• Aging with MS means different things to people.
• Increased age makes some people’s MS symptoms worse.
• MS symptoms make 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.
The Experience and Meaning of Aging with Multiple Sclerosis: An Existential Phenomenological Approach

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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
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Introduction

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 advances have, in part, shifted the life expectancy of persons with MS with a median increase of 7 years (Marrie et al., 2015). As such, there is now a ‘greying’ phenomenon within the global MS population characterized by a demographic shift in the median age of adults with MS (Wallin et al., 2019). This ‘greying’ of the MS population represents an emerging problem of aging while living with a chronic, disabling condition (Sanai et al., 2016). MS is caused when an immune mediated response attacks white and grey matter tissue in the central nervous system. The resulting damage in the brain, spinal cord, and optic nerves result in scars that cause numerous symptoms including, but not limited to, fatigue, pain, walking dysfunction, bladder and bowel dysfunction, cognitive impairment, functional deficits, depression and anxiety (Motl, 2010). The phenomenon of living with MS, of course, goes far beyond these symptoms. The chronicity of MS means that living with this illness is an ongoing process of negotiating one’s self-concept and self-identity as deterioration of mobility, function, cognition, sight and independence follows an uncertain course; negotiation of the self, relationships, roles, life purpose and meaning are continually assessed and amended (Reynolds and Prior, 2003). Though these symptoms are common across persons living with MS, there are two distinct disease courses. Relapsing remitting MS (RRMS) is the most common and is characterised by clearly defined relapses of new or increased symptoms followed by periods of partial or full remission. Progressive MS is less common and is characterised by a steady decline of worsening symptoms. RRMS often transitions into a progressive course of MS over time, with current rates of transition being 50% within 10 years and 90% of people
with RRMS transitioning to progressive MS within 25 years (NMSS, 2020). Aging thus plays a considerable role in the MS experience.

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

The above research paints a stark picture of aging with MS, yet some researchers have reported positive features of this phenomena. There is tentative evidence that the inflammatory phase of MS can ‘burn out’ with increasing age such that people with MS experience a stability or plateau of MS symptoms (Hua et al., 2019). Qualitative explorations have also highlighted that early experiences of MS may better prepare persons for the ‘normal’ aging process compared with peers who do not have MS (Dilorenzo, Becker-Feigles, Halper, and Picone, 2008). Research further has suggested that older persons with MS may have enhanced resilience, and may better adjust to meet the physical and psychosocial changes associated with aging (Finlayson, 2002; Finlayson, Van Denend, and DalMonte, 2005). Collectively, this past research presents aging with MS as a complex and nuanced experience that does not follow a set phenotype.
Importantly, the majority of research on aging with MS, particularly qualitative studies exploring lived experiences (Dilorenzo, Becker-Feigles, Halper, and Picone, 2008; Finlayson, 2002; Finlayson, Van Denend, and DalMonte, 2005), was conducted over 10 years ago and does not necessarily reflect the current pharmacological or therapeutic landscape now afforded to older adults with MS. For example, over the last 10 years the number of approved MS disease modifying therapies (DMTs) for RRMS has increased from 7 in 2010 (Binks and Dobson, 2015) to 20 in 2020 (NMSS, 2020). Moreover, the first approved DMT for treating progressive MS was released in 2019, and this has now increased to 3 (Healthline, 2020) highlighting the advances that have been made over the last decade. Therapeutically, advancement has been made through the creation (Latimeur-Cheung et al., 2013), feasibility (Learmonth et al., 2017) and testing (Motl et al., 2019) of exercise guidelines to improve symptoms of MS. These advancements have shifted the life expectancy and landscape of persons aging with MS, and the meaning and experience of aging with MS may too have shifted. The time is ripe for a new contemporary exploration of the lived experiences and meaning of aging with MS that reflects this shifted landscape. The resulting knowledge will be a foundation for future lines of research, and can answer the call to place increasing emphasis on studying healthy-aging and wellness among persons living with MS (Motl et al., 2018). Studying healthy aging and wellness, however, requires establishing what aging with MS ‘means’ among persons experiencing this phenomena as a starting point. Such research can be conducted in a meaningful way using the qualitative tradition of phenomenology.

From the Greek ‘phainomenon’, phenomenology is the study of things as they present themselves and are perceived in consciousness; or ‘phenomena’ (Husserl, 1961). Phenomenology in a ‘modern’ sense, was spearheaded by Edmund Husserl to address what he perceived as the inadequacies of the objective ‘scientific’ method to appreciate the essence of human experience. Since Husserl, phenomenology has expanded to include a myriad of strands, interpretations, perspectives and traditions;
realist, constitutive, existentialist and hermeneutic (Embree and Mohanty, 1997). In this work, we use an existential phenomenological approach. The focus of existential phenomenology involves how the body is experienced and perceived through time and space, and how it is interrelated and mediated through actions with other people and the social environment (Merleau-Ponty, 1969). Existential phenomenology therefore places the body as a subject of culture, and world, body and consciousness are fundamentally intertwined, inter-related, and mutually influential and the self is culturally constituted (Merleau-Ponty, 1969). Accordingly, an existential phenomenological approach is a strong and robust method for exploring aging and MS, as both experiences (aging and MS) are inherently physical, embodied experiences, and are shaped through cultural understandings and perceptions. The exploration of these dual lived experiences through a corporeal frame, and how these are understood through social structures, embodiment and consciousness can bring a greater understanding of what it is to ‘age with MS’.

Though different strands exist, at it’s core essence, phenomenology seeks detailed, complex descriptions of subjective, human experience within context, and is shaped by 4 principles or cornerstones for individuals endeavouring to undertake phenomenologically inspired research. Derived from Husserlian phenomenology, these 4 cornerstones are description, epoché, essences, and intentionality. Description requires researchers to suspend as much as possible prior knowledge and assumptions of the thing being studied to ‘get at’ the phenomena itself. In so doing, we assert the core of the experience and its essential characteristics. To do this, researchers engage in epoché, Epoché, like the origin of phenomenology, is derived from the Greek meaning to ‘abstain’ or ‘to distance from’. In the phenomenological ‘method’, this requires us to separate or ‘bracket’ our taken for granted, (pre) assumptions of an experience in order to cut through layers of context to arrive at essential core essences and characteristics of a phenomenon. Intentionality refers to the concept that we are always conscious of
something, thus it is intentionally brought into focus. Following reducing the phenomenon to its ‘eidos’ (core meanings) through description and epoché, the essence of a phenomena can be established. In this way, core meanings and taken for granted knowledge of an experience can be identified. Intentionality then allows us to direct our attention on a phenomena (e.g. aging with MS) to explain why different people perceive and experience the ‘same phenomena’ in completely different ways. These cornerstones shape the ‘method’ of phenomenological research, but in actuality these cornerstones represent a way of being and thinking about the data through a specific reflexive lens, rather than as a method in itself. We explain how we utilized these cornerstones in our research in the data analysis section.

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

What is it like to experience aging with MS?

How do persons over 60 with MS interpret aging?

What should future research target for optimizing quality of life among older persons with MS?
Such empirical data will become a road map that guides future research on lifestyle interventions and wellness, and support collaborations that improve wellness and quality of life among older persons with MS.

Method

Design and Philosophical Assumptions

This study aligned to an existential phenomenological design. The numerous approaches of phenomenology mean that there are numerous slants to assumptions of epistemology and ontology (Allen-Collison, 2016). Under an existential phenomenological approach, there is a ‘third way’ epistemologically and ontologically speaking (Allen-Collinson, 2009). In this way, epistemological and ontological assumptions are not that of an ‘objective’ world outside of us, nor of a perceived consciousness within us, but that ‘our way of being in the world’ is through a dialogical, interconnected relationship where world, body and consciousness are intertwined and mutually influencing (MerleauPonty, 2001). In other words, the lived body acts as the standpoint from which all things are perceived and experienced, bringing together this world-body-consciousness nexus (Merleau-Ponty, 1969). As experiencing and making meaning from aging with MS is deeply embodied, interpreted through consciousness, and influenced by cultural stories all working together to form understanding, an existential phenomenological approach is an appropriate method for this study.

Sampling and Participants

The authors received ethical approval from the Institutional Review Board before the study began. Participants were recruited through an e-mail blast through the National Multiple Sclerosis Society (NMSS). The email blast described a study on aging with MS focusing on lived experiences of aging, and perceptions of wellness.
The inclusion criteria were (i) age of 60 years or older, (ii) confirmed diagnosis of MS, (iii) fluent in English, and (iv) willingness to take part in a recorded interview lasting between 1 and 2 hours.

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

To screen participants, the first author called interested persons, explained the study in more detail and conducted the phone screen. If participants did not meet the inclusion criteria or chose not to participate, the first author contacted another participant within that geographical area. This resulted in the inclusion of 40 participants from 33 states. Of the 40, 29 participants were female, and 11 were male.
Age ranged between 60 and 85 years with a mean age of 67.5 years. Disease duration of MS ranged between 3 and 55 years with a mean disease duration of 25 years. Nineteen participants had RRMS, 21 had progressive MS. Eighteen were ambulatory, 17 used a walking aid, and 5 a wheelchair or powerchair. Thirty-three were retired, 5 were employed on a part time basis, and 2 on a full-time basis.

Data Collection

Data were collected through Internet based, face-to-face, semi-structured interviews. Online interviewing techniques were selected, in part, as it is the preferred method within the MS population as such techniques allow for representation of persons who may not otherwise be able to participate.

Indeed, it has been posited that data can be richer as the participant has not expended excessive energy travelling to an in-person interview (Synnot, Hill, Summers, and Taylor, 2014). Though advantageous, limitations of using online methods included some difficulties with internet signal meaning breaks in interviews and flow, an inability to read non-verbal cues, and an inability to create as strong a rapport as is possible in person. Nevertheless, the utilization of internet-based interviewing strategies further enabled a wide geographic representation of aging with MS.

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

Participants gave verbal consent to being recorded before the interview began. Interviews ranged between 58 and 118 minutes with a mean interview length of 78 minutes. There was a total of 3,116
minutes (54.5 hours) of raw interview data. Participants received a $50 gift card as a thank you for participating. Raw audio data were sent to an external transcription company immediately after the interview and this allowed for a written transcript within 24 hours of the interview conclusion. Thereafter, the transcript was changed to pseudonyms, and checked for accuracy against the original recording. Pseudonyms are used in the direct quotations in the results section.

Data Analysis

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

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

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

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

Rigor and Trustworthiness

To ensure rigor and trustworthiness through the research process, we adopted a relativist approach. In other words, we chose quality standards that aligned to the purpose and method of the research (Burke, 2016; Gergen 2014), specifically how to rigorously do an existential phenomenological study. We therefore drew upon the ongoing ‘lists’ for quality and rigor first proposed by Smith and Caddick (2012) and the list proposed by Tracy (2010). First, we chose “worthy topic.” The worthy topic
criteria stipulate that the research must be timely, significant, interesting and relevant (Sparkes and Smith, 2013). We highlighted the worthiness of our topic through justification in the introduction regarding why a contemporary, phenomenological understanding of aging with MS is currently needed. Second, we chose the criteria of sincerity whereby the study is steeped in self-reflection about values, biases and presumptions of the researcher (Tracey, 2010). Considering the requirement to engage in epoché within phenomenology, worthy topic was appropriate and important to use. We engaged in sincerity throughout the process by reflecting on our presumptions about aging with MS and engaging in epoché exercises, outlined in the data analysis section. Third, throughout the analysis and data collection process we used member reflections to ensure that the meaning and experience of aging with MS constructed by the researcher was recognizable to participants in the study. Member reflections are an important process within phenomenology as the researcher attempts to reconstruct the reality of participants by creating a relatable and resonating representation of someone’s lived experience (Grant, 2012). Reflections were done through reflexive conversations with participants throughout the research process. Fourth, we sought to make a significant contribution to the literature. The criteria call for researchers to make a meaningful impact on our understanding of what is being researched theoretically, conceptually, practically or methodologically (Sparkes and Smith, 2013). We ensured we made a meaningful contribution by conceptualizing and theorizing aging with MS within aging and chronic illness frameworks, providing recommendations for practice and future research, and highlighting how existentially phenomenology can be used to illuminate the meaning of an experience not well understood. Our significant contribution to the literature is shown in the results and discussion, and concluding remarks sections.
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:
It was all right until about 10 years ago, until about the time I retired in '95. It's gone downhill from there, slowly. I went from a cane to a walker to a wheelchair to a wheelchair and a walker, to now a specialty wheelchair. (Becky, 34, 68, F, SPMS)

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

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

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

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

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

For these particular individuals, the value of walking diminished and the value of continued
participation increased; “You know, it's incredible how much value we place in certain things, like the ability to walk for example realized that once you're in that situation, it's no longer an issue” (Jennifer, 67, F, progressive MS).

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

Individuals who perceived walking aids as ‘energy-savers’ that allowed participation may have viewed physical dysfunction through an aging lens. Aging lenses cast physical dysfunction as a natural progression that every individual will at some point experience (Gullette, 2004). The ‘normality’ of physical dysfunction at an older age therefore casts a different meaning of walking aids. For some older people, a walking aid is perceived as ‘being confident and independent’ (Brannstrom, Backman, and Fischer, 2003). For example, the adoption of a wheelchair or power chair may be perceived as a positive adaptation and maintaining control for continued participation (Finlayson and Van Denend, 2003).

Further, with age, the value of ‘objective’ measures of walking mobility (i.e. steps taken, distance covered) are superseded by the ability to ambulate in general (Dilorenzo, et al., 2008; Finlayson, and Van Denend, 2003). The change in valuing walking unaided is a phenomenon further discussed in sociological perspectives of illness whereby modifications in one’s embodied experiences modifies
one’s values (Carel, 2016). Thus, perceptions of physical dysfunction and walking age were interpreted differently by participants.

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

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

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

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

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

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

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

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

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

Individuals with MS cannot escape the natural biological process of aging. The compounding effect of aging plus MS can mean that persons with MS have worse physical functioning compared to the older general population (Riazi et al., 2003) and are more likely to have mobility issues (Paltamaa et
al., 2006). Thus, the natural experience of aging may be worsened by additional complications resultant from MS that can compromise participation and quality of life.

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

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

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

A real concern was that the combined effects of MS and aging on cognitive dysfunction may mean older persons with MS are more at risk of dementia or Alzheimer’s:

I think, probably, my ultimate fear, or anyone's ultimate fear, is losing your mind, or dementia, or not being able to communicate or know who is sitting across the table from you. That worries me. With MS affecting my sleep and already having cognitive issues, I’m terrified all that together is going to make me more likely to get dementia. (Johanna, 62, F, RRMS)
Participants feared that MS as well as aging could mean increased likelihood of severe cognitive issues. Age related cognitive issues include the gradual decline of conceptual reasoning, memory, and processing speed (Harada, Love, and Triebel, 2014). MS related cognitive issues include slowed processing speed, impaired memory and episodic memory, and executive function (Bobhdz and Rao, 2003; Chiarvalloti and DeLuca, 2008; Rao, Lea, Bernardn, and Unverzagt, 1991). Work on cognition across the lifespan concluded that there were meaningful cognitive differences between older persons with MS and those without (Bollaert et al., 2016), and some work does hypothesize that the combined effects of MS related and age-related cognition increased the risk of developing age-related neurodegenerative dementia (Roy et al., 2018).

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

Aging made my MS better

Contrary to the above embodied experiences of MS and aging, some participants perceived that aging made symptoms of MS better. Specifically, participants described aging improved MS through (i) improved physical function and (ii) normalizing cognitive issues.
Improved physical function: Participants who perceived aging made MS better stated they could objectively see improvements in function and participation compared to younger age:

I had really severe MS at onset. I was quadriplegic with my first episode. I was in the hospital. I went to every hospital to talk to all the specialists and ask them what's the prognosis. They said, "Terrible. Five to 10 years you're going to be bed-bound," which they were totally wrong...Compared to 10 or 15 years ago, I'm 100% better...Honestly, waking up in the morning and being able to get out of bed, because for years I couldn't do that. My back muscles were too weak. I had to crab it sideways and I'd just fall off the bed and then try and get up. To just jump out of bed in the morning now, right there, that's heavenly right there. (Jack, 67, M, progressive MS)

Moreover, some participants believed MS had ‘burned-out’, and had successfully discontinued all DMTs for MS without relapse:

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

The pathology of aging with MS is not well understood. In this paper, we have highlighted the phenomenon of the ‘double-impact’ of aging and MS, but the above testimonies describe a phenomena of MS symptoms improving with age. For some participants, they experienced severe and rapid onset of symptoms and disability at the beginning of their MS journey. Many participants were diagnosed in the 1970s and 1980s when there was little understanding of MS, no DMTs available, and few rehabilitation or therapeutic options. This meant a poor future prognosis for many, and the real fear of dying at a very young age. The successful progression of age and MS may therefore feel empowering for persons with MS as they are experiencing not only a counter narrative to what they were told about MS, but a counter
narrative to aging (Phoenix and Smith, 2011) whereby they perceive they are improving and in better health rather than declining.

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

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

And that other parts of MS. Cognitive. I have some issues with cognitive. And the hard part is I'm getting older. So when I say I can't remember a word, people go, "Oh, I can't either. Everyone does when we get older." So is it my brain or is it my memory? I don't know. Getting older, again, starts crossing that line of, well that's just you, that's just getting older, or that's 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.

(Ruth, 65, F, RRMS)

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

I have these brain fogs…They've gotten to where now, and it's funny...All my church friends are the same way. They just laugh and say, "Heh, I do it all the time too." I say, "No, I really do." I forget where I'm at in the middle of a sentence, you know? We all just have a big time. We laugh about a lot of things that I used to worry about. I didn't want to talk to people, because I would lose track of where I was at. (Sarah, 60, F, RRMS)
The compounding effects of MS and age-related cognitive impairment is not well-understood. Research proposes different hypothesis regarding the potential dual impact of these issues and the risk of dementia. Some posit the double source of cognitive impairment means older persons with MS are more at risk (discussed in the previous theme), but others posit this to be false. Indeed, work comparing motor and cognitive decline of persons with MS and persons without found motor decline was amplified by age, but cognitive impairments did not vary across the lifespan (Roy et al., 2017), and there is no more risk to persons with MS developing dementia than the general population (Branco et al., 2019).

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

**MS makes my aging better**

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

Participants discussed the perception that peers had ‘caught up’ with them disability wise, and therefore the participants were aging more successfully than peers:

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

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

Aging literature focuses on the underlying social, cultural, and individual processes that shape experiences of aging (Moody, 2008). For participants in this study, aging experiences were strongly intersected by past and present experiences of MS. For example, participants perceived they experienced
aging before their time. Now they are at an ‘acceptable’ age for these experiences, they perceive they are normal. Persons over 60 with MS may live a different biography to societal expectations of decline as they experience aging phenomena at a much younger age. When peers reach this same age, persons with MS become ‘normal’ through a lens of Western aging culture whereby physical and cognitive deficits are expected (Gullette, 2004). Experiences of ‘abnormal’ aging at a young age may however allow older persons with MS to age more successfully and could have a perceived higher quality of life than older persons without MS. As such, it may be that persons with MS reach a perceived peak life with older age relative to peers, highlighting real positivity for the future.

Concluding Remarks

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

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

[Figure 1 about here]
Persons aging with MS therefore can experience these two embodied experiences in different ways; for some there is a decline and negative interaction between the two, while others perceive a peak of life and positive interactions. Depending on a person’s biography, MS symptom experiences, perception of aging and MS expectations, and trajectory of MS, participants interpreted aging and MS differently. The intersection of aging and MS is therefore a complex and nuanced experience that means different things to different people, and can follow different trajectories.

A phenomenology of aging with MS compliments previous phenomenological works of the lived experiences of MS (Finlay, 2005; Strickland, Worth and Kennedy, 2015, 2016; Toombs, 1995). In particular, past works have described the renegotiation and reconstruction of the self upon diagnosis (Toombs, 1995) and the liminal self with MS as one transitions to reincorporating MS as part of the self (Strickland, Worth and Kennedy, 2017). Our findings regarding aging further this work by showing that, with age, there may be a threshold whereby another stage of transition occurs. That is, a reconstructing of the self through an aging lens such that (i) MS may no longer be part of self-concept (e.g. if persons perceive aging made MS better and they have ‘aged out’), (ii) MS is merely part of self-concept but not the definite construct (e.g. if persons experience other age related deficits that are more problematic then MS), or (iii) age adds another element to one’s biography such that one must renegotiate the self not only within a chronically ill body, but now an aging body. This is an important finding to consider regarding social and relational recommendations for supporting successful aging with MS. Taking the liminal self as a framework, there is a threshold by which persons newly diagnosed with MS seek information and support (Strickland, Worth and Kennedy, 2017). We posit there is another threshold among persons aging with MS whereby information and support for aging with MS is sought. Currently, however, this is lacking with persons aging with MS under-served and under supported by the research, health care providers, and other support networks. An important recommendation for the wider MS field
is to create a focused research effort investigating aging with MS, and to craft ways to share this
information with those that require it. Further, specific support is required for this group, as we highlight
various ways in which aging with MS can impact wellness that require social and relation support. This
is as yet missing.

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

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

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

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

Also, we acknowledge that a limitation of our methodological choice of employing phenomenology in the analysis of qualitative data meant that we were reliant only on semi-structured interviews. Using only semi-structured interviews can be problematic as this method can ‘impose’ pre-supposed meanings on participants and, despite researchers best efforts to bracket presumptions, filter through to the questions asked (Allen-Collinson, 2016). Future research utilizing the phenomenological tradition to
explore aging and MS should combine interviews with participant observations in order for richer, more authentic descriptions to be constructed (Ravn, 2016).

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

The authors declare no conflicts of interest.
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Figure 1: Perceptions of Aging with MS

Embodied perceptions of aging with MS

- Aging makes MS worse
- MS makes aging worse
- Aging makes MS better
- MS makes aging better