of Alzheimer's disease scale: A new  
762 measure designed to assess anticipatory dementia in older adults. *International journal of*  
763 *geriatric psychiatry*, 27(5), 521-528.
- 764 Gergen, K. J. (2014). Pursuing excellence in qualitative inquiry. *Qualitative Psychology*, 1(1), 49.
- 765 Goffman, E. (1963). Stigma and social identity. *Understanding Deviance: Connecting Classical and*  
766 *Contemporary Perspectives*, 256-265.
- 767 Grant., B. (2012). An insider's view on physical activity in later life. *Psychology of Sport and Exercise*,  
768 9, 817-829.
- 769 Gullette, M. M. (2004). *Aged by culture*. Illinois: University of Chicago Press.
- 770 Harada, C. N., Love, M. C. N., & Triebel, K. L. (2013). Normal cognitive aging. *Clinics in geriatric*  
771 *medicine*, 29(4), 737-752.
- 772 Healthline. (2020). New medication and treatment options for secondary progressive MS. Retrieved  
773 from <https://www.healthline.com/health/secondary-progressive-ms/new-treatments> on 20th  
774 August 2020.
- 775 Hua, L. H., Fan, T. H., Conway, D., Thompson, N., & Kinzy, T. G. (2019). Discontinuation of disease-  
776 modifying therapy in patients with multiple sclerosis over age 60. *Multiple Sclerosis*  
777 *Journal*, 25(5), 699-708.

- 778 Iezzoni, L. (2003). *When walking fails: Mobility problems of adults with chronic conditions* (Vol. 8).  
 779 California: Univ of California Press.
- 780 Jick, S. S., Li, L., Falcone, G. J., Vassilev, Z. P., & Wallander, M. A. (2015). Epidemiology of multiple  
 781 sclerosis: results from a large observational study in the UK. *Journal of Neurology*, 262(9),  
 782 2033-2041.
- 783 Latimer-Cheung, A. E., Ginis, K. A. M., Hicks, A. L., Motl, R. W., Pilutti, L. A., Duggan, M., ... &  
 784 Smith, K. M. (2013). Development of evidence-informed physical activity guidelines for adults  
 785 with multiple sclerosis. *Archives of physical medicine and rehabilitation*, 94(9), 1829-1836.
- 786 Learmonth, Y. C., Adamson, B. C., Kinnett-Hopkins, D., Bohri, M., & Motl, R. W. (2017). Results of a  
 787 feasibility randomised controlled study of the guidelines for exercise in multiple sclerosis  
 788 project. *Contemporary clinical trials*, 54, 84-97.
- 789 Marrie, R. A., Elliott, L., Marriott, J., Cossoy, M., Blanchard, J., Leung, S., & Yu, N. (2015). Effect of  
 790 comorbidity on mortality in multiple sclerosis. *Neurology*, 85(3), 240-247.
- 791 Merleau-Ponty, M. (1969). *The structure of behavior* (trans A. L. Fisher). Boston, MA: Beacon Press.
- 792 Merleau-Ponty, M. (2001). *Phenomenology of perception* (trans C. Smith). London: Routledge & Kegan  
 793 Paul.
- 794 Metz, L. M., McGuinness, S. D., & Harris, C. (1998). Urinary tract infections may trigger relapse in  
 795 multiple sclerosis. *Journal of Urology*, 19(4), 67-70.
- 796 Minden, S. L., Frankel, D., Hadden, L. S., Srinath, K. P., & Perloff, J. N. (2004). Disability in elderly  
 797 people with multiple sclerosis: an analysis of baseline data from the Sonya Slifka Longitudinal  
 798 Multiple Sclerosis Study. *NeuroRehabilitation*, 19(1), 55-67.

- 799 Molton, I. R., & Yorkston, K. M. (2017). Growing older with a physical disability: A special application  
 800 of the successful aging paradigm. *The Journals of Gerontology: Series B*, 72(2), 290-299.
- 801 Monforte, J., Smith, B., & Pérez-Samaniego, V. (2019). ‘It’s not a part of me, but it is what it is’: the  
 802 struggle of becoming en-wheeled after spinal cord injury. *Disability and Rehabilitation*, 1-7.
- 803 Moody, H. R. (2008). The maturing of critical gerontology. *Journal of Aging Studies*, 2(22), 205-209.
- 804 Motl, R. W. (2010). Physical activity and irreversible disability in multiple sclerosis. *Exercise Sport*  
 805 *Science Review*, 38(4), 186–191
- 806 Motl, R. W., Backus, D., Neal, W. N., Cutter, G., Palmer, L., McBurney, R., ... & McCully, K. K.  
 807 (2019). Rationale and design of the STEP for MS Trial: comparative effectiveness of  
 808 Supervised versus Telerehabilitation Exercise Programs for Multiple Sclerosis. *Contemporary*  
 809 *clinical trials*, 81, 110-122.
- 810 Motl, R. W., Chaparro, G., Hernandez, M. E., Balto, J. M., & Sandroff, B. M. (2018). Physical function  
 811 in older adults with multiple sclerosis: an application of the short physical performance battery.  
 812 *Journal of Geriatric Physical Therapy*, 41(3), 155-160.
- 813 Motl, R. W., Mowry, E. M., Ehde, D. M., LaRocca, N. G., Smith, K. E., Costello, K., ... & McCully, K.  
 814 K. (2018). Wellness and multiple sclerosis: The National MS Society establishes a Wellness  
 815 Research Working Group and research priorities. *Multiple Sclerosis Journal*, 24(3), 262-267.
- 816 National Multiple Sclerosis Society. (NMSS). Types of MS. Retrieved from  
 817 <https://www.nationalmssociety.org/What-is-MS/Types-of-MS/Secondary-progressive-MS> on  
 818 20th August 2020.
- 819 Paltamaa, J., Sarasoja, T., Wikström, J., & Mälkiä, E. (2006). Physical functioning in multiple sclerosis:



- 820 a population-based study in central Finland. *Journal of Rehabilitation Medicine*, 38(6),  
821 339345.
- 822 Papadimitriou, C. (2008). Becoming en. wheeled: the situated accomplishment of re. embodiment as a  
823 wheelchair user after spinal cord injury. *Disability & society*, 23(7), 691-704.
- 824 Phé, V., Pakzad, M., Curtis, C., Porter, B., Haslam, C., Chataway, J., & Panicker, J. N. (2016). Urinary  
825 tract infections in multiple sclerosis. *Multiple Sclerosis Journal*, 22(7), 855-861.
- 826 Phoenix, C., & Smith, B. (2011). Telling a (good?) counterstory of aging: Natural bodybuilding meets  
827 the narrative of decline. *Journals of Gerontology Series B: Psychological Sciences and Social  
828 Sciences*, 66(5), 628-639.
- 829 Ploughman, M., Beaulieu, S., Harris, C., Hogan, S., Manning, O. J., Alderdice, P. W., ... & Metz, L. M.  
830 (2014). The Canadian survey of health, lifestyle and ageing with multiple sclerosis:  
831 methodology and initial results. *BMJ Open*, 4(7), e005718.
- 832 Rao, S. M., Leo, G. J., Bernardin, L., & Unverzagt, F. (1991). Cognitive dysfunction in multiple  
833 sclerosis.: I. Frequency, patterns, and prediction. *Neurology*, 41(5), 685-691.
- 834 Ravn, S. (2016). Phenomenological analysis in sport and exercise. In B. Smith and A. Sparkes (Eds.),  
835 *Routledge Handbook of Qualitative Research in Sport and Exercise* (pp. 206-218). London:  
836 Routledge.
- 837 Reynolds, F., & Prior, S. (2003). "Sticking jewels in your life": Exploring women's strategies for  
838 negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health  
839 Research*, 13(9), 1225-1251.

- 840 Riazi, A., Hobart, J. C., Lamping, D. L., Fitzpatrick, R., Freeman, J. A., Jenkinson, C. A. A., ... &  
841 Thompson, A. J. (2003). Using the SF-36 measure to compare the health impact of multiple  
842 sclerosis and Parkinson's disease with normal population health profiles. *Journal of Neurology,*  
843 *Neurosurgery & Psychiatry, 74(6), 710-714.*
- 844 Richardson, E. V., Smith, B., & Papatomas, A. (2017). Collective Stories of Exercise: Making Sense of  
845 Gym Experiences With Disabled Peers. *Adapted Physical Activity Quarterly, 34(3), 276-294.*
- 846 Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical  
847 guide. *Qualitative Research in Psychology, 11(1), 25-41.*
- 848 Roy, S., Drake, A., Snyder, S., Cline, B., Khan, A., Fuchs, T., ... & Benedict, R. H. (2018). Preliminary  
849 investigation of cognitive function in aged multiple sclerosis patients: challenges in detecting  
850 comorbid Alzheimer's disease. *Multiple Sclerosis and Related Disorders, 22, 52-56.*
- 851 Roy, S., Frndak, S., Drake, A. S., Irwin, L., Zivadinov, R., Weinstock-Guttman, B., & Benedict, R. H.  
852 (2017). Differential effects of aging on motor and cognitive functioning in multiple  
853 sclerosis. *Multiple Sclerosis Journal, 23(10), 1385-1393.*
- 854 Ruano, L., Portaccio, E., Goretti, B., Niccolai, C., Severo, M., Patti, F., ... & Roscio, M. (2017). Age and  
855 disability drive cognitive impairment in multiple sclerosis across disease subtypes. *Multiple*  
856 *Sclerosis Journal, 23(9), 1258-1267.*
- 857 Sanai, S. A., Saini, V., Benedict, R. H., Zivadinov, R., Teter, B. E., Ramanathan, M., & Weinstock-  
858 Guttman, B. (2016). Aging and multiple sclerosis. *Multiple Sclerosis Journal, 22(6), 717-725.*
- 859 Silveira, S. L., Richardson, E. V., & Motl, R. W. (2019). Informing the design of exercise programs for

- 860 persons with multiple sclerosis who use wheelchairs: a qualitative inquiry of perceived  
 861 components. *Disability and Rehabilitation*, 1-11.
- 862 Silverman, A. M., Verrall, A. M., Alschuler, K. N., Smith, A. E., & Ehde, D. M. (2017). Bouncing back  
 863 again, and again: a qualitative study of resilience in people with multiple sclerosis. *Disability  
 864 and Rehabilitation*, 39(1), 14-22.
- 865 Smith, B. (2018). Generalizability in qualitative research: Misunderstandings, opportunities and  
 866 recommendations for the sport and exercise sciences. *Qualitative research in sport, exercise  
 867 and health*, 10(1), 137-149.
- 868 Smith, B. M., & Sparkes, A. C. (Eds.). (2016). *Routledge handbook of qualitative research in sport and  
 869 exercise*. London: Routledge.
- 870 Smith, B., & Caddick, N. (2012). Qualitative methods in sport: A concise overview for guiding social  
 871 scientific sport research. *Asia Pacific journal of sport and social science*, 1(1), 60-73.
- 872 Solana R, Tarazona R, Gayoso I, et al. Innate immunosenescence: Effect of aging on cells and receptors  
 873 of the innate immune system in humans. *Semin Immunol* 2012; 24: 331–341.
- 874 Solaro, C., Ponzio, M., Moran, E., Tanganelli, P., Pizio, R., Ribizzi, G., ... & Battaglia, M. A. (2015).  
 875 The changing face of multiple sclerosis: Prevalence and incidence in an aging  
 876 population. *Multiple Sclerosis Journal*, 21(10), 1244-1250.
- 877 Sparkes, A. C., & Smith, B. (2013). *Qualitative research methods in sport, exercise and health: From  
 878 process to product*. Routledge.
- 879 Starr, J. M. (1983). Toward a social phenomenology of aging: Studying the self process in biographical  
 880 work. *The International Journal of Aging and Human Development*, 16(4), 255-270.

- 881 Strickland K, Worth, A., & Kennedy, C. (2015). The experiences of support persons of people newly  
 882 diagnosed with Multiple Sclerosis: an interpretative phenomenological study. *Journal of*  
 883 *Advanced Nursing* 71, 2811–2821.
- 884 Strickland, K., Worth, A., & Kennedy, C. (2017). The liminal self in people with multiple sclerosis: an  
 885 interpretative phenomenological exploration of being diagnosed. *Journal of clinical nursing*,  
 886 26(11-12), 1714-1724.
- 887 Synnot, A., Hill, S., Summers, M., & Taylor, M. (2014). Comparing face-to-face and online qualitative  
 888 research with people with multiple sclerosis. *Qualitative Health Research*, 24(3), 431-438.
- 889 Toombs, S. K. (1995). The lived experience of disability. *Human studies*, 18(1), 9-23.
- 890 Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative  
 891 research. *Qualitative inquiry*, 16(10), 837-851.
- 892 Trojano, M., Liguori, M., Bosco Zimatore, G., Bugarini, R., Avolio, C., Paolicelli, D., ... & Livrea, P.  
 893 (2002). Age-related disability in multiple sclerosis. *Annals of Neurology: Official Journal of*  
 894 *the American Neurological Association and the Child Neurology Society*, 51(4), 475-480.
- 895 Wallin, M. T., Culpepper, W. J., Campbell, J. D., Nelson, L. M., Langer-Gould, A., Marrie, R. A., ... &  
 896 Buka, S. L. (2019). The prevalence of MS in the United States: a population-based estimate  
 897 using health claims data. *Neurology*, 92(10), e1029-e1040.
- 898 Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. Psychology  
 899 Press.
- 900 Wressle, E., & Samuelsson, K. (2004). User satisfaction with mobility assistive devices. *Scandinavian*  
 901 *Journal of Occupational Therapy*, 11(3), 143-150.

902 Žiaková, K., Čáp, J., Miertová, M., Gurková, E., & Kurucová, R. (2020). An interpretative  
903 phenomenological analysis of dignity in people with multiple sclerosis. *Nursing Ethics*, 27(3),  
904 686-700.

905

906

907

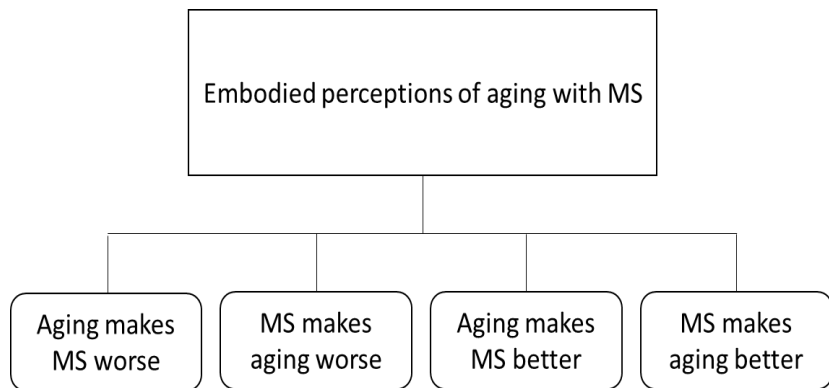
908

909

|

1. **Figures**

Figure 1: Perceptions of Aging with MS



911

914

915