Clinical and socio-demographic characteristics of people with multiple sclerosis at the time of diagnosis: Influences on outcome trajectories

What was the study about?

In multiple sclerosis (MS), most research has focused on how the disease develops many years after diagnosis rather than what happens at the time of diagnosis and in the first few years afterwards. The aim of this study was to examine the health, symptoms, and life circumstances of people with MS when they are first diagnosed, and how these factors may influence their health over time. It studied:

- What symptoms and other health conditions people already have at diagnosis
- How their health, disability, and quality of life change over the next few years
- Whether different groups of people follow different "trajectories" or paths
- How factors such as mood, sleep, smoking, and deprivation influence these paths

What did the study involve?

The study used information from the large UK research project - **TONiC-MS study (Trajectories of Outcome in Neurological Conditions)**. Researchers compared two groups of people with MS:

- **An "inception" group** – 813 people who had been diagnosed with MS within the previous year
- **A "decade" group** – 679 people who had been living with MS for around 9–11 years

Participants completed questionnaires about their health and daily life about once per year (so that factors could be tracked over time and for trajectory analysis). These measured:

- Physical disability
- Fatigue
- Overall health status
- Quality of life
- Depression and anxiety
- Sleep problems
- Employment status
- Other health conditions (comorbidities)

Participants also used a body map to show which parts of their body were affected by MS symptoms, and were asked about factors like age, social deprivation, and smoking history.

The researchers then used statistical methods to identify different patterns of health outcomes over time, rather than just looking at average results.

What was found?

- **Many symptoms were already present at diagnosis.** Even at the time of diagnosis, many people with MS were already experiencing issues such as fatigue, reduced quality of life, poor health status and some level of disability.
- **Other health conditions were common.** More than half (57.3%) had at least one other medical condition, and over a third had two or more. The most common were depression, migraine, and anxiety disorders. Many of these conditions had been present for years before MS was diagnosed.
- **People followed different health paths.** Although the average health status looked stable over three years, this was misleading. The researchers found two very different health-status trajectories:
  - In the early stages, most people had good and stable health
  - A smaller group (13.8%) had poor health status from diagnosis, which stayed poor.

  This second, smaller group had more sleep problems, more depression, and were less likely to be in work. They were also more likely to live in areas of higher deprivation.
- **Disability and quality of life also varied.** The study identified:
  - Three disability trajectories (improving, worsening, or stable but high disability)
  - Four quality-of-life trajectories.

  Mental health, comorbidities, education, smoking and social factors strongly influenced which path someone followed.

Why this matters?

This study shows that MS care must be personalised from the moment of diagnosis. People start their MS journey in very different places, and these early differences can shape their health for years.

Looking only at average results can hide the fact that some people experience much greater difficulties early on.

Recognising these differences is important for improving care. The results suggest that healthcare services should identify people who may be at higher risk of poorer outcomes as early as possible, ideally from the time of diagnosis.

Providing early support for symptoms such as fatigue, mental health difficulties, sleep problems, and disability could help improve quality of life for many people with MS.

Overall, this study shows that MS care should be personalised from the start, and that support services need to be available from the diagnostic stage rather than only later in the disease. At present, many services offer a standard package at diagnosis and most support is focused on later stages, on the assumption that people do not develop problems until the disease progresses.

Better understanding of early patterns of health in MS can help clinicians plan more effective care and ensure that people who need the most support receive it at the right time.