

# Exploring the impact of multiple sclerosis on couples: A pilot study

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## Key words

■ Caregiver-receiver dyad ■ Qualitative research ■ Multiple sclerosis

## Mots clés

■ Tandem soignant-bénéficiaire ■ Recherche qualitative ■ Sclérose en plaques

## Abstract

**Background.** Multiple sclerosis (MS) is a disease that affects the everyday lives of people with MS and their partners. **Purpose.** The purpose of this study was to explore the impact of MS on the lives of two couples living with this disease and their coping strategies. **Methods.** Three semi-structured interviews with each couple were completed. Partners were interviewed together as a couple and separately. **Results.** Two major themes emerged from the analysis: increasing awareness of change and use of coping strategies. Participants expressed concerns stemming from the progression of MS and changes related to this progression over time. They discussed several coping strategies. **Practice Implications.** These findings offer occupational therapists guidance with their treatment focus in clinical practice and suggest topics for further qualitative research on couples living with MS.

## Résumé

**Description.** La sclérose en plaques est une maladie qui affecte la vie quotidienne des personnes atteintes de la maladie et de leur conjoint. **But.** Le but de cette étude était d'examiner les effets de la sclérose en plaques sur la vie de deux couples devant vivre avec cette maladie ainsi que leurs stratégies d'adaptation. **Méthodologie.** Trois entrevues semi-structurées ont été réalisées auprès de chaque couple. Les conjoints ont été interviewés seuls et en compagnie de leur partenaire. **Résultats.** Deux principaux thèmes ont été mis en évidence à la suite de l'analyse : une augmentation de la conscience du changement et l'utilisation de stratégies d'adaptation. Les participants ont exprimé de l'inquiétude face à la progression de la sclérose en plaques et aux changements associés à cette progression au fil du temps. Ils ont discuté de plusieurs stratégies d'adaptation. **Conséquences pour la pratique.** Ces résultats offrent une direction aux ergothérapeutes qui cherchent à orienter leur pratique clinique et proposent des sujets pour la poursuite d'études qualitatives sur les couples qui doivent vivre avec la sclérose en plaques.

**M**ultiple sclerosis (MS) is a chronic, debilitating, neurological illness that has significant impact on the lives of people with MS and their family members (DesRosier, Catanzaro & Piller, 1992; Hakim et al., 2000; O'Brien, Wineman & Nealon, 1995). Common symptoms of MS (e.g., fatigue, weakness, balance problems, pain) often result in difficulties engaging in activities of daily living (Aronson, 1996; Zeldow & Pavlou, 1994) and maintaining employment (Marks, 1990). Due to these changes in functional performance experienced by the person with MS, family members often assume the role of informal caregivers (Zeldow & Pavlou, 1994; O'Brien, 1993a, 1993b). For the purposes of this paper, an informal caregiver will be defined as an individual who provides a significant amount of unpaid care and assistance.

Becoming an informal caregiver can be stressful for family members, particularly if the demands of fulfilling caregiver responsibilities are substantial or if the caregiver has inadequate resources (e.g., limited finances, social support or community services) (Wollin & Sato, 2001). The stress of caregiving can also

disrupt patterns of performance and life roles, which often results in caregiver burden (also referred to as carer burden or carer strain) (Chipchase & Lincoln, 2001; Nolan, Grant & Ellis, 1990). Caregiver burden may require the development of new coping strategies (O'Brien, 1993b) in the areas of self-care, work and leisure. The need for assistance can have a negative impact on the dynamics of the relationship between the person with MS and the informal caregiver, causing stress related to emotional and economic concerns (Aronson, 1996).

Currently, there is a small but developing body of literature on the issues faced by spousal caregivers of people with MS. However, very few articles consider the perspectives of both the person with MS and the spousal caregiver simultaneously. If people with MS and their informal caregivers are to cope effectively with the everyday stress of living in the community with MS, then both perspectives need to be understood. The purpose of this study was to explore the impact of MS on the lives of two couples who are affected by this disease and who are currently living together in the community.

## Literature Review

Overall, there is a significant amount of literature on informal caregiving. Topics such as caregiver burden (Borden & Berlin, 1990), predictors of caregiver coping (Batt-Leiba, Hills, Johnsons & Bloch, 1998; Hooker, Frazier & Monahan, 1994), and marital adaptations to manage caregiver stress (Carter & Carter, 1994) have been addressed in this literature. Across these topics, the focus tends to be on informal caregiving for adults over 65 years of age (Kramer, 1993). Specifically, the focus has been on family caregiving for people with Alzheimer's disease or related dementia (Batt-Leiba et al., 1998; Borden & Berlin, 1990; Hooker et al., 1994). However, studies have also addressed issues of informal caregiving for people with other chronic illnesses, including Parkinson's disease (Carter & Carter, 1994) and rheumatoid arthritis (Revensen & Majerovitz, 1991). Between 1990 and 2002, twenty-four studies were published that specifically addressed caregiving and MS (McKeown, Porter-Armstrong, & Baxter, 2003).

The majority of these studies have been quantitative and have considered either the person with MS or the caregiver, not the couple as a unit. Only one qualitative study was found that examined the roles of couples living with MS, including the effect of the disease on their relationship, and their overall commitment to each other (Boeije, Duijnste, & Grypdonck, 2003). However, in this study the participants were not interviewed together. Therefore, there was no opportunity for the researchers to observe the couples' interactions with each other, or compare the participants' responses and reactions to the interview questions, both with and without their partner present.

In the caregiving literature, in general, the focus tends to be on caregiver burden and/or coping strategies. The literature on caregiver burden focuses more specifically upon physical and emotional health problems experienced by informal caregivers due to stressors experienced in the caregiving role (Baumgarten, 1989; Nolan, Grant, & Ellis, 1990). Stressors relate to "specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.141). Nolan et al. (1990) found that caregiver burden included the caregiver's perceptions of the demands of the caring role, the caregiver's relationship with the care receiver, and feelings of guilt the caregiver may experience when caring for the other person. The study found that the caregiver was more likely to experience caregiver burden when the caregiver perceived a lack of family support or financial resources as stressful (Nolan et al., 1990). These findings are consistent with the work of Aronson, Cleghorn, and Goldenberg (1996).

Coping strategies used by informal spousal caregivers and care receivers are the second major focus within the caregiving literature (Hooker et al., 1994; Kramer, 1993; O'Brien, 1993b; Pakenham, 1998). In those studies that address MS,

coping strategies used by spouses and significant others (e.g., taking time for self, using personal strengths) were identified as ways to adapt to the challenges of living with MS (Gulick, 1994; O'Brien, 1993a). Major stressors for caregivers of people with MS include changes in personal plans and confinement to the caregiving environment (DesRosier, Catanzaro, & Piller, 1992; O'Brien, 1993a). Coping strategies include the use of informal social supports (e.g., family, church groups) (Revensen & Majerovitz, 1991), as well as more formal community support services (e.g., home health aide, visiting nurse, occupational therapist and/or physical therapist) (Cockerill & Warren, 1990; Winslow & O'Brien, 1992). Informal social supports and community support services are typically presented in the literature as mediators of caregiver stress (Revensen & Majerovitz, 1991).

Nevertheless, MS studies have found that caregivers tend to underutilize available services (Aronson et al., 1996; Cockerill & Warren, 1990). Winslow and O'Brien (1992) found that 34% of caregivers in their study utilized formal community resources. Similarly, Aronson et al. (1996) reported that 40% of caregivers in their study used support services (e.g., private agencies, respite care, day care) during a two-year period and only 4% of all caregivers used any respite care. Winslow and O'Brien (1992) also found that significant positive correlations existed between use of community resources (e.g., home health aid/homemaker, visiting nurse, occupational or vocational assessment) and the functional incapacity of the care receiver, the caregiver's age and the number of caregiving tasks.

As already noted, most research in this area has considered the person with MS or his/her caregiver, rather than the couple as a unit. Interviewing couples together provides an opportunity to observe their interactions and joint responses regarding the impact of MS on their lives as a couple. The purpose of this study was to explore how MS influenced the lives of two couples with a focus on the strategies they used in the context of their lives.

## Design and Methods

This pilot study was conducted from May 2001 to July 2002 and involved the use of face-to-face, in-depth interviews with two couples affected by MS, field notes recorded directly after the interviews, and journal entries provided voluntarily by one of the caregivers. The Institutional Review Board of the researchers' university reviewed and approved the study.

## Participants

The two participating couples were selected purposively because they were known within the MS community as articulate and willing to share their caregiving stories. The second author knew of these two couples through her network in the MS community, but was not personally known

to either couple. The couples were approached and provided with a recruitment letter and fact sheet about the study (i.e., purpose, inclusion criteria, specific interview questions). Both couples agreed to participate and written consent was obtained from the participants.

## Procedures

The first author conducted three interviews with each couple using three separate semi-structured interview guides. The first interview with the caregiver and the person with MS together focused on issues surrounding the impact of living with MS (e.g., participation in everyday activities, changes in household responsibilities). The second interview with the caregiver individually addressed his or her personal perceptions of caregiving for a spouse with MS. Finally the third interview with the person with MS focused on the care recipient's personal perceptions of living with MS. All interviews were conducted in the couples' homes. The person with MS for the first couple was too fatigued to complete the third interview. The interviews with this couple occurred over a 10-day time period. The second couple completed the interviews over three weeks.

At the end of the second interview the 24-item, five-subscale Caregiver Burden Inventory was administered to the caregiver. The reliability and validity of the Caregiver Burden Inventory has been established in previous work (Novak & Guest, 1989). Although the Caregiver Burden Inventory was originally developed for caregivers of persons with Alzheimer's disease, it was used in this study because it addresses demands of caregiving identified as important in the MS literature. These areas include: Time Dependence Burden (burden due to caregiver's time restrictions), Developmental Burden (caregiver's experiences of burden in their development with respect to peers), Physical Burden (caregiver's issues with chronic fatigue and impaired physical health), Social Burden (role conflict experienced by caregiver), and Emotional Burden (caregiver's negative feelings toward care receiver). In addition, the Caregiver Burden Inventory was selected because its questions address topics similar to the qualitative questions; these data provided a source of triangulation for the interview data in this study.

All couple interviews were audio-taped with the permission of the participants and then transcribed in full for qualitative analysis. Additional notes were received from one of the caregivers. These notes were selectively dated and included relevant journal entries that documented the caregiver's perceptions of the impact of MS on her husband over time. This spousal caregiver had begun tracking relevant information prior to being contacted for this study. She offered these notes to the first author on her own accord as background information.

## Analysis

During the analysis of the data, the first and second authors met regularly to review the data and emerging findings. For the first round of analysis, the first author wrote a detailed, narrative description of the interaction with each couple based on field notes and general impressions of the interviews. Participants' names were changed for the purpose of protecting their identities. The main purpose of the narrative description was to capture an overall impression of each couple and to identify emerging themes. The second round of analysis involved a review of the two sets of interview transcripts and a comparison of the themes that emerged. A thematic analysis was used which consisted of coding transcript passages, then sorting these passages into categories and later into broader themes (Weiss, 1994). The analysis was content-oriented and involved identifying the strategies discussed by participants, and then labeling and listing them.

## Results

The following are brief descriptive narratives of each couple based on the data that were gathered. Their caregiving challenges, as described in the interviews and on the Caregiver Burden Inventory, are outlined, and then cross-cutting themes from the interviews are presented.

### Sara and Michael

At the time of the interviews Sara and Michael, both retired, had been married for 49 years and had raised three children. Michael, 71, first experienced symptoms of MS in 1962 and was officially diagnosed with progressive-type MS in 1969. They lived in a middle-class residential neighborhood in a city of approximately 700,000 people. An electric lift was positioned just to the right of the stairs that led to the front door, and there was a Hoyer lift in Michael's bedroom. For the past ten years, Michael had used a customized, toggle-controlled power wheelchair to assist him with functional mobility.

During the couple's first interview, Michael appeared fatigued and demonstrated difficulty speaking clearly to answer the presented questions. When Michael struggled to speak, Sara, 69, often stepped in to clarify: "What he means to say..." she would begin and then pick up the sentence that had trailed off. She spoke matter-of-factly and there was often a great deal of emotion behind her words, particularly during the caregiver interview, when she discussed her own personal experiences of living with MS.

According to Sara's responses to the Caregiver Burden Inventory questions, she experienced the greatest caregiving challenges in the area of time dependence. With the other areas of the Caregiver Burden Inventory (i.e., developmental, physical, emotional and social), Sara did not report high levels of concerns or challenges in her role as a caregiver. The finding that Sara's time dependence burden heavily influ-

enced her perceived caregiver burden was supported by the qualitative interviews. For example, Sara described a typical morning routine with her husband and the significant amount of time that was needed for her to perform her caregiver role:

Sara: I set my alarm at 7 o'clock [to] get up and take the remote off the door for the orderly to come in. And then I usually get up around 8:30 when he's finished with Michael. Then I make breakfast and I have to help him with his breakfast and feed him... And he either wants me to change the remote or use the remote to change the channel for him, or wipe his nose, or make him some tea, or warm up his coffee, or just whatever (Interview 2).

Sara also discussed the difficulty she encountered as a caregiver when she needed to run errands or accomplish tasks outside of the home.

Sara: Now I find it a little hard, that if I've got a busy day, and I start out late to do errands, for example, and I look at my watch, 'Oh, God, I've got to get home and feed Michael.' And then just make sure that everything's OK, if the orderly is coming in the afternoon, if he's going to sleep or whatever. Then I start off again to what I have to do... I plan ahead and watch the clock. I always say I'm governed by the clock and the day (Interview 2).

Sara's responses to the qualitative questioning were consistent with her responses to the Caregiver Burden Inventory questions that relate to social and emotional burden. She indicated that she did not perceive herself as being in role conflict as a caregiver, and felt that she had minimal negative feelings toward her husband due to her caregiver role. For example, Sara described a very busy social life, in which she participated in various community events (e.g., church activities, fundraisers) as well as MS Society events. From the qualitative data, she did not appear to resent her husband because of the impact of MS on their lives. Sara stated: "A lot of things have changed, you know, through the years and that, but he's still at home and that's a blessing" (Interview 2).

## Seymour and Natalie

Seymour and Natalie lived in a high-rise condominium in an affluent downtown neighborhood, located in a metropolitan area of 8 million people. The main room in their home was lined with shelves filled with thick books, as both were avid readers. They had been married 12 years and had no children together, although Seymour had a grown child from a previous marriage. Natalie, 53, was first diagnosed with secondary progressive MS in 1988, around the time that she and Seymour first met. Before her MS diagnosis, Natalie walked with a cane as a result of injuries from a rock climbing accident; she now used a walker due to her MS symptoms. Natalie worked full-time as a librarian and participated as a member of her condo association board. Seymour, 63, was a self-employed consultant and worked from home. They used

to enjoy going for walks, but Natalie found that walking more than four blocks fatigued her. During their interviews together and individually, both of them were matter-of-fact when talking about their relationship and describing how MS affected their everyday lives.

According to Seymour's responses to the Caregiver Burden Inventory questions, he experienced few caregiving challenges overall. His areas of greatest burden were time dependence and developmental burden. In comparison, Seymour's interview data suggested that he did not feel burdened in either of these areas. Seymour detailed how his morning routine consisted of providing assistance to Natalie for the self-care tasks that she could not manage:

Seymour: Elements of my caregiving routine, again, part of launching the morning is putting some breakfast in her...getting her socks on, getting her shoes with the AFO [ankle foot orthosis] on, now sometimes buckling her cuffs or collar or fastening her necklace...Sometimes slipping stuff on, for instance, if she's got to wear the AFO, then it can be hard for the pant leg to cover it...And again, I usually have the door open for her as she goes out...So I think here we're counting here all the things that she absolutely cannot manage by herself (Interview 2).

Although Seymour discussed how he assisted Natalie with her self-care routine, he never described his caregiver role as particularly time consuming. On the contrary:

Interviewer: What kind of caregiver would you say you are?

Seymour: I'm OK as far as I go. I'd say, especially in this reflection, I haven't been tested very much. I haven't had to do much. I've done it OK (Interview 2).

Seymour felt that he did not fit the mold of a traditional caregiver, because he was self-employed and worked from home. He stated:

Seymour: As it happens, probably unlike most couples where the woman has MS, I tend to be a househusband partly because [Natalie] needs some support, but also because my work, my base of operation for my work is [at home], whereas she goes out on a 9 to 5 basis. So that whole side of things can be construed as simply a division of labor with the couple (Interview 2).

Therefore, Seymour considered the duties of his "househusband" role (e.g., cleaning, cooking) separate from his caregiving tasks.

His responses to the Caregiver Burden Inventory did not indicate that he felt emotionally burdened as a caregiver. In comparison, Seymour noted during the interviews that he sometimes felt unappreciated by Natalie. However, he felt that this lack of appreciation was broader than just caregiving.

Seymour: We sometimes have rocky times emotionally and then part of the tough side for me is feeling that what I do isn't really noticed or appreciated. But even

then, that does not really apply to the strictly caregiving side of things...It's just there, it's very matter-of-fact. Basic mechanics in our life as a couple (Interview 2).

## Cross-Cutting Themes

Qualitative analysis across all six of the interviews indicated two primary themes: *increasing awareness of change over time* and *use of coping strategies*. Each theme will be discussed below.

### Increasing Awareness of Change Over Time

During the qualitative interviews, both spousal caregivers and persons with MS described how they became increasingly aware of changes caused by the MS over time. The couples discussed how loss of independence and mobility issues caused difficulty in living their everyday lives, due to the gradual progression of MS symptoms.

For the person with MS, loss of independence meant difficulty getting dressed, eating, getting around the house, or getting to and from work. For example, Michael needed assistance to complete his activities of daily living, such as bathing, dressing, and eating. In the morning, an orderly assisted Michael to get dressed and then out of bed and into the power wheelchair with use of the Hoyer lift. Sara prepared breakfast and then assisted Michael with eating. She recalled:

Sara: Well before, when Michael's hands were better, I could leave him a plate and he could pick up the food and eat and everything like that. It made it easier for me to go and do whatever I had to do and that. Now I do help him with his food, so I can't leave him anymore to feed himself. He can't do it, so that has changed a lot (Interview 1).

Michael's loss of independence was evident in several aspects of his everyday life. In comparison, Natalie's independence losses related more to the amount of time she needed to complete her ADL routine. If Natalie was running late in the morning, then Seymour provided more assistance to complete tasks, such as fastening her shirt buttons and necklace, donning the AFO and putting on socks and shoes.

Natalie and Seymour both described how Natalie's MS symptoms (e.g., loss of balance, decreased strength and endurance) contributed over time to a loss of independence in food preparation.

Natalie: If you could imagine cooking...over the stove and me having to reach overhead to get a hot casserole dish and get it safely down, that scares me. It didn't used to, but it does now. And I just have visions of disaster, so I don't do it.

Seymour: I would agree with what Natalie just said. Also I would say that just standing at a counter or sitting on a high stool, just doing stuff, chopping stuff, mixing stuff...calls on a certain amount of endurance, strength and balance that's not necessarily in the ball game.(Interview 1)

Both Michael and Natalie also experienced mobility issues because of MS. In a note written by Sara, she provided a poignant example of Michael's loss of mobility:

Sara: While [Michael] was in his manual chair he was very stubborn in many ways, one being I wanted to get him [a personal emergency response service], and he refused for a year. One day I came home from work...and he had slipped out of his wheelchair just inside the front door. He crawled on his elbows and stomach to the kitchen to try to reach the phone to call for help. We figure he must have taken more than two hours to cover that stretch of hall. Needless to say...[the service] was installed the next day (Sara's Notes, dated: 6/13/02).

Prior to her MS diagnosis, Natalie had used a cane following injuries sustained in a rock climbing accident. However, she gradually developed further difficulties with mobility due to MS symptoms, including leg spasticity, fatigue, and extreme sensitivity to warm weather:

Natalie: I used to walk...a long, long time ago I used to walk a fair amount. And then about six or seven years ago, I was doing well to go four blocks round trip. And now it takes me about forty minutes to go two blocks. So I used to be able to say, "It's OK. I can walk to [her destination], it's only two blocks. But then it would take me forty minutes (Interview 3).

Another reminder of Natalie's gradual changes in independence and mobility was her difficulty walking distances, even with the use of her walker. Regarding her mobility issues, Natalie remarked: "My horizons have shrunk quite a bit" (Interview 3).

Both couples also reported changes over time in the kinds of leisure activities they participated in together as a result of mobility issues and loss of independence. For example, Seymour and Natalie used to spend their leisure time at the movies, going to the theatre or concerts, attending baseball games and participating in sports, such as swimming. However, with the progression of MS symptoms, particularly with Natalie's decreased strength and sensitivity to temperature change, the couple had to change their lifestyle. They now spend more of their leisure time at home, participating in activities such as reading and using the computer. As Natalie commented, "It's a question of accessibility. If it's too much of a pain to go there, I'm not interested in going." (Interview 1)

Over the years Michael and Sara also experienced a change in their joint and individual participation in hobbies and other interests because of living with MS. Michael was previously involved in a public speaking organization before MS impaired his ability to speak. Prior to living with MS, the couple would often go dancing and take weekend trips with their children. As Michael's MS symptoms progressed, the weekend trips became day trips. When Michael first used a manual wheelchair over 20 years ago, the couple participated in an adaptive bowling league with Sara working occasionally

as a volunteer. They also became active participants in their local MS Society and the local independent living centre. Individually, Sara participated in theatre productions, a movie club and church fundraisers. As she explained:

Sara: We try to do as many things as we can together, but there are certain situations that come up that are not feasible, because of his orderly service, or the timing or whatever. But it's something that we learn to live with" (Interview 1).

### Use of Coping Strategies

The use of coping strategies was the second primary theme that emerged from the interview transcripts. Coping strategies are methods or techniques used by the informal caregiver and/or the person with MS to meet the challenges of living with MS. The strategies that were specifically noted by the participants in this study are listed in Table 1, together with quotes that illustrate each strategy. The coping strategies

identified in this pilot study generally appeared to benefit both caregiver and care recipient.

In coping with the influences of MS, the couples' selection of coping strategies appeared to be a dynamic process. As the person with MS and/or the spousal caregiver became aware of MS-related changes over time, they modified their choice of coping strategies to meet the needs of their current situation. For example, Michael employed the coping strategy of using denial/avoidance following his initial symptoms of MS. According to Sara, he would not admit that he had MS for many years. When he was first diagnosed with MS, he made excuses for the increasing muscle weakness in his legs, and declined invitations to attend disability support groups. However, Michael eventually came to rely on a wheelchair for mobility, making it much more difficult for him to deny the effects of MS. After Michael began to use a wheelchair, he became a regular participant in disability support groups,

TABLE 1 STRATEGIES IDENTIFIED BY COUPLES

<b>Coping Strategies</b>	<b>Sara &amp; Michael</b>	<b>Seymour &amp; Natalie</b>	<b>Illustrative Quote</b>
Taking time for self	X	X	Sara: We both have to have space. If we give each other space, I don't think we'll have any problems. And that's basically how it's been, right? [to Michael] Michael: Yeah. Sara: I mean, he's never ever said, you can't do this or you can't go here, you can't do that. Never, ever.
Having a positive attitude	X		Sara: There are always other situations that are worse than your own.
Using personal strengths	X	X	Seymour: I think an important part of what makes the caretaking work for me is ...the tone Natalie sets, or that we both set, which is pretty matter-of-fact.
Shifting expectations	X	X	Sara: We really should be replacing the rugs and everything else, but with the wheelchair there's no point...It's very difficult, very hard on it. On everything. It doesn't bother me as much now, but it sure did a few years ago. Oh, yeah. I was just so annoyed...I had to accept it. I can't do anything about it. And he's not doing it deliberately.
Using denial/avoidance	X	X	Natalie: I don't go to support groups or other events for people with disabilities. I don't care to be characterized by my disability. I think that's part of what happens if you're in the Disability Rights movement. You are accepting that at some level as an essential part of your character, and I don't choose to do that.
Accepting for/accepting help	X	X	Natalie: I've had to learn that accepting help is not the same as being helpless.
Using informal social supports	X	X	Natalie: The staff in [my] building and other residents look out for me when I am taking the elevator. They help me, hold the door and stuff, and that's wonderful.
Using formal support services	X	X	Michael: The orderlies, we couldn't do without them.

including the MS Society. Sara also became involved in the MS Society and other disability support groups.

As the MS progressed, Michael's role as care-recipient changed; he experienced decreased independence in functional activities, particularly self-care. Consequently, Sara's caregiver role also changed over time to include more caregiving tasks. Gradually the impact of MS on the couple's relationship caused Sara and Michael to cope using additional support services, such as orderlies to assist with Michael's daily routine, and occasional respite services for Sara to help her to maintain her caregiver role. The couple's relationship and coping strategies appeared to be influenced by gradual physical changes and subsequent loss of mobility on the part of the person with MS, changes in caregiving tasks on the part of the caregiver, and changes in the level of stress experienced by the couple. The couple's additional use of services (e.g., disability support groups, respite service, use of orderlies) over time illustrates the dynamic process in which couples living with MS may adapt their use of coping strategies as a result of the progressive impact of MS in their lives. These findings are consistent with work in the Netherlands, in which researchers found that couples living with MS interpreted the experience as requiring gradual acceptance of change over time (Boeije et al., 2003).

Natalie and Seymour chose not to use respite services or disability support groups to cope with the effects of MS. The couple may have felt that their current coping strategies (e.g., using denial/avoidance and personal strengths) were adequate to meet their present needs. In his caregiver role, Seymour assisted Natalie with some aspects of self-care (e.g., fastening jewelry, assistance with buttons) and functional mobility. Seymour also carried out meal preparation and other household duties, and considered these activities separate from his caregiver role. These duties had already been primarily Seymour's responsibility prior to Natalie's MS diagnosis. This differentiation between caregiver and household duties may have made it easier for Seymour to deny or minimize the effects of MS, which may have served as a coping strategy for the couple in their everyday lives.

Based on the stories shared by the participants, specific stressors of caregiving (e.g., time dependency and physical burden) may be perceived by the informal caregiver to be separate from marital difficulties in the couple's relationship. During the interviews, Seymour indicated that the stressors he experienced with his spouse were not related to caregiving, but rather to issues within the relationship. In other words, he felt that these marital stressors would have existed whether or not Natalie had MS. These findings relate to the study by Berman and Zbrowski (1990) in which marriage, in itself, was perceived as a life stressor to which spouses needed to adapt.

## Discussion

The purpose of this study was to explore the impact of MS on the lives of two couples to help inform occupational therapy practice and further knowledge in this area. The experience of the two couples suggest that coping strategies for living with MS may evolve over time in response to the amount of stress experienced by the couple, the amount of caregiver assistance needed by the person with MS, and the number of caregiver tasks required in relation to the time provided for caregivers to perform their tasks. These influences occurred through the gradual decline of mobility and functional independence for the person with MS and the couples' increasing awareness of these changes.

The couples' perceptions about their use of coping strategies correspond with what is known from the MS and chronic illness literature. Coping strategies used by couples living with chronic illness appear to be influenced by the needs of the person with MS and/or the informal caregiver. These strategies include utilizing respite care (Aronson et al., 1996), attending disability support groups (Aronson et al., 1996), taking time for self (DesRosier et al., 1992; O'Brien, 1993a), using denial/avoidance (Pakenham, 1998), and drawing on family and friends for support (Gulick, 1994; O'Brien, 1993a). Additional strategies used by participants in this pilot study not specifically mentioned in the literature included using personal strengths, shifting expectations, asking for/accepting help, and having a positive attitude. Further research on these additional strategies to explore their use and effectiveness with couples coping with MS is needed.

Interestingly, the majority of previous studies in the MS literature that addressed coping strategies offered only a broad interpretation of the coping strategies used by informal caregivers and people with MS. Coping strategies were generally portrayed in descriptive terms (e.g., problem-focused vs. emotion-focused) and use of community support services were broadly categorized. The findings of this study provide more specific labels and examples of the strategies used by couples affected by MS, which could prove useful to occupational therapists designing intervention programs to help facilitate effective coping strategies.

Each couple appeared to cope with living with MS through a dynamic use of strategies that helped them respond to changes in mobility and functional independence occurring over time. As the progression of MS gradually altered the daily lives of each couple and presented new caregiving demands, the choice of coping strategies also appeared to change. Seven coping strategies were shared by both couples: taking time for self, using personal strengths, using denial/avoidance, shifting expectations, asking for/accepting help, using informal social supports, and using formal support services. Further research to examine the general helpfulness of these strategies and how occupational therapists may support effective strategies would be useful.

Limitations of this study included a small number of couples (N=2 couples) and a similar order for interviewing the couples together and separately. Future studies might consider interviewing individuals separately prior to interviewing them as a couple to determine the effects of sequencing interviews on the findings. In addition, a larger sample would be useful to expand our knowledge in this area, as would studies with a longitudinal component. Further research could also compare the coping strategies used by caregiver-receiver dyads with different characteristics (e.g., sub-type of MS, number of years with MS, level of disability, length of marriage, economic resources).

## Conclusion

The findings of this pilot study indicate that the everyday life of two couples living with MS was characterized by an awareness of change over time, particularly with regards to issues of mobility and functional independence. Various coping strategies used by these two couples to adapt to the effects of living with MS included use of community support services, such as formal social services (e.g., respite care, transportation services) and informal services (e.g., friends and family support, disability support groups). This study suggests that coping with MS is a dynamic process in which strategies utilized vary depending on personal needs and overall readiness to acknowledge the gradual changes brought on by MS. This knowledge may assist occupational therapists as they plan assessment procedures and intervention methods, and may provide direction for further research with this group of potential clients.

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