Lay Summary

Ando 2021: Understanding quality of life across different clinical subtypes of multiple sclerosis: a thematic analysis

a) What was the study about?

This study explored what affects quality of life (QoL) for people living with multiple sclerosis (MS), and whether these experiences differ between the three main MS types: **relapsing-remitting MS (RRMS)**, where symptoms flare up and then improve, and **secondary progressive MS (SPMS)** or **primary progressive MS (PPMS)**, where symptoms gradually worsen over time.

Quality of life is about much more than physical health. It includes how people feel about their lives, their ability to do things they enjoy, their relationships, their hopes for the future, and their sense of who they are.

b) What did the study involve?

The researchers interviewed **43 adults with MS** in the United Kingdom, including

- 16 with RRMS
- 14 with SPMS
- 13 with PPMS

Each person took part in a one-to-one interview, allowing them to talk openly about how they feel MS has affected their daily life and overall quality of life.

Interviews lasted between **20 and 120 minutes**, were recorded, and then transcribed word-for-word. The team used **thematic analysis**, a method where interviews are read to identify common patterns in people's experiences. They first analysed each MS subtype separately, then compared them to see what was shared and what differed.

c) What was found?

The researchers identified **four main themes** that influenced quality of life across all three MS subtypes.

Restricted and disrupted enjoyment: Many participants described no longer being able to take part in hobbies, work, social activities, or family life in the way they wanted. People with RRMS also described relapses as sudden and traumatic events that interrupted their lives and enjoyment.

Disturbed future: Many people worried about what the future might hold. Those with progressive MS often focused on the gradual worsening of symptoms, while people with RRMS were more concerned about the uncertainty of future relapses or whether their condition would become progressive. People with RRMS also expressed their concerns about the possibility of getting adverse side effects from disease modifying therapies.

Challenged sense of self: MS affected how people saw themselves. Changes in independence, employment, mobility, parenting, relationships, and intimacy sometimes made participants feel they had lost part of their identity.

Well-being of significant others: Many participants expressed how important it is to know that people they value, such as family members or friends, were doing well. Participants were worried about the impact of MS on their partners, children, family members, and friends. Some felt guilty about needing support or about limiting the opportunities of those close to them.

Overall, while many experiences were shared across all MS types, the way people thought about their illness and future was influenced by whether their MS followed a relapsing or progressive course.

Differences between MS types were linked to **illness trajectory**:

- RRMS: trauma of relapses, fear of the next relapse
- SPMS/PPMS: steady worsening, loss of abilities over time

d) Why this matters?

This study highlights that quality of life in MS is shaped by social/psychological factors and physical symptoms, as well as how participants viewed their circumstances. It shows that people with different types of MS may face different challenges and concerns, meaning that a "one-size-fits-all" approach to care may not meet everyone's needs.

The study shows that:

- MS may affect more than physical symptoms — such as identity, relationships, and future expectations.
- RRMS and progressive MS bring **different challenges**, so support needs to be tailored.
- Enjoyment, maintaining some sense of self that is unaffected by MS, and concern for the wellbeing of significant others are all influential determinants of people's quality of life.

Healthcare professionals should consider not only symptom management but also how MS could affect identity, future plans, enjoyment of life, and family relationships. Providing personalised support that reflects each person's MS subtype and their unique experiences is important. The findings also emphasise the importance of including patients' own experiences and perceptions of their futures when designing services, developing treatments, and planning research to improve quality of life for everyone living with MS.