ASV multiple sclerosis from the patient's perspective - a case study

Citation reference

Ziech, P.: "ASV multiple sclerosis from the patient's perspective - a case study", in "Monitor Versorgungsforschung" (06/25), p. 45.
http://doi.org/10.24945/MVF.06.25.1866-0533.2774



Dr PH Patrick Ziech

>> Outpatient specialised care (ASV) is intended to guarantee structured, cross-sectoral care for people with rare diseases or special disease progressions. A corresponding legal basis can be found in Section 116b (1) sentence 1 no. 1e SGB V. In 2022, the G-BA decided that ASV should also be offered for people with multiple sclerosis (MS) (G-BA 2022a). The explanatory memorandum states that patients with MS require interdisciplinary or complex care (Federal Joint Committee 2022b). One of the aims of ASV is to avoid unnecessary interruptions in the treatment process for diseases that require a coordinated care concept. The position paper of the Multiple Sclerosis Therapy Consensus Group points out that the requirements for complex treatment can only be met through cross-sector cooperation (Mäurer et al. 2023). The experts particularly emphasised the deficits in the quality of diagnostic imaging. These are of essential clinical relevance for "diagnosis, prognostic assessment and therapy monitoring" (Mäurer et al. 2023).

So much for the legal and professional requirements, which appear to be well understood by patients and their relatives. The following is a real-life case study that shows some deficits in the practical implementation of the above-mentioned requirements.

Case study

The patient in question is aged between 60 and 70 and has been diagnosed with progressive multiple sclerosis. His mobility is already severely

restricted and requires a walking frame even for short distances.

The patient was recommended by his treating neurologist to enrol in an ocrelizumab therapy programme. After contacting him accordingly, he received a letter in March 2025 to make an appointment at the neurological infusion outpatient clinic for a therapy discussion at the end of August 2025. This letter explicitly referred to the referral in accordance with Section 116b SGB V. An additional sheet was even included, which provided a sample of the exact details for a correct referral form. No further documents were requested, nor were any relevant information documents on therapy or ASV sent along.

As part of the patient counselling interview, the doctor asked about the course of the illness. Unfortunately, the medical reports were missing. X-ray and MRI findings were available digitally on a platform. However, the doctor was not allowed to access this platform from the duty PC. He therefore solved the problem by accessing the reports from his private mobile phone. The doctor then said that he needed the MRI images and findings on CD for technical reasons. This would not be a problem in principle, as the outpatient radiology practice would produce these CDs on request for a fee of 5 euros. This could be realised within a few hours. However, the doctor then realised that the MRI findings of the brain were already five months old at the time of the consultation. For the therapy, the MRI findings had to be a maximum of 3 months old. When asked whether it would not make sense in terms of the procedure and the required image quality to carry out the MRI diagnostics directly within the neurological infusion outpatient clinic or the affiliated maximum care hospital, the doctor was not very optimistic. The treatment was carried out in the outpatient clinic and there was no co-operation between the inpatient and outpatient areas of the hospital. So an appointment had to be made with the outpatient practice. However, the outpatient practice only made an appointment once the referral from the treating GP or specialist had been received, which posed additional logistical challenges for the patient and their relatives.

During the consultation, it was once again made clear that the patient would be more susceptible to infections as a result of the ocrelizumab therapy. Other side effects were not discussed in detail. The informing doctor in the neurological infusion outpatient clinic also did not mention any necessary vaccinations. An appointment was made for the start of treatment at the end of November.

At a routine appointment with the treating neurologist in mid-October, it emerged that ocrelizumab therapy required a pneumococcal vaccination,

among other things. Due to the delay, the originally agreed treatment date in October was jeopardised because the vaccination must be given at least 6 weeks before the start of treatment.

Conclusion

The case study is certainly not typical for the care of people with MS, but it nevertheless highlights the shortcomings between the demands and reality of medical care. In particular, cross-sectoral care, patient-centricity and digitalisation show considerable potential for optimisation in this specific case. This makes it all the more regrettable that the problems described could actually have been avoided through well-established care (keyword "ASV"). <<

Literature: Federal Joint Committee (2022a): Announcement of a decision by the Federal Joint Committee on an amendment to the guideline on outpatient specialised care Section 116b of the Fifth Book of the German Social Code (SGB V): Addition to Annex 1.2 - Letter a Multiple Sclerosis. Ed. by the BMG.

Federal Joint Committee (2022b): Supporting reasons for the decision of the Federal Joint Committee on an amendment to the guideline on outpatient specialised care § 116b SGB V: Addition to Annex 1.2 - Letter a Multiple sclerosis. Available online at https://t1p.de/080gs, last checked on 3 November 2025. Mäurer, Mathias; Meier, Uwe; Wattjes, Mike P.; Ziemssen, Tjalf; Wiendl, Heinz; Bayas, Antonios et al. (2023): Outpatient specialised care (ASV) for multiple sclerosis. In: DGNeurology 6 (6), pp. 481-492. DOI: 10.1007/s42451-023-00594-4.