

# Experiencing the loss of mobility: perspectives of older adults with MS

MARCIA FINLAYSON\* and TONI VAN DENEND

Department of Occupational Therapy, University of Illinois at Chicago, Chicago, USA

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## Abstract

*Purpose:* The purpose of this study was to develop an understanding the experience and meaning of mobility loss among older adults with multiple sclerosis (MS). This work is part of a larger study on the health concerns and service needs of older adults with MS.

*Methods:* Twenty-seven people with MS (mean age = 62 years, range = 55–82) were interviewed using a phenomenological approach.

*Results:* Thematic analysis found that three factors contributed to participants' experience of mobility as a person with MS: *reality of having MS, mobility needs, and contextual factors*. Participants discussed how the reality of MS meant variability in their ability to get around and the importance of trying to remain in control over their mobility experiences. The experience of mobility lead participants to *mourn losses, take action, and contemplate their futures*. They expressed concerns about the continual declines in their mobility, losing independence, becoming a burden on caregivers, and the potential for having to move into a nursing home.

*Conclusions:* Findings provide insight into the experience of mobility loss among older adults with MS, and point to potential strategies that can be used to help people cope with and adapt to these losses.

## Introduction

Multiple sclerosis (MS) is a chronic, often disabling neurological disease that is typically diagnosed among individuals between the ages of 20 and 50.<sup>1</sup> The progress and severity of the disease is unpredictable making it difficult for many people to adapt to and cope with their diagnosis and its consequences. Common symptoms of MS include weakness, numbness, fatigue, tremor, loss of vision, pain, paralysis, loss of balance, and bladder and bowel dysfunction.<sup>2</sup>

\* Author for correspondence; M. Finlayson, Department of Occupational Therapy, University of Illinois at Chicago, 1919 West Taylor Street, Mail Code 811, Chicago, IL 60612, USA. e-mail: marciaf@uic.edu

Prevalence figures suggest that MS may affect as many as 2.5 million individuals worldwide.<sup>1</sup> Regional estimates range from 0.77 cases per 100 000 in Hong Kong,<sup>3</sup> to as many as 200 per 100 000 in Northern Europe, Northern USA and Canada.<sup>4</sup> Conservative estimates suggest that between 250 000 to 350 000 individuals in the USA have MS, and that approximately 45% of these people (i.e., 112 000 to 158 000) are over 55 years of age.<sup>5, 6</sup>

Mobility impairment is a major consequence of MS.<sup>7</sup> Declines in functional mobility are associated with loss of social connections, reduced participation and altered abilities to perform self-care, productivity and leisure occupations. These declines have been described among people with MS,<sup>8, 9</sup> people with other chronic conditions,<sup>10, 11</sup> as well as among older adults in general.<sup>12</sup> Ongoing and progressive changes in functional mobility require the affected individual to adapt perceptually, psychologically, emotionally and physically.<sup>13, 14</sup>

Existing studies on MS and mobility issues have tended to use quantitative research approaches to describe nature of mobility loss, and therapies or strategies for compensating for mobility loss (e.g., physical therapy, use of canes or wheelchairs).<sup>15–17</sup> While the broader literature in disability studies and gerontology provide some insights into the impact of mobility loss on people with chronic disabling conditions, there are no reports to date that explore the experience of mobility loss from the perspectives of older adults with MS. Because of the progressive nature of MS, and the fact that the disease does not significantly reduce life expectancy,<sup>18, 19</sup> understanding the experiences of mobility loss from the perspective of these individuals may provide additional insights that can inform the development of programmes, services and advocacy efforts that support people with MS as they age.

Using data from a broader study examining the health concerns and service issues expressed by older adults with MS, this paper presents findings related

to the ongoing experience of mobility loss among older adults with MS, and discusses the potential implications of these findings for the practice of occupational therapy.

### **Literature review**

Different types of mobility are identified in the literature, including personal mobility and community mobility. Personal mobility includes activities such as moving around in one's house, transferring, and going up and down stairs. Community mobility includes walking longer distances, driving and the use of various forms of public transportation (e.g., taxis, buses, airplanes).<sup>20, 21</sup> A number of the symptoms of MS may potentially influence both of these types of mobility, for example, fatigue, problems with balance, weakness, numbness, pain, spasticity, loss or coordination and tremors. A number of research studies have explored the prevalence of these types of symptoms among people with MS. For example, balance disturbance and/or ataxia is reported to occur in 23–84% of persons with MS, while prevalence of numbness/tingling ranges from 41–84%. Prevalence of motor weakness is reported in the range of 43–80%.<sup>22–24</sup> Reports for the prevalence of fatigue range from 84–92%.<sup>25, 26</sup> Any one of the many symptoms of MS may challenge either community or personal mobility, but in combination their disabling effects can be dramatically increased. These effects are evidenced by the high prevalence rates of mobility related problems that are reported in the MS literature.

Shepherd<sup>27</sup> studied 557 patients with a diagnosis of MS using the McAlpine & Compston disability scale. The results showed that only 23% of participants were unrestricted in their personal mobility. Among the remaining participants, 28% experienced some restrictions, 19% experienced marked restrictions and 16% were wheelchair users. In a study of 1145 persons with MS, Baum and Rothschild<sup>28</sup> found that approximately 51% of participants reported that they needed help with personal mobility both indoors and outdoors. Few of the respondents (4%) reported using crutches, but approximately 12% reported using walkers or canes while 40% reported using a wheelchair.

In a study examining the possession of adapted equipment among adults with MS in Atlantic Canada,<sup>24</sup> ownership of mobility related equipment ranged from 8% for electric wheelchairs to 61% for manual wheelchairs. Walkers were possessed by 39% of respondents, and 44% had either a cane or crutches.<sup>24</sup> Other studies have found comparable rates for equipment use.<sup>29</sup>

Work by Kohler *et al.*<sup>10</sup> suggests that altered mobility can have a range of psychosocial implications, including emotional loss, altered self-image and self esteem, decreased opportunity to socialize leading to isolation, fear of rejection and abandonment, stress and decreased independence to travel from one location to another. Studies focusing on quality of life among people with disabilities have found that greater physical dysfunction is associated with negative changes in well-being and social contacts,<sup>30, 31</sup> as well as higher rates of depression, fear, anxiety, confusion, obesity, poor vision, dizziness, imbalance and other worrisome feelings.<sup>33</sup>

In addition to describing the psychosocial and quality of life changes with mobility loss, the literature also addresses various issues related to managing and coping with this loss. For example, Avillion<sup>33</sup> examined the relationship between client-perceived barriers to ADL performance and self-esteem of individuals using wheelchairs. The study found that self-esteem scores among people who had been using a wheelchair more than 6 years were significantly higher than people who had been using a wheelchair for less than 5 years. This finding suggests that adaptation to mobility changes may be time dependent, and this is consistent with the idea that adaptation to mobility loss is a process.<sup>9, 11, 34</sup> Charmaz<sup>11</sup> reports that 'people must learn to plan the minutiae of their lives, if they are to remain independent' (p. 137), while Wiener<sup>34</sup> describes how individuals adjust to the reduced activity by changing their expectations and developing a new set of ideals for activity. These changes enable him/her to cope with the uncertainty and instability of potential functional status change. Toombs<sup>9</sup> eloquently describes how mobility loss changes the way she plans and performs activities, and how it changes the character of the spaces in which she functions.

As mobility status declines, people with mobility impairments are faced with the decision to utilize assistive technology or continue to attempt activities without aid. A qualitative study by Iezzoni<sup>35</sup> found that using mobility equipment (e.g., wheelchair, scooter) can be seen as 'giving up' or 'not trying' and that the 'decision to use a wheelchair can appear equivalent to losing hope'. In another qualitative study, Miles-Tapping and MacDonald<sup>36</sup> interviewed people using power wheelchairs about the effects and consequences of power mobility. They found that these individuals went through the process of defining his/her disability as permanent, had to learn how to deal with others' reactions, had to come to terms with the new equipment, and had to learn how to manage the freedom and independence power mobility provides.

In more theoretical work, Carp<sup>21</sup> describes a conceptual framework outlining the significance of community mobility for the well-being of older adults. Carp's model outlines the connections between community mobility and the meaning, the determinants and the dynamics of well-being among older adults. The model contains four components including mobility moderators, qualities of mobility, needs and resources for mobility, and outcomes of mobility. The model reflects the need for congruence between mobility-related needs (e.g., obtaining food, clothing, health care and accessing social, recreation, and worship opportunities) and the community resources required to meet those needs. Carp hypothesizes that if mobility needs and resources are incongruent, independent living and well-being will be compromised. The model also recognizes that feasibility, safety and personal control over community mobility (together labelled quality of mobility) influence one's capacity to address mobility needs and access resources. Socioeconomic status, location of residence and technology moderate the overall quality of mobility. According to Carp, these moderators can enhance or limit the fit between an individual's abilities and his/her physical environment.

Loss of mobility, either within the community or personal, is a major consequence of having multiple sclerosis. Aging may compound this situation. Existing literature describes the extent of altered mobility status among people with MS, and the related literature provides some insight into the impact of these changes on populations other than people with MS. With this background, this study addressed the following research questions:

- (1) What are the mobility related concerns among older adults with MS?
- (2) What are the consequences of mobility loss among older adults with MS?

## Methods

As previously noted, the broader study upon which this paper is based focused on describing the health concerns and service needs of older adults with MS. The study employed a cross-sectional descriptive design that included two interviews with each participant. A phenomenological approach was used in order to focus on the lived experience of the participants, and to develop an understanding of the experience and meaning of mobility impairment from their own perspectives. The Institutional Review Board of the University of Illinois at Chicago reviewed and approved the study.

## SAMPLE

Study participants were recruited through a convenience sampling strategy through MS support groups associated with the Greater Illinois Chapter of the National MS Society. Criteria for inclusion were: (1) born in 1947 or before, (2) self-report having MS for at least 15 years, (3) able to complete interview in English, and (4) access to private location for interview. Screening and interviews were completed in the summer and fall of 2001. Thirty-two people volunteered and were screened. Twenty-nine were deemed eligible, and were scheduled for an interview. Two individuals dropped out of the study prior to being interviewed due to exacerbations of their MS, and therefore 27 people participated. Twenty-three were female, and four were male. Their average age was 62 years ( $SD = 7$ , range = 55–82). The majority were married ( $n = 19$ ), and living in a single family home ( $n = 18$ ). Three participants resided in a nursing home. Self-reported health ratings among participants included very good ( $n = 7$ ), good ( $n = 9$ ), fair ( $n = 8$ ) and poor ( $n = 3$ ). One-third of the participants were on one of the major MS disease modifying agents (e.g., Betaseron, Avonex or Copaxone).

## INSTRUMENTATION AND PROCEDURES

As noted above, each participant was interviewed twice. In all but two cases, interviews were conducted in the participant's home. Four interviewers were involved with this study, two with extensive research interviewing experience and two who were trained specifically to collect data for this study.

An in-depth, semi-structured interview guided the first contact, and focused on the participant's perspectives about aging with multiple sclerosis, the meaning of health and any associated concerns related to this context. First interviews took 107 min to complete, on average. The second interview was conducted 1–3 weeks later, depending on the participant's schedule. The interviewer clarified points from the first interview and also administered the Multiple Sclerosis Quality of Life Inventory,<sup>37</sup> and modified versions of physical health, ADL and services supplement sections of the Older Adults Resources and Services Functional Assessment Questionnaire.<sup>38</sup> Since the focus of this paper is on the experiences of the participants with respect to mobility, data from the quantitative instruments will not be discussed further.

## ANALYSIS

Interviews were transcribed in full and then imported into Atlas<sup>ti</sup>, a qualitative analysis software program. Throughout the data collection process, interviewers met to discuss emerging themes in the qualitative interviews. Fieldnotes and preliminary analytic ideas were recorded during these meetings. Near the end of data collection, a list of qualitative codes and corresponding definitions was developed based on the notes from the team meetings.<sup>40</sup> Mobility was one of the codes identified at this time.

Three members of the research team used these codes and definitions to conduct an initial analysis on five of the interviews. After completing coding on these interviews, the codes and definitions were revisited and revised to better reflect the data. The transcripts were divided among the three research team members for the second round of analysis. After all interviews had been coded, the retrieve feature of Atlas was used to extract codes and quotations reflecting major themes, and then these transcript excerpts were re-evaluated and recoded using more specific sub-codes. Efforts were made to graphically depict the relationships between the codes, and literature was reviewed to assist in this process.

At this time, Carp's model on community mobility needs of older adults was found to loosely correspond with the mobility themes in the data, and therefore was used as a beginning framework for the remainder of the analysis on mobility issues and concerns among the participants.

## Results

During the interviews, the 27 participants reported a range of MS symptoms that may influence both personal and community mobility. Overall, loss of balance was the most common of the symptoms that may influence mobility, with 26 participants reporting problems. Among these individuals, 14 reported that it interfered a lot with their daily activities. In comparison, 23 people reported having weakness, 21 reported experiencing spasticity, and 18 reported having incoordination. For each of these symptoms, the majority of people experiencing them reported that the particular symptom interfered a little rather than a lot with daily activities.

In terms of personal mobility, 21 participants reported being 'limited a lot' in their ability to walk one block. Over half of the participants reported being 'limited a lot' in climbing one flight of stairs.

None of the participants felt they could walk several flights of stairs without limitation. In terms of the use of mobility aids, twelve of the 27 individuals used a manual wheelchair or an electric wheelchair or scooter always.

For community mobility, 14 people provided their own transportation, with five of them using hand controls all the time when driving. Among these individuals, 71% (10 out of 14) reported getting out into the community to conduct business or engage in social or leisure activities four times per week or more. Only 31% (4 out of 13) of people who did not drive were able to get out into the community this number of times in a week. Seven of these 13 people indicated that they needed more access to transportation.

Through the qualitative interviews, a broad perspective was obtained from participants about their overall *Experience of Mobility as a Person with MS*. Through the process of analysis, we found that we were unable to describe the experience of mobility as a singular entity. Instead, we found that it is a complex interaction of factors that contribute to and shape mobility experiences, as well as result in a series of consequences. As such, the contributing factors and consequences are a part of the mobility experience itself. Ultimately, the analysis uncovered three major factors that were contributing to the mobility experience, and they included: reality of having MS, mobility needs; and contextual factors. The actual experience of mobility had, in turn, three primary consequences for participants, and these included: mourning losses, taking action, and contemplating the future. Each of the themes and sub-themes are presented and described below, and figure 1 provides a graphic depiction of their relationships.

As noted in the literature review, mobility loss is a common consequence of MS. During interviews, participants talked at length about what the experience of mobility was like for them as a person with MS. They talked about their current experiences and challenges, as well as the changes they had observed in their mobility abilities over time. They talked about factors that influenced their experiences, as well as the consequences of their experiences. Three factors influenced their experiences, in both positive and negative ways.

### INFLUENCING FACTOR: REALITY OF HAVING MS

Having MS pervaded almost all aspects of the mobility experience for the participants of this study, regardless of whether the mobility was personal or community

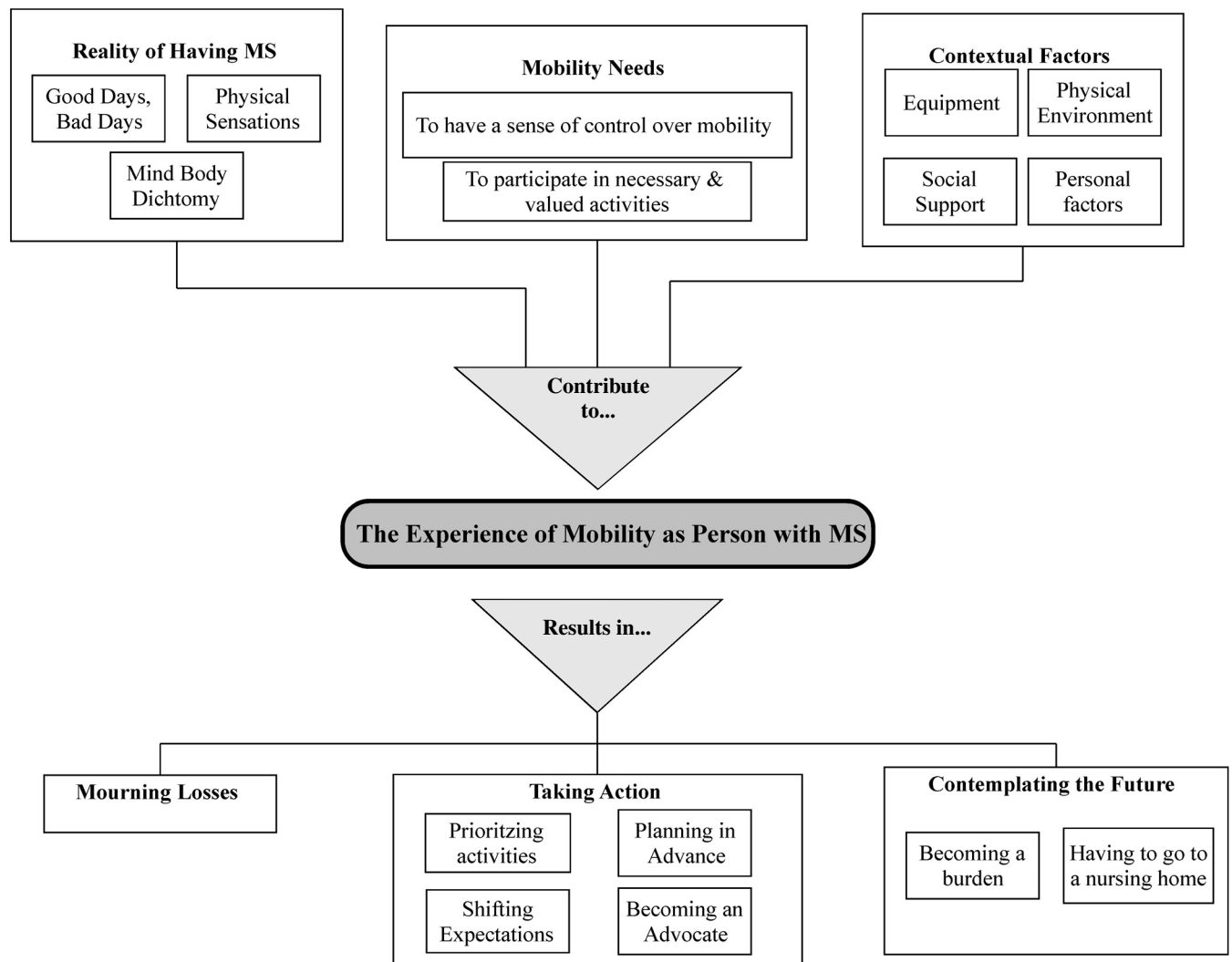


Figure 1 Graphic depiction of the themes and sub-themes emerging from the data analysis.

in nature. They experienced many *physical sensations* such as pain, tingling, loss of balance, and feelings of limb heaviness. The participants often described these sensations and the role that they played in their mobility difficulties.

... I was a klutz. I would fall down. I realized I was losing my balance.

[It feels] like my left leg is pulling or dragging.

I had numbness and tingling in my right leg and it got worse. It started traveling further up the body. I woke up paralyzed from the waist down ... and I went to get up and fell down.

... every once and a while I had to do a lot of walking ... I would get a tingle in my right leg, like pins and needles, kind of.

While the physical sensations that accompany MS did not generally prevent participants from moving around in their homes or communities, they did influence the nature and extent of the mobility experience. Participants chose different methods of mobility (e.g., using aids vs. not), or made other alterations in order to accommodate the sensations that they were experiencing.

Another component of the reality of having MS was identified as the mind-body dichotomy. During the interviews, it was common for participants to talk about

how in their mind they wanted to do one thing but how their body prevented them from taking action or fulfilling their mobility desires. While participants recognized this dichotomy as part of the disease experience, they found it frustrating, discouraging and difficult to deal with. Often the dichotomy was described like a battle between the mind and the body, sometimes with the mind winning while often the body winning. Overall, the dichotomy made them feel older than their chronological years:

From my waist up I feel 30, but from my waist down I feel 90. My mind wants to do things, but my body says 'No I don't think so'.

Sometimes my body is totally in control. I mean sometimes it's like you cannot move. I mean I have missed meals. I have stayed in bed for two or three days and lived on water because the fatigue is just so overwhelming. And today could have been one of those days cause your body gets heavy and stiff and it just doesn't want to move. So today my mind is telling my body what to do.

Another component of the reality of having MS that participants discussed was the good days, bad days phenomenon. Discussions revolved around the variability of the disease, and how its day-to-day unpredictability and variability contributed to their everyday experiences of mobility. Participants described how their symptoms came and went, and how they often did not know from day to day how their mobility and other capabilities would be. The unpredictability of MS was frustrating, as it put participants in situations where they were either unable or reluctant to plan ahead:

I used to enjoy planning holidays and parties and that's out of the question. Shopping for gifts you don't do. I mainly get gift certificates. There are just so many things that you took for granted and you can no longer do.

I will have days when I'm really on top of things. I have other days when I feel absolutely crummy and don't feel like doing anything. So its sort of a lost day when I should have done this or should have done that.

Good days provided participants with the opportunity to do the things that they wanted to do, and they took advantage of these times. Having good days and

bad days was a major component of the experience of mobility for the participants:

Someone with MS gets up in the morning are my legs working? I can do for myself. I feel fairly good. When you have your bad days, you can be nauseous. There's always pain there, but on a good day it's not as bad . . . I guess it's just being able to get up and take my shower and fix my breakfast and do what I want to do. On a bad day, it's kind of, well, as much as you tell your body you're going to do something, your body doesn't do it . . . You don't move around a lot.

#### INFLUENCING FACTOR: MOBILITY NEEDS

Regardless of their level of disability or the extent of their mobility impairment, all participants in the study wanted to be able to move around to complete everyday tasks related to self care (e.g., household mobility, transfers, getting to appointments, etc) and household maintenance (e.g., shopping, getting to work, banking), and to have the option of getting out to socialize with family and friends, or alternatively, to move around in one's own home in order to entertain others. Close examination of the transcripts uncovered that underlying these more concrete action-oriented needs, participants had fundamental mobility needs related to being in control of the mobility experience, and having the option to participate in valued activities.

Across both of these areas, data suggest that the greater the mobility impairment, the greater was the emphasis that a participant placed on control and choice, particularly within the home environment. For example, participants who primarily used a wheelchair to get around or who were unable to get around in the community without the assistance of another person tended to emphasize their needs to stay in control of personal mobility activities such as bed and toilet transfers, and moving around in the house. This emphasis seemed to reflect an acknowledgement of losses that had already occurred, and a desire to maintain some level independence or control over their own mobility.

I was for many many years a very independent woman. And when you know you got to depend on someone [for shopping], that makes it harder. . . . Just even getting up in the morning, you want to do things on your own. You don't want someone to help you get dressed. That's what my fear is and I hope I never get in that situation.

INFLUENCING FACTOR: CONTEXTUAL FACTORS

In addition to managing the reality of having MS and taking into account their mobility needs, participants also discussed how a range of contextual factors contributed to their overall experience of mobility. These contextual factors included the physical environment, the use of equipment, the availability of social supports, and more personal factors, for example, the decisions that they were making on a day-to-day basis.

The physical environment, both within the home and in the broader community, played a huge role in the participants' ability to move around and engage in the activities that they either wanted or needed to do. While participants did talk about the accessibility of their own homes, the primary focus of discussions related to the challenges they faced because of the lack of physical accessibility of the community. Participants discussed the problems they experienced in trying to get into some buildings, and the challenges associated with using particular spaces.

I guess the thing is when I get into some of the stores that it would be nice if they had carts that people that were handicapped could use.

... medical facilities are notorious for being inaccessible. Parking is very difficult. The doors, they have those wonderful wheelchair emblems on there, which somebody has to open for you and you have to through another set of doors.

In addition, participants discussed how the physical environment of the places and spaces they wished to use influenced not only the mobility experience itself, but the planning that was required *prior to* the experience:

I mean we would like to, both my husband and I, would love to travel and we would like to do more, but, even now it's uh, finding out, I mean I'm having to do a lot more investigating ahead of time to find out if places are accessible.

Availability and accessibility of transportation within the community also was a major concern among participants:

I think there's got to be some really reliable means of getting around. Yeah, it's such a problem ... I think transportation is a real problem for anybody but uh, particularly for disabled people ... So I

would love to see any programs that have some transportation attached.

Another contextual factor that contributed to participants' mobility experiences were social supports such as family and friends. For the most part, family and friends were generally found to have a positive influence on the mobility experience by providing physical assistance during mobility activities, adapting the environment to accommodate the participants' mobility needs, or by modifying the amount or extent of mobility related tasks that must be done by the person with MS. Friends with MS were also discussed as a positive factor influencing participants' mobility as these other individuals were able to provide them with information, ideas and resources to manage mobility losses and challenges:

Many times they [support group friends] have suggestions. We have this one woman. She's older than myself. She's 70. And she said when she falls, which she does, she tries to get over to a stairway to walk her way up to get into an upright position and I remembered that the other day. I did happen to fall and there happened to be a stairway there. And someone asked can I help you up? I said no, let me see if I can use the stairway. I did it on my own.

Assistive technology played a large role in the experience of mobility for the participants in the study. Wheelchairs, scooters, elevators, ramps and vehicle hand controls all enabled the participants to move around in their homes and communities with greater ease and with less fatigue.

I use an electric scooter when I have to go out to get around more ... But it was getting rough for me just to get to the back of the car to get it out. ... So two years ago we went to the disability expo and I bought a van that has a ramp that I can ride in and out of and terrific. Makes me very independent.

Nevertheless, while equipment did make some aspects of mobility easier, it also complicated the mobility experience as well. The expense associated with purchasing assistive technology was noted by a number of participants:

But unfortunately, when you have a disability, it's extremely expensive. Expensive. Some people have these phenomenal motor homes that are for inde-

pendence or these full-size vans that spin around and do everything but wipe your face. But you know we're talking thousands of dollars... Now with the lift, I got it at half price for 800 dollars, but I had to wait for all that.

The final contextual factor that participants' discussed as contributing to their mobility experience was their own decisions, attitudes and choices particularly about using equipment. Although participants talked about equipment as making their mobility easier, as described above, they also talked about how they had to come to terms with using it and they had to make a conscious decision to acquire equipment initially. For the majority of people in the study, these decisions did not come easily, as using equipment was initially perceived as giving up or giving in to the disease. It also marked them as a person with a disability to the broader community:

So, um, when I finally had to start using a cane... I finally kind of had to deal with it... Well, it was at least 10 years ago or so when I started using the cane. And then I would only use the cane if I were going to like a mall or some place where I had to do a lot of walking. And even then I would only go to malls that were far away, because I didn't want people, I didn't want to run into anyone that I knew. I really had a hang-up about it. And now I've... well now, particularly now the walker, I mean, obviously something is wrong with me.

Eventually, the use of mobility aids proved to be valuable and participants talked about how impractical they were to have resisted equipment. They commonly reflected about their initial resistance, and their current realization that choosing to use equipment provides them with greater opportunities for mobility:

And my one girlfriend rented one of these things [scooter] and she comes driving up in this thing. 'What is that?' She said, 'It's yours.' 'It's mine? That's not mine. I didn't buy that.' She says, 'I know but you're going to use it here.' I said, 'Oh no I'm not.' She says, 'How are you going to get around Great America with a cane?' One little stinky cane. I see it now. It's like a tooth pick. ... I would say half the day was gone and I'm still limping around and the kids are playing with this thing and she was in it with the baby and finally I says, 'Get out of that thing.' And I got in there and that was it.

My oldest son was telling me after a day [on vacation] ... 'now you can do all the sights and come with us? ... we've got a special car for you' and that was a wheelchair, which I did not want to sit in it ... But I found with that wheelchair the boys made it such a joy. ... Overall, it was a wise decision because I couldn't have ever done all the sightseeing. ... I always thought in a wheelchair you're really disabled, but I found it wasn't that way of thinking. It was so I wouldn't be as tired and that I could participate in all the sightseeing ...

While many factors contributed to participants' experiences of mobility as people with MS, there were also consequences of their experiences. The three primary consequences that emerged through the interviews were mourning losses, taking action, and contemplating the future. Each of these will be discussed in turn.

#### CONSEQUENCE: MOURNING LOSSES

Throughout the course of their disease, the participants of the study had experienced numerous losses related to their mobility, at both the personal and community level. While some participants had a great deal of difficulty dealing with these losses, others took them in stride and were able to redefine who they were, and what independence meant to them. They were able to make modifications to their lives that allowed them to fulfill their mobility needs (i.e., control and participation) through the use of social supports, equipment and environmental modification. Nevertheless, all participants mourned the loss of their mobility to a greater or lesser extent:

The worst thing about having MS is my mobility. I miss being able to walk without support ... I miss going to malls. I use to be a great mall shopper. I used to bowl. I liked bowling. Anything that involved walking, that's the biggest thing I miss. I mean I was never really an athletic person but the walking end of it I think is the hardest thing.

It's been slowly downhill since that time because of the legs and the lack of balance ... well that's the basic thing that I miss ... I envy people when I see them walking by. I'm thinking—do you realize how lucky you are? We see them out here jogging and things like that. Things you take for granted.

And the grocery shopping. You know a simple thing like that I haven't done in years. Going to stores, I had started even little stores I like to look around at those dollar bill stores. I can't stand that long to be able to walk around and look around and then get back out ... I miss those things.

#### CONSEQUENCE: TAKING ACTION

In response to their experiences of mobility as a person with MS, the participants of the study chose to take a number of different actions to manage future mobility experiences. The actions that participants discussed included planning in advance, becoming an advocate, prioritizing activities, and shifting expectations. The first two actions that participants' described related more to their community mobility and their use of public spaces such as restaurants and stores. Participants' talked about doing 'drive bys' to examine entranceway accessibility and availability of handicapped parking places at places they were thinking about using. They also talked about locating all accessible washrooms in malls and stores prior to deciding if they would remain to complete their shopping at a particular location. In addition, participants talked about how they had started speaking out about community accessibility to managers of public spaces and to store owners, and how they had started to take on advocacy roles related to this issue:

... my friend said, 'Well I'm sure they have a wheelchair here'. She walked the whole pier and they don't have anything. I'm serious. I'm feeling like a big advocate. You know they have strollers for little kids. I thought well that's not fair ... I'm becoming more mouthy about it.

I think it's the accessibility of things that I want to do. I'm almost on a first name basis with the Attorney General's office ... The restaurant that I go to ... they never had handicap signs ... so I go there all the time and I said to the manager I'm leaving for a week on vacation. I said if you don't have handicap signs out there when I get back, we're going to have problems. When I got back, they had handicap signs.

Actions related to prioritizing activities and shifting expectations were more related to personal mobility activities among the participants. For these actions, participants talked about how, because of mobility chal-

lenges and losses, they needed to make tough decisions about what activities to participate in, which ones could be accomplished through different means (e.g., from a scooter, by someone else) and which ones were going to simply be abandoned:

... even before I got really bad and a lot of times I didn't want to get out of the car cause it just took so much effort. And I would just sit in the car while my husband ran into the store to get something ...

As I said, now I can't do a lot of the things around the house that I would want to do. I just stopped ...

... there's a thousand footsteps that need to be taken and I can't do that. It's out of my reach. So I have my limitations and I know where it is at. A lot I can do. A lot can be done from a chair as much as I hate it.

It is important to note the important interaction between the actions participants took in response to their mobility experiences, and the contextual factors that contributed to these same experiences. For example, many participants shared experiences of encountering a barrier in the physical environment that impeded their mobility, either within their home or in the community. Because of their experience with this barrier, they were later able to use this mobility experience to take actions to avoid similar barriers in the future. As such, an important feedback loop existed between contextual factors and taking actions that enabled participants to develop and enhance skills to moderate their future mobility experiences.

#### CONSEQUENCE: CONTEMPLATING THE FUTURE

The final consequence of the mobility experiences described by participants was their contemplations of the future and what it held for them. All of the participants were acutely aware that their disease was likely to continue to progress, although they did not know how fast or what exactly would occur. While many participants were cautiously optimistic about their future, many more expressed fears and uncertainties about what further mobility losses would mean for their families or caregivers, as well as their living arrangements. These anticipated losses enhanced participants concerns about becoming a burden to family, friends

and professional caregivers. Even the three individuals living in a nursing home expressed concerns about becoming a burden. For example, one of them explained:

Well I've become less mobile that's for sure. And I feel that I have to depend on somebody else to do a lot of stuff that I used to do myself. So you want to be careful you don't overload your requests on people ... You got to be careful that whatever you decide to do, that you're careful I mean for yourself and for other people. If you don't make too many demands on other people, you keep your friends longer than if you ask them to do something all the time.

Among the individuals who were living at home with family members, concerns about becoming a burden tended to focus on the relationship with one's spouse or significant other:

And so you try to kind of spread out your favors or whatever ... Even with my friends or my family I know that I could ask them, but I don't want to do that all of the time either, so it's kind of a concern.

My wife keeps saying, [name], don't worry you know ... I don't like to be a burden ... I feel I would be holding her back ... But I think again using the word burden, my wife tells me not to use it, but I'm going to need more help than other people. I realize that the little help I get now—I'm afraid it's going to get a lot worse.

I just feel more like a burden than a wife. I'm not a wife anymore.

Among the 24 participants who were not currently living in a nursing home, the concerns about future mobility losses and becoming a burden on family members lead to their subsequent fear that, at some point, their care would become so heavy that family members or friends were not going to be able to support them to remain at home.

... I visited people in nursing homes with MS and I'm in good shape compared to many other people that I know. I've got friends [with MS] that can't talk, that can't get out of bed at all. They have to be in nursing homes. They can't drink water. So I keep saying—is this going to be me?

But it was the nursing home thing... everybody has these fears about things as you grow older but with MS I think you feel like you've been cheated out of some time. That somehow I shouldn't be going through this at 55 ... I should be 75 or whatever when I have to deal with going to a nursing home ... so that's kind of the scary.

My fear is of being in a nursing home ... MS does not affect your mind. It takes away your physical abilities ... You're in another world.

## **Discussion**

The intent of this paper was to describe the mobility experiences of older adults with MS, including their mobility-related concerns and the consequences they experienced as a result of mobility losses and challenges. Although this study focused on older adults, the symptoms, mobility limitations, and use of mobility equipment reported by participants in this study are consistent with previously published literature on adults with MS.<sup>2, 8, 24, 30</sup>

Through the qualitative interviews, participants described how the reality of having MS, their own mobility needs and the context in which they functioned contributed to their mobility experiences. These experiences, in turn, resulted in mourning over mobility losses, taking actions to modify future mobility experiences, and contemplating what the future might hold. A number of parallels can be found between these findings and the existing literature, both in terms of content as well as theory.

Existing MS literature addresses mobility loss primarily from the perspective of how the symptoms of the disease contribute to mobility impairments and the use of related assistive technologies. Stories from the participants validate this body of literature, while at the same time contributing depth to currently published statistics. Gait and motor disturbances are common complaint among people with MS. Stories from our participants support this finding, but also provide insight into the possible reasons behind this complaint, for example, having to give up valued activities, managing variability in abilities on a day-to-day basis, and having to plan ahead to accommodate mobility impairments.

The variability of the disease (i.e., components of the *Reality of Having MS* theme) played a large role in the mobility experiences of the participants of this study, and also framed many of the consequences that these experiences brought about, particularly mourning losses and contemplating the future. These findings point to

the need for health care providers to talk to their MS clients about the reasons behind their symptom complaints rather than simply taking them at face value. With respect to mobility losses, participants' stories suggest that mobility interventions need to deal with the mechanics of getting around, as well as address strategies to manage the overall mobility process (e.g., planning, problem-solving, modifying activities). This intervention combination may help clients maintain or enhance their sense of control over their mobility experiences, and thereby address some of their mobility needs.

Participants' discussions about the physical environment and mobility equipment illustrate the complexity of mobility experiences, as well as the challenges associated with adjusting to mobility losses. These discussions also illustrated the extent to which participants' mobility-related decisions had to be highly conscious and explicit in order to maintain their sense of control over their mobility experiences. These findings are consistent with the work of Charmaz,<sup>11</sup> Wiener<sup>34</sup> and Toombs,<sup>9</sup> all of who have written about the process of adapting to mobility losses.

The discomfort expressed by many of the participants in this study about using mobility equipment is consistent with the work of Iezzoni<sup>35</sup> and Miles-Tapping and MacDonald.<sup>36</sup> Like the participants in these earlier studies, participants in the current study often talked about their initial negative feelings about using mobility equipment and then their sense of freedom and control once the decision to use mobility equipment was made. These findings point to the need to talk with clients about their feelings toward the use of mobility aids. Strategies such as short-term loans that allow people to try out equipment may facilitate the process of transitioning to the use of mobility aids for persons with MS. Peer supports may also be useful in this regard in order to share ideas, experiences and feelings with someone who is personally attune to the concerns of the person with MS. There are likely other potential strategies to facilitate the transition into the use of mobility equipment. All of them require further exploration and testing.

The consequences of the mobility experiences that emerged from this study are consistent with the work of both Kohler *et al.*<sup>10</sup> and Iezzoni *et al.*<sup>32</sup> These authors have previously described the psychosocial implications of mobility loss, including emotional loss, altered self-image, decreased opportunities to socialize, fear of abandonment, and decreased independence. All of these implications were seen in the transcripts from this study, and are reflected in the themes of *mourning losses* and *contemplating the future*.

From a theoretical perspective, the findings of this study add to the theoretical work of Carp,<sup>21</sup> which focuses primarily on community mobility. The model that emerged from the themes in this study suggest that the factors that contribute to or moderate personal mobility experiences are the same as those that contribute to community mobility experiences, even though the scope and extent of the relationship may vary. In addition, the themes in this study elaborate Carp's model, by expanding and detailing concepts of control and well-being outcomes. The findings also support her presentation that many factors can both support as well as hinder mobility. Together, the findings in this study and Carp's model are consistent with the emphasis in the field of disability studies on the importance of empowerment and control among persons with disabilities, and the need to challenge current conceptualizations of what it means to be independent.

Although this study produced rich findings about the experience of mobility among older adults with MS, it is limited by the fact that the data were part of a broader study on health concerns and service issues. In addition, no specific MS measure of disability was used in this study making comparisons to more general populations with MS very difficult. While the interview guide addressed broad questions about the experience of having MS, coping with the variability of the disease, and the best and worst parts of having it, there were no specific questions about mobility experiences and losses. At the same time, the fact that participants discussed mobility issues to the extent that they did reinforces the importance that this topic has for this group. The findings also point to the need to reconsider the underlying assumptions of mobility interventions for older adults with MS, and to begin work to reconceptualize what mobility interventions can and should include. Future researchers may want to examine the issues presented in this paper with younger persons with MS, as the current findings are unable to address the extent to which the themes identified are unique to older adults. This is a limitation of the current work.

## Conclusions

This cross-sectional descriptive study used a phenomenological approach to develop an understanding of the experience and meaning of mobility impairment among older adults with MS. This chronic disabling disease is unpredictable in its progress and severity, therefore making it difficult for many people to adapt to and cope with its consequences. The findings from this study show

how the reality of having MS, together with the need for control and choice, interacts with contextual factors to contribute to the overall experience of mobility among persons with MS. These experiences in turn, lead the participants of the study to mourn their mobility losses, and to take actions to influence their future mobility experiences. Nevertheless, their experiences framed their thoughts about the future and lead many of them to fear becoming a burden on family members and worry about having to move to a nursing home. The findings of this study point to the complexity of living with and adapting to progressive mobility impairment, and emphasize that technically-oriented rehabilitation programmes focused on mobility compensation are unlikely to address many of the underlying concerns expressed by participants.

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