

PARTICIPANTS' PERSPECTIVES ON A HOME-BASED PALLIATIVE APPROACH FOR PEOPLE WITH SEVERE MULTIPLE SCLEROSIS: A QUALITATIVE STUDY NESTED IN A RANDOMIZED CONTROLLED TRIAL



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Background: We undertook a multicenter randomized controlled trial to assess the effectiveness of a home-based palliative approach (HPA) for adults with severe multiple sclerosis (MS) and their caregivers. The PeNSAMI (Palliative Network for Severely Affected Adults with Multiple Sclerosis in Italy) trial assessed a home palliative approach (HPA) in 50 patient-caregiver dyads versus usual care in 26 dyads. Although the PeNSAMI intervention was carefully planned with the direct participation of key stakeholders [1], it was less effective than anticipated: while symptom burden was reduced, the reduction was later than expected, and changes in QOL and other patient and caregiver outcomes did not differ compared to usual care [2].

We performed a qualitative study to better understand the experiences of patients, their caregivers, patient referring physicians, and the teams who delivered the HPA intervention.

Methods: We performed semi-structured one-on-one interviews with 12 patients and 15 informal caregivers chosen using a maximum variation strategy, two focus group meetings with patient referring physicians (4 participants each), and one with the HPA teams (9 participants).

The methods of framework analysis were applied to the data. Framework analysis uses an inductive approach to identify the themes and categories that emerged from the interviews and meetings [3-6]. Two psychologists (EB and CB) experienced in qualitative research and not involved in MS patient care, analyzed the transcripts (personal interviews and focus group meetings) in six hierarchical steps.

Results: Thirty-eight sub-categories emerged, which were grouped into 12 categories and 3 themes: 'expectations,' 'met and unmet needs,' and 'barriers'.

Expectations: participants reported both positive and negative expectations about the intervention. Despite being sceptical, participants were curious about the project and had a general positive attitude towards the trial, expecting it to increase scientific knowledge and improve disease management.

Category	Positive expectations			Negative expectations
	Attitudes	Disease management	Research & knowledge	Attitudes
Sub-category	<ul style="list-style-type: none"> Curiosity 	<ul style="list-style-type: none"> Sharing disease experience Receiving expert opinion Receiving practical and tangible support Clinical improvement 	<ul style="list-style-type: none"> Increasing scientific knowledge 	<ul style="list-style-type: none"> Skepticism Disillusionment

Met and unmet needs: participants distinguished between met and unmet needs. Emerged categories were divided in two areas: "Disease management" & "Psychological and social issues". Intervention benefits can be summarized as follows: improved control of symptoms, more information received and reduced sense of isolation of the dyads.

Category	Disease management		Psychological and social issues	
	Met need	Unmet need	Met need	Unmet need
Sub-category	<ul style="list-style-type: none"> Symptom management Aids & medical devices Point of reference 	<ul style="list-style-type: none"> Home health care Qualified MS health professionals & a case manager Physiotherapy 	<ul style="list-style-type: none"> Emotional support Reassurance Communication Information Administrative issue 	<ul style="list-style-type: none"> Social integration To help others Psychological support Management of family problems Reduction of caregiver burden

Barriers: Participants, particularly the HPA team identified some limitations: 1) factors related to experimental design (difficulty of dyads in identifying examiner and team roles, additional burden for caregivers); 2) team issues (insufficient team building /supervision, competing priorities); 3) limitations of the intervention itself (insufficient length, lack of rehabilitation input); 4) and external factors (resource limitations, under-responsive services/professionals).

Category	Barriers			
	Organization/Structure	Experimental design	Team	Dyad
Sub-category	<ul style="list-style-type: none"> Insufficient services Lack of networking facilities Complex administrative procedures Unsuitable housing 	<ul style="list-style-type: none"> Intervention too short Burdensome examiner visits & telephone interviews Dyad difficulty in identifying examiner & team roles Invasiveness Hands off role of team 	<ul style="list-style-type: none"> Lack of other health care professionals Need for more teambuilding Insufficient supervision of teams 	<ul style="list-style-type: none"> Difficulty expressing needs Dysfunctional dyads

Conclusion: The HPA reduced patient symptoms and sense of isolation in patients and caregivers. The indirect role of the HPA teams, and insufficient length of the intervention were key limitations. The experimental design imposed additional burdens on the dyads. Key barriers were the paucity of available services, the demanding administrative procedures, and lack of networking facilities. These findings suggest that two major requirements are necessary for home palliative care to be effective in this patient population: HPA teams well-connected with MS rehabilitation services, and care delivered over the long-term, with variable intensity.

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