A Grounded Theory Analysis of the Occupational Impact of Caring for a Partner who has Multiple Sclerosis

Kate Heward, Matthew Molineux & Brendan Gough

Abstract
Chronic progressive conditions such as multiple sclerosis impact engagement in and orchestration of daily occupations by people with the condition, and their family members. This qualitative study addressed the way in which multiple sclerosis can affect family life, particularly exploring how it affects the occupations of the partner of a person with the condition. The study involved in-depth interviewing and grounded theory analysis to explore the occupational nature of being a partner of someone who has multiple sclerosis. Findings reveal how partners’ occupations are affected over time, with occupational opportunities inspired by multiple sclerosis and occupational constraints provoked by the disorder, including nostalgia for an multiple sclerosis free existence, the transition to being a carer and an occupationally uncertain future.

Key Words
Occupation
Multiple sclerosis
Carers
Caregiving

Multiple sclerosis is the most common disease of the central nervous system affecting young adults in the United Kingdom. Although the epidemiology of the disorder and the experience of people diagnosed with it have been researched, there has been little focus on carer, partner or family perspectives. This article reports a qualitative study, which addressed the question: “What are the occupational issues for partners of people with multiple sclerosis?”

This question is important because there are an estimated 2,500,000 people in the world living with multiple sclerosis, approximately 85,000 of whom live in the United Kingdom. Living with somebody who has been diagnosed with multiple sclerosis often leads to providing care. Almost six million people in Britain are carers (Department of Health, 1999), defined here as “a family member or paid helper who regularly looks after a sick, elderly or disabled person” (Soanes & Stevenson, 2004, p. 213). The nature of the care provided is shaped by the health condition. With multiple sclerosis, twice as many women are diagnosed with the disease as men (Multiple Sclerosis Trust, 2004). The condition is usually progressive and while four general patterns have been identified, individual experience varies and cannot be predicted (Finlayson, van Denend, & DalMonte, 2005; Lindsay & Bone, 2004). The unpredictability of the condition is one of the most anxiety provoking issues for those diagnosed with the condition and those closest to them (Monks, 1990; Robinson, Jones & Segal, 1990; Silcox, 2003). Diagnosis of multiple sclerosis is often a very lengthy process whereby people undergo numerous investigations and experience months, and sometimes years of concerning symptoms before a clear diagnosis is made (Monks, 1990; Silcox, 2003). The condition is complex, featuring a range of physical symptoms including loss of mobility, spasticity, loss of bladder control, visual disturbances, fatigue, cognitive problems such as memory loss, and associated psychological issues such as depression and adjustment to change (Lindsay & Bone, 2004; Silcox). There is no known cure and so treatments aim to relieve symptoms, slow the progression of the disease and manage its impact (Lindsay & Bone; Silcox). Individuals diagnosed with multiple sclerosis can live for many years with the condition (Weinshenker, 1995) and may experience many of the symptoms highlighted or relatively few depending on whether they are have a progressive or relapsing remitting form of the condition (Buljevac et al., 2003).

Multiple sclerosis has the potential to affect the whole family, including their gene is often diagnosed: being made in term relationships, (Cheung & Cleghorn, 1996; C & Cleghorn; 1996; C Cleghorn & Cleghorn, 1996; C Cleghorn & Cleghorn) and future occupational Carers’ perspectives: people have be the National Health Disabled Child Act National Inspection (Furut, 1996). The People (DoH, 2000) be consulted about published National Conditions (DoH), been informed by needs both as carers

The Occupational Impacts

A number of studies have found that the occupation of people with multiple sclerosis often leads to providing care. Almost six million people in Britain are carers (Department of Health, 1999), with the experience of indiv (2003) found that w metonymically, as the “saviour”, which en condition. Similarly renegotiated the rel she learned to live with earlier work th in that it helps peq (Robinson, I., 1990)

A small number of people with multiple (2003), & Baxter, 2003), various coping stru members use whe sclerosis. These in planning, and em emotional or phys caring role (Gulick, relationships and so multiple sclerosis (C) relationships as the more recent quality carers’ of people wit paradoxes that cap experience, such as caring (Cheung & H
The Occupational Impact of Caring for a Partner who has Multiple Sclerosis

K. Heward, M. Molineux & B. Gough

including their general lifestyle (Cheung & Hocking, 2004). It is often diagnosed at a time when critical life decisions are being made in terms of furthering careers, establishing long-term relationships, or having children (Aronson, Goldenberg, & Cleghorn, 1996; Grima et al., 2000; Nolan & Nolan, 1998). This insight has the potential to disrupt established, evolving and future occupations.

Carers’ perspectives are high on the British government’s agenda, and have been informed by carer perspectives and recognises their importance. The National Service Framework for Longer Term Conditions (DoH, 2005), including multiple sclerosis, has been published National Service Framework for Older People (DoH, 2000b) has also highlighted that carers should be consulted about their views and needs. The recently published National Service Framework for Older People (DoH, 2000b) has also highlighted that carers should be consulted about their views and needs. The recently published National Service Framework for Longer Term Conditions (DoH, 2005), including multiple sclerosis, has been informed by carer perspectives and recognises their needs both as carers and in their own right.

The Occupational Impact of Multiple Sclerosis: Emerging Research Findings

A number of studies have focussed on the occupational performance of people diagnosed with multiple sclerosis (Finlayson, Van Denend, & DalMonte, 2005; Jackson & Quaal, 1991), with a few highlighting the wider occupational experience of individuals with the disorder. Wright-St. Clair (2003) found that women with multiple sclerosis experience it metaphorically, as an “adversary”, “guest”, “aggressor” or “saviour”, which enables them to somehow survive with the condition. Similarly, Finlay (2003) described how one woman renegotiated the relationship between mind and body, whilst she learned to live with the diagnosis. These insights align with earlier work that stressed the importance of story telling, in that it helps people take positive control over the disease (Robinson, 1990).

A small number of studies have focussed on the caregivers of people with multiple sclerosis (McKeown, Porter-Armstrong, & Baxter, 2003). Amongst these, some have identified the coping strategies that spouses, partners or other family members use when caring for somebody with multiple sclerosis. These include problem-based strategies such as planning, and emotional strategies such as temporary emotional or physical withdrawal in order to cope with the caring role (Gulick, 1995). Others have alluded to changes in relationships and socialisation (Esgate, 1995), and people with multiple sclerosis can feel their condition will inhibit sexual relationships as the caring role increases (Silcox, 2003). A more recent qualitative study of the experiences of ‘spousal caregivers’ of people with multiple sclerosis identified a number of paradoxes that captured the participants’ positive and negative experiences, such as feeling both enabled and limited through caring (Cheung & Hocking, 2004).

Whilst carers do not experience multiple sclerosis physically, they often experience it emotionally and practically in their everyday life (Ohman & Soderberg, 2004). One study identified specific occupational impacts multiple sclerosis may have on carers, including the negative financial impact of being forced to give up work or change their planned career development to accommodate increasing care duties (Esgate, 1995). While this study did not identify the nature of the caring relationship, partners frequently become carers of people with disabilities. As multiple sclerosis is most commonly diagnosed when people are at the peak of their working lives and often at a time when they are in or considering serious relationships or families, this disorder may have a significant impact on the partner of the person diagnosed (Ohman & Soderberg, 2004; Pakenham, 2005).

These findings are important because the positive links between meaningful occupation and health are well-documented (Clark, 1993; Jackson, Carlson, Mandel, Zemke, & Clark, 1998; Wilcock, 1998a, 1998b; Yetta, 1998). In line with such perspectives, United Kingdom government policies have outlined that carers have a right to their own lives (DoH, 2005). Accordingly, the aim of this study was to investigate the occupational issues for partners of people with multiple sclerosis. Partners were chosen as the focus because they are likely to have a significantly different relationship with the person with multiple sclerosis than other family members or friends and because the caring role may extend over many years, unless the strain becomes too much as the caring role increases (Chipchase & Lincoln, 2001). Therefore, we were keen to identify what occupational issues arise when facing a chronic health condition, and whether there is any disruption to partners’ occupational choices, participation and meaning.

Method

Although qualitative studies are usually more time consuming and expensive than quantitative inquiries (Hancock, 2000), their strength is in the depth of information obtained from small numbers of participants (Smith, 2004; Willig, 2001). Qualitative methods also allow the flexibility to develop the methods as the research evolves (Belgrave, Zablotsky, & Guadagno, 2002; Denzin & Lincoln, 1994). Since this study sought to elicit participants’ perspectives, we were interested in the depth and richness of information rather than its generalisability.

The chosen methodology was constructionist grounded theory, which recognises the prior knowledge and creativity of the researcher (Strauss & Corbin, 1990). In particular, we used a social constructionist version of grounded theory introduced by Charmaz (1990), which suggests categories and theories do not emerge from the theory but are constructed by the researcher, through interaction with the data. The constructionist approach to grounded theory analysis recognises and accepts that researchers bring their own experiences to the research, which presents opportunities for enriching rather than biasing analysis (Charmaz, 1990; Strauss & Corbin, 1998).

Data were collected via in-depth individual semi-structured
The Occupational Impact of Caring for a Partner who has Multiple Sclerosis

K. Heward, M. Molineux & B. Gough

Interviews (Laliberte-Rudman & Moll, 2001) conducted by the first author. Data were first read using grounded theory methods (Charmaz, 1990; Strauss & Corbin, 1998), which are designed to facilitate the process of discovery or generation of theories (Charmaz, 1990; Strauss & Corbin, 1998).

We chose to use interviewing because it allows detailed exploration of participants’ views and it is an established method of data collection within qualitative research (Willig, 2001) including grounded theory (Charmaz, 2000). An interview schedule was constructed, informed by the literature (Creswell, 1998; Laliberte-Rudman & Moll, 2001). The aims of the study also highlighted topic areas for the interview, as did the clinical experience of the occupational therapists in the research team. The interviewer guided participants through their past, present, and future, identifying their occupational engagement at different stages. Examples of questions asked in relation to shared occupations and the relationship of health and occupation are listed in Table 1.

Table 1. Example Questions from the Interview Schedule

<table>
<thead>
<tr>
<th>Question</th>
<th>Probe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have the things you do together changed over the years?</td>
<td>• How have they changed? • How does it feel (to carry out the same occupations/different ones)? • How much time do you spend on these occupations, is that more or less time than you used to? • How would you feel if you couldn’t carry out the occupations you enjoy anymore because of your partner’s multiple sclerosis? • How much do you think the changes have been due to multiple sclerosis, and how much do you put down to natural life changes?</td>
</tr>
<tr>
<td>How is your health currently?</td>
<td>• What in your opinion contributes to your well-being? • Is this related to multiple sclerosis in your opinion? • What are the things you do that you believe affect your health in both a positive and negative way? • What do you think would improve your health occupationally? (Taking part in new occupations, recovering old ones)</td>
</tr>
<tr>
<td>How do you see the future?</td>
<td>• Do you make plans? (Elaborate) • Are they independent of your partner? With your partner?</td>
</tr>
</tbody>
</table>

Participants

It is not possible to precisely determine the number of participants prior to a study (Whalley Hammell, 2002) and this is especially true when using grounded theory (Charmaz, 1990; Lincoln & Guba, 1985; Pidgeon & Henwood, 1997).

Analysis of the data ran concurrently with the data collection, which is typical of a grounded theory study (Whalley Hammell, 2002; Willig, 2001). Each interview was coded line-by-line and clustering was used to develop themes. There were initially a vast number of descriptive themes, but through constant comparative analysis (Strauss & Corbin, 1998) they were developed into fewer analytical themes. A journal was maintained by the primary researcher to capture ongoing reflections and observations (Valiante Cook, 2001). Reflections were recorded immediately after interviews, relating to the non-verbal communication of the participant and emotions witnessed during the interview. Other reflections arose as the transcriptions were analysed in relation to phrases and emotions witnessed during the interview. Other reflections arose as the transcriptions were analysed in relation to phrases and emotions witnessed during the interview.

Trustworthiness

Credibility is crucial to all research and so strategies were instituted to ensure trustworthiness, validity, quality and rigour. The second and third authors listened to tape recordings and read transcripts, and analysis was carried out independently on a sample of the transcripts by all authors of the paper (Charmaz, 1990; Lincoln & Guba, 1985; Pidgeon & Henwood, 1997).

Member checking was initiated approximately two months post interview, to allow time to carry out in-depth analysis of the transcripts (Willig, 2001). Contact was made with each of the participants to clarify interpretations of the transcripts and it was found that participants endorsed the analysis.

Table 3. Description of Study Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>9</td>
</tr>
<tr>
<td>Time with partner</td>
<td>9</td>
</tr>
<tr>
<td>Time since partner diagnosed with multiple sclerosis</td>
<td>9</td>
</tr>
<tr>
<td>Employment status</td>
<td>9</td>
</tr>
<tr>
<td>Employment type</td>
<td>9</td>
</tr>
<tr>
<td>Employment status - individual with multiple sclerosis</td>
<td>9</td>
</tr>
<tr>
<td>Physical ability of person with multip bladder complaints</td>
<td>9</td>
</tr>
<tr>
<td>Individuals who are crisis situations</td>
<td>9</td>
</tr>
<tr>
<td>Partner to have had relationship with the diagnosed with multiple sclerosis</td>
<td>9</td>
</tr>
</tbody>
</table>
The Occupational Impact of Caring for a Partner who has Multiple Sclerosis  

K. Heward, M. Molineux & B. Gough

Table 2. Participant Criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relapsing/remitting or secondary progressive multiple sclerosis</td>
<td>Benign or primary progressive multiple sclerosis</td>
<td>A greater percentage of the multiple sclerosis population will have relapsing remitting or secondary progressive multiple sclerosis at any one time, making recruitment to the study easier. It is also more representative of the multiple sclerosis population.</td>
</tr>
<tr>
<td>Partner to have had an intimate relationship with the individual diagnosed with multiple sclerosis before diagnosis</td>
<td>Partner who has not had an intimate relationship with the person diagnosed with multiple sclerosis before diagnosis</td>
<td>Experiences can be compared before and after diagnosis.</td>
</tr>
<tr>
<td>Partner to have no major health complaints</td>
<td>Partners who have major health complaints</td>
<td>The experience of partners who have health complaints are likely to have encountered different issues to those who are well.</td>
</tr>
<tr>
<td>Individuals who are not going through crisis situations</td>
<td>Individuals who are experiencing crisis e.g., within their relationship, or in relation to their partners multiple sclerosis</td>
<td>The topic area is sensitive in nature and it would be ethically inappropriate to interview individuals who are already experiencing sensitive issues.</td>
</tr>
</tbody>
</table>

Table 3. Description of the Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participant Feature</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>4</td>
</tr>
<tr>
<td>Time with partner</td>
<td>Mean (years)</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>Range (years)</td>
<td>15-55</td>
</tr>
<tr>
<td>Time since partner diagnosed with multiple sclerosis</td>
<td>Mean (years)</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Range (years)</td>
<td>3-40</td>
</tr>
<tr>
<td>Employment status</td>
<td>Full time paid</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Early retirement due to partners condition</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Given up paid employment to become partner’s carer</td>
<td>1</td>
</tr>
<tr>
<td>Employment type</td>
<td>Healthcare</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Executive</td>
<td>1</td>
</tr>
<tr>
<td>Employment status of individual with multiple sclerosis</td>
<td>Full time paid</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Part time paid</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Retired due to ill health</td>
<td>7</td>
</tr>
<tr>
<td>Physical ability of person with multiple sclerosis (as reported by partner)</td>
<td>Mobile</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Some mobility but decreasing</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Wheelchair dependent</td>
<td>6</td>
</tr>
</tbody>
</table>

Findings

Two core themes were identified: multiple sclerosis provoked occupational constraints and multiple sclerosis inspired occupational opportunities. Within the theme of multiple sclerosis provoked occupational constraints were three sub themes: nostalgia for a multiple sclerosis free existence, the transition to carer and an occupationally uncertain future.

Multiple sclerosis provoked occupational constraints

The all-encompassing reach of multiple sclerosis was very apparent in how participants perceived the future, their perceptions of the present and, for those who had lived with it for a long time, their recollections of the past. This is supported by Blair (2000), who examined transitions from an occupational perspective. She confirmed that throughout life, changes occur which require individuals to adapt and adjust what they do and how they do it. Adams, Hayes and Hopson (1976) described four different transitions of a predictable and unpredictable nature. These reflect the findings of this study in that there were predictable voluntary and involuntary life changes occurring for participants, in their relationships and employment issues, which occurred in spite of the multiple sclerosis. However, there are also the unpredictable voluntary and involuntary transitions which could be attributed to the multiple sclerosis, where again employment may be an example. In this study, these could be the same life issues as the predictable changes if a partner’s condition deteriorated unexpectedly and occupational adjustments were made in the face of this. Participants in the study highlighted the ways they had made changes to their lifestyle to accommodate their partner’s multiple sclerosis, or the ways that changes had been...
imposed on them, when they had been expected to adjust.

The participants described how their occupational engagement was restricted. Jennifer expressed how restricted she sometimes felt as a result of her husband having multiple sclerosis and how her husband having multiple sclerosis had influenced her recent decision to reduce her working hours: I think the last couple of years it did get to me a bit…. I was still working full time, there was the children and the washing and the cleaning and he was doing things but it involved a lot more effort…. I couldn’t maintain a decent sort of quality life at work and at home and I was just feeling pulled both ways. So I’ve just gone for three months, sort of four days a week so I can do the boring housework (laughs) or have the energy to do the boring housework.

Their marital life was perceived as more of a partnership before the multiple sclerosis was diagnosed with equality in roles and responsibilities. After diagnosis and with progression of the condition, responsibilities were gradually shifted to Jennifer, and restrictions were imposed on her own time: I don’t mind but I would rather go and do things. I’d rather go out for the day and visit somewhere, meet people or create something… I’ve just got to adjust…. but I’ve already got a lot more done at home.

Cockerill and Warren (1990) also found that caregivers’ activities had been curtailed, although these were in direct response to being able to arrange appropriate care in order for the caregiver to attend a social event or holiday. Further, the results of a systematic review of the literature emphasized that caring for someone with multiple sclerosis has a detrimental effect on many areas of a carer’s life, including their social and work life (McKrow & et al., 2003). The findings of our study suggest issues of occupational constraint when the roles and responsibilities have shifted so that the partner is taking on tasks that were once not theirs, rather than those specifically linked to direct care for their partner. This assumption of extra duties meant there was less time to engage in leisure occupations or paid employment.

Some participants expressed how let down they can feel when they have planned an outing which is cancelled at the last minute: Then all of a sudden it’s, you know, I can’t go because I don’t feel well enough. So actually going out is a problem and planning to do something. (Jim)

Fatigue is a very disabling symptom of multiple sclerosis and even though someone might appear physically very able, their lives and those around them can become very restricted (Colosimo et al, 1995; Krupp, Alvarez, Larocca, & Schenberg, 1988). The uncertainty of the symptoms of multiple sclerosis and how it will affect someone in the space of days, months and years also contributes to the constraints partners can feel. Cheung and Hocking (2004) reflected these issues of uncertainty through their study, highlighting how partners were concerned about what function their partner would lose next. This study further links the inability to plan with the uncertainty of the condition: The big thing now is that we plan for six months in advance, whereas a few years ago we would plan a year in advance. Maybe in another few years we’ll only be doing 3 months. (Carol)

This statement also illustrates what Ohman and Soderberg (2004) referred to as a “shrinking life” (p. 406) in that plans become further constrained and restricted due to the erratic, fluctuating and progressive nature of multiple sclerosis.

Nostalgia for a multiple sclerosis free existence

Many of the participants described occupations they engaged in, and what those occupations meant to them, before the disruption of multiple sclerosis. They portrayed a time when they did not fear for the future and had freedom to undertake their own occupations. For those whose experience of multiple sclerosis within their lives was more recent, the nostalgia for a multiple sclerosis free existence was more powerful than for those who had lived with it for many years. Graham, whose wife had only been diagnosed with multiple sclerosis six years earlier described in detail the occupations he used to do, those he shared with his wife and what they meant to him.

We were both earning well, no family ties, life was fairly easy, we could do anything we wanted, holidays, whatever we wanted to do. We golfed, we were off to events, horse racing, whatever, a whole series of things…. It was really a matter of having fun I guess. (Graham)

Graham described the freedom they felt through the occupations they shared. However, his wife’s multiple sclerosis related disabilities had advanced quickly in a short time, and although they still managed to go on holiday they had lost many of their other occupations they shared. This had resulted in the balance of leisure and productivity shifting, so more time was spent preparing meals and managing household tasks with less on leisure. He predicted further loss and changes in the future as his wife’s multiple sclerosis progressed. This finding is consistent with previous reports that caregivers of people with chronic illnesses experience both loss of lifestyle and loss of relationships as they once knew them (Robinson, K., 1990). Cheung and Hocking (2004) highlighted a death of literature relating to grief as a response to non-death related losses (p. 154). Loss when a partner who knew them (Robinson, K., 1990). Cheung and Hocking (2004) highlighted a death of literature relating to grief as a response to non-death related losses (p. 154). Loss when a partner who knew them (Robinson, K., 1990). Cheung and Hocking (2004) highlighted a death of literature relating to grief as a response to non-death related losses (p. 154). Loss when a partner who knew them (Robinson, K., 1990). Cheung and Hocking (2004) highlighted a death of literature relating to grief as a response to non-death related losses (p. 154).


The transition to care

For some participants of everyday life was accepted. Lifestyle is associated with having multiple sclerosis. Carol described: Get up in a morning, can't do anything. So I make his meals and make sure all his clothes are lower clothes on very very slowly, his independence. Acceptance was refl… that had to be performed. Although the carer, Carol did not describe carers in a was apparent through a stated how she to the multiple sclerosis w… do something having your hat with multiple scl

This statement high with being a carer t accepts a carer's idea illustrate someone ' partner to being a carer was tarnished forced into a role th...
The Occupational Impact of Caring for a Partner who has Multiple Sclerosis

K. Heward, M. Molineux & B. Gough

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felt through the is wife’s multiple I quickly in a short go on holiday they ey shared. This had luctivity shifting, so managing household d further loss and multiple sclerosis ith previous reports illnesses experience iships as they once and Hocking (2004) a grief as a response when a partner who i condition such as a number of years, n of their partner’s talgia for a life as it ile sclerosis was his wife’s life have on because his wife the local pub. This ldren grew up wives cause his wife rarely litly issues, he felt ry wife not being

nice name for a slave or dogsbody. (Harold)

Harold believed he no longer had any rights in his role as a carer and could not spend the amount of time he used to do on his own occupations: “It’s very hard not to sort of feel a sense of resentment”. For others there was a sense of postponing the transition. Graham discussed the impositions of caring and how that could impinge on daily life:

The difficulty is if you are away, if you are late. She can’t grip anything, so she can’t go near a pan, she would be hurting herself. So, if I happen to get delayed at work…. I have an hour, hour and a half when I get home when I am preparing tea and having tea, and that’s time taken up that wouldn’t have been taken up before (Graham).

Graham’s anxieties regarding his wife’s ability were apparent as were his concerns regarding his own capacity to fulfil his new roles. The urgency with which he spoke illustrated the pressure that was increasingly becoming a reality in their home life. The considerable lifestyle changes were also highlighted for a man whose career had been all encompassing, compared with his current situation where the impact of his wife’s multiple sclerosis had become the most significant part of his life. These issues were accentuated by other participants who described occupations that had been imposed upon them due to their partners multiple sclerosis.

Jim noted occupations that had been transferred to him as his wife has become more disabled:

Sheila is getting progressively worse with fatigue. I am taking on more of the roles of helping around the house although she can drive… I drive everywhere… she finds it a bit too much… [I spend a lot of time] dropping the children off at school and running them around… It was as if realisation that there were things to do with the family and home that I would need to take on. (Jim)

All these issues are supported in the literature. Lackey and Gates (2001) and van Exel, van den Berg, Koopmanschap and van den Bos (2004) found caring duties can encroach adversely on other daily life activities, highlighting the burden that can ultimately arise.

An occupationally uncertain future

When looking forwards in time, participants were unable to recognise a future that was not dominated and directed by multiple sclerosis. All the participants identified being unable to make long-term plans as they were unsure of the progression of their partner’s condition. Multiple sclerosis was the determinant of what would happen in the future. Some suggested practical plans that could be in place so that the occupations they shared and those they were still able to do might have a chance of being sustained. Graham described the shared occupation of holidaying in Spain, an occupation they wanted to continue but one that in the future is likely to dramatically change.

The apartment [we have] in Spain is a first floor one. It’s a lovely apartment… but we have got it up for sale…. If we can sell it… buy a villa we could modify, so that we can get walk in showers instead of baths, some wider doors and things, so not in the height of
The Occupational Impact of Caring for a Partner who has Multiple Sclerosis

K. Heward, M. Molineux & B. Gough

The research had become involved in the multiple sclerosis as they seek and hold jobs within the HIV/AIDS industry. People who are diagnosed with HIV literally making it a career (McDonald, 2000). One mechanism they describe is through the disabilities increase. However, if plans are not made, an admission that he wants to fulfil with his wife, but that the steady, albeit unpredictable progression of multiple sclerosis means that he has condemned himself to a bleak retirement. They have made no firm plans to control over the multiple sclerosis by accommodating it, so that he and his wife could continue to share holidays abroad together. Cheung and Hocking (2004) also observed that even though many spousal carers of people with multiple sclerosis may have to give up many of their chosen occupations to look after their partners, they could still continue to lead positive lives by developing ways of living with the misfortunes the condition might bring. Paradoxically Graham was postponing the future, by delaying his retirement from paid employment: ‘I actually retired last April, but the company asked me to cover while they got a replacement…. I’m still working full time, it’s scheduled until the end of March… then they have asked me to work until June… so that’s the time.’ (Graham)

In describing his new role, Jim said he experienced ‘Personal satisfaction, helping people with multiple sclerosis through the work I do’. This new occupation had broadened his horizons further in that he had enrolled for various college courses not related to multiple sclerosis, finding a new enthusiasm for learning and developing himself, using education as an outlet. In the trajectory of Jim’s life, this would have been less of an opportunity if his wife had not been diagnosed with multiple sclerosis. When Jim described his history, he claimed his wife to have been the academic one within their relationship and the one with the motivation to succeed in her career. The opportunities that had been presented to him since his wife was diagnosed enabled him to excel at learning and find personal satisfaction. Literature supports the need for carers to look after their own health needs (McKeown et al., 2003) and for some people this might mean a new career linked to their partner’s multiple sclerosis. Jim found confidence and an increase in self-esteem through undertaking college courses and taking an active role within the Multiple Sclerosis Society.

Multiple sclerosis inspired occupational opportunities did not only relate to taking on roles within societies or establishing new non-multiple sclerosis related occupations. It also was an investigative vocation for a number of participants, as evident when participants discussed the time up to and including diagnosis. Partners predicted what the illness could be, could outline symptoms, used medical language when describing the tests their partners had undergone and developed an in depth knowledge of the condition. When they get multiple sclerosis and thought she’s got something like that, so I did a bit of reading and thought perhaps it is…. They did a lumbar puncture but they were a bit vague—she’s had a long remission… I did a lot of reading about it. (Phil)

Although there is literature that supports this investigative focus by those diagnosed with a life threatening or long term condition (Bartos & McDonald, 2000; Robinson, I., 1990), there was no literature available on whether this is an occupational role undertaken by those closest to the person diagnosed. Gallick (1995), however, described coping approaches used by spouses of people with multiple sclerosis, suggesting a systematic planning approach that concentrates on investigating the problem relating to multiple sclerosis and learning new ways of dealing with the problem.
Occupational adjustment for some participants was the key to coping with occupational constraints, and creating opportunities. These individuals believed they were expected to accommodate for their loss, and adjusted accordingly. Some participants viewed this more positively than others. Phil did not view adjustment as negative, as he talked about maintenance of holidays although they were an adjustment from the types of holidays and way they travelled before his wife was diagnosed some years ago. He firstly explained how he bought a four-wheel drive vehicle: “We needed something she can climb into and roll out of” (Phil). He then went on to say how their actual holidaying style had adjusted: ‘She was still mobile. We still went out for weekends, we didn’t go camping as much… (Now) instead of camping we go in chalets. We’ve also got a caravan, we go there a lot because she can get in and out, and we don’t have to book’. (Phil).

Phil highlighted that it was still possible to take part in the occupation of holidaying and even though the way they used to enjoy doing it had been lost. They had adjusted and were still able to visit similar places, but more importantly they enjoyed it and holidaying was a part of their lives that they continued to share. Two participants described adjustment that came from the transfer of occupations but led to opportunity and ultimately satisfaction. When we had the other house Geoff always did the gardens. When we moved, I said ‘They are my gardens now because you can’t do them’. I get a lot of enjoyment out of my garden. I like to see it looking nice. (Jayne)

For Jayne, the opportunity of gardening has become a therapeutic outlet and had become a place where she could escape, highlighting the significance of occupation as an emotional outlet, and to maintain physical and emotional well-being.

Similarly Carol described the occupational opportunity of going to the cinema, which had arisen because her husband’s eyesight was no longer good enough to read. They had therefore developed a shared occupation out of one that had been lost to him: “The pictures became a bit part for us, taking over from his books” (Carol). Cheung and Hocking (2004) also found participants in their study of spousal carers of people with multiple sclerosis became involved in jobs and hobbies that were possible within the limits of caring for someone with multiple sclerosis.

The participants were animated when they described the occupations they were able to do that were meaningful to them, whether it was ones they were either still able to do despite their partner’s multiple sclerosis, or new ones they had discovered as a result of their partner’s multiple sclerosis. The participants were able to make a positive link between being able to engage in occupations that were important to them, and maintaining well-being. Harold described the feeling of still being able to go mountain biking with friends and escape from home: ‘It’s just being out in the fresh air, it’s just the beautiful scenery. It’s also the companionship and the fun you have with mates. It’s just feeds a need’ (Harold).

K. Heward, M. Molineux & B. Gough

The Occupational Impact of Caring for a Partner who has Multiple Sclerosis

Harold’s need for freedom was important to him, in that it enabled him to live within his home situation and was in drastic contrast to his statement about carers being ‘slaves’. His experiences of his current life were extremes between having no life as a carer and being free and escaping. When the occupations participants found fulfilling were not possible because of their partner’s multiple sclerosis, life generally became more difficult and the pressures of living with multiple sclerosis more challenging.

Conclusions

This exploratory study aimed to develop an understanding of the occupational impact of multiple sclerosis for the partners of people diagnosed with the condition. Although it is recognised that relationships are dynamic and change over time, such changes are compounded when living with somebody who has multiple sclerosis. This research has highlighted that partners of people with multiple sclerosis can restore or develop new occupational pathways, as a couple or independently, and can make occupational plans for the future even in the face of an unpredictable condition.

This research has also highlighted how multiple sclerosis can bring partners occupational opportunities, either directly or indirectly linked to multiple sclerosis, which have a positive effect on their lives, through engagement in enjoyable occupations have had positive physical, psychological and emotional effects. Although this finding aligns with other authors (Clark, 1993; Jackson, 1998; Jackson et al., 1998; Wilcock & Hocking, 2004; Verka et al., 1999), the importance for partners of people who have a long term chronic condition such as multiple sclerosis, and their occupational behaviours, have not been previously identified.

The results of this study point to a number of areas for future study, both in investigation of whether parallels can be drawn between partners of people with multiple sclerosis and those with other progressive conditions, and in the occupational behaviour of other family members. Areas for future study may include the occupational impact of multiple sclerosis on younger members of the family, particularly children, who are at the age of making career choices and who are also carers. It is also important to explore whether gender influences the role and occupational choices of partners of people with multiple sclerosis, and the occupational issues they experience, particularly those relating to productivity.

References


The Occupational Impact of Caring for a Partner who has Multiple Sclerosis

K. Heward, M. Molineux & B. Gough


