Responses to the Acquisition and Use of Power Mobility by Individuals Who Have Multiple Sclerosis and Their Families

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PURPOSE. To develop an understanding of family members’ reactions to the acquisition of power mobility by persons with multiple sclerosis (MS) from the perspectives of the end users and their family members.

METHODS. Data were obtained through semistructured interviews with seven persons with MS using or considering power mobility and four of their family members.

RESULTS. Three major themes emerged from the data. Recognizing the Need for Power Mobility resulted from the interaction between multiple sclerosis progression and the participants’ desired performance. Family decision making and communication, insurance funding and approval, and the physical and social environment were just some of the factors affecting the process of Deciding and Obtaining the Power Mobility. Using Power Mobility resulted in positive, negative, and neutral outcomes.

CONCLUSIONS. This study uncovered an overall lack of resources and some issues within the family environment, such as communication and decision making, both of which can negatively impact the acquisition and use of power mobility for persons with MS. Understanding these challenges may assist occupational therapists to facilitate this transition with their clients.


Introduction

Multiple sclerosis (MS) is a disease of the central nervous system that often presents in young adulthood and lasts a lifetime. The majority of individuals with the disease will eventually need some type of assistance with mobility (Baum & Rothschild, 1983). According to the literature, assistive technology can provide help with both mobility and everyday functional activities (Scherer, 1996). Assistive technology is defined as any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (Assistive Technology Act of 2004). A wide range of assistive devices are available specifically for individuals with mobility limitations; for example, canes, walkers, and manual and power wheelchairs (Copolillo, 2001; Scherer).

A power mobility device, a term that includes both power wheelchairs and motorized scooters, can have a positive impact on the everyday functioning of persons with mobility limitations (Miles-Tapping & MacDonald, 1994). Because of fatigue, balance, and coordination concerns for persons who have MS, a power mobility device offers both a reliable method to get around and an energy conservation solution. Despite the benefits, the process of introducing and matching new assistive technology to each individual is complicated. Both the technological options and the varying characteristics or needs of each client are complex (Kraskowsky & Finlayson, 2001). Literature cites diagnosis, prognosis, preferences, functional status, familiarity, funding, environment, and social supports as important factors in deciding how and when a specific assistive technology device might suit an individual (Scherer, 1996).

For many individuals with MS, family members provide the majority of the care necessary to promote functioning in daily life and therefore can play a big role.
in the decision to use assistive technology (Cockerill & Warren, 1990; Schwartz & Kraft, 1999). Family members may also be affected by other factors that accompany the acquisition of power mobility including those related to finances and the environment (Blustein, 1993). By examining the reaction of a client and his or her family to the acquisition and use of power mobility, it is possible to better understand who can benefit from using power mobility and how family education and communication can facilitate the transition.

The purpose of this study was to develop an understanding of family members’ reactions to the acquisition and use of power mobility by persons with MS from two different perspectives: those of power mobility end users and their family members.

**Literature Review**

MS is one of the most common causes of disabling illness in young adults, affecting approximately 400,000 people in the United States, and more than 2.5 million people worldwide (Dean, 1994; Joy & Johnston, 2001; National Multiple Sclerosis Society, 2004). MS symptoms that influence mobility include balance, ataxia, weakness, fatigue, spasticity, and sensory loss (Ford, Gerry, Johnson, & Tennant, 2000; Freeman, 2001). Mobility impairment is commonly experienced in almost all individuals with MS due to the degenerative nature of the disease (Fay & Boninger, 2002; Freeman).

Research has shown that mobility loss is a major consequence for persons with MS and greatly impacts participation in their daily lives (Fay & Boninger, 2002; Finlayson & Van Denend, 2003). Ford et al. (2000) showed that the higher the individuals' physical functioning and mobility capacity is, the better their quality of life. In a qualitative study by Finlayson & Van Denend, qualitative data from older adults with MS indicated that adjustment to mobility loss is an ongoing process and that the reality of having MS, individual mobility needs (a sense of control and an ability to participate in necessary or valued activities), and contextual factors (equipment, social support, physical environment, and personal factors) all play a part in determining the process of adapting to mobility loss.

Restrictions in mobility can also affect functional status by influencing one’s ability to perform the activities of everyday life. The provision of assistive technology can restore function to persons by offering alternative strategies for accomplishing many of life’s tasks (Blake & Bodine, 2002). Assistive technology increases functional ability and offers independence by either adjusting the task or by performing it in a less physically or mentally demanding way. Assitive technology is an option for someone with MS who is facing mobility loss and is subsequently at risk for decreased function and quality of life (Scherer, 1996).

Attitudes about mobility loss and level of disability are often entangled with the decision to acquire and use assistive technology (Copolillo, 2001; Miles-Tapping & MacDonald, 1994). It is difficult for the person with MS, the therapist, and the family to know the best time to make that transition and how best to begin to adapt psychologically to the introduction of the equipment (Copolillo; Scherer, 1996). The psychological perspectives of everyone involved about disability, equipment, assistance, and environment seem to play a role in decision making (Scherer).

A power mobility device is an example of assistive technology that can offer a mobility solution for persons with MS. Power mobility serves persons with MS by expanding their environment and enabling the users to be more productive. Studies by Buning, Angelo, and Schmeler (2001) and Miles-Tapping and MacDonald (1994), indicated that in addition to increased functioning and independent mobility, power mobility also offers psychosocial benefits that lead to increased participation in life. Yet, environmental inaccessibility, high cost, and lack of adaptation to disability are strong deterrents of power mobility use (Blake & Bodine, 2002; Kraskowsky & Finlayson, 2001). Alternatively, increased use of power mobility has been found in supportive physical and social environments and when family encouragement and realistic expectations are present (Copolillo, 2001).

For many individuals with MS, family members provide the majority of the care necessary to promote functioning in their daily lives (Cockerill & Warren, 1990). In addition, family members are the major source of social support (Wineman, 1990; Cockerill & Warren). Because of their emotional and caregiving proximity, family members can play a major role in any health-related decisions (Blustein, 1993). Family members become a key part of the decision making surrounding power mobility because they are potentially affected in two different ways—financially and by environmental modifications needed to accommodate the mobility device (Blake & Bodine, 2002; Wineman). In addition, the acquisition of a power mobility device will likely affect family members through their loved ones’ newly discovered mobility, means of energy conservation, and increased participation in life (Freeman, 2001). Consequently, the reactions of family members need to be factored into decisions regarding the transition to power mobility. As part of the environment, family members can represent either a barrier for someone with MS or a support in terms of making decisions and participating in life.
Therefore the reactions of family members to transitioning to power mobility are especially important, yet, this piece is absent in the literature. Thus, the guiding questions for this study were:

• What factors lead to the acquisition of power mobility for persons with MS?
• How do family members react to the acquisition of power mobility by a person with MS?
• How are personal reactions and the reactions of family members understood by persons with MS in relation to their power mobility use?

Design and Methods

The study used a grounded theory approach to address the research purpose and questions, given that little is known about the role of the family in the acquisition and use of power mobility (DePoy & Gitlin, 1998). The data were collected through semistructured interviews that were conducted with two groups of persons: power mobility users currently living with family, and family members of persons with MS (currently power mobility users or those in the process of acquiring power mobility). All methods for this study were approved by the university’s human subjects ethical review board (IRB).

Recruitment and Sampling

Convenience sampling methods were employed with both power mobility users and family members of power mobility users. Recruitment involved: doing a presentation to four local MS support groups, sending 29 letters of invitation to participate to previous participants of another MS study (Finlayson, NMSS Contract #HC0049), and a snowball sampling of current participants.

When persons called to express interest in the study, they were screened to determine whether or not they fit the inclusion criteria: having MS, 18 years of age or older, already acquired or in the process of deciding to acquire power mobility, living with at least one family member, and using (or desiring to use) power mobility inside and outside the home. Inclusion criteria for family members included: living with a family member with an MS diagnosis, 18 years or older, having a family member who has power mobility or is deciding to acquire it, and the family member uses (or desires to use) power mobility inside and outside the home. Potential participants were excluded from either group if they were not able to speak English or were unable to schedule an interview in the 4-month period in which data collection occurred.

Three persons with MS were recruited through the support groups, six persons with MS were recruited through the existing study, and four family members were recruited through snowball sampling. Two persons with MS were excluded because they were not living with family and not using power mobility (or desiring to), resulting in 11 study participants.

Procedures

The participants were notified at the time of the screening about the consent process. They were sent a copy of the consent form immediately after screening and were phoned within 1 week to find out if they had any questions and to arrange an interview. Each interview began by explaining the consent process and signing the consent form. The data were then obtained through face-to-face semistructured interviews designed to identify concepts related to the acquisition of power mobility and family members’ reaction to this acquisition. Examples of some of the questions asked during the interview included: What made you first start thinking about getting a power wheelchair or scooter? What factors seemed important to consider when making the decision? How did the power wheelchair or scooter change normal household operations? (probe: physically, socially). In addition, the interviews provided insight into how concepts were contextualized in one’s everyday life. The Canadian Model of Occupational Performance (CMOP) was used as a backdrop for the interview guide development to ensure a strong person–environment focus was used and that broad environmental issues were addressed (i.e., physical, cultural, social, and institutional) (Canadian Association of Occupational Therapists, 1997).

The interviews each lasted between 25 minutes and 100 minutes (mean: 52 minutes, standard deviation: 14 minutes). The first author conducted and audiotaped all interviews. Each interview took place in the participant’s home, at his or her request. The interview ended with the participants filling out the sociodemographic questionnaires that provided basic information used to describe the sample (e.g., age, length of MS diagnosis, common MS symptoms, type of assistive technology used, etc.). The questionnaire for family members was adjusted so that questions were framed in relation to the person with MS. After the interview, all interviewees participated in a member-checking process. As part of this process, a short summary of the main points of the interview was prepared and mailed to the participant. One to 2 weeks later, the first author contacted the participant by phone to obtain feedback about the accuracy and interpretation of the themes within the summary. Changes to the summary were negotiated with the participant.
Data Analysis

The first author transcribed all of the interviews verbatim and the transcript was checked against the audiotapes for accuracy. Data were then analyzed through the constant comparative method, which systemizes the continuous comparison of previously analyzed data and new information (DePoy & Gitlin, 1998; Strauss & Corbin, 1990). As part of this method, the data analysis included the specific procedures of open coding, axial coding, and conclusion drawing.

Both authors independently used open coding techniques to analyze the first four transcripts. Open coding can be defined as the operation of selecting, creating, and naming categories from looking at the raw data (Miles & Huberman, 1994). Each author constructed a master list of themes that she saw emerging consistently in the transcripts. The authors then met to share the main themes that they found and to discuss how the themes could be defined. Using these agreed-upon definitions, subsequent transcripts were coded by both authors. Notes were made regarding inconsistent themes or new codes not addressed by the initial master list. The authors met again to revise the list of themes and definitions and to begin to discuss how the themes were relating to each other. “Hunches” or questions about the meaning and ordering of particular parts of the transcripts were recorded in analytic memos for later reflection. Computer software (ATLAS) was used in the coding process after the open-coding steps to allow for management and flexibility while analyzing the meaning and prevalence of codes (Muhr, 1998).

Axial coding was the second phase of the analysis process (Strauss & Corbin, 1990). During the phase, transcripts were compared to identify differing conditions and circumstances across all participants. The ATLAS program was used to assist in the organization and comparison processes (Muhr, 1998). Emerging patterns were examined, and how, when, and with what frequency themes arose. The member-checking and analytic memos were used during this part of the analysis to increase the rigor of the analysis. This triangulation of the data, checking ideas from multiple sources, strengthened the accuracy of the interpretations. The final stage of analysis was conclusion drawing, during which each major theme was prepared in narrative format to demonstrate the nuances of the data. Key participant quotes were chosen to illustrate the theme and capture the experiences of persons with MS and their family members.

Results

Throughout the process of analyzing the data, it became apparent that the themes within the interviews with the persons with MS were the same as those in the family member interviews. Yet, the experiences with MS for the persons who had the disease were inherently different than those of family members. Therefore, throughout the results, the participants will be identified as a person with MS (PWMS) or a family member (FM) so that these differences can be highlighted. Table 1 provides basic descriptive information about each of the participants in order to provide context for the participant's quotes. It is important to note that while the term “power mobility” is most often used in the literature, “electric wheelchair” was most often used by study participants. Furthermore, other common terms in literature and used by participants include “power chair” and “power wheelchair.” All terms are used interchangeably in this section.

During the qualitative interviews, three major themes and seven minor themes emerged. The major themes are as follows: Recognizing the Need for Power Mobility, Deciding and Obtaining the Power Mobility, and Using Power Mobility. Each will be discussed in turn.

Table 1. Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>PWMS or FM</th>
<th>Age</th>
<th>Sex</th>
<th>Years With MS</th>
<th>Years With PM</th>
<th>Current PM Status</th>
<th>Spouse in Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sandy</td>
<td>MS</td>
<td>31</td>
<td>F</td>
<td>9</td>
<td>3</td>
<td>Scooter</td>
<td>Sam</td>
</tr>
<tr>
<td>Irene</td>
<td>MS</td>
<td>60</td>
<td>F</td>
<td>22</td>
<td>0</td>
<td>Waiting</td>
<td>-</td>
</tr>
<tr>
<td>Karen</td>
<td>MS</td>
<td>65</td>
<td>F</td>
<td>24</td>
<td>20</td>
<td>PWC</td>
<td>Ken</td>
</tr>
<tr>
<td>Phillip</td>
<td>MS</td>
<td>66</td>
<td>M</td>
<td>28</td>
<td>20</td>
<td>PWC</td>
<td>Kathy</td>
</tr>
<tr>
<td>Susie</td>
<td>MS</td>
<td>49</td>
<td>F</td>
<td>18</td>
<td>9</td>
<td>Scooter</td>
<td>-</td>
</tr>
<tr>
<td>Robert</td>
<td>MS</td>
<td>72</td>
<td>M</td>
<td>30</td>
<td>5</td>
<td>PWC</td>
<td>Linda</td>
</tr>
<tr>
<td>Julie</td>
<td>MS</td>
<td>65</td>
<td>F</td>
<td>30</td>
<td>7</td>
<td>PWC</td>
<td>-</td>
</tr>
<tr>
<td>Sam</td>
<td>Family</td>
<td>32</td>
<td>M</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Sandy</td>
</tr>
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<td>62</td>
<td>F</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Phillip</td>
</tr>
<tr>
<td>Ken</td>
<td>Family</td>
<td>65</td>
<td>M</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Karen</td>
</tr>
<tr>
<td>Linda</td>
<td>Family</td>
<td>69</td>
<td>F</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Robert</td>
</tr>
</tbody>
</table>

Note. Current PM Status = kind of power mobility that the person owns or is currently using most often; F = female; M = male; MS = multiple sclerosis; PM = power mobility; PWC = Power wheelchair (4-wheel); Years With MS = number of years person has been diagnosed with MS; Years With PM = number of years person has owned power mobility of any kind; Spouse in Research = participant has a spouse that was interviewed and is also part of the table.
Recognizing the Need for Power Mobility

The minor themes within this first major theme (Figure 1) centered on the fact that although persons had often considered power mobility for an extended period of time, they described a moment when they had to face the reality of needing power mobility. This reality stemmed from a dynamic interaction between: recognition of necessity, MS progression or perceived loss of independence, desired performance, and perceptions.

Recognition of necessity: Many factors lead to participants’ final decision to acquire a power mobility device. Despite this variability, each participant discussed a moment in time when they recognized that the power mobility device was necessary. This recognition often came as a result of the MS symptoms worsening or loss of the ability to participate in a valued activity. Irene (PWMS) was in the process of trying to transition to power mobility at the time of the interview. She explained her mindset at that time:

*I don’t think we had a choice in any of these matters. . . . I mean, you have MS and you can’t walk, you’ve got to do something to give you mobility.*

Phillip (PWMS), a 66-year-old man who had been using power mobility for almost 20 years at the time of the interview, described the moment that he and his wife, Kathy, decided they were ready for power mobility:

*And we needed something, it was almost a mutual thing. There wasn’t really time you thought about it. It was not a shocking . . . it was more of a mutual understanding.*

This moment of “knowing” was often discussed in the context of “lack of choice” or something they had been “denying”; for example, Karen (PWMS) noted: “I admit that I couldn’t do it anymore.” Interestingly, throughout the interviews, there was only one example of any medical professional (doctor, physical therapist, occupational therapist) recognizing the need for power mobility and presenting it to the participant. In other words, even in the absence of any professional guidance, participants with MS and their family members are recognizing the need to “go out on their own” to get this done.

Multiple sclerosis progression or perceived loss of independence: When asked to discuss their transition to power mobility, both the participants with MS and family members would preface their response by describing their “story” with the disease. Participants discussed the MS progression in terms of a lack of ability to do things and intertwined the increasing symptom severity of the MS with being less useful or independent.

*At this point, um, his physical, um, state is getting worse and I need help. It’s been overwhelming for quite a while.*

(Linda–FM)

Others discussed the way that specific symptoms progressed and how that was evidenced in their everyday lives or the lives of their family members. Most participants with MS discussed the way that their walking was affected by the MS progression, and they listed their difficulties walking as a major catalyst to obtaining the power mobility. Sandy (PWMS) explained the way that weakness had led to her acquisition of power mobility when the interviewer asked what issues had seemed important to consider during this transition:

*The weakness that I had in my legs. The inability to walk at all, or even move my legs . . . the helplessness that I felt when I couldn’t do those things . . .*

Karen and Robert, two participants with MS, discussed their progression no differently than other participants with MS; however, their caregivers both discussed how debilitated they had become in much greater detail and for a longer period of time than any other caregiver. The differences in the way participants talked about this theme influenced whether they really seemed to see the decision to obtain power mobility as a choice “to do something about problems walking” or as an inevitable sign of “becoming useless.”

Desired Performance: This theme ultimately centered around one specific expectation or desire for performance that was only possible if power mobility was used. This theme often appeared in conjunction with the participant’s discussion of the way that the MS had progressed to limit their participation in this valued activity. Sandy (PWMS) explained how the activity of washing clothes in her apartment building’s basement changed when she transitioned to power mobility:

*I was thinking how much I can wash now . . . You know, whenever I can’t walk, I can’t walk down those flight of stairs and then half the time I can’t even walk to the hallway to get to the elevator.*

Julie (PWMS) explained why she had wanted to transition originally from the manual wheelchair:

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Figure 1. Recognizing the need for power mobility.
No, I wanted it...because it got to the point when I had to go
to the bathroom...he [husband] had to push me. He had to
take me to the bathroom all the time.

Irene (PWMS), who has not yet acquired power mobility,
mentioned that she can’t wait to go to the mall once she
makes the transition, “to buy things or not, just to go.”
Overall, participants with MS had a much clearer descrip-
tion of what they had wanted to participate in once they
acquired power mobility, whereas family member partici-
pants really just discussed “getting around” as the only val-
ued activity that gave rise to needing the power mobility. In
other words, family members’ perspectives on the need for
and value of power mobility were more limited, whereas for
the persons with MS, power mobility was viewed as a tool
through which a wide range of everyday activities could be
enabled.

Perceptions: In some cases it was the person with MS
alone recognizing the need for power mobility, and in some
cases it was only the family member “faced with making
those types of decisions as to what’s best.” Occasionally
there was close consultation between family members and
the person with MS. Regardless of who was recognizing the
need, the participants thought about some similar questions
during the process like “Is the MS getting worse?” or “Does
the doctor have an opinion?” Although the persons with
MS were also considering how the power mobility might
make them more independent, family members were hop-
ing the power mobility might decrease the amount of care-
giving they were doing. Likewise, persons with MS often
wanted to acquire power mobility to engage in a specific
meaningful activity, and caregivers were really only hoping
it would get their loved ones “around better.”

Deciding and Obtaining the Power Mobility

The emphasis of the second major theme (Figure 2) in the
participant’s interviews revolved around the process of deciding
to acquire power mobility. This theme included the sub-
theme of finding information and advice. The quotes and
context of this theme include the participants’ challenges
and creativity while finding and using resources for obtain-
ing a power mobility device. After the complex and chal-
lenging process of deciding to obtain power mobility, the
participants then discussed the many influencing factors that
made an impact on the quality of the match between the
person, the power mobility device, and their environment.

Process of deciding: This theme emerged in the partici-
pants’ narratives once they (either persons with MS or their
family members) recognized the need for power mobility and
involved exploring the questions related to acquiring
power mobility. In this case, the process of deciding encom-
passed the period of answering all of the ambiguous ques-
tions related to acquiring power mobility like, “what kind,
from whom, when, where, how, etc.?”

Finding information and advice: In the interviews, par-
ticipants with MS and their family members described the
process of exploring initial acquisition of power mobility by
finding information and advice. It was during this time that
participants with MS and their family members explored
what resources were available. They looked to television,
salespeople, the National Multiple Sclerosis Society, health
professionals and people on the street. Overall, the opinion
of the resources available for a person with MS about to
make the transition was very negative. The participants
described the process as challenging, not only to find the
resources but also because the key figures involved showed
a lack of respect for the persons with MS and their family
members. Kathy (FM) had this to say:

...People who supply medical paraphernalia are the most
insensitive, give you the least service, the worst service, I've just
never seen such a group of people. But of course, they can do
whatever they want to because if you need a wheelchair, you're
going to have to buy a wheelchair, you know what I mean?

Phillip (PWMS) is a man who has needed resources in
obtaining several kinds of power mobility over the last 20
years:
I don’t remember what the questions were, they were probably silly questions, but I’m a customer. And the therapist was like, oh, pooh-poohing me, don’t worry about it.

Julie (PWMS) has been using power mobility for 7 years and explained her doctor’s reaction when she first went in to ask about information or a prescription for power mobility:

Yeah, he goes like this. After 25, 26 years, I guess he knows me. “What do you want this time, Julie?”

But as Kathy (FM) pointed out, the participants couldn’t avoid power mobility just because they couldn’t depend on salespeople or medical professionals. Some participants and family members just bought the first power mobility device that they found, whether it was the only store they could find in the yellow pages or the one they had seen advertised on TV. Other participants talked about the importance of being a good consumer. They emphasized trying several different electric wheelchairs and scooters and pushing salespeople to meet their needs. By far, the best source of advice that participants identified was other persons with MS whom they saw on the streets or met in MS support groups. Many participants also stressed that the process of finding information and advice was an ongoing one as long as they were using the equipment.

Influencing factors: In determining how positive their experience was and whether or not the participants acquired the right kind of power mobility seemed dependent on many different factors. Family decision making and communication, insurance funding and approval, the physical environment, and the social environment all had an impact on how well the power mobility offered the solution the participants were hoping for. Two other themes, matching types of power mobility and further MS progression/changing needs, were also discovered but weren’t mentioned as frequently, so will not be discussed below.

Family decision making and communication: The participants talked about the way their family made the decision to acquire power mobility and other important health care decisions related to MS. In some cases, members of the same family had different interpretations of how decision making was done. One couple, Robert and Linda, described their communication regarding acquiring the power mobility. When Robert (PWMS) was asked how his acquisition of power mobility 5 years ago affected his wife, he implied that he hadn’t actually asked her and “hoped she didn’t mind.” In her interview, Linda (FM) described how the chair “just showed up one day” and how she didn’t have “any say at all.” Ken (FM) described how he often makes the final decision himself:

You know, we talk about things and um, if nothing gets done, I may just eventually just force the issue and go do something

. . . Since as the caregiver, I’m faced with making those types of decisions as to what’s best.

Lack of communication or joint decision making seemed to influence the way one perceived power mobility. In addition, the level of equality and power dynamics between family members in the decision making, communication, and support around health care issues played an important role in determining the nature of the reactions and adjustment to power mobility. Although participants with MS did not discuss giving up their share of ideas or decision making in the context of any family issues, several caregiving family members expressed that, as the caregiver, they were “burdened with decision making,” with doing what they “had to do” and always had to “figure out what to do.”

Insurance funding and approval: A stressful part of transitioning to power mobility was dealing with the logistical issues such as getting the doctor’s prescription, getting insurance approval, and/or paying for the equipment. The common experience described by the participants was that once they decided independently to acquire power mobility, they then had to ask the doctor for a prescription. Ironically, this often included explaining to the doctor why they felt that they needed power mobility or even “asking permission.” In addition, most participants also explained that they had to orchestrate the communication between the insurance company and the doctor’s office. Sandy (PWMS) explained the difficulties she had with the communication between parties when recently acquiring her power mobility device. It took multiple tries to get the doctor to give the needed content to the insurance company so she could be approved.

None of the participants were actually kept from obtaining power mobility because of insurance coverage, but many had to appeal a denial more than once to eventually receive funding. The cost of the equipment, varying from company to company on insurance coverage, was equally a major concern for persons with MS and their family members.

Physical environment: Inability to get in and out of places had a big impact on persons using power mobility. Participants explained how it was common practice to call wedding halls, restaurants, movie theatres, and friends’ homes to check for accessible entrances, seating, and bathrooms. Participants with MS and their family members explained the way they always plan ahead to be aware of physical environment including accessibility obstacles. But inaccessibility was a problem that also existed in the majority of the homes of persons being interviewed.

I’m thankful for the chair. But I’m, I’m a little, I guess you could say, unthankful for the space that we have. The limited amount of space . . . (Sandy–PWMS)
The social environment also influenced the daily lives of persons with MS using power mobility. The first way in which participants talked about the social environment was as a negative societal attitude that they felt was aimed at their “obvious” disability while sitting in a power wheelchair. Sam (FM) described how the social environment influences him when he goes out in public with his wife in her electric wheelchair. He sees “people staring” and wondering why his wife is in a wheelchair, but he just tries to ignore them. Other times, the reactions from persons are more overt and difficult to ignore as Irene (PWMS) spoke about how the power mobility can scare children. Societal stigma associated with disability can even vary depending on what kind of equipment a person with MS is using.

The other way that participants discussed the social environment was in terms of their immediate social network of relationships: neighbors, friends, and family members. Susie (PWMS) describes the negative social environment she is exposed to daily in her place of residence.

Well, there’s people in this building that are pretty nasty when they see scooters. Not everybody’s nice, so . . . they just don’t like the fact that um, disability is noted.

The social environment was also discussed in a positive light. There was some consensus between participants and family members that the negative social reactions often became easier to adjust to and respond to as time with the equipment increased.

**Using Power Mobility**

**Outcomes:** Outcomes are the effects that occur as a result of the decision to acquire and use power mobility. Outcomes can be classified not only by being more inherently positive (or negative or neutral) but also by the temporality of the outcomes (see Table 2).

**Positive outcomes:** One of the first positive outcomes that resulted from power mobility was better mobility. Participants explained they had more control over their mobility, they could move more quickly with less effort, and that they were less dependent on others to get around.

Okay, I can go from one room to the other very quickly and uh, you know, for me to walk from here to the bedroom or the bathroom, would be difficult and this thing makes it very simple. (Robert–PWMS)

The most frequently emphasized positive outcome that emerged from the interviews resonated around the word “freedom.” Participants with MS talked about freedom to do things on their own, and family member caregivers talked about the freedom they found in their own lives by leaving their loved ones on their own. Kathy (FM) poignantly explains the positive impact for her husband:

So now with the van and the electric wheelchair, then he can just leave here and does. Or get himself out to the garage to practice, and then I won’t hear him for a while and he’ll say, oh, I decided to take a ride, went to visit someone or you know, went to get a hamburger or something. Which is just something he hadn’t done, ever, do what he wants to do.

**Negative outcomes:** The negative outcomes of acquiring and using power mobility were also scattered throughout all of the interviews. Some interviews were more inherently positive towards the equipment, with the negative outcomes discussed as being only minor annoyances. But a few of the interviewees discussed that it was the negative outcomes that had more of an impact on their lives. Julie (PWMS) discussed the destructive force of the equipment, which was one of the major findings in terms of negative outcomes of power mobility. Julie sadly mentioned that when she hits and leaves marks on the walls, the door frames, and the floor, she was “ruining the house.” Lack of access was another major component of the negative consequences of power mobility. Participants described their experiences with lack of ability to get into places they really feel they need to go.

Most of my children’s homes are not handicap accessible. And so, we have been invited less . . . (Linda–FM)

Facing stigma, although also a part of the social environment and an influencing factor affecting power mobility use, was another negative outcome. Karen (PWMS) describes that often people ask her husband questions for her, because they just assume “if she can’t walk, she can’t talk.”

Interestingly, most of the caregivers who were interviewed (three out of four) all mentioned that safety concerns were also a negative outcome for using power mobility. The caregivers described that they were constantly worried that unlimited mobility would tend to get their loved ones into unsafe situations that they couldn’t get out
of. None of the participants with MS mentioned similar concerns.

Adjustments: The last subtheme discussed what the participants’ “hindsight” had taught them. They emphasized that regardless of what one’s experience was, some adjustments were required as part of this power mobility experience. They talked about the knowledge and expertise they had acquired from just taking part in the process of acquiring and using power mobility. Within this subtheme, the participants identified the following components as major “learning lessons” of the experience: get equipment earlier than you think you should, be your own advocate in society and in the health care system, and learn to modify your home to make life easier.

Discussion

The purpose of the study was to examine the reactions and interactions between persons with MS and their family members to acquiring and using power mobility applying a grounded theory approach. Participants’ interviews revealed some interesting dynamics around family communication on the topic of recognizing the need for power mobility. The results showed that lack of communication was the norm rather than the exception. As a result of the poor communication, spouses were not making health care decisions together or even talking about MS issues as they pertained to decision making. Consequently, it was often just the family member or just the person with MS alone making the decision to acquire power mobility. This finding of poor family communication is important given Wineman’s (1990) findings about the influence of interactions between the person with MS and their family members, and that decreased adaptation to the MS can occur if interactions are perceived as unsupportive. Furthermore, when just the family member is making the decision, there could be a detrimental effect on the psychosocial well-being of persons with MS if they feel they don’t even have some control over or input into what kind of equipment they obtain. Previously published literature supports this concern by citing that spousal responses to the MS that are negative or overly concerned lead to greater MS disability and emotional distress (Schwartz & Kraft, 1999).

Most of the research about persons with MS and their family members is from the perspective of urging health care professionals to make an effort to consider the family when providing best health care practice (Blustein, 1993; Cockerill & Warren, 1990). However in this study, the participants with MS were obtaining power mobility independently of a health care professional. A major finding of the participants’ interviews was the absence of resources and/or credible information available for persons with MS and their families while in the process of acquiring and using power mobility. This finding is quite striking given that participants were recruited through the National Multiple Sclerosis Society. Both the assistive technology and the MS literature commonly support the idea that health care professionals, including physicians, neurologists, and therapists, are front and center when prescribing power mobility to first time users (Buning, Angelo, & Schmeler, 2001; Copolillo, 2001). Instead, according to these participants, almost all of them bought their power mobility device directly from the vendor without any kind of intervening professional expertise, much less the seating and technology specialists that are located at the top rehabilitation clinics. As a result, the participants with MS and their family members had negative perceptions of their physicians and neurologists for not answering their questions, anticipating their needs, or making helpful referrals. Family member participants also emphasized that a major part of their caregiving duties included discovering things on their own and that most of their experiences with equipment vendors were extremely negative.

Although the literature based on samples from clinical populations counters the idea that persons with MS don’t have access to the resources and professional expertise they need, the findings from this study are consistent with Iezzoni (2003). Iezzoni discusses the only way the current situation could be remedied, with her own fictional creation—the “mobility mart”—where information about diverse mobility equipment, peer counselors, health insurance specialists, physiatrists, therapists, and mobility training would all be available with one-stop shopping. Iezzoni also emphasizes that access to resources could be improved if doctors and neurologists made referrals to therapists and specialists on a more consistent basis.

When considering all of the factors influencing the process of obtaining power mobility and the overall lack of access to information and advice, it is not surprising that the persons with MS in this study often found that they did not always find the best match with their first power mobility device. One article focused on the initial experiences with power mobility and discussed how it offers a unique solution for increased participation in life (Miles-Tapping & MacDonald, 1994). Whereas some of this study’s participants described the same benefits with power mobility, they also discussed acquisition as a never-ending cycle. Based on either their MS progression or other environmental factors, one particular power mobility device was not the final solution. The implication for professionals is to determine how to be there to provide the appropriate resources to make a better match between the device, the person, and the environment.
The outcomes that participants discussed in their interviews were varied and included many positive and negative effects of using the power mobility in their everyday lives. Although there were more varied negative outcomes named by participants, the overall feeling from most of the participants is that they wouldn’t know how to get along without it. The literature supports the study’s findings that users describe their power mobility-afforded freedom with great zeal (Miles-Tapping & MacDonald, 1994).

Another component to the outcomes of using power mobility that has not been widely explored in the literature is the temporal aspects of the effects of power mobility. Although some participants did not use power mobility all day everyday, they will most likely be power mobility users for life. Based on the interviews of participants (some had been using power mobility for over 20 years), it was possible to ascertain how some of the outcomes changed over time. For example, although societal reactions to disability might (or might not) change, the impact of stigma on a person’s daily life may be reduced over time. In further exploration, it would be interesting to discover what kind of outcomes are short-term, long-term, or variable in length.

The findings of this study must be considered in the context of its limitations. First, only four family members were interviewed, and therefore important family perspectives could have been missed. In addition, the recruitment strategy likely biased the sample towards individuals who had already thought about their power mobility use, either positively or negatively, and wanted to share their ideas. A third limitation of the study was interviewing the participants only one time. Whether they had newly acquired the power mobility device, or had been using power mobility devices in some form or another for 20 years, the participants were very much engrossed in what their current situation was. They had difficulty reflecting on how things had become easier, more difficult, or how they anticipated changes as time went on. Future research should address the acquisition and use of power mobility from a longitudinal perspective. Finally, all participants lived within a large urban center, and therefore the perspectives of individuals from more rural areas were not obtained. It would be reasonable to assume that persons with MS in more rural areas might have less access to health care specialists than the participants in this study.

Conclusion

The purpose of this study was to examine the process of power mobility acquisition and use for persons with MS. Results illustrated that there were three major phases of the process: recognizing the need for power mobility, deciding on and obtaining power mobility, and using power mobility. The findings further showed that family members often did not communicate regarding MS issues or make power mobility or health care related decisions together. In addition, the findings revealed that persons with MS and their family member caregivers encountered difficulties in finding credible sources for information and advice concerning power mobility.

As a result of this study, two major clinical implications for occupational therapists became evident. First, when working with a person with MS, it is important to also work to understand a particular family environment before recommending power mobility in an effort to improve the match of the person, equipment, and environment and future outcomes. Health care professionals have a responsibility to provide resources and equipment that can change as clients’ needs change. The study has further shown that actions must be taken for health care professionals to anticipate the resource needs of persons with MS and their family member caregivers. Individuals in the study were going to vendors first because health care providers were not raising the issue of power mobility with them.

References


