

Feedback of Home Psychological Support in ALS patients and their families

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Introduction

Data related to anxiety and depression in the patient and the caregiver are very mixed, but there is common agreement that ALS patients and their caregivers show depression and anxiety in response to the disease, mainly in the first stage, in which anger, hopelessness, and suicidal ideation are described (Palmieri et al., 2010; Pagnini et al., 2012).

As depression has detrimental effects on survival and quality of life, its treatment is recommended in ALS patient and in their caregiver (Thankore et al., 2016).

The project was funded by AISLA Section of Ferrara, 8 families participated to the study. Our aim was to evaluate satisfaction of home psychological support through a specially designed questionnaire.

Materials and Methods

The satisfaction has been evaluated through the use of a dedicated questionnaire and consists of a few simple questions. The questions regarding: demographic characteristics (age, name and gender), information about the disease (data of the diagnosis, natural or assisted ventilation, natural or artificial feeding, possible or impossible verbal communication), and questions relating to the satisfaction about the service (general psychological training appreciation, frequency of visits, visit duration, intervention validity, patient and caregiver outcome), by using a graded qualitative scale: low, sufficient, good and excellent. The questionnaire was administered to 8 (2 women and 6 men) subjects attended by the Neurology Unit of Sant'Anna Hospital (Ferrara). The average age was 65 (range 55-80); average disease duration = 89 months (range 15-2). 4 patients were undergoing ventilation treatment. 2 patients used verbal communicator. Only 1 patient received enteral nutrition.

Results

The data analysis showed a high satisfaction on all items investigated. Patients gave an average rating of 'good' and 'excellent' for the items concerning: general psychological training appreciation, frequency of visits, visit duration, intervention validity, efficacy of service on patients and caregiver.

Everybody stated that the initiative was to be repeated.

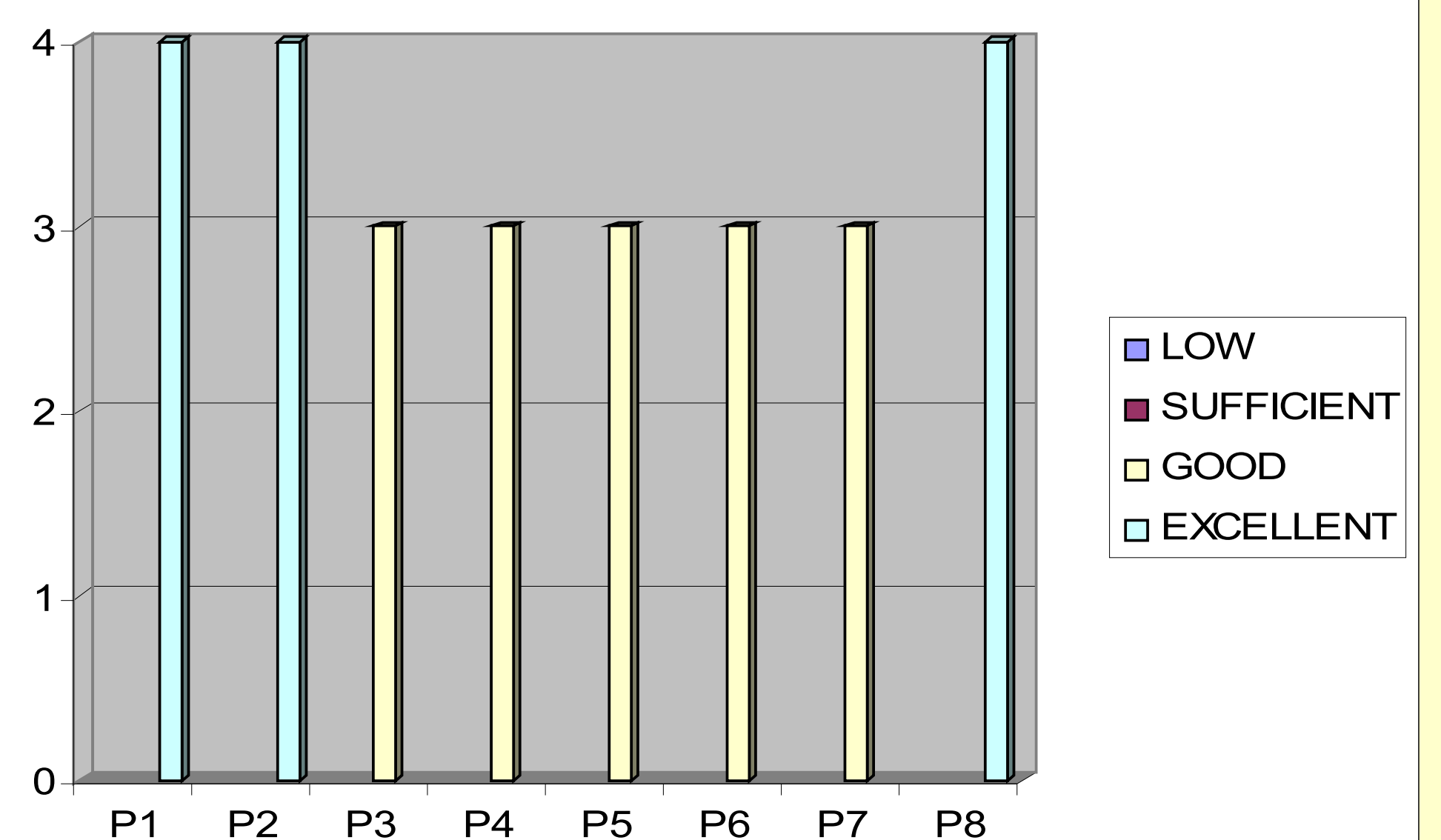
Discussion and Conclusion

Our data, even if limited to few cases, shows a high need for psychological support dedicated both to ALS patients and caregivers. This approach ensures continuity of care inside the team to correctly manage the emotional aspects of the disease in between the hospital and home assistential setting.

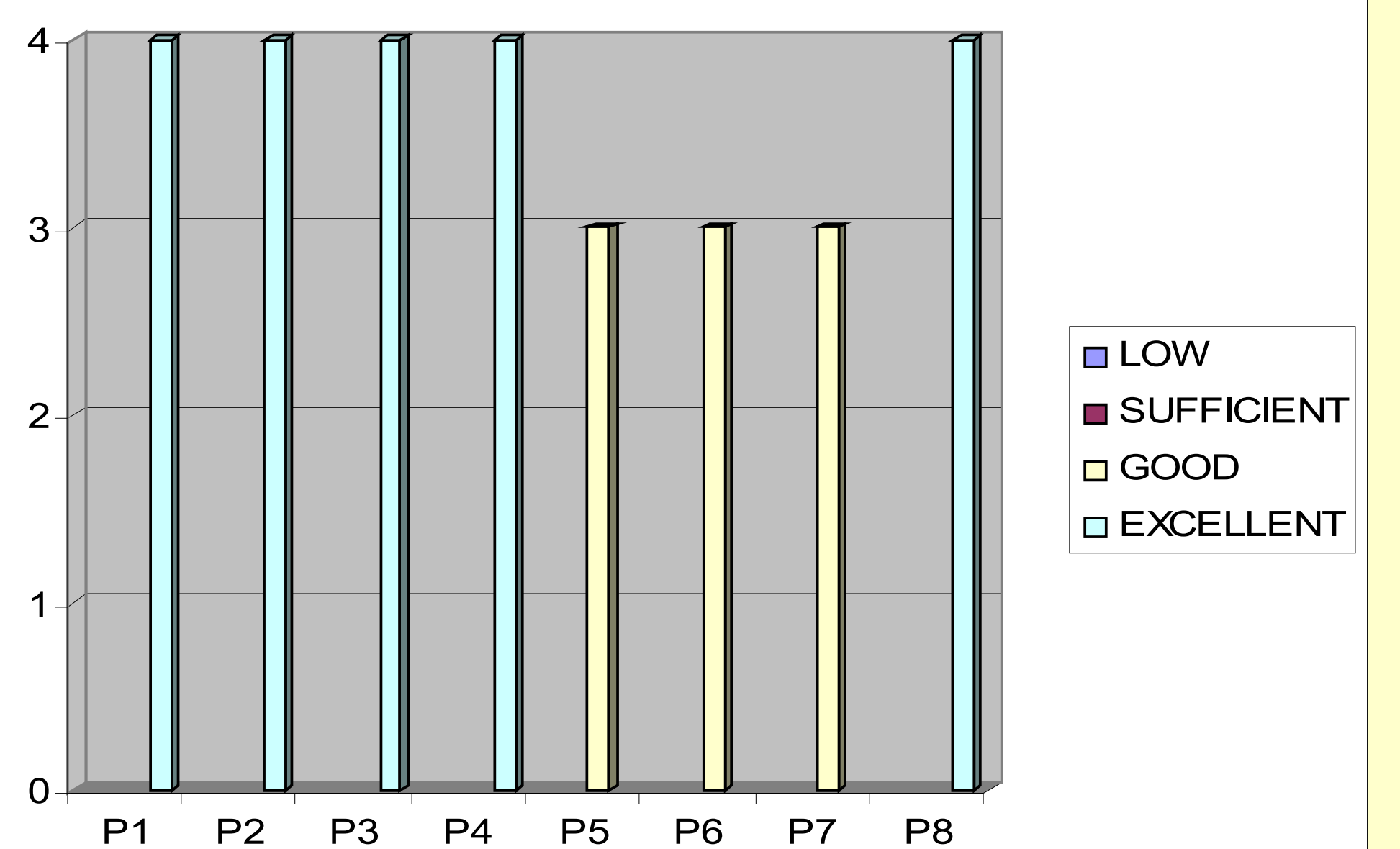
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GENERAL PSYCHOLOGICAL TRAINING APPRECIATION



EFFICACY OF SERVICE ON PATIENTS



EFFICACY OF SERVICE ON CAREGIVER

