

**P605****Experiences and information needs of people with multiple sclerosis regarding their long-term prognosis and the role of data-driven predictions**

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**Introduction:** People with multiple sclerosis (PwMS) face substantial uncertainty regarding their long-term prognosis, which affects their psychological well-being. Although data-driven prognostic tools are being developed to support personalised care, their successful implementation depends on alignment with patient needs and expectations.

**Objectives/Aims:** This study explored PwMS' experiences with prognostic communication, their information preferences, and perceptions of predictive tools within personalised care.

**Methods:** This mixed-methods study was conducted in Belgium. In the qualitative part, four focus groups (three in-person, one online) were held with PwMS (n=22) with diverse disease histories. Using a semi-structured interview guide, we explored (1) experiences with receiving prognostic information, emotional responses, impact on coping and outlook, and (2) views on timing, content, certainty level and usage context of data-driven predictions. Focus groups were transcribed verbatim and analysed thematically. In the quantitative part, participants completed a survey assessing the sufficiency of prior prognostic communication, need for additional information, and trust in prognostic tools.

**Results:** Prognostic information was described as rare and vague, with many participants initiating the topic themselves. Several noted they first needed to build health literacy to ask effective questions. Discussing prognosis increased participants' awareness of their condition, and what was disclosed impacted their lifestyle and -decisions. Emotional responses to prognostic information ranged from reassurance to fear and frustration related to the consistency and accuracy of provided information. Becoming wheelchair-bound remained a distressing association. Information needs varied by disease phase. There were two attitudes toward prognostic estimates: (1) fixation on unfavourable outcomes, and (2) seeing the opportunity to improve their outcome. Survey data showed that 68% wanted more prognostic information, 55% expected it to be reassuring, and 32% anticipated increased worry. Overall, 82% reported at least moderate trust in prognostic tools, with 59% preferring to use them with their neurologist.

**Conclusion:** PwMS express diverse and nuanced information needs. Data-driven tools may support communication when embedded in personalised, clinician-led care. Data collection and analysis are currently ongoing and will refine these insights to be able to inform prognostic interventions in MS care.

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