



# Multiple Sclerosis & Employment in Europe

## Literature Summary



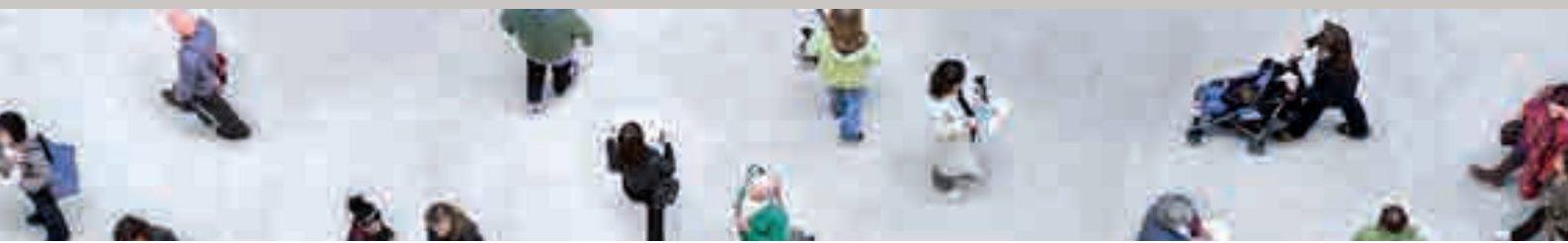
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# Literature Summary

Multiple sclerosis (MS) is a chronic disease that impairs functioning of the central nervous system. MS is estimated to affect some 2.3 million across the world (MSIF 2013). In Europe, it is estimated that between 500,000 and 700,000 people are living with MS (Kobelt and Kasteng, 2009; International MS Society (MSIF) 2013).

## What is MS?

MS is an inflammatory disease, which causes damage to (demyelination and scarring) nerve axons in the brain and spinal cord. A variety of neurological symptoms associated with MS result from a weakening ability of the cells to conduct nerve signals. MS can cause disability progressively over time, including difficulty with mobility and upper limb function, bladder, bowel, and sexual dysfunction, speech and swallowing, vision and cognition. Treatment reduces the symptoms, but currently there is no cure to stop the disease.

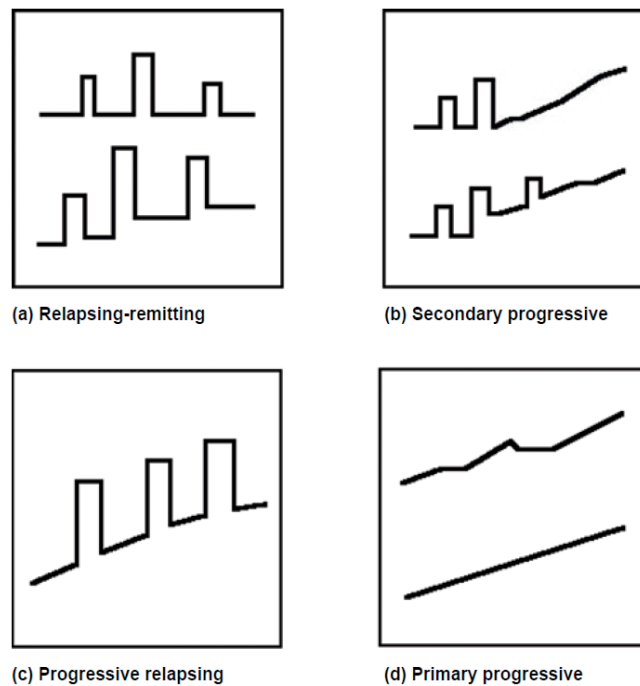
Even with advances in medicine, it remains difficult to diagnose MS with certainty (Fox, Bensa, Bray and Zajicek, 2004). Several MS subtypes are defined by the progression of the disease (WHO, 2007). The patterns of progression are (see figure 1):

- The majority of patients (80 per cent) are diagnosed with **relapsing-remitting** MS, which is characterized by periodic disease exacerbations. Exacerbations arise when a sudden onset or increase in symptoms occurs. The symptoms recede fully or partially over the course of a few weeks or months. As time progresses, the relapses may become more severe and recovery may be less complete.
- As the disease progresses, patients may receive another diagnosis of **secondary progressive** MS, which is similar to primary progressive course (see below). About 50 per cent of people with relapsing-remitting MS develop secondary progressive MS. Symptoms continue to worsen gradually without distinct remission periods.
- Patients diagnosed with the **primary progressive** course of MS experience a steady worsening of symptoms without preceding exacerbations. About 10 per cent to 15 per cent of patients experience gradual progress of disability from the onset of the disease. This is the second most common course of MS.
- Some patients who have progressive MS from the start also experience relapses on top of the clear progression. This is sometimes described as **progressive relapsing MS**<sup>1</sup>
- **Benign MS** is diagnosed retrospectively when accumulated disability from relapsing-remitting MS is mild or non-existent after a long period.

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<sup>1</sup> <https://www.mssociety.org.uk/what-is-ms/types-of-ms/primary-progressive-ppms>

**Figure 1: Progression of MS by type**



Source: Lublin and Reingold (1996)

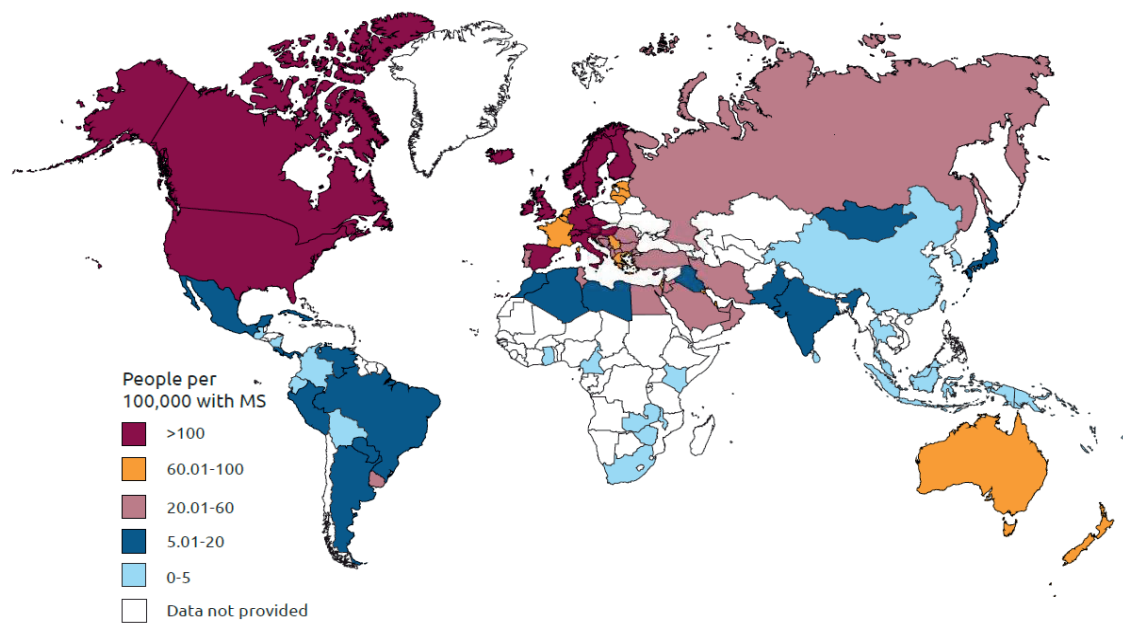
## Prevalence and incidence of MS

Often diagnosed between the ages of 20 and 40 (Rumrill, 2009), the prevalence rate of MS in Europe is highest for the 35 to 64 years age group (Pugliatti, Rosati, Carton, Riise, Drulovic, Vecsei et al., 2006). This suggests, MS often impacts individuals during their most economically productive middle years (Richards, Sampon, Beard and Tappenden, 2002).

The prevalence of MS is greater in women – as is the case with other autoimmune conditions (Koutsouraki et al, 2010; Harbo et al, 2013). Across all age-groups, the incidence of relapse-remitting MS per 100,000 person years is 6.6 for women and 2.6 for men, and the incidence of primary progressive MS per 100,000 person years is 0.5 for women and 0.5 for men (Alonso, Jick, Olek and Hernán, 2007). This indicates the gender gap is less clear for primary progressive MS, but many more women than men experience relapsing-remitting MS. This trend might be increasing (Koutsouraki et al, 2010) - with the MS prevalence ratio of women to men increasing markedly during the last decades (Harbo et al, 2014).

Though MS is found across the world, reported prevalence rates are notably higher in European and North American countries (MSIF 2013). To some extent this may be associated with varying levels of diseases ascertainment across countries (Pugliatti et al., 2006). The highest prevalence in Europe is 189 per 100,000 in Sweden, and the lowest is 22 per 100,000 in Albania (MSIF 2013)

**Figure 2: Prevalence of MS by country 2013**



Source: Multiple Sclerosis International Federation (2014) Atlas of MS 2013

Though the cause of MS is not known, it is believed that MS risk is determined by genetic factors (such as frequencies of Human Leukocyte Antigen alleles) interacting in a complex manner with environmental risk factors, such as UV exposure and smoking (Handel, Handunnethi, Giovannoni, Ebers and Ramagopalan, 2010; Ebers, 2008).

## MS symptoms and their impact

Sampson, Beard and Tappenden, 2002). It can be unpredictable in its course, and the fluctuating nature of MS can be particularly difficult. We have been unable to ascertain which behavioural and psychological factors moderate the relationship between functional limitation, disability and quality of life (Stuifbergen, Brown and Phillips, 2009).

The uncertainty associated with a diagnosis of MS, has been suggested to encompass three levels of uncertainty (Bevan, S., Zheltoukova, K., McGee, R. & Blazey, R. 2011):

1. Day to day variability in symptoms;
2. Month to years variability in terms of relapses and residual disability;
3. Long-term variability in how disability will accumulate.

Though the presentation can vary considerably in individuals, the following symptoms are seen as relatively commonly experienced (MS Society, 2010; Richards, Sampson, Beard and Tappenden, 2002):



- fatigue,
- pain,
- visual impairment,
- numbness,
- bladder or bowel problems (frequency and incontinence);
- sensory symptoms (disturbances in touch, for example),
- weakness,
- loss of balance,
- loss of mobility,
- spasticity,
- depression, and
- cognitive problems.

Individuals with MS consistently report **lower health-related quality of life** compared with other conditions (Jones, Pohar, Warren, Turpin and Warren, 2008; Warren, Turpin, Pohar, Jones and Warren, 2009). A more aggressive disease course is associated with lower levels of health-related quality of life, marked by patient rated emotional adjustment to illness and patient rated handicap (Benito-Léon, Morales, Rivera-Navarro and Mitchell, 2003). Comorbidity – co-occurring long-term health conditions - can further worsen health-related quality of life, for example, urinary incontinence and depression, as can other health-related factors such as cognitive impairment and fatigue (Warren et al., 2009; Benito-Léon, Morales, Rivera-Navarro and Mitchell, 2003).

Approximately 80 per cent of MS patients experience restrictions in daily activities, primarily due to **fatigue** (Wynia, Middel, van Dijk, de Keyser and Reijneveld, 2008). Fatigue may make balancing work and life responsibilities difficult. For example, after working all day, some may have little energy for family and/or social life, and this may factor into decisions to leave work earlier (Malcomson, Lowe-Strong and Dunwoody, 2008).

Many people with MS are also living with **depression** (Marrie, Horwitz, Cutter, Tyry, Campagnolo and Vollmer, 2009). The MS Trust (2010) suggests that about 50 per cent of people with MS will experience an episode of depression. The prevalence of depressive disorders among MS patients is two to three times that of the general population (Kraft, Johnson, Yorkston, Amtmann, Bamer, Bombardier et al. 2008). As reflects prevalence in the general population, women with MS have a higher rate of major depression compared to men with MS (Patten, Metz and Reimer, 2000). Though causes of depression are complex, it has been suggested that the unpredictable disease course and uncertainty associated with MS is a contributing factor (MS Trust, 2010). It is likely that many other MS patients have depressive symptoms that are unrecognized and remain untreated (McGuigan and Hutchinson, 2006; Sollom and Kneebone, 2007). This is of particular concern because depression affects psychosocial functioning and adherence to treatment (Zwibel, 2009).

High levels of **stress and anxiety** are also associated with having MS – with the additional challenges of managing the disease and dealing with unpredictable exacerbations of symptoms likely influences (Malcomson, Lowe-Strong and Dunwoody, 2008). For individuals with MS, anxiety (Chwastiak and Ehde, 2007) and stress are associated with reduced quality of life, treatment adherence and functional status (Mohr and Cox, 2000; Chwastiak and Ehde, 2007). Anecdotally, many MS patients identify stress as a potential contributing factor to relapse (Bevan et al., 2010), though there is insufficient evidence to suggest high stress as a cause of relapse.

It is estimated that between 43 per cent and 70 per cent of individuals with MS have **cognitive impairment** (Chiaravalloti and DeLuca, 2008). Cognitive impairment may play an important role in



functional capability, which includes ability to work and participate in social activities (Chiaravalloti and DeLuca, 2008). Aspects of cognitive functioning that might be affected include the following (Chiaravalloti and DeLuca, 2008; Prakash, Snook, Lewis, Motl and Kramer, 2008):

- attention,
- executive functioning,
- information processing efficiency,
- memory and learning,
- motor functioning,
- mood and psychological status,
- processing speed.

Prakash et al. (2008) identified **motor functioning and mood status** as the cognitive impairments most frequently reported for individuals with relapsing-remitting MS. Some of these impairments may occur early on in the disease stage or may progress with the duration of the diagnosis; additionally fatigue and depression may influence cognitive function (Chiaravalloti and DeLuca, 2008). The role of cognitive functioning is highlighted by the findings of Honarmand, Akbar, Kou and Feinstein (2011) who established the scores on the Multiple Sclerosis Functional Composite – a composite measure of both physical and cognitive functioning – to be the most robust predictor of employment status, exceeding the predictive value of scores on a measure of general disability (the Expanded Disability Status Scale), and individual and global measures of cognitive decline.

## Caregivers

MS does not only impact the person diagnosed with it, but also family and friends who may provide informal care. Caregivers play an important role in supporting individuals with MS. The fine balance between providing care and assistance, but also enabling the individuals with MS to continue living and functioning to the best of their ability can be hard to find. MS may also strain relationships, because family members may feel a need to take on additional responsibilities (Halper, 2007). Caregiving partners may feel uncertainty about the future, financial difficulties, social disruption and isolation (Halper, 2007).

## MS and working life years

MS is seen as having an adverse effect on employment outcomes. Along with the symptoms of the condition (see box A), this effect may be worsened by other disease-factors, in particular the unpredictable nature of the onset, severity, and length of relapses. The majority of people with MS self-report that it affects their ability to remain in and progress in work (Green, Todd and Pevalin, 2007). This is reflected in income, with people with MS identified as much more likely to have a 'below average' household income (Green, Todd and Pevalin, 2007).

Though unemployment rates for people with MS vary across studies and across countries, it is clear from the data that they are much higher than the unemployment rates of the usual population (Julian et al., 2008). A review of MS across nine countries in Europe found employment rates highest in Italy (42%) and the lower in Spain (26%) (Kobelt, Berg, Lindgren, Fredrikson and Jonsson, 2006a). A similar pattern (though much higher rates) were found in later study looking at MS patients across five European countries (the TRIBUNE study), where the highest rates of employment/self-employment were in Italy (78%) , and the lowest in Spain (51%) (Karampampa et al 2012).

### Effect of MS symptoms on work

- Fatigue, anxiety and depression affecting work patterns and ability to concentrate;
- Pain and heat intolerance affecting interactions and comfort with the work environment;
- Limitations in mobility place restrictions on physical access to work environment;
- Reduced dexterity complicates handwriting, working on a keyboard, performing manual tasks;
- Slurred speech (dysarthria) impacts communication, use of phone and presentation skills;
- Urinary and faecal frequency and urgency with fear of incontinence presents emotional challenges;
- Visual impairment affects reading;
- Cognitive impairment causing memory and concentration difficulties.

Source: British Society of Rehabilitation Medicine (BSRM), 2010; Julian, Vella, Vollmer, Hadjinichael and Mohr, 2008; Simmons, Tribe and McDonald, 2010

People with MS are more likely to leave employment earlier than the usual population, and unemployment rates increase with longer duration of MS (O'Connor, Cano, Torrenta, Thompson and Playford, 2005). Around 15 years after the onset of MS, between 60 per cent and 80 per cent of patients would have lost their jobs (Zwibel, 2009). Kobelt et al (2006a) found an estimated thirty-five per cent of MS patients in Europe retired early because of the condition. The mean retirement age found among MS patients across nine European countries ranged from 45.1 to 53.4 years – the lowest average age of early retirement was found in Belgium and the highest in Austria (Kobelt, et al., 2006a). The variation in early retirement rates across countries could be a result of differences in general workforce participation and welfare systems (Kobelt et al., 2006a). The data suggests a loss on average of over 10 working years. Later data from the TRIBUNE study found that 23 per cent had retired early due to their MS, though this varied hugely by country – with 27 per cent of the Spanish cohort retiring early against just 4 per cent in Italy (Karampampa et al, 2011).

Perhaps the most obvious predictor of employment is condition severity. Naci, Fleurence, Birt and Duhig (2010) highlight a 1998 study<sup>2</sup> which found less than four in ten (37%) of individuals with mild MS are employed, with the employment rate dropping to just 4 per cent for those with severe MS. As outlined in Bevan et al (2010), Karampampa et al (2011) identified that older age and higher levels of disability (an Expanded Disability Status Scale (EDSS) score of 5 or more) are associated with early retirement among people with MS. They further identified that those who have retired early due to having MS were more likely than those who were still employed to have depression - found in 53 per cent compared to 30 per cent of those employed, and urinary incontinence (53 per cent) compared with those still working (29 per cent).<sup>3</sup>

A number of studies have examined which aspects of MS influence people's ability or inability to continue working. One of the factors identified is the course of the disease. Unsurprisingly higher employment rates are found among benign MS patients compared with non-benign groups (83 per cent compared to 35 per cent) (Glad, Nyland, Aarseth, Riise and Myhr, 2010). However, amongst those experiencing a non-benign form of MS, variations in ability to work can still be seen with a non-

<sup>2</sup> Auty A, Belanger C, Bouchard JP, et al. Burden of illness of multiple sclerosis: part II. Quality of life. *Can J Neurol Sci* 1998; 25 (1): 31-8

<sup>3</sup> The data are cross-sectional. Therefore, the data do not indicate a causal relationship between retiring due to MS and health outcomes

remittent course negatively influencing people's ability to work (Grønning, Hannisdal and Mellgren, 1990; Glad et al., 2010; Honarmand, Akbar, Kou, and Feinstein, 2011). The longer the course of the illness, and the greater the degree of disability experienced by the individual, have also been identified as risk factors for unemployment in MS (Honarmand, Akbar, Kou, and Feinstein, 2011; O'Connor et al., 2005). As mentioned earlier, unemployment rates range from between 60 per cent and 80 per cent around 15 years after the onset of MS (Zwibel, 2009). Individuals with MS have a 'below average' household income compared to those without MS even though many have higher education levels and social class (Green, Todd and Pevalin, 2007). With that said, research from Denmark suggests that if individuals with MS remain in work, they maintain a similar income as the general population (Pfleger, Flachs and Koch-Henriksen, 2010a).

Many of factors relating to the ability to remain in work are disease related. A study by O'Connor et al. (2005) identified fatigue (28 per cent), and difficulties with handwriting (26 per cent), balance and walking difficulties (45 per cent) as all having a significant impact on more than a quarter of respondents' ability to work. Similarly, Simmons, Tribe and McDonald (2010) found that for those individuals who left work as a result of their MS, the most common reasons given were related to MS symptoms, particularly: fatigue, problems with legs, feet, arms or hands, difficulty with memory, concentration or thinking, balance or dizziness, and heat sensitivity.

The impact of MS-related symptoms on individuals' ability to work is also highlighted by the finding that significant worsening of symptoms in the last six months were found to be predictive of employment loss when changes in employment over time in MS were examined (Julian et al., 2008). A key aspect of these findings is that it is not simply the physical symptoms that affect the person's ability to work, but a combination of both physical and cognitive functioning. One stakeholder explained that it is difficult to understand when an MS patient will '*look the same but not feel or function in the same.*' This can be particularly difficult for employers to understand.

With symptomatic factors playing a strong role in the ability to remain in work, as well as to perform certain kinds of jobs, Simmons, Tribe and McDonald (2010) conclude that more effective symptom management in the workplace is likely to be an important factor in maintaining employment.

The employment environment can also play a role in employment outcomes for individuals with MS. The type of work carried out appears to influence whether a person with MS is able to stay in work. While Simmons et al. (2010) found no clear pattern to suggest an association between leaving employment due to MS and occupation type, other findings have indicated that individuals who undertake physical work should be considered at higher risk for early unemployment due to MS (Grønning, Hannisdal and Mellgren, 1990; Pfleger, Flachs and Koch-Henriksen, 2010b; Glad et al., 2010; Pompeii, Moon and McCrory, 2005). While the evidence reviewed above suggests symptom related issues more strongly influence the ability to stay in work than factors relating to the workplace, this highlights that workplace issues should not be ignored. Specific issues that have been identified are difficulties in travelling to and from work, and access while at work (e.g. wheelchair access) (O'Connor et al., 2005). Furthermore, research conducted by the MS Society highlights particular challenges for individuals with MS in that symptoms may not always be visible to employers or colleagues, and there is a perceived lack of knowledge about the symptoms associated with MS, particularly their fluctuating nature, and a lack of understanding about the impact of these symptoms (Staley and Hanley, 2006).

Research examining job satisfaction and turnover intentions (i.e. plans to voluntarily leave one's job) amongst individuals with MS may also be helpful in considering what the precursors are to individuals leaving employment. Roessler, Fitzgerald and Rumrill (2004) find that person-job fit, in addition to adequacy of income, was predictive of job satisfaction in employed people with MS and argue that acknowledgement of a poor job match may reflect perceived early signs of inability to perform the job and to meet personal needs through work. Poorly recognised mismatch between job demands, work patterns and changing individual capacity contributes to reduced employment among people with MS (BSRM, 2010).

Additional, external factors influencing participation of people with MS in the labour market include, poor adjustment of the employment structures to the needs of patients, including physical obstacles, such as open plan offices or inaccessible toilet, inflexible work patterns and lack of employer/colleagues' support (Johnson, Klasner, Amtmann, Kuehn, and Yorkston, 2004). Pack, Turner, Roessler and Robertson (2007) examined the issue from the perspective of turnover intentions amongst employed adults with MS and showed that symptom severity, perceived stress levels and coping ability, job satisfaction, and employer support were all significant predictors of turnover intention. Pack, Turner, Roessler and Robertson (2007) argue that focusing rehabilitation on each of these areas may enable people with MS to retain employment. Again, creative workplace design may resolve many issues that challenge productivity of individuals with MS.

A further perspective that should be considered is the extent to which individuals with MS are able to re-enter the labour market. Much of the focus of welfare reform is the provision of support for people to find employment which is appropriate to their functional capacity. With a fluctuating condition such as MS it might be assumed that re-entering the labour market after having left it might be an especially difficult challenge. Julian et al. (2008) examined this issue in their study looking at changes in employment across time and found evidence to suggest that employment status in MS should be considered a dynamic process, with 5 per cent of those not working at the first assessment entering into employment by the second time point. Those with higher levels of educational attainment and who were younger were more likely to continue working, as well as those with reductions in symptoms relating to mobility, hand function and cognitive function. The findings relating to the demographic variables of age and educational attainment mirror the relationship found elsewhere showing age and educational attainment as correlates of unemployment in MS (Grønning, Hannisdal and Mellgren, 1990; Pflieger, Flachs and Koch-Henriksen, 2010b).

A particular challenge in moving into employment for individuals with MS is the unpredictability of their symptoms, the need to have a realistic understanding of their capacity for work, and to be able to anticipate feeling unwell in the future even if they feel well at the current time (Staley and Hanley, 2006). Flexibility in the workplace in terms of being able to adapt working patterns to fit with periods when individuals are feeling well was identified as a key component of employer support in overcoming some of these issues (Staley and Hanley, 2006). However, it has also been identified that there are a high proportion of individuals who do not receive any support to remain in employment, both for individuals looking to return to work and those who are currently in work (O'Connor et al., 2005). This highlights the need to address some of the issues identified here that influence whether people are able to participate fully in the labour market.

## Costs of MS

MS is one of the most costly neurological diseases, due to its early onset, long duration and significant effects on work and daily activities (Battaglia, Zagami and Messmer, 2000). Management of relapses, progressing disability and comorbidities linked to MS may present a significant financial burden for the patients, the health care system and the economy. In a review of 29 cost-of-illness studies, Naci, Fleurence, Birt and Duhig (2010) identify the following types of costs:

- **Direct medical costs:** hospital stay, inpatient and outpatient care, tests and imaging, pharmaceuticals, transport, social assistance, physiotherapy sessions.
- **Direct non-medical costs:** adaptive devices (e.g. wheelchair), domestic help, retraining, informal care, personal expenses.
- **Indirect costs:** total productivity costs (short-term and long-term absence, early retirement), changes in employment status of patients and carers, societal losses, disability payments, lost opportunity costs, foregone income due to premature mortality and disability, patient and caregiver time loss, community assistance, home modifications.

- **Intangible costs:** costs associated with pain, social functioning, ability to perform daily activities, anxiety, quality of life, health-related quality of life.

The **direct medical costs** associated with MS can be considerable. For example, individuals with MS visit the hospital and consultants twice as much as individuals without MS (Naci, Fleurence, Birt and Duhig, 2010). Costs associated with disease modifying drugs vary across Europe, but they typically comprise one of the largest direct medical costs (Naci, Fleurence, Birt and Duhig, 2010). An exception to this is the UK where disease modifying drugs constitute only a small proportion of costs (McCrone, Heslin, Knapp, Bull and Thompson, 2008) - though it is noted that some of those costs are carried by individuals with MS. Other **direct non-medical costs** that may fall on individuals or social services include those associated with home or residential care, adaptations to the home (e.g. grab rails, hoists, stairlifts and shower rooms) or provision of wheelchairs (Curtis, 2010).

A large proportion of MS-related costs are **indirect**, and felt through **reduced workability** (Battaglia, Zagami and Messmer, 2000). A recent review of the literature on societal costs of MS, suggested that on average, 55% of all costs associated with MS are 'indirect', highlighting in particular the effect MS can have on a person's ability to work, as well as their need for informal care and supports.

Indeed, the costs associated with lost working capacity are larger than the costs to health care and social services (McCrone et al., 2008). A study for the Swiss MS Society (Knülle et al., 2011) estimated that the costs of MS across Europe were in excess of €15bn, with lost productivity accounting for 36 per cent of these costs. Indirect costs may increase as patients and carers have to change their employment status or even leave the labour market (Phillips and Humphreys, 2009). According to Hakim et al. (2000, as cited in WHO, 2007) who studied the social impact of MS in the UK, 53 per cent of MS patients in the UK who were employed at the time of diagnosis stopped working and for 37 per cent of patients and their families the standard of living declined as a direct result of the disease. As earning power diminishes, it may become increasingly more difficult for patients to afford the direct out-of-pocket expenses associated with MS, which are estimated to be between £1,100 – £2,600 a year (Tyas, Kerrigan, Russell and Nixon, 2007).

A few studies suggest a higher proportion of the costs are attributed to **informal care** in the UK compared to other European countries, Canada and the US (Kobelt, Lindgren, Parkin, Francis, Johnson, Bates et al., 2000; Naci, Fleurence, Birt and Duhig, 2010). Caregiver burden measured by caregivers' lost time and foregone income contributes to overall societal costs of the disease (Murphy, Confavreux, Haas, König, Rouillet, Sailer et al., 1998). For example, professional careers of 57 per cent of relatives were adversely affected by the patient's MS (Hakim et al., 2000, as cited in WHO, 2007). Additionally, the quality of life of MS caregivers was estimated to be lower than quality of life of diabetic and psychiatric carers: it appeared to correlate strongly with perceived patients' quality of life and was associated with carers developing fear of MS (Alshubaili, Ohaeri, Awadalla and Mabrouk, 2008).

Some researchers also seek to measure the **intangible costs** associated with MS – pain, helplessness, anxiety, and other symptoms associated with MS can dramatically affect quality of life in patients and their caregivers (Casado, Romero, Gubieras, Alonso, Moral, Martinez-Yelamoz et al., 2007). While difficult to quantify, an increasing number of studies consider the burden of intangible costs. Some research suggests that intangible costs account for between 17.5 per cent and 47.8 per cent of total costs of MS; the wide range may be the result of the varied approaches to evaluating quality of life (Wundes, Brown, Bienen and Coleman, 2010).



As mentioned, MS is unpredictable in its course. Therefore, the costs associated with MS can vary widely by patient. For example, the costs in the UK are estimated to vary from £12,000 for patients with low disability scores to £60,000 for patients with severe disability stage (Kobelt et al., 2006b). Naci, Fleurence, Birt and Duhig (2008) and Kobelt et al. (2006a) suggest that working to delay the progression of MS can reduce the associated costs.

Due to the significant variation of MS costs between patients with mild and severe disability it is difficult to extrapolate the average per-patient cost of the disease onto a societal scale. One comparative analysis across thirty European countries (and over 13000 patients) estimated the total annual mean costs per patient (classified using the EDSS) at being **€18000 for mild disease**, and **€36500 for moderate disease** and **€62000 for severe disease**, with intangible costs estimated at a €13000 per patient (Kobelt et al., 2006b). The study gathered evidence from national registries and published sources, as well as self-reported data from a patient questionnaire in order to provide maximally comprehensive assessment of direct, indirect and intangible costs incurred by the disease (Kobelt et al., 2006b).

The above does not consider costs in terms of welfare benefits. In Bevan et al 2010 it is suggested that in the UK, the costs to the welfare system of premature loss of work for someone with MS who could have been supported to stay in work might be substantial – at £61000 per individual who has an average early retirement. Further costs will occur through the loss of income tax.

## Conclusion and Evidence Gaps

MS is an unpredictable and fluctuating condition that impacts individuals differently. It affects both mental and physical health. Many of the symptoms are invisible to others and can worsen or improve rapidly. A number of symptoms and co-occurring conditions accompany a diagnosis of MS, including fatigue, depression, incontinence and pain. In the work setting, MS symptoms play a significant role in maintaining employment, but the work environment is also an important factor. Some of the most costly aspects of MS are related to indirect costs, such as the loss in ability to work and informal caregiving. This impacts household finances as well as the greater society. Yet most people who develop MS are of working age and want to work.

Focusing on job retention, with adjustments, could provide both clinical and financial benefits. If people with MS across Europe lose at (on average) at least 10 years of working life, and those who are not working have worse health outcomes (including higher rates of depression and disability), then clinical and workplace interventions that retain people in employment could greatly benefit not only individuals but also wider society.

Overall, the literature is helpful in mapping out the prevalence and impact of MS on employment and productivity. However, we have identified a number of evidence gaps. These are set out below:

- There are few employer-based case studies which focus on the detail of interventions to promote job retention, rehabilitation, workplace adjustments etc;
- There is very little evidence of interventions in Small & Medium-Sized Enterprises (SMEs) which takes account of the specific challenges these employers face;
- There are very few economic evaluations of the cost-effectiveness of workplace interventions which might contribute to a 'business case' argument for action;
- Many of the published studies originate in Western Europe and North America, with relatively little evidence from Eastern Europe;
- The evidence on the therapeutic benefits of remaining in work for people living with MS is not extensively researched. While there is research on the health benefits of 'Good Work' across a range of chronic conditions and for mental health especially, the specific health benefits of work in the case of MS have not been extensively examined;

- For some conditions there is evidence that improving employment rates for people living with chronic illness reduces healthcare resource utilisation. However, this is a gap in the MS & employment literature;
- Although self-management of MS is increasingly part of the clinical literature, it features less prominently in employment settings where, with other conditions, there is evidence that equipping people with self-management & self-advocacy tools can improve confidence and job retention;
- While there is some evidence that people living with MS can have an elevated risk of developing comorbid conditions such as depression, there is relatively little research looking at how this might affect both employment rates and success in sustaining job retention and return to work efforts.





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