



Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Effectiveness of two home ergonomic programs in reducing pain and enhancing quality of life in informal caregivers of post-stroke patients: A pilot randomized controlled clinical trial

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ARTICLE INFO

Article history:

Received 14 December 2017

Received in revised form

18 January 2018

Accepted 20 January 2018

Keywords:

Quality of life

Ergonomics

Rehabilitation

Caregivers

Stroke

ABSTRACT

Background: Informal caregivers of post-stroke patients usually undergo high levels of pain and stress and have a reduced quality of life.

Objective: To evaluate the effectiveness of two home ergonomic interventions aimed at reducing pain intensity and perceived stress and enhancing the quality of life in informal caregivers of chronic post-stroke patients.

Methods: A randomized single-blind controlled clinical trial was conducted, with a sample of 33 informal caregivers of patients with stroke. Three groups were included: one received postural hygiene training and kinesiotherapy, for 12 weeks, two days a week, one hour per session; another received adaptation of the home environment, and the third was a control group. Pain intensity, stress level and general quality of life were evaluated at three-time points: pre-intervention, post-intervention, and after a follow-up period of three months.

Results: Neck pain decreased in the two experimental groups, and increased in the control group. Pain in the shoulders and knees was alleviated in the group that received postural hygiene and kinesiotherapy. In addition, regarding quality of life, this group obtained an improvement in the physical health dimension, while the home adaptation group reported improved social relationships.

Conclusions: These results suggest that 12 weeks of training in postural hygiene, combined with kinesiotherapy, and home adaptations can reduce pain and improve several aspects of the quality of life of this population.

ClinicalTrials.gov ID: NCT03284580.

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Introduction

Stroke survivors often present physical, mental, and/or social limitations, which interfere with functional independence and the basic skills of daily life.^{1,2} Improvements in health care have led to

an increase in the numbers of post-stroke survivors, but disability levels remain high in this population.³ The support provided by family caregivers is crucial for the status of these patients when they cease to attend rehabilitation services.^{4–9} Although informal caregivers should be valued and assisted by the health system, they usually receive little guidance from healthcare personnel.^{2,10} This lack of information and preparation can lead caregivers to take care of their relatives in an intuitive way, on the basis of beliefs and previous experience. The negative consequences of the caregiving

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role can have a detrimental impact on stroke survivors.^{4–9} In turn, caregivers of these patients commonly report low back pain, alterations to their emotional state and high levels of anxiety.^{11,12}

Health professionals can assist informal caregivers from various clinical standpoints, such as preventive or rehabilitative actions, or health maintenance or compensatory strategies.^{13,14} These approaches may address aspects such as ergonomics, biomechanics, or kinesiotherapy. Architectural barriers in the home environment or the presence of inappropriate furniture can hinder the independence of post-stroke individuals and overload caregivers.^{13,14} Then, studies have also highlighted the importance of ergonomic adaptations in the home to facilitate the day-to-day activities of post-stroke patients and their caregivers.^{15,16} Therefore, longitudinal studies are needed, to address the health variables that are altered by the occurrence of stroke and to enhance the quality of life of caregivers of post-stroke patients.^{4,8,9,16,17} Health strategies for patients with chronic stroke should be complemented with interventions focused on their informal caregivers. Accordingly, programs designed to prevent overload and the negative emotional impact that can affect the health and quality of life of the caregiver population should be developed.¹⁰

For these reasons, the main goal of this pilot clinical trial was to evaluate the effectiveness of two home ergonomic intervention programs, compared to a control group, on levels of pain, perceived stress and quality of life of informal caregivers of post-stroke patients' survivors.

Method

Study design

A pilot randomized control single-blind (outcome assessor-blinded) comparative effectiveness trial of two active interventions.

Participants

The initial sample consisted of 60 caregivers of post-stroke patients, selected by the Municipal Health Secretariat (Health District I), as part of the Family Health Program, in the city of João Pessoa, Paraíba (Brazil). Flow diagram of the study participants is depicted in Fig. 1.

The following inclusion criteria were applied. Caregivers should: 1) be caring for a person with chronic stroke, of at least four months' duration; 2) present some degree of musculoskeletal alteration arising from this situation (having presented subjective complaints of these alterations to a health professional in the last month); 3) be over 18 years of age; 4) be fulfilling the duties of a full-time caregiver; 5) not be remunerated for caregiving (nor registered as a caretaker for social security purposes); 6) have some degree of kinship or close relationship motivating care for the patient. Moreover, the patient should be medically stable. The exclusion criteria were: 1) be caring for patients with any other neurological disorder; 2) the presence of a comorbid pathology; 3) if the post-stroke patient requires hospital admission during the study; 4) if the patient enters an acute period of stroke.

Ethical aspects

This study was approved by the Research Ethics Committee of the Lauro Wanderley University Hospital, with the identification number: CAAE 13011613613.0.0.00.00.5183. All participants were informed of the aims and procedure of the study and provided written consent to participate.

Outcome measures

The following sociodemographic information was collected from the informal caregivers: age, sex, marital status, education background, caregiving role (training in this regard, duration of care responsibilities and degree of kinship). In addition, healthy/unhealthy lifestyles information was collected.

A visual analogue scale was used to assess pain intensity and degree of relief experienced by patients, scored from 0 points (no pain) to 10 points (unbearable pain) during the preceding week. Its test-retest reliability analysis revealed a correlation of 0.64 for the visual numeric version in Brazilian.¹⁸ Pain intensity was measured at 16 body sites, 11 of which were bilateral.

The level of perceived stress was measured by the Cohen Perceived Stress Scale, derived from a self-report questionnaire to assess the perceived stress level over the last four weeks. This scale has 14 items with a five-point frequency response scale, ranging from 0 (never) to 4 points (very often). Higher scores indicate a higher level of perceived stress.¹⁹

The WhoQol-Bref was used to assess a person's quality of life and satisfaction with their health. This instrument contains 26 questions and has four subscales: physical, social, psychological, and environmental. The first two questions assess the perception of quality of life (question 1) and general perception of health (question 2). The answers are scored on a Likert scale, ranging from 1 to 5 points, where the higher the score, the better the quality of life. The raw score for each domain is used to calculate the transformed score.²⁰

Randomization

The randomization was performed using a computerized random number generator created before the start of data collection by a researcher who did not participate in the recruitment or treatment of patients. Individual tabs numbered sequentially were prepared. The cards were folded and placed in closed opaque envelopes. Other therapists, blinded to the pre-treatment evaluation, proceeded with the treatment according to the assignment to the groups. The outcome measures were evaluated before the first treatment session (baseline assessment), after the 12-week intervention period (post-treatment evaluation) and at 12 weeks after the end of treatment (follow-up evaluation).

Interventions

The interventions were carried out by three physiotherapists at the Health Units of District I, each of whom had over 10 years' experience in the treatment of stroke patients and their informal caregivers. In every case, the intervention program was for 12 weeks, with 60-min sessions provided twice weekly.

Postural hygiene and kinesiotherapy program

The intervention program was composed of ergonomic adjustments, postural advice and kinesiotherapy in the home context. Ergonomic and postural intervention included preparation of the patient's environment, postural hygiene during patient transfers, management of the patient during activities of daily life, the caregiver's posture in performing daily activities such as cleaning the bathroom, among others.^{21,22} The kinesiotherapy exercises were designed to promote stretching, flexibility, resistance and relaxation and to train caregivers in bodily awareness and in good practices in breathing. The body awareness exercises were aimed at strengthening the mind-body relationship, at planning the movement before performing it, and at automating movements whilst

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