Background. Advance care planning (ACP) practice in people with progressive multiple sclerosis (PwPMS) remains limited. The ConCure-SM project aims to assess the effectiveness of a structured ACP intervention (clinician's training and use of a booklet during the ACP conversations) using a multi-phased design.

Methods. Single-arm pilot/feasibility trial involving PwPMS, their significant others (SOs), and clinicians from six Italian centers. The primary study outcome was completion of an advance care plan document (ACP-Doc). Other outcomes included safety, feasibility of enrollment and assessment, Hospital Anxiety and Depression Scale (HADS), 4-item ACP-Engagement survey, Quality of Communication questionnaire, health-related quality of life (MSQOL-29), and caregiver burden. Participants were interviewed to identify factors influencing the ACP implementation process.

Results. Between March 2022 and March 2023, 164 subjects were screened, and 89 were excluded. Of 75 eligible PwPMS, 56 (75%) refused to participate and 19 (nine with their SO) were included. Of these, 11 (58% vs 30% hypothesized) completed the ACP-Doc. A total of 25 adverse events (increase in anxiety) occurred, three possibly related to the intervention. This mirrored an increase of the HADS-Anxiety score (p=0.02) and a worsening of the MSQOL-29 mental composite score (p=0.04) during follow-up. Analysis of individual interviews (5 with PwPMS, 4 with SOs) and focus groups (2, overall 13 clinicians) identified 4 overarching themes: significance of the ACP process (on the individual, on relation with clinicians), its impact (on emotions, on family relations), preparedness as key, and challenges (practicability, resistance of SOs).

Conclusions. The ConCure-SM training program and use of the booklet supported neurologists in guiding PwPMS in their ACP. Trial findings and the high proportion of refusals point to the need to enrich the intervention with a new component targeting PwPMS and SOs.

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