Constantly Changing Lives: Experiences of People With Multiple Sclerosis

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The purpose of this study was to gain an enhanced understanding of how people with multiple sclerosis (MS) experience their engagement in occupations. We interviewed 10 people and then analyzed the data gathered using the constant comparative method of grounded theory. The findings encompassed the core category “essentials of a constantly changing life,” showing that along a continuum of change, the participants experienced a decreasing engagement in occupations that forced them to continuously struggle to maintain engagement. This struggle changed them and required them to construct a different life than before. Our findings suggest that professionals working in MS rehabilitation need to broaden their repertoire of interventions relevant to conditions in clients’ social environment, with the intention of influencing those occupations that are individually most meaningful. Occupational therapists should focus on the client’s engagement in occupations and its consequences for the client’s life and self-identity.


A major aim for occupational therapists and other rehabilitation professionals is to enable clients to engage in meaningful and purposeful occupations. Kielhofner (2008) defined occupations as consisting of three broad areas of doing: (1) activities of daily living (ADLs; life tasks required for self-care and self-maintenance), (2) play (e.g., hobbies, games), and (3) productivity (unpaid and paid work). In recent years, the concept of engagement in occupations has been introduced and defined as the person’s involvement in and motivation to participate in an occupation even if he or she cannot perform it independently (Kielhofner, 2008; Townsend & Polatajko, 2007). It is, therefore, crucial for professionals to learn more about how clients experience engagement in occupations, the conditions influencing engagement, and how possible changes in engagement influence clients.

It is well known that as it progresses, multiple sclerosis (MS) leads to limitations in occupational performance (Doble, Fisk, Fisher, Ritvo, & Murray, 1994; Einarsson et al., 2003; Granger, Cotter, Hamilton, Fiedler, & Hens, 1990; Månsson & Lexell, 2004). More specifically, when people with MS were asked about the occupations they found difficult to perform, they reported all types of occupations, but household management was most prominent (Finlayson, Impey, Nicolle, & Edwards, 1998; Lexell, Iwarsson, & Lexell, 2006). Likewise, household occupations were found to be more difficult to perform than self-care occupations when objective, standardized assessments of performance were used (Månsson & Lexell, 2004). Moreover, when people with MS rated their performance and satisfaction with their performance, ratings were generally low, but no further analysis has been conducted to determine why (Lexell et al., 2006). Thus, previous studies on occupations of people with MS focused on limitations of performance, described
which occupations clients perceived to be difficult, and described the extent to which people have difficulties performing different occupations. Because these studies focused on performance, the circumstances influencing performance were not explored. There is reason to believe that if the possibility of performing meaningful occupation changes, engagement in occupation will be influenced, but this remains to be explored.

Although research on engagement in occupations is rare, several studies of women with disabilities, some of whom had MS, have explored engagement in occupations; these studies concentrated on the impact that occupations have on identity and the role that the home environment plays in engagement. The studies on identity revealed that changed or reduced occupations influenced the women’s identity and that the possibility of continuing engagement in meaningful occupations could provide a source of positive identity for people living with chronic illness (Magnus, 2001; Reynolds & Prior, 2003). A study of the home environment concluded that person–environment interactions influenced participants’ experiences of engaging in occupations and the meaning their home held for them (Lund & Nygård, 2004).

In addition to these studies, other studies have explored the experience of living with MS, focusing on psychological aspects (Courts, Buchanan, & Werstein, 2004; Miller, 1997), common physical symptoms (Flensner, Ek, & Söderhamn, 2003; Koch & Kelly, 1999; Olsson, Lexell, & Söderberg, 2005), and quality of life (Reynolds & Prior, 2003; Somerset, Sharp, & Campbell, 2002). These studies only briefly touched on occupations but showed that common MS symptoms influence engagement in occupations and that being able to engage in occupations is important to having positive quality of life and living with MS. Because these studies focused on only certain aspects of the experience of engagement or indirectly on occupations, the entire range of consequences of engagement in occupations remains to be explored in people with MS.

Our aim in this study was to gain an enhanced understanding of how people with MS experience their engagement in occupations.

**Method**

**Research Design**

We adopted a qualitative approach aimed at describing experience from the participants’ perspective. We chose the constant comparative method of Grounded Theory (Strauss & Corbin, 1998) to reveal, inductively, interaction experiences and their meaning, such as person–environment–task interactions during engagement in occupations.

**Sociopolitical Context**

We should provide some basic information on sick-leave benefits and social service support in Sweden. When a person falls ill for >14 days, he or she is entitled to sickness benefit through the National Social Insurance Agency. In addition, people between ages 30 and 64 who have a reduced work capacity, whether permanent or temporary, can also apply for full or partial sickness compensation, which will depend on the agency’s assessment and formal decision (Swedish Social Insurance Agency, 2009).

Turning to the diverse legislation regarding social support, we should state that an underlying principle is that all humans are of equal worth and have the right to be able to participate in society equally. One public act regulates the social services that those with disabilities can receive from the municipality in the form of, for example, home help. Another act regulates the service support available to people with more severe disabilities who are in need of more frequent assistance, for example, personal assistants.

**Participants**

The participants were 6 women and 4 men with MS, of whom 8 had secondary progressive MS and 2 had relapsing remitting MS. They were selected from among 38 people with MS who had completed a period of interdisciplinary rehabilitation at a rehabilitation center in the south of Sweden during 2005.

Potential participants were identified by a clinical occupational therapist and Eva Månsson Lexell, working together. A purposive sampling strategy guided the selection (Patton, 1990), using these three inclusion criteria: (1) moderate limitations according to different assessments of occupational performance during the rehabilitation period, (2) ability to understand and actively take part in an interview, and (3) having no other diseases influencing occupational performance. We sought a heterogeneous sample to reflect a variety of experiences. Thus, several factors, such as age, sex, and type of limitations on occupational performance, underlaid participant selection. In the first phase, 9 potential participants received written and verbal information about the study, 6 of whom gave their informed consent to participate. When the interviews had been completed, another 4 people were contacted to include more women’s experiences, reflecting the higher proportion of women with MS and to broaden the spectrum of occupational performance limitations. The 10 completed interviews were found to have enough variety to ensure the study’s quality.

According to the assessments of occupational performance recorded during the rehabilitation period, the participants had difficulties in all areas of occupation (i.e., self-care,
play, productivity). All stated that they received assistance with different occupations from their family, friends, or both. One participant had been offered home help but had rejected it. Eva Månsson Lexell performed an assessment using the Expanded Disability Status Scale (EDSS; Kurtzke, 1983) after every interview had been completed to describe each participant’s severity of disease. EDSS rates disease severity on a scale ranging from 0 (normal) to 10 (death due to MS). A score of 0 to 5.5 indicates no assistance required when walking, 6.0 to 6.5 indicates the need for unilateral or bilateral assistance and an ability to walk 100 m or less with or without rest, 7.0 to 7.5 indicates that the person moves about mainly in a wheelchair, and 8.0 to 8.5 indicates that the person is restricted to an electric wheelchair. Table 1 summarizes the participants’ characteristics.

The regional ethical review board in Lund, Sweden, approved the study (LU-270/2006).

Data Collection

All of the interviews were undertaken by Eva Månsson Lexell and took place in the participants’ homes. The interviews included questions concerning how the participants experienced their engagement in occupations, using a semistructured interview guide (Kvale, 1997). Every participant was asked to recount his or her experiences in as much detail as desired. When clarification was needed, Lexell posed follow-up questions, using the wording provided in the relevant participant’s descriptions. During the interview, participants were asked which occupations they were involved in on a typical day and whether they were aware of how their engagement in occupations had changed over the years since the onset of the disease. If their engagement in certain occupations had ceased or new or alternative occupations had been initiated, they explained this, but on a more moderate level. When participants were aware that their engagement was no longer the same as it had been, they were asked to explain how it had changed. Participants were also asked whether there were occupations in which they would like to engage and whether they had to change their daily routine of occupational performance. Finally, each participant was also asked whether and how personal assistive devices, support, or both influenced engagement in occupations.

All participants were interviewed once, with one exception; 1 participant was interviewed twice because of technical problems that occurred during the recording. All interviews were tape recorded and transcribed verbatim. The mean length of interviews was 82 min (range = 38–133 min).

Data Analysis

We analyzed the data by means of the constant comparative method (Strauss & Corbin, 1998), starting with reading each interview carefully to gain an understanding of its content. A line-by-line analysis followed, and clusters of text reflecting similar experiences of engagement in occupations were coded; this process continued until all text was coded. We then moved on to a comparison of the codes, performed separately for each participant, gathering those with similar content until every interview contained a set of preliminary categories. We then continued by comparing the codes and the preliminary categories of all interviews, identifying similarities and differences, and thereby determining the properties and dimensions of the main categories. Finally, we scrutinized these main categories and their interactions, with the aim of finding a core category. Eva Månsson Lexell and Maria Larsson Lund were responsible for the main analysis, and every step taken by one of them was checked and discussed with the other. Subsequently, as the findings evolved, they were discussed in conjunction with Susanne Iwarsson, who read four of the coded interviews, but who also had access to all raw data.

Table 1. Participant Characteristics (N = 10)

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Vocational Situation</th>
<th>Living Arrangements</th>
<th>Social Service</th>
<th>Years Since MS Onset</th>
<th>Disease Severity (EDSS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>54</td>
<td>Male</td>
<td>100% SC</td>
<td>Single</td>
<td>Private help with cleaning</td>
<td>7</td>
<td>6.5</td>
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<tr>
<td>41</td>
<td>Male</td>
<td>100% SC</td>
<td>Single w/ children</td>
<td>Home help once a week</td>
<td>31</td>
<td>6.5</td>
</tr>
<tr>
<td>43</td>
<td>Female</td>
<td>100% SC</td>
<td>Married w/ children</td>
<td>Personal assistance and home help</td>
<td>16</td>
<td>8.0</td>
</tr>
<tr>
<td>50</td>
<td>Female</td>
<td>100% SC</td>
<td>Married</td>
<td>None</td>
<td>27</td>
<td>6.5</td>
</tr>
<tr>
<td>50</td>
<td>Male</td>
<td>100% temporary SC</td>
<td>Married</td>
<td>None</td>
<td>10</td>
<td>6.0</td>
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<tr>
<td>67</td>
<td>Female</td>
<td>Retired</td>
<td>Single</td>
<td>Daily home help</td>
<td>12</td>
<td>8.0</td>
</tr>
<tr>
<td>49</td>
<td>Female</td>
<td>100% SC</td>
<td>Married w/ children</td>
<td>None</td>
<td>4</td>
<td>5.0</td>
</tr>
<tr>
<td>63</td>
<td>Male</td>
<td>100% SC</td>
<td>Single</td>
<td>Home help once every 2 weeks</td>
<td>30</td>
<td>5.5</td>
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<tr>
<td>65</td>
<td>Female</td>
<td>Retired</td>
<td>Married</td>
<td>Personal assistance and daily home help</td>
<td>26</td>
<td>8.0</td>
</tr>
<tr>
<td>52</td>
<td>Female</td>
<td>75% temporary SC; 25% vocational training</td>
<td>Single</td>
<td>None</td>
<td>4</td>
<td>6.0</td>
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Note. EDSS = Expanded Disability Status Scale; MS = multiple sclerosis; SC = sickness compensation.

*The EDSS rates disease severity on a scale ranging from 0 (normal) to 10 (death due to MS).*
Findings

The participants’ experiences of engagement in daily occupations formed the core category *essentials of a constantly changing life*, made up of four underlying categories: (1) decreasing engagement in meaningful occupations, (2) constantly struggling for engagement in occupations, (3) being a different person, and (4) living life differently. The underlying categories interacted and influenced one another (Figure 1), and overall the participants reported that their engagement in occupations was decreasing. This process forced them to continuously struggle to maintain their engagement. Their testimony revealed that this struggle changed them as people and required them to live a different life from that they had lived before. Although the underlying categories represent continuums (each consisting of three properties), we describe them separately (Table 2).

**Decreasing Engagement in Meaningful Occupations**

This category and its three underlying properties pertain to the participants’ experiences of having a decreased ability to perform occupations.

*Decreasing Ability to Perform Occupations According to Personal Preferences.* The participants described how they could no longer perform occupations as they had previously or in the way in which they preferred. This decreasing ability not only influenced the performance itself but also had a negative influence on the meaning of engaging in specific occupations. Often, participants were able to perform only part of an occupation or some actions required to complete an entire occupation. They said that the occupations they performed were conducted at a slower pace than desired, and they described how they had a limited ability to perform several tasks simultaneously or in sequence.

They also said that the individual actions that together made up the performance of an occupation often needed to be planned in detail and performed with full attention if it was to be completed successfully. Thus, the spontaneity and ease of performing an occupation was significantly affected:

I want to feel that I can go into town to do this and that, and not have to phone [the municipality] and tell them that I want an assistant 3 days in advance because I want to go to an exhibition or something. . . . That’s what I miss the most, not being able to improvise.

*Decreasing Number of Occupations to Choose Among.* The participants described how they often had to give up previous occupations and that these occupations tended to be difficult to replace. Consequently, fewer occupations remained for them to choose among, and most of these were home based. Occupations were described as being too physically and psychologically demanding and more time and energy consuming than they had been before. For example, participants perceived as physically demanding having to check whether shops or friends had accessible toilets before visiting them or receiving assistive devices that did not address their needs. Psychologically demanding aspects of occupations could be finding the correct change at a cashier’s desk in a grocery shop or, in the workplace, knowing that one cannot contribute to work tasks as fully as before. Participants described feeling as though they were a hindrance to others. Irrespective of whether certain occupations were experienced as being physically or psychologically demanding, performance was complicated, and therefore participants refrained from undertaking these occupations.

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<th>Table 2. An Overview of the Core Category, Underlying Categories, and Properties, as Described by the Participants With Multiple Sclerosis</th>
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<tr>
<td>Core Category</td>
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<tr>
<td>Essentials of a constantly changing life</td>
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Figure 1. Participants’ experiences of engagement in daily occupations formed the core category (essentials of a constantly changing life) and its four underlying categories.
Some participants also stated that they had become vulnerable to seasonal demands, either during the winter because of snow and ice or during the summer as a result of high temperatures, and this vulnerability negatively affected their choice of possible occupations.

**Decreasing Possibility of Planning and Balancing Occupations Over Time.** The participants expressed how, because of the variation in their ability, they had difficulty planning ahead. This difficulty in planning affected their pleasure in anticipating occupations and diminished the meaning of engagement in occupations they had previously enjoyed. Participants stated that they prioritized occupations that were necessary and that could be conducted at any time over those they most desired to do. In addition, accomplishing such occupations tended to take up most of the day or most of the participants' available resources, leaving less time for other, more meaningful occupations, which led to an imbalance between necessary and desired occupations. One woman exemplified this imbalance, saying,

Two days a week I shower, and afterward I’m too tired to do anything else . . . then the 3rd and 4th days are occupied with cleaning and some fun things, hopefully, but [nowadays] I haven’t managed to do a lot [of fun things].

Another issue was that participants often perceived time use to be influenced by the availability of support from others—from the municipality, for example—and from family or friends. Thus, sometimes many occupations were clustered into certain time periods because participants had to perform them at times that were convenient for others; then too many passive hours followed, resulting in an imbalance in the participant’s use of time. As 1 participant expressed,

If I decide there is one thing per day that I [wish to do] . . . they [the assistants] can change this where laundry and cleaning and such are concerned, . . . then suddenly I have three, four things taking place on the same day and a lot of people come here, and as a result, I can become very tired.

**Constantly Struggling for Engagement in Occupations**

This category included three properties pertaining to the struggle to stay engaged in occupations. The struggle was influenced by different forces—society, other people, body restrictions, or all of these—each of which affected the participants differently, with none of the forces being more salient than the others. The struggle was described as ongoing and dynamic, with different intensities, with not all forces necessarily applying at the same moment.

**Struggling to Engage in Occupations on the Basis of Conditions Imposed by Society.** A common experience among the participants was that laws and regulations could restrict engagement in occupations and determine how the occupations were carried out. Thus, several participants had to struggle with the municipality to gain the requisite approval for social services assistance to be provided, and the participants were often responsible for proving their specific needs, which was especially difficult for those who were cohabiting because they did not want to have an extra burden laid on their next of kin. However, the municipality often expected next of kin to take on a larger responsibility for household occupations. Moreover, some participants stated that there were certain occupations for which they could not receive support, even if they clarified why they had certain needs. As 1 participant said,

The municipality said, “No . . . when one has a travel pass [including taxi rides partly paid for by the municipality] to get to work, [the journey] should be from the home to the place of work . . . You’re not allowed to go past day care [to pick up a child], even if the personnel at the day care center dressed him [the son], and brought him out to the car so I didn’t have to leave the car.

When support had been granted, the participants expressed how they struggled to influence decisions regarding the delivery of social services, often because the municipality had difficulty finding and hiring suitable personnel. However, even when suitable personnel were available, participants experienced difficulties influencing when and how support was provided.

They also described how the support given was uneven, often as a result of constant personnel changes. These changes meant that participants had to describe their daily routines to new caregivers and provide instructions concerning how they wanted tasks to be carried out. Some also found personnel changes humiliating because they had to receive help with intimate occupations, such as dressing or toileting, from unknown caregivers.

**Struggling to Engage in Occupations on a Level Footing With Others.** The participants described how they had less contact with many of those whom they used to encounter when engaging in occupations, and some people had totally disappeared from their lives. They recounted how they had to constantly struggle to maintain social relations and explained that they had to socialize under different conditions than before. Socialization was somewhat one sided because others tended to do more for the participants than the participants could do for them. According to the participants, this imbalance had a negative impact on their social network. For most participants, their remaining social network, besides family, was limited to people in the same situation as them, and yet they longed for more social interaction with healthy people.

Another experience concerning the struggle to engage in occupations on a level footing with others was that other
people’s attitudes influenced engagement in occupations. For example, when employers had a negative attitude and focused on difficulties rather than possibilities during voca-
tional training, the opportunity to engage in work-related occupations was reduced. By contrast, some participants shared examples in which other people had a positive attitude and therefore enhanced possible engagement in occupations, as illustrated by this quote:

Some of my nearest friends . . . don’t force me, but they know me . . . often when they call me [to go with them to the cinema], first I say yes, then maybe 2 days before the trip, I begin to, umm, [hesitate]. . . . then she just says I will come and pick you up and that’s the end of the story . . . and I always feel good afterward.

Struggling to Engage in Occupations Because of Body Restrictions. The participants experienced a constant struggle to engage in occupations because of limitations imposed by their bodies. They described how variations in their ability and an overwhelming feeling of tiredness—physical and mental—interrupted and obstructed occupational engagement. The tiredness required them to rest several times during the day, and others experienced the tiredness as an obstacle to continuing social relations. As 1 participant described, “It’s me who has a problem [in socializing]. . . . I can’t concentrate on anything, it just hums in my head. . . . I just can’t manage to sit there for very long and be alert.”

Another experience was a feeling of shame over lost physical condition. This feeling of shame made participants feel uncertain and anxious about failure during engagement in occupations, which undermined their engagement even further.

The participants also struggled to be less dependent on the conditions imposed by the body and nourished a hope of regaining body condition through physical training. For some, the restoration of physical condition was a requirement before they could again to engage in certain occupations.

Being a Different Person

This category contains experiences about how diminishing engagement in occupations influenced participants as occupational beings.

Being and Feeling Incapable. Because they could no longer engage in occupations as they used to, participants most of the time perceived themselves as being incapable of engaging in occupations. For some, this incapability meant that they felt like “nobodies,” and they expressed a fear of being a burden to others. Moreover, they were afraid they would be perceived as incapable if they made fools of themselves during the performance of an occupation they could no longer master. Others said they experienced a feeling of being in the way rather than being a contributor. As 1 participant said, “Sometimes it feels as if one is in the way . . . that I need to be helped all the time.”

Some of the participants also described how the inability to perform some occupations had a negative influence on their self-confidence and thereby influenced their self-
perception and capacity to perform other occupations. Another issue related to feeling incapable was grief felt in response to losing roles and having to assume other undesired roles, which confirmed for these participants that they now belonged to a category made up of incapable people—for example, they had to resign themselves to the role of a person receiving permanent sickness compensation.

Aspiring to Feel and Be Valued as a Capable Person. The participants stated that it had become important for them to feel and be seen as capable, independent people who could make and carry out decisions and earn an honest living. As 1 participant said,

I directed my life to be doing things . . . to do my best to be someone, and I thought it was great to be someone, and as an entertainer, one stands in the spotlight . . . all the spotlights on me . . . and [I] was successful . . . had a lot of work and felt like I was someone.

Participants also experienced a desire to be someone whose competence was requested. Those people who were still working or who had recently received a disability pension expressed a longing to hold a position in society that could confirm their competence. Participants also expressed a desire for others to accept and value them despite their disability.

Limitations in Occupations Altering Personal Identity. Some participants described that when they could no longer perform occupations that had previously been important to their sense of self, other occupations that were easier for them to perform had become more valuable. One participant said,

This place is not well cleaned at all, or anything, but yet . . . I didn’t used to bother so much, but for some reason I have changed . . . I can’t explain it but they [the cleaning and putting things away] are my tasks.

Living Life Differently

This category consisted of three underlying properties that showed variation in the way in which participants lived their lives.

Living a Restrained Life. The participants said that they lived a structured life, but even if they perceived that living life this way was easier, they often no longer experienced occupations as contributing to their well-being in the same way as before. Participants described lacking the joy of being able to fulfill future dreams, such as going on a holiday or pursuing a successful career. However, even though they
experienced restrictions that affected their occupations, some were satisfied with life and felt that they could enjoy the life they had at the moment. Others expressed the view that their life was not much of a life because their engagement in occupations was very restricted, and a few even said that they lived solely to survive. One participant stated, “I have a life, but I don’t feel I live it, or is it the other way around? I live, but I have no life.” The participant chuckled, then continued, “No, sadly that’s how it is . . . a person who lives is one who does something.”

Living on Positive Life Experiences. Independent of their experience of life at the time of the interviews, the participants appreciated their previous occupational experiences, which had become more important for them after the onset of disease. Indeed, some participants found the memories of their past occupational experiences enough to sustain them. Still, they expressed a hope to regain an active life in the future. Others referred to positive experiences related to the consequences of living with MS. For example, 1 participant described how, because her life was restricted to the home, she spent more time with her children, which had enhanced their relationship and given her a richer family life.

Intrusion in Private Life. As a consequence of the restrictions on engagement in occupations, several participants felt that their private lives had diminished. They recounted how they had limited possibilities to make and carry out decisions on their own, and they needed to discuss things related to their lives with their families in a different way than before. Some of those who were dependent on social services experienced this dependency as an intrusion into their private family life because they had to include such personnel in their lives. As 1 participant described it, referring to their home help,

They have said they don’t take any consideration of my husband, that’s not a part of their routine, so when he needs to sleep in, they can’t help me to go to the toilet quietly, without talking. . . . There is no respect for the family; they aren’t used to that.

Discussion

The participants in this study felt that their lives were constantly changing because of the difficulties that forced them to struggle to maintain engagement in desired occupations. This constant change, in turn, influenced their occupational roles and their perceptions of themselves. For people with MS, engagement in occupations is a complex phenomenon. In accordance with the occupational therapy literature, engagement in occupations is considered to constitute a person’s life and to form his or her identity. When a person’s occupations must be revised for some reason, his or her sense of identity changes, and he or she must alter the way he or she conducts daily life (Christiansen, 1999; Kielhofner, 2002).

Our participants explained how their engagement in occupations was becoming increasingly difficult, marked by having to relinquish the performance of occupations in a preferred way. Research has only briefly described the significance of not being able to perform either whole occupations or a series of occupations at a time or in succession. It is important for therapists to consider the consequences of having to forfeit preferred occupations when planning client-centered occupational therapy interventions for clients with MS.

Not surprisingly, the participants explained how barriers in the physical environment substantially limited the number of possible occupations in which they could engage. Little knowledge of the transaction between person, environment, and occupation for people with MS exists, although research in gerontology has shown that such a transaction is complex and constantly changing (Oswald et al., 2007). Moreover, the number of occupations in which participants could engage was also influenced by psychological stress, which was more salient than but not as evident as physical demands. Thus, for a client to be able to successfully engage in an occupation, it is crucial to consider different types of demands, especially if the occupational performance occurs outside of the home environment.

People with MS are well known to experience a loss of energy because of fatigue (Flensner et al., 2003; Koch & Kelly, 1999; Olsson et al., 2005), which limits their ability to plan and balance occupations over time; therefore, addressing energy conservation is a common intervention during occupational therapy and rehabilitation (Mathiowetz, Matuska, & Murphy, 2001; Tipping, 2002). Our results are in accordance with those of others, but our participants also claimed that they were forced to prioritize the most necessary occupations over the most desired occupations and those that could be conducted at any time over those that needed to be preplanned. A recent study of how people with MS experienced an energy conservation program found that the program had implications for daily life, beyond its direct implications for MS fatigue (Holberg & Finlayson, 2007). These findings, together with those from our study, suggest that planning and addressing the balance of occupations over time is a more complex situation than previously recognized, and one that should be addressed during intervention for clients with MS independently of whether they experience fatigue. Moreover, because the planning and balance of occupations over time seems to be strongly influenced by other people, interventions must be aimed not only at the
client but also at other people involved in the client’s occupational engagement.

Our participants perceived themselves as being in a constant struggle with different forces to remain engaged in occupations that they found meaningful. Much of this struggle was associated with conditions imposed by society and the participants’ immediate social environment. Two studies from England and Australia (Edmonds, Vivat, Burman, Silber, & Higginson, 2007; Wollin, Yates, & Kristjanson, 2006) have reported that people with MS feel that they have to fight to obtain the services, benefits, and assistive devices they need. Our findings also demonstrate that people with MS living in Sweden feel limited by societally imposed conditions and experience the presence of social services as an intrusion into their private lives. The research suggests that struggling to overcome the conditions imposed by society can be a universal problem, even if different countries have different regulations concerning social services. Our findings are also in agreement with those of previous studies of other populations demonstrating the significance of a supportive environment for engagement in occupations (Isaksson, Lexell, & Skär, 2007; Lund & Nygård, 2004; Nyman & Lund, 2007). Again, because our participants stressed that much of their engagement in occupations was dependent on other people, we cannot overemphasize the value of including these others in all steps of rehabilitation.

Many of the participants struggled with declining physical conditions that they hoped to regain. Some believed that regaining physical capability was a prerequisite to engaging in occupations. Clients in rehabilitation often want to focus on physical training, hoping that this training alone will enable them to reengage in desired occupation. Evidence has shown that exercise can be beneficial for people with MS (Rietberg, Brooks, Utdehaag, & Kwakkel, 2004), but most of our participants had secondary progressive MS, which, together with a relatively pronounced disease severity (EDSS score, median = 6.5; see Table 1), suggests that physical training might not be adequate as the only solution to enhance occupational engagement. Their experiences, however, could be indicative of the type of rehabilitation that had been offered to them and how well they had adapted to the consequences of their disease.

A recent article introduced an approach called the Life Thread Model (Ellis-Hill, Payne, & Ward, 2007), which is based on narrative theory and focuses on issues of reidentification of self rather than physical recovery alone. Ellis-Hill et al. (2007) emphasized that rehabilitation should be seen as a physical, psychological, and social process rather than only a bodily one in which regaining physical condition is viewed as the ultimate goal. Polkinghorne (1996) also emphasized this view and suggested that clients who experience decreased engagement in occupations tend to change their self-identity from an agentic one to a victimic one—meaning that they assume a passive identity and approach societal participation. By regaining engagement in occupations, clients can retrieve their agentic self-identity and actively set and achieve life goals. Polkinghorne (1996) concluded that therapists should have a broader focus than the straightforward performance of single tasks.

The participants in our study emphasized that not being able to engage in their previous occupations in a satisfactory way had a negative impact on their personal identification and made them strive to feel competent by searching for other occupations in which they could engage. Other studies of engagement in occupations conducted with different groups of people with chronic disorders (i.e., Alzheimer’s disease, mental illness) have identified previous occupations as contributing to autonomy and as ways in which to communicate a person’s identity (Hvalse & Josephsson, 2003; Öhman & Nygård, 2005). These findings show that irrespective of how clients experience the occupations in which they were previously engaged, professionals need to be attentive to and support the search for occupations that can facilitate each client’s experience of competency.

Participants’ experiences of occupational engagement and the different meanings occupations had in their lives varied widely, but a common experience was that occupations no longer contributed to well-being as they had before. Several factors may account for the differences in participants’ experiences; for example, participants had lived with their disease for varying numbers of years and had adapted differently to their changed engagement. Little is known about how people with MS adapt their engagement in occupations as the disease gradually progresses and their capability deteriorates. Focus has instead been on psychological aspects of living with MS (Courts et al., 2004; Miller, 1997), experiences of specific symptoms (Flensner et al., 2003; Koch & Kelly, 1999; Olsson et al., 2005), and experiences of quality of life (Reynolds & Prior, 2003; Somerset et al., 2002). To support client-centered interventions, professionals need to have knowledge about how people with MS adapt their engagement in occupations to their changed capabilities; greater study in this area is warranted.

**Limitations and Future Research**

Our findings cannot be generalized to all people with MS because of the study’s qualitative design, but they may be transferable (Lincoln & Guba, 1985) to other people in the same situation. Moreover, data collected from additional participants, until saturation occurred, could have yielded more extensive information, widening our perspective on
engagement in occupations. We judged this study, however, to be sufficiently comprehensive because the participants’ backgrounds were diverse and extensive. Although it was beyond the scope of the study to focus on potential differences arising from disease duration, type of MS, or age differences, future studies designed to detect differences in occupational engagement related to these background variables in people with MS are warranted. We used the constant comparative method to analyze the interviews, but for practical reasons we could not intertwine the selection, interviews, and analyses (Strauss & Corbin, 1998), which is a possible limitation of the study’s credibility. Credibility of data collection, however, was enhanced because we used a semistructured format during the interviews, enabling the participants to tell their own stories (Kvale, 1997). We further enhanced credibility by tape recording and transcribing all interviews verbatim. Interviews were read and discussed several times through the steps of analysis, ensuring confirmability of data.

Conclusion

Our findings show that along a continuum of change, people with MS experience a constant struggle to continue to be engaged in occupations. This constant struggle influences occupational performance and personal identity. In addition, we found engagement in occupations to be influenced to a large extent by societal regulations and other people’s attitudes. Professionals working in MS rehabilitation need to broaden their repertoire of interventions, in particular to address the social conditions that influence meaningful occupations for each specific client but also, in a wider perspective, to work toward a change in society’s attitudes and regulations. Moreover, rather than focusing solely on performance of occupations, practitioners should focus on the client’s engagement in occupations and its consequences for his or her life and sense of self-identity. ▲

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References


