


Physiotherapy in palliative medicine: patient and caregiver wellness

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ABSTRACT

Objectives Despite the demonstrated efficacy of physiotherapy in palliative care programmes, there are scarce data of its real-life impact on patients' and caregivers' wellness and stress. Our aim was to assess effectiveness of a 30-day physiotherapy programme in psychological wellness and health-related quality of life (HRQoL) of patients with advanced chronic diseases or cancer and in their caregivers' stress. **Methods** Quasiexperimental before–after study applying personalised kinesitherapy, exercise with curative effects, respiratory physiotherapy, therapeutic massages and ergotherapy. Psychological wellness, HRQoL and caregiver's strain outcomes were measured.

Results 207 patients (60% men, with a mean age of 73.6±12 years) were included; 129 (62.3%) with advanced cancer, and the remaining 78 with advanced chronic diseases. Psychological wellness (Emotional Stress Detection Tool decreased from 12.4±3 to 11±3; $p<0.0001$), caregiver's strain (Caregiver Strain Index decreased from 8.5±3.2 to 7.9±3.5; $p<0.0001$) and HRQoL (WHO-BREF physical health domain increased from 8.3±2.6 to 9.4±2.9; $p<0.0001$) showed a significant improvement after the physiotherapy programme. Global satisfaction with the physiotherapy intervention was also high (Client Satisfaction Questionnaire-8 of 28.3±3.3 points).

Conclusions A personalised physiotherapy programme incorporated to integral palliative care improved psychological wellness, HRQoL and caregivers' strain of patients with advanced chronic diseases and cancer.

INTRODUCTION

One of the main clinical problems and complaints of patients in their end-of-life trajectories is severe functional decline and dependence.^{1,2} In these terminal stages of many diseases, severe dependence plays

Key messages

What was already known?

⇒ In palliative care programs, the impact of physiotherapy in patients' and caregivers' wellness is not well addressed.

What are the new findings?

⇒ Physiotherapy improved patients' psychological wellness, health-related quality of life, and caregivers' strain.

What is their significance?

⇒ Including physiotherapy in palliative care programs can contribute to patient's wellness and reduce caregiver's strain

a deleterious role in many life aspects: it worsens many physical symptoms like constipation, pain, asthenia and fatigue, or sleep disorders; impacts negatively in mood and psychological wellness; develops per se new syndromes and complications like pressure skin ulcers, delirium, faecal impaction or urinary tract obstruction; and generates caregivers' stress and eventually family exhaustion.^{3–8}

Reversing, slowing down and optimising the adaptation of patients to the disability cascade is one of the global aims of rehabilitation and physiotherapy. This general objective is of nuclear importance in the progressively emerging aged and vulnerable populations but also plays an important role in patients attended in palliative care programmes.^{9–17} Palliative care programmes were ancillary designed towards patients with advanced cancer, but since many years, they also incorporate patients with end-stage organ dysfunctions, as well as those with severe and advanced neurodegenerative diseases to such an extent that nowadays, patients with advanced medical conditions

comprise 40%–50% of all patients in these kind of programmes.^{18–20}

In last years, the benefits of rehabilitation and physiotherapy programmes applied to patients receiving palliative care have been demonstrated in clinical trials of patients with cancer as well as in those with other medical terminal conditions.^{21–24} These results have prompted to embed rehabilitation within palliative care. Rehabilitative palliative care can help patients in self-management, pain, mood and psychological wellness, but such an approach requires engagement from all members of the palliative care team and often there is a lack of knowledge and understanding of such viewpoints. For these reasons, there are scarce data of real-life effectiveness in daily clinical practice scenarios. As a matter of fact, there are still many concerns about the usefulness of these therapies in the setting of a standard programme of palliative care, mainly with doubts of considering them futile or even an oxymoron.^{13 25–27}

Whereas functional improvement has already been demonstrated,^{21–24 28} the impact of physiotherapy in patients' psychological wellness, and caregivers' stress, remains not fully addressed yet. For all these reasons, we have performed the present study with the aim of determining the real-practice effectiveness of a complete physiotherapeutic intervention incorporated to palliative care in the improvement of psychological wellness and caregivers' stress of patients with severe and advanced chronic diseases or cancer.

PATIENTS AND METHODS

This was a pragmatic real-life before–after intervention study, with participation of two tertiary care centres from Southern Spain. Inclusion period ranged from March 2016 to September 2017.

Reference population

All patients treated in the internal medicine, palliative care and hospital-at-home areas (in-hospital, as well as in outpatient clinics) from the two Spanish hospitals participating in the study (participant centres are listed on the FISEA Researchers list).

Sample conformation

Originally, sample size was calculated to detect a significant change in the performance of activities of daily living (ADL) (a change of 5 or more points in Barthel's index (BI)).²⁸ Accepting alpha and beta error risks of 0.05 and 0.02, respectively, and a presumptive maximum loss of 20% of patients, 194 patients were needed to fulfil establish conclusions. All patients were included prospectively by convenience sampling.

Inclusion criteria

The inclusion was offered to patients ≥ 18 years old, who were attended in palliative care programme with advanced organ failure (PALIAR score > 3 points or a PROFUND score ≥ 3 points) or advanced cancer

(these had to present a Palliative Prognostic Index (PPI) < 6 points or an ECOG-PS score ≤ 3 points), moderate–severe or total dependence (BI < 90 points), and with the availability of a main caregiver. They were included, after providing their written informed consent.

Patients with a presumed very short life expectancy (< 3 weeks), unstable fractures, acute stroke (in previous 14 days), or with delirium, those being already in a rehabilitation programme, and those who did not agree to participate in the study were excluded.

Physiotherapy intervention

The intervention was established in four visits: visit 1 (V1) at inclusion, visit 2 (V2) at day +7, visit 3 (V3) at day +15 and visit 4 (V4) at day +30. These visits were done at patients' home or at the hospital depending on patients' condition.

At V1, a global physical and mobility evaluation was performed in order to establish personalised objectives, and a specific physiotherapy programme, adapted to patients' needs. For this purpose, the following techniques were in a personalised way offered:

1. Kinesitherapy: with the aim of improving joint and muscular balance, and depending on the clinical features and lesions' types, we used passive (when active movements were contraindicated or when established palsies were present); partially assisted active (when low muscle strength, partial denervation, pain or spasticity were present); and active or resisted active (to improve neuromuscular control, physical condition and strength).
2. Exercise with curative effects: with the aim to prevent cardiovascular events, and improve chronic stable osteo-articular conditions, obesity, diabetes control, depressive and anxiety disorders, we used different and personalised exercise routines. These exercise programmes also intended to reduce pain, and maintain and improve joint range, muscle strength, neuromuscular coordination and motor re-education.
3. Respiratory physiotherapy: we used airway permeabilisation techniques to drain bronchial secretions and respiratory re-education to work ventilation and adapt to stress.
4. Therapeutic massage and myofascial release: we used pressures, stretches, massages and muscle contractions at specific points of muscles and fascias, primarily affected, to relieve pain. For this purpose, we performed massage of soft tissues, such as muscles, ligaments, tendons and frictional forces, pressure and stretching, with the aim to improve local circulation, fluids excess drainage and muscle relaxation.
5. Ergotherapy: with the aim of active re-education, we used manual work activities and support products for enhancing autonomy. The most frequent training techniques were moving autonomously from bed to wheelchair, from chair to car, environmental adaptations (such as modifying heights and widths of furniture and spaces for wheelchair access) or using ergonomically adapted products (cutlery, comb and keyboard...).

After this evaluation, in V2, V3 and V4, a 45 min sessions protocol of multicomponent physiotherapy was performed, as detailed in [table 1](#).

Table 1 Physiotherapy programme for patients with advanced medical disease or cancer in a palliative care programme

Visit	Visit 1 (day 0) 45 min	Visit 2 (day +7) 45–60 min	Visit 3 (day +14) 45–60 min	Visit 4 (day +30) 45–60 min
Routines	Mobility evaluation <ul style="list-style-type: none"> ▶ Turning in bed. ▶ Buttock lifting. ▶ Moving arms. ▶ Sitting. ▶ Standing up. ▶ Walking. ▶ Balance. Dyspnoea evaluation. <ul style="list-style-type: none"> ▶ NYHA*/mMRC† Specific evaluation <ul style="list-style-type: none"> ▶ Oedema, skin integrity... 	Progressive mobilisation <ul style="list-style-type: none"> ▶ Active and resisted active kinesitherapy. ▶ Massage. ▶ Turning in bed. ▶ Sitting. Respiratory physiotherapy. <ul style="list-style-type: none"> ▶ Abdominal breathing. 	Progressive mobilisation <ul style="list-style-type: none"> ▶ Muscle activity. ▶ Transfers. ▶ Balance. ▶ Standing up. Respiratory physiotherapy <ul style="list-style-type: none"> ▶ Diaphragmatic breathing. ▶ Forced exhalation. 	Progressive mobilisation <ul style="list-style-type: none"> ▶ Muscle activity. ▶ Walking. Respiratory physiotherapy <ul style="list-style-type: none"> ▶ Breathing retraining. Personalised ergotherapy <ul style="list-style-type: none"> ▶ Function reeducation. ▶ Environment adaptation.

*New York Heart Association functional class.
†Modified Medical Research Council dyspnoea level.

Development of the study, data collection and follow-up

After receiving informed consent, a complete set of demographical, sociofamilial, clinical, functional and pharmacological data were collected from all included patients.

Demographic and sociofamilial data included age, gender, residence, employment data, the need for a caregiver and the main caregiver's profile. Clinical data included the different diseases, and all possible comorbidities, stage of different diseases (New York Heart Association class and modified Medical Research Council dyspnoea score^{29 30} and Child-Pugh stage³¹), assessment of PROFUND and PALIAR indices,^{32 33} different symptoms and signs and number of hospital admissions in the last 12 and 3 months, respectively. Psychoemotional features were evaluated by the Emotional Stress Detection tool (ESD) and the Hospital Anxiety and Depression Scale (HADS). Health-related quality of life (HRQoL) was measured by the administration of the WHOQOL-BREF questionnaire, and the following five-degree Likert scale question: 'How do you perceive your health status?' (1: very bad, 2: bad, 3: fair, 4: good and 5: very good).^{34–36} Caregivers' features and their burden of care were measured by means of the Caregiver Strain Index.³⁷ Finally, global satisfaction with the physiotherapy programme was also assessed using the Client Satisfaction Questionnaire (CSQ-8).³⁸

These data were collected by clinicians in charge who were active members of the investigation team. All patients were followed during 30 days, in which the four visits of physiotherapy intervention were programmed.

Outcome measures

The main outcome measures were patients' psychoemotional improvement with respect to their basal status, as well as improvement of caregivers' burden of care. Secondary outcome measures were improvements in HRQoL and caregivers' burden with respect to their basal status and global satisfaction with the physiotherapy programme.

Statistical analysis

The dichotomous variables were described as integers and percentages and the continuous variables as mean and SD (or median and rank in those with no criteria of normal distribution). The distribution of all variables was analysed with the Kolmogorov-Smirnov test. Possible differences in the outcome measures were investigated performing a per-protocol analysis using pair-wise Student's t-test for normally distributed quantitative variables and Wilcoxon test in the case of quantitative variables that were not normally distributed. The strength of associations was quantified by calculating OR using 95% CIs. Statistics were performed using the SPSS V.22.0 software.

Ethical issues

This study was conducted in accordance with the principles of the Declaration of Helsinki and ICH Guidelines for Good Clinical Practice and in full conformity with relevant regulations. The protocol, informed consent form, participant information sheet and any applicable documents were approved by the Andalusian, as well as by all local ethics committees of participant centres and the Spanish Regulatory Authorities (internal code 0248N-16). Documents constituting the master file of the study included all the documents established in the good clinical practice (CPMP/ICH/135/95). In this project, the collection, process and analysis of all data were anonymously carried out and only for the purposes of the project. All data were protected in accordance with the European Union directive 2016/679 of the European Parliament and the European Council, of 27 April 2016, regarding the protection of persons and their personal data.

RESULTS

We included a total of 207 patients (60% men, with a mean age of 73.6±12 years). Inclusions were performed during hospital at home care in 122 patients (58.9%), palliative care hospitalisation in 45 (21.7%) and internal medicine hospitalisation in the remaining 40 (19.3%). The main clinical features are

Table 2 Main clinical features of a multicentre sample of patients with advanced medical diseases or cancer at inclusion in a physiotherapy programme

Clinical features (n=207)	Mean (SD)/median (IQR)/N° (%)
Age and male gender	73.6±12 years/124 men (60)
Advanced cancer/advanced medical diseases	129 (62.3) / 78 (37.7)
Prevalence of major advanced diseases	
Metastatic cancer	92 (44.5)
Locally advanced cancer	37 (18)
Cancer location	
Colon	25 (12)
Lung	17 (8.2)
Prostate	12 (5.8)
Renal and urothelial	10 (4.8)
Breast	9 (4.3)
Heart diseases	46 (22.2)
Lung diseases	33 (16)
Renal diseases	20 (9.7)
Neurological diseases	20 (9.7)
Number of other comorbidities per patient	2 (1–4)
Most frequent comorbidities	
Hypertension	82 (39.6)
Diabetes mellitus	57 (27.5)
Depression	53 (25)
Dyslipidaemia	45 (22)
Anaemia	45 (22)
Anxiety	38 (18)
Atrial fibrillation	34 (16.4)
Benign prostate hyperplasia	25 (12)
Pressure ulcers	23 (11)
Number of prescribed drugs at inclusion	59 (3–9)
ECOG-PS ≥2	149 (72)
Palliative Performance Index	3.5 (2.5–3.5)
NYHA dyspnoea class ≥3	54 (26)
Patients with home oxygen therapy	32 (15.5)
Hospitalisations in last 12 months/3 months	1.7 (1.4)/1.1 (0.8)
PROFUND index	10 (7–12)
PALIAR index	3.5 (0–6.5)
ESAS	40 (14)
Barthel's index	35(10-55)
ESD	12.5 (3)
HADS	19.7 (8)
WHOQOL-BREF	
Physical health	8.3 (2.6)
Psychological health	10.9 (3.2)
Social relationships	11.7 (3.1)
Environmental health	12.3 (3.5)
Subjective perception of health status (1–5)*	1(1–2)
Caregiver strain index	8.8±3.16

* 1 (very bad)–5 (very good).
 ECOG-PS, Eastern Cooperative Oncology Group Performance Status; ESAS, Edmonton Symptoms Assessment Scale; ESD, Emotional Stress Detection tool; HADS, Hospital Anxiety and Depression Scale; NYHA, New York Heart Association; WHOQOL-BREF, WHO Quality of Life Questionnaire.;

detailed in table 2. They were mainly moderately aged men, who suffered predominantly from advanced cancer and had a high somatic and psychoemotional

symptoms' burden, as well as functional deterioration. The most frequently prescribed drugs for symptoms control were corticosteroids (in 42% of patients),

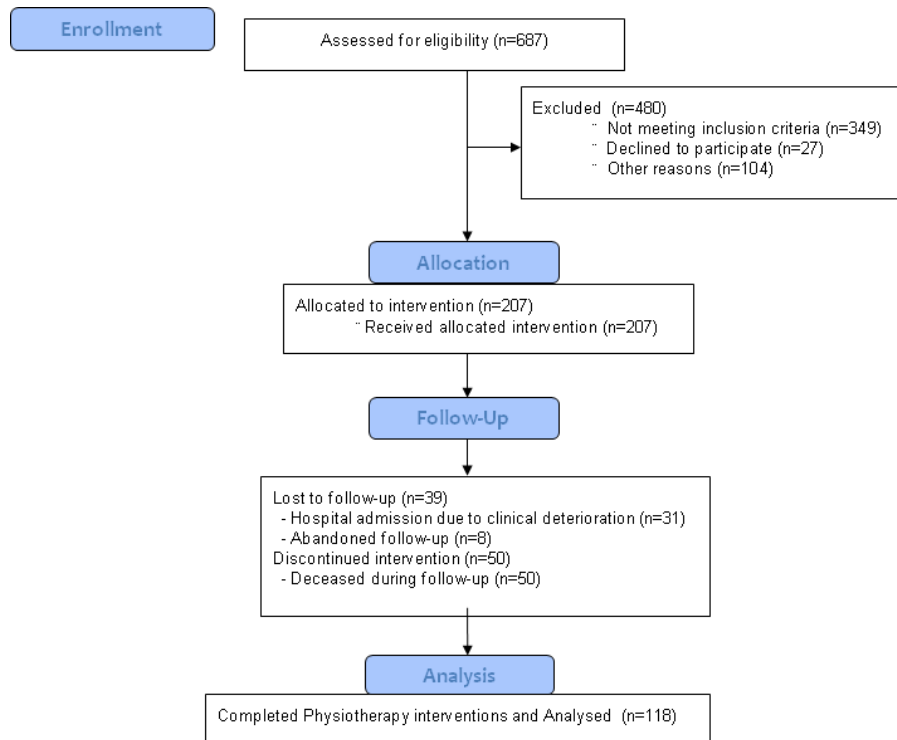


Figure 1 Consort 2010 flow chart of patients with advanced chronic diseases or cancer included in a physiotherapy programme.

non-steroidal anti-inflammatory drugs (39%), opiates (36%), benzodiazepines (34%), antidepressants (30%), other symptom adjuvant drugs (22%) and antipsychotics (13%).

Most of the patients (97%) lived in their own or family homes, and 189 (91.3%) had a caregiver. Most caregivers were women (82%, mean age 59 ± 15 years) and patients' relatives (spouses: 106 (56%), daughters and sons: 42 (22%) and other: 16 (8.5%)). Fifty-four per cent of the caregivers required a full-time dedication to caring for patients, and 109 (58%) required additional help (in 76% of them by another family member and in the remaining by professional caregivers). Only 30 patients (14.4%) received additional official support by means of dependency laws.

The study flow chart is detailed in figure 1. During follow-up, 50 patients (26.2%) died and 39 (20.4%) were lost for follow-up. Finally 118 patients (57%) completed the physiotherapy programme and were per-protocol evaluated.

Figure 2 summarises the main outcome measures. A significant improvement was observed in patients' psychoemotional features (by the ESD) and in caregivers' strain. No significant improvement could be observed in patients' anxiety and depression (by the HADS).

The effect of the physiotherapy programme on HRQoL assessed by WHOQOL-BREF is represented in figure 3. A significant improvement was observed in the physical health domain, but this improvement was not carried over the remaining domains. In addition, a significant improvement in the subjective perception

of health status was also noted (1 (1–2) vs 2 (1–3); $p < 0.0001$).

Global satisfaction with the physiotherapy intervention measured by CSQ-8 was high (mean score

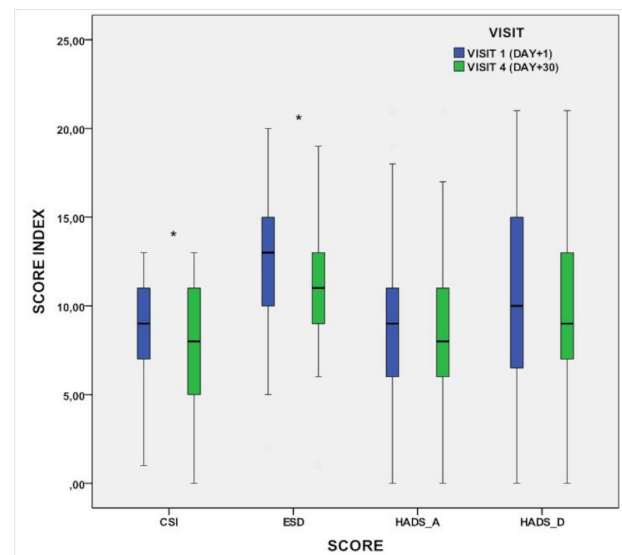


Figure 2 Differential scoring of the remaining main outcome measures before (visit 1) and after a physiotherapy programme (visit 4) in patients with advanced chronic diseases or cancer. CSI, caregiver strain index (8.5 ± 3.2 vs 7.9 ± 3.5); ESD, Emotional Stress Detection Tool (12.4 ± 3 vs 11 ± 3); ESAS, Edmonton Symptoms Assessment Scale (40.2 ± 13.7 vs 36.7 ± 14); HADS_A, Hospital Anxiety and Depression Scale-anxiety summary (8.3 ± 4.6 vs 8.3 ± 4.2); HADS_D, Hospital Anxiety and Depression Scale-depression summary (10.6 ± 5 vs 10.3 ± 4.6). * $P < 0.0001$.

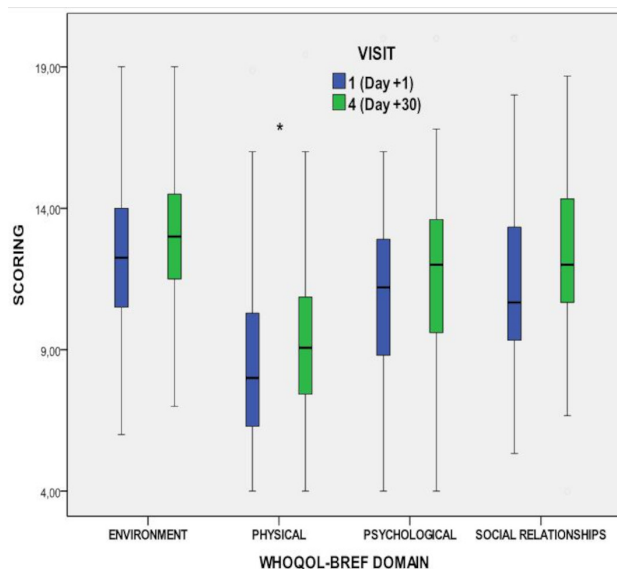


Figure 3 Differential scoring of the four domains of WHOQOL-BREF health-related quality of life questionnaire before (visit 1) and after a physiotherapy programme (visit 4) in patients with advanced chronic diseases or cancer. The scoring range was 4 (worst)–20 (best). Environment: 12.3±2.5 versus 12.9±2.4; physical (physical health): 8.3±2.6 versus 9.4±2.9; psychological health: 10.9±3.2 versus 11.4±3.2; social relationships: 11.7±3.1 versus 12.2±3.1. *P<0.0001.

28.3±3.3 points (8=worst–32=best)). A detailed representation of the eight dimensions of CSQ-8 is stated in [figure 4](#).

DISCUSSION

The incorporation of a personalised physiotherapy intervention in the clinical care of patients with advanced chronic diseases and cancer improved psychological wellness, health-related quality of life

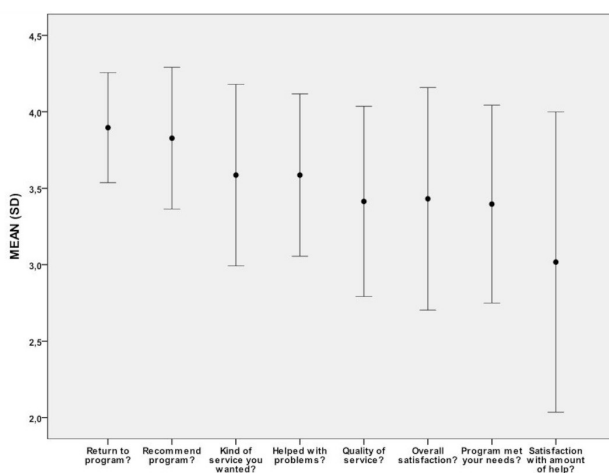


Figure 4 Service satisfaction by means of the eight dimensions of CSQ-8 questionnaire in patients with advanced chronic conditions or cancer, after having received a physiotherapy programme. Scoring ranges from 1 (lowest satisfaction) to 4 (highest satisfaction). CSQ-8, Client Satisfaction Questionnaire.

and caregivers' strain. The programme had a high acceptability, and the satisfaction of patients and relatives with it was high. These results are concordant to previous efficacy trials and confirm the usefulness of physical therapy in daily clinical practice scenarios, thus supporting its real-practice effectiveness.^{21–24}

We already demonstrated significant improvement in functional outcomes, as well as symptoms' burden that probably contributed to the improvement of the results evaluated in this analysis.²⁵ As a matter of fact, patients experienced a decrease in psychoemotional stress. Physical activity itself induces a series of physiological changes releasing different molecules, which contribute to improving cognitive processes, memory, analgesia and even induces antidepressant effects and a sense of well-being.³⁹ However, recovering some independence for ADLs like transfers, eating or bladder and bowels undoubtedly has a positive impact in mood, psychological wellness and dignity. Since ancient times, one of the most repeated human aim is to preserve the dignity during the end-of-life trajectory; in this sense, physical therapies with the objective of maintaining reasonable functional autonomy surely contributes to patient's perception of self dignity.⁴⁰

Additional interesting results were those referred to the improvement in HRQoL, specifically in the physical domain and the high satisfaction level of patients. Physical domain improvement is probably a direct consequence of functional improvement, and the maintenance of a certain independence the most basic ADLs, reflecting the deep relation of physical function with quality of life. The high satisfaction level reflects the importance of aiming real needs of patients and programming activities with a high acceptability of potential receptors.¹⁶

The positive impact of physiotherapy programme in the real life was also observed in the families and their stress. As a matter of fact, caregiver strain index decreased significantly, which is a logical consequence of the improvement of functional abilities, symptoms burden and psychological wellness of the patients. This reflects the importance of focusing interventions also towards patients' families and caregivers, and physical therapy has demonstrated, among other tasks, benefits in this area.⁴¹

This study has some limitations. First of all, the possible regression to the mean error, which appears frequently in quasiexperimental studies, and in interventions in high-risk populations, could be an alternative explanation to the obtained results; in this sense, the robustness and consistency of the different areas of main outcome variables make this effect unlikely. Second, patients' losses could influence the results; however, our results reflect what happens usually in real life in patients included in palliative care programmes, in which refocusing treatment objectives, according to changing situations and disease progression, are frequent. In this sense, in spite of the strict

selection criteria (based on a low PPI index), a 26% of the included patients died during the follow-up period; this outcomes are frequent in the palliative care setting, so we should raise the question of offering this intervention to a wider range of patients assuming more losses and abandon rates or refine even more the selection criteria, which surely will leave out patients who would potentially benefit of a physiotherapy programme.

In conclusion, a personalised physiotherapy programme incorporated to a real-life integral palliative care scenario improved psychological well-being, HRQoL and caregivers' strain of patients with advanced chronic diseases and cancer.

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