

## **Randomized Controlled Trial of a Home-Based Palliative Approach for People with Severe Multiple Sclerosis**

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### **Abstract**

**Background:** Evidence on the efficacy of palliative care in persons with severe multiple sclerosis (MS) is scarce.

**Objective:** To assess the efficacy of a home-based palliative approach (HPA) for adults with severe MS and their carers.

**Methods:** Adults with severe MS-carer dyads were assigned (2:1 ratio) to either HPA or usual care (UC). At each center, a multi-professional team delivered the 6-month intervention. A blind examiner assessed dyads at baseline, 3 months, and 6 months. Primary outcome measures were Palliative care Outcome Scale-Symptoms-MS (POS-S-MS) and Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW, not assessed in severely cognitively compromised patients).

**Results:** Of 78 dyads randomized, 76 (50 HPA, 26 UC) were analyzed. Symptom burden (POS-S-MS) significantly reduced in HPA group compared to UC ( $p = 0.047$ ). Effect size was 0.20 at 3 months and 0.32 at 6 months, and statistical significance was borderline in per-protocol analysis ( $p = 0.062$ ). Changes in SEIQoL-DW index did not differ in the two groups, as changes in secondary patient and carer outcomes.

**Conclusion:** HPA slightly reduced symptoms burden. We found no evidence of HPA efficacy on patient quality of life and on secondary outcomes.

**Strengths:** One of first studies to explore effectiveness of integrating home palliative services in care for chronic progressive neurological illness such as MS. Robust study design (multicenter RTC), validated outcome measure tools, good sample size for a not very common disease.

**Weaknesses:** Short follow up (possibly insufficient to produce effect on most outcome measures), study participants not blind to intervention, HPA goals not achieved in some psychosocial and organizational domains (to consider in planning future studies), fragmented care (additional services needed to be attracted at times), non-Canadian culture and health care infrastructure

**Relevance to Palliative Medicine:** Patients with MS may live many years severely disabled. Palliative care should be a routine aspect of care for this patient group together with multidisciplinary team care often coordinated through neurology or physiatry. There is increasing evidence that multidisciplinary approach to MS increases patient and carer satisfaction with care and length of survival. However, neurology teams may receive little education in palliative care principles, which is now an emerging neurological subspecialty on its own. There is also limited published literature on the scope, timing and efficacy of palliative care.