Specialist Palliative Care Service for People Severely Affected by Neurodegenerative Conditions: Does this Make a Difference to Palliative Care Outcomes? Results of Ne-Pal – An Explorative Randomized Controlled Trial

Abstract:

Background: Palliative care has been proposed for progressive non-cancer conditions but there have been few evaluations of service developments. This study analysed the impact on palliative care outcomes (PCO) of a new specialist palliative care service (SPCS) for patients severely affected by Amyotrophic Lateral Sclerosis (ALSMND), Multiple Sclerosis (MS), Parkinson's Disease (PD) and related disorders (MSA-PSP). Methods: The design followed the MRC Framework for the Evaluation of Complex Interventions. In phase II a RCT was undertaken comparing an immediate referral to the service (-FT- fast-track) to a 16-week wait (-ST-standard best practice). The main outcome measures were: Quality of Life (measured with SEIQoL-DW 0-100), burden of the carers (Caregivers Burden Inventory CBI 0-96) and symptom load (Numerical Rating Scales 0-10). Analysis of Covariance (ANCOVA) and a non parametric test (Mann-Whitney U) were used to compare the 2 groups. Results: 50 patients severely affected by neurodegenerative conditions (ALSMND=16, MS=18, PD=12, MSA=2, PSP=2) and their 45 informal carers -CG- were randomized: 25 FT (24 CG), 25 ST (21 CG). At baseline (T0) there were no differences between groups. 4 patients died during the follow-up (2FT, 2ST) and 2 FT patients dropped out before the end of the study. After 16 weeks (T1) FT participants scored significant improvement in SEIQoL-DW index [mean difference (MD) +20,12 p< .001], reduction in Pain MD=-2,41 p< ,001;Dyspnoea MD=-2,26 p=,001; Sleep disturbance MD=-2,14 p=,003; Bowel symptoms MD=-2,07 p=,008; Urinary symptoms MD=-1,74 p=,004; and Mouth discomfort MD=-1,24 p=,020. Conclusion: This exploratory RCT provides evidence that no harm was experienced by SPCS on patients, severely affected by neurodegenerative disorders, as there was the same mortality in the 2 groups and there was significant improvement in some important PCO such as QoL and symptom control. Caregiver burden was improved but with lower significance.

Keywords: *palliative cares, neurodegenerative, sclerosis.*