

WORK DISABILITY, ECONOMIC SITUATION, AND SOCIETAL COSTS OF MULTIPLE SCLEROSIS IN SWEDEN

THESIS FOR DOCTORAL DEGREE (Ph.D.) By Chantelle Ellen Murley

I research the working life and income of people with multiple sclerosis (MS) as well as the societal costs of MS from healthcare use and days off work. MS is a chronic and often progressive neurological disease. People with MS may require sickness absence (SA) or disability pension (DP) benefits if they are unable to work because of their MS. Receiving SA or DP benefits is referred to as having work disability. In this thesis, I studied aspects of work disability among people in Sweden around the time of their MS diagnosis in four register-based studies. In Study I, I observed different trajectories of disposable income in the years around diagnosis. In Study II, I described the working-life patterns and their financial implications in the years following diagnosis with MS. Being able to work is not only important for people with MS but also for society. I quantified the hypothetical loss of production to society using the number of days off work with work disability in Studies III and IV. In these two studies, I examined the excess costs of MS. These are a quantification of how much larger the productivity losses and healthcare costs to society are because of MS. The findings of this thesis highlight the importance of non-clinical outcomes in early MS. Importantly, in the first years after MS diagnosis, most individuals stayed in work and had stable or increasing disposable income. However, work disability was often and increasingly a part of their working life and was associated with static or decreasing disposable income trajectories. Excess costs of MS for lost production and increased healthcare use occurred before the MS diagnosis and increased with time. These early excess costs of MS indicate that early intervention and support may help people with MS.

Multiple sclerosis (MS) is a neurological disease that can affect many parts of everyday life. Living with a chronic disease can have far reaching consequences not only for the individual, but for their families, employers, healthcare systems, and society too. The wide-ranging symptoms of MS can pose challenges with daily activities, including work. Although work can have wider meaning than simply generating money, this thesis focuses on socioeconomic outcomes of MS. Being unable to work because of a disease can be referred to as work disability. Work disability is an important consequence of MS because the chronic and uncertain disease largely affects individuals of working ages. Therefore, MS has previously been associated with reduced earnings and changes in employment. Sickness absence (SA) and disability pension (DP) are the two social insurances in Sweden that compensate lost earnings in situations of temporary and permanent or long-term work disability. In this thesis, work disability was defined using information on days with SA and DP benefits. When an individual has work disability, this can mean a loss of earnings, but also a loss to society from the reduced productivity of the individual. The costs of lost productivity alongside the costs for healthcare use provide information on the socioeconomic burden of MS from society's perspective. This thesis combines the scientific disciplines of insurance medicine and health economics to gain further insight on the socioeconomic burden of MS.

The four studies comprising this thesis examined different aspects of the socioeconomic burden of MS using Swedish register data. The aspects studied included both work disability and incomes among the people with MS as well as the costs to society from work disability and healthcare use. Study I and II investigated the annual incomes and working life of individuals with MS. In Studies III and IV, a societal perspective to work disability was applied. In these cost-of-illness studies, the socioeconomic burden of MS was quantified in monetary terms as the excess costs to society because of MS.



In **Study I**, annual mean disposable income (DI), earnings, and days with work disability of all working-aged people diagnosed with MS in 2008-9 were analysed from 7 years before to 4 years after their MS diagnosis year. DI is the after-tax sum of income from earnings, transfer payments such as SA and DP benefits, and capital gains. The people with MS had rather smooth and increasing trends for DI over the study. However, the year of MS diagnosis was noticeable in the dynamic trends for earnings and work disability. Seven distinct DI trajectories were identified among this group of people with MS using a method called group-based trajectory modelling. With this method, I identified subgroups or “trajectory groups” that had different patterns of DI: Two groups with consistently low and flat trajectories (50.7% of individuals); four groups with increasing trajectories (39.0%); and one decreasing trajectory (10.3%). The members of the trajectory groups had different sociodemographic and work disability profiles. The increasing trajectories had higher proportions of older-aged men. The consistently low-flat and decreasing trajectories had smaller proportions with university education and larger proportions of individuals with work disability in the diagnosis year. For many people with MS, there was stable and even increasing annual DI. DI can represent the total monetary resources available to the individuals and suggested that the social insurances were largely compensating for lost earnings. However, around 10% of people with MS were observed to have a decline in monetary resources in the years around MS diagnosis.

In **Study II**, working lives of all working-aged individuals with an MS diagnosis in 2008-11 were investigated. Sequences describing the working life of people with MS in terms of being in activity (e.g., working or studying) or with work disability were constructed from 1 year before to 5 years after the diagnosis year. I found 633 unique patterns of working life. A third

of the studied individuals were in activity throughout their sequence. At lower levels of work disability, one was equally as likely to return to activity as to progress to a higher level of work disability in the next year. Being in activity became less frequent with time. There were more transitions later in the sequences, suggesting more changes and increasing diversity in working-life patterns. I identified six different types of working-life sequences from the individual sequences using cluster analysis. The types differed by the levels, timing, and patterns of activity and work disability within the sequences. All sequence types had higher DI in the final study year than the first, except for sequences with full-time SA/DP throughout. This study adds to Study I, by showing that most people in the years directly following their MS diagnosis have increasing monetary resources.

In **Study III**, I studied the excess costs of MS to society from 4 years before to 4 years after the year of MS diagnosis. For each year, healthcare use (inpatient healthcare, specialised outpatient healthcare and prescribed drugs dispensed at pharmacies) and days of lost productivity due to work disability were counted and then their costs were estimated. Excess costs of MS were calculated as the difference in the costs between all working-aged individuals diagnosed with MS in 2010-12 and those of a group of individuals without MS. I found that there were excess costs of MS already before diagnosis. The magnitude of the excess costs of MS from productivity losses was larger than from healthcare use. With time, the annual excess costs of MS became larger, with a steep increase around MS diagnosis for both healthcare and productivity losses. People with MS had annual costs for healthcare that were five-times higher than people without MS, when summarising all study years, and two-times higher costs from lost production. The excess costs of MS before diagnosis could suggest unmet needs of people with MS with their morbidity and work situation. Earlier diagnosis and starting treatment quicker may reduce or delay future costs of MS.

People with MS also have healthcare costs for primary healthcare and disease modifying therapies. These costs were included in **Study IV** in addition to those in Study III. I calculated costs from resource use in 2018 for all working-aged residents in Stockholm with MS and a group of Stockholm residents without MS. When quantified into monetary terms, there was an annual mean excess cost of 77,383 SEK per person with MS, in addition to the usual healthcare costs. The largest part (48%) of these costs came from disease modifying therapies and primary healthcare accounted for 9%. Excess costs of MS for primary healthcare were largely from visits to healthcare professionals other than doctors. There was a mean annual excess productivity loss of 138,121 SEK per person with MS, mainly from DP (79%). The excess productivity losses of MS became larger with time from MS diagnosis. The excess costs of MS from healthcare were similar but the type of healthcare use differed by time since MS diagnosis. People newly diagnosed with MS had excess healthcare costs of MS mostly from disease modifying therapies whereas inpatient and primary healthcare drove the excess healthcare costs among people with a longer time since their MS diagnosis.

The findings of this thesis highlight the importance of socioeconomic outcomes of MS for both the individual and society around MS diagnosis. There is an important time window in the early stages of MS for appropriate treatment to help people with MS and potentially prevent or postpone future costs to society from disease worsening and progression. This thesis described the working life and economic situation of people with MS as well as the progression of excess costs of MS to society within this window. Most people with early MS stay in activity and have stable or increasing annual DI. However, this thesis found that work disability is often and increasingly a part of the diverse working lives of people with MS. Work disability was associated with static or decreasing DI. Excess costs of MS for lost production owing to work disability and healthcare use are incurred already before MS diagnosis. The pattern and sizes of the cost categories change with time. The increasing excess costs of MS to society at early stages of MS from productivity losses reflect the challenges people with MS may face with their work and morbidity.

Link to thesis: <http://hdl.handle.net/10616/47911>

Chantelle Ellen Murley, 2022

