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Original article

Design evaluation of a physical-therapeutic exercise program for patients with amyotrophic lateral sclerosis

Evaluación de diseño de un programa de ejercicios físico-terapéuticos para pacientes con esclerosis lateral amiotrófica

Avaliação do projeto de um programa de exercícios físico-terapêuticos para pacientes com esclerose lateral amiotrófica

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ABSTRACT

The lack of a methodological pathway specifically for the physical rehabilitation of patients with amyotrophic lateral sclerosis (ALS) that contributes to slowing their progression by attenuating symptoms, signs and complications that occur in the course of the disease justifies the development of a program of physical-therapeutic exercises for the rehabilitation of these patients. The purpose of this work is to evaluate the proposed programing in its design. The scientific proposal for a particular context, the Institute of Neurology and Neurosurgery, was evaluated through the expert criterion method. A group of people, not individuals themselves, took over as an expert. The expert selected was a 20 members multidisciplinary group of care for patients with neurodegenerative diseases of that institution, and for which five external specialists of maximum competence in the area of knowledge of Prophylactic and Therapeutic Physical Culture were invited. The participatory or consensus-seeking technique "Phillips 66" was used, which facilitated the participation of the large group by dividing it into subgroups to facilitate and order discussion. The design evaluation allowed confirmation that it is actually a program because it responds to the formal structure of what is considered as such and, and it is a good program for the context to which it is addressed, in addition to informing that the program qualifies to be evaluated in its development and results.

Keywords: Program; physical-therapeutic Exercises; Amyotrophic lateral sclerosis.

RESUMEN

La carencia de una vía metodológica con especificidad para la rehabilitación física de pacientes con esclerosis lateral amiotrófica (ELA), que contribuya a retardar su progresión, atenuando síntomas, signos y complicaciones que van apareciendo en el transcurso de la enfermedad, justifica la elaboración de un programa de ejercicios físico-terapéuticos para la rehabilitación de estos pacientes. El presente trabajo tiene como objetivo evaluar el programa propuesto en su diseño. Se evaluó la propuesta científica para un contexto particular, el Instituto de Neurología y Neurocirugía, mediante el método de criterio de expertos. Se asumió como expertos a un grupo de personas, no individuos en sí. El experto seleccionado fue el grupo multidisciplinario de atención a pacientes con enfermedades neurodegenerativas de esa institución, con 20 integrantes y al que se invitaron cinco especialistas externos de máxima competencia del área del conocimiento de Cultura Física Profiláctica y Terapéutica. Se utilizó la técnica participativa o de búsqueda de consenso "Philips 66", la cual facilitó la participación del grupo numeroso, al dividirlo en subgrupos para facilitar y ordenar la discusión. La evaluación de diseño permitió la confirmación de que sí es realmente un programa porque responde a la estructura formal de lo que se considera como tal y sí es un buen programa para el contexto al que se dirige, además de informar que el programa reúne las condiciones para poder ser evaluado en su desarrollo y en sus resultados.

Palabras clave: Programa; Ejercicios físico-terapéuticos; Esclerosis lateral amiotrófica.

RESUMO

A falta de um caminho metodológico co especificidades para a reabilitação física de pacientes com esclerose lateral amiotrófica (ELA) que contribua para retardar sua progressão por atenuar sintomas, sinais e complicações que surgem durante a doença justifica o desenvolvimento de um programa de exercícios físico-terapêuticos para a reabilitação desses pacientes. O presente trabalho tem como objetivo avaliar o programa proposto na sua concepção. A proposta científica para um determinado contexto, o

Instituto de Neurologia e Neurocirurgia, foi avaliada pelo método do julgamento de peritos. Um grupo de pessoas era considerado um especialista, não indivíduos em si. O especialista selecionado foi o grupo multiprofissional de atendimento a pacientes com doenças neurodegenerativas daquela instituição, com 20 membros, e para o qual foram convidados cinco especialistas externos de máxima competência da área de conhecimento de Cultura Física Profilática e Terapêutica. Foi utilizada a técnica participativa ou de busca de consenso "Phillips 66", que facilitou a participação do grande grupo dividindo-o em subgrupos para facilitar e ordenar a discussão. A avaliação do desenho permitiu a constatação de que se trata mesmo de um programa porque responde à estrutura formal do que se considera como tal e, sim, é um bom programa para o contexto a que se dirige, além de informar que o programa reúne condições para poder ser avaliado em seu desenvolvimento e seus resultados.

Palavras-chave: Programa; Exercícios físico-terapêuticos; Esclerose lateral amiotrófica.

INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS) is a progressive, neurodegenerative and inevitably fatal disease. There is no cure for ALS and life expectancy is usually two to five years after the onset of symptoms. Despite the lack of a cure and the rapidly progressive nature of the disease, ALS is considered a "treatable disease" and rehabilitation is part of optimal, comprehensive care, along with other medical and paramedical specialties that make up the multidisciplinary team. Physiotherapy plays a key role in the overall treatment of ALS patients, it is adapted to the individual's needs and goals. It focuses on addressing symptoms, maximizing function and enables ALS patients to live their lives to the fullest and with quality (Dal Bello-Haas, 2018; Jones *et al.*, 2019).

The physical-therapeutic exercise program for the rehabilitation of patients with ALS arises as an alternative solution to the lack of a methodological approach with specificity for the physical rehabilitation of these patients. It is a proposal to contribute to the delay of the progression of the disease, attenuating symptoms, signs and complications that appear in the evolutionary course of the disease as a result of the loss of upper and lower motor neurons.

In this sense, an accurate diagnosis from the initial stages becomes relevant in order to establish therapeutic intervention strategies based on a supportive and palliative rehabilitation, with three complementary domains, but separated from each other, aimed at the physical, functional and psychosocial aspects, according to the needs of each patient. In addition, the rehabilitation process through the use of physical therapeutic exercises should include personalized intervention strategies for this type of patient because the pathophysiological mechanisms of the disease require establishing a system of regressive physical loads at each stage (Cañadilla and Cañete, 2021).

This study was carried out in the Physical Medicine and Rehabilitation Service of the Institute of Neurology and Neurosurgery (INN in Spanish) in Havana, Cuba. It has the necessary equipment and human resources for the care of patients with neurological diseases, in addition, it has a multidisciplinary group for the care of patients with neurodegenerative diseases. In the process of elaborating the program, it was foreseen the evaluation of its design, implementation and results.

The design evaluation of a program basically covers three aspects (Tejedor, 2000): 1) Characteristics of the formal/intrinsic quality of the program (content validity), 2) the adequacy and adaptation to the context and 3) acceptance. To evaluate the program in its design, the criteria of experts was used and a group was selected as an expert, which is justified by assuming the redefinition proposed by López Fernández *et al.,* (2016) who consider the following:

> An expert is understood as an individual, group of people or organizations capable of offering, with a maximum of competence, conclusive assessments on a given problem, making real and objective prognoses on effect, applicability, feasibility and relevance that the proposed solution may have in practice and providing recommendations of what to do to improve it. (p. 20)

This way of evaluating programs based on expert criteria has been used in many contemporary researches. In this circumstance, this form is based on different phases or steps that can be used for evaluation by experts (Carvajal, Centeno, Watson, Martínez, & Sanz, 2011; Escobar-Pérez & Cuervo-Martínez, 2008; Fleitas, Mesa, & Guardo, 2013; Mesa, Fleitas, & Vidaurreta, 2015a; Robles & Rojas, 2015; Vega, Comas, Morillo, & Sánchez, 2018). In this research, the following steps are assumed (Mesa, Fleitas and Vidaurreta, 2015b).

From these steps the following actions are performed:

1. Elaboration of the objective.
2. Selection of experts.
3. Choice of methodology.
4. Application of the selected methodology.
5. Information processing.

This expert criterion has a duality of functions: it is a participatory modality and generates consensus: participatory because it is based on the informative collaboration of patients who belong to or know well the place or problem to be studied and consensus because it also assumes that people think and debate about a situation, it can be the starting point for the solution of that problem (Jara, 2017).

By taking into consideration this form of evaluation, the authors of this work project as an objective to offer the evaluation of the design of the proposed program. Consequently, to this, the answer on how the method of experts' criterion was executed is specified, which can serve as a reference source in the application to another proposal in similar conditions. It corresponds then to specify the answer to how the expert criterion method was executed to evaluate the design of the physical therapeutic exercise program for the rehabilitation of ALS patients. That answer is the objective of this work that, in turn, can serve as a reference source in the realization of any other in similar conditions.

MATERIALS AND METHODS

Within the methods declared in this research, the consultation to experts is found. With this way it was intended to evaluate in its design the physical-therapeutic exercise program for the rehabilitation of patients with ALS. The evaluation in its design would confirm if it is a program and if it is an adequate option to the context it is directed, besides informing that the program meets the conditions to be able to be evaluated in its development and in its results.

As stated above, this evaluation basically covers three aspects, which are detailed below:

a) Characteristics of the formal/intrinsic quality of the program, which refers to the knowledge of the technical characteristics of the program, i.e. it tries to answer the following questions:

- What program is it?
- What are its goals?
- Who are the recipients?
- What is the structure and content of the program?
- Which agents are responsible for carrying it out?
- What is the timing of it?
- What kind of resources does it require?
- What kind of activities, strategies or skills are involved?
- What methodology does it require?

b) Adequacy and adaptation to the context. It is about answering the question: Is the program adequate and adaptable to the context where it is directed? To do so, a series of questions are raised that are derived from the general one:

- Does the program to be evaluated start from an analysis of the context?
- Does it arise from a needs analysis; what is/are the starting need(s)?
- Does the center have the necessary resources or is it willing to provide them?
- Does the organizational structure of the center allow the program to be carried out?

c) Acceptance which seeks to answer the question: is the program acceptable in the context in which it is directed; in order to answer, it also raises a number of questions, the most salient of which are the following:

- Is it accepted by all the actors involved?
- Is it integrated in INN research projects?

The selected expert was the multidisciplinary group for the care of patients with neurodegenerative diseases of the INN of Cuba. This group, since 2005, created a multidisciplinary consultation to follow up and diagnose patients with clinical suspicion of ALS, with collaboration in secondary health care institutions throughout the country.

On the other hand, it has collaborated in research projects and exchanges of experiences with experts from other countries such as Ireland, Chile and Uruguay. Specifically, it was composed of 20 professionals knowledgeable in the subject, both for their academic training and work experience, which brings recognition in the care of patients with ALS. The group, among other functions, has been assigned the establishment or confirmation of diagnosis; design research projects to propose therapeutic intervention strategies for patients with neurodegenerative diseases; to watch over the fulfillment of the results of the projects and it is the one that proposes that such results be evaluated in the Scientific Council of the institution; for then, its implementation is approved.

In order to ensure the content validity of the program, five external specialists of the highest competence in the area of knowledge of Prophylactic and Therapeutic Physical Culture were invited to the group.

The characterization of the expert group by specialty, years of experience, those with academic degree, scientific degree, teaching category and those with scientific production on the disease is as follows: (Table 1).

Table 1. - Characterization of the expert group

Specialty	Neurology	5
	Clinical Genetics	1
	Neuropsychology	1
	Neurointensivism	1
	Physical Medicine and Rehabilitation	2
	Graduates in Physiotherapy	4
	Graduates in Physical Culture	2
	Speech Therapy and Phoniatrics	1
	Nutrition	3
	Prophylactic and Therapeutic Physical Culture	5
Years of experience	Less than 5 years old	1
	Between 5 and 10 years	3
	More than 10 years	21
With academic degree		19
With scientific degree		12
With scientific category		15
Teaching category		20
With scientific production on the disease		13

With the previous reflection, regarding the group as an expert, it was proceeded to the choice of the methodology. For this, it was taken into account that the expert is a group, and for this reason the choice was a participatory technique or a consensus seeking technique. However, the group is large, therefore, the chosen methodology was the Phillips 66 technique.

The Phillips 66 technique is used to facilitate large group participation. The large group that participates is divided into subgroups to facilitate and order the discussion. These subgroups are made up of six people who discuss the topic for six minutes. Afterwards, a representative from each group presents the conclusions they have reached and the researcher or facilitator writes them down on a blackboard. Once the conclusions of all the subgroups are known, the large group discusses them until a general consensus is reached.

Before the application of the technique, there is a preparation stage where the problem is exposed to the group and each of its members is given the complete program for its analysis, that is, a stage of identification of the problem and of making known what is desired as a final result. Therefore, they are given the aspects to be assessed, which respond to:

- The formal and intrinsic quality of the program designed (its technical characteristics, the quality of its formal structure, and aspects such as its congruence with the theoretical frame of reference and with the previous diagnosis),
- Adaptation and adequacy to the context in which it is aimed,
- The acceptance of the proposal in that context. The possibility is offered to relate other aspects that were relevant to them.

The head of the multidisciplinary group of care for patients with neurodegenerative diseases of the INN is the guide or moderator, who offers an explanation of objectives, presentation of participants and definition of rules, as well as leads the conduction towards conclusions or synthesis or suggestions.

The group leader and the researcher (also a member of the group) lead and facilitate, respectively, the activity. The six subgroups of six members are organized according to specialty and the representatives of each one are designated.

RESULTS AND DISCUSSION

The result is given in the confirmation that the evaluated proposal is a program and it is a good program endorsed by the results of the aspects that measure the formal and intrinsic quality of the program, the acceptance, the adaptation and adequacy to the context.

The group discussed the findings of all the subgroups until a general consensus was reached, as follows.

On the formal and intrinsic quality of the program

- Its objectives are clearly specified, measurable and observable.

- The structure and components are properly defined.
- The planned activities are sufficient to achieve the objectives set. The specific objectives are reflected in concrete activities. The activities refer to the objectives. The activities favour the proposed objectives.
- The actions or activities to be carried out are delimited in space/time coordinates (the time is specified, the space is adequate and a sequence is evident).
- The material and human resources available to implement the program are known (the materials for each proposed activity are specified and the person responsible for each activity is determined).
- On adaptation and adequacy to the context
- The program to be evaluated starts with an analysis of the context.
- It arises from a needs analysis. The starting need is the lack of a methodological approach with specificity for the physical rehabilitation of patients diagnosed with ALS that contributes to slow the progression of the disease, palliating symptoms, signs and complications that appear during the course of the disease.

On Acceptance

- The center has the necessary resources and is willing to provide them.
- The organizational structure of the INN allows for the implementation of the program.

The following recommendations emerged from the group's evaluation and were taken into account:

- To take into consideration in the guidelines the need to train patients, relatives and caregivers to actively participate in the rehabilitation process by the multidisciplinary team.
- Establish the training of those involved in program development, taking advantage of professionals who have experience in ALS, who can address current issues and can provide anticipatory guidance regarding future needs.
- To take into account, in addition to the selected elements for staging patients with ALS, periodic evaluations using other diagnostic and prognostic criteria for respiratory function, such as the values of maximum respiratory pressures (MPR): maximum inspiratory pressure (MIP) and maximum expiratory pressure (MEP).

The first recommendation was accepted when the need to provide support and guidance to the family to participate in the activities of the process was understood, since a biopsychosocial rehabilitation approach is established, aimed at treating physical (pain, spasticity, difficulty moving) and psychological problems (such as depression, apathy, anger, reduced motivation, confusion, lack of willpower, insomnia), which can limit the success of palliative and supportive rehabilitation. It was considered, then, that the training of patients, family members and caregivers to actively participate in the care process should be carried out under the supervision of physiotherapists trained to

mitigate symptoms, signs and complications of the evolutionary process and irremediable course of the disease. These should understand that the support and palliative rehabilitation should be aimed at people to actively participate in treatment, be able to follow instructions to carry out the treatment and maintain or improve the performance of activities of daily living, maximize self-esteem, self-preservation instinct, sense of independence and dignity.

The second recommendation is supported by the results of the diagnostic work-up which revealed that there is not always a comprehensive understanding of the nature and course of the disease and this limits appropriate and effective decision making.

The importance of the third recommendation is recognized, as it allows early identification of involvement in the bulbar region, as well as the presence of respiratory signs and symptoms. In this sense, an evaluation of the respiratory system should be performed from diagnosis, periodically and every three months of treatment. This recommendation coincides with that proposed by Barrera *et al.,* (2017) as it is the main cause of hospital admission and mortality in people with ALS.

CONCLUSIONS

In conclusion, it is summarized that the evaluation of the design of the physical therapeutic exercise program for the rehabilitation of patients diagnosed with ALS confirmed that it is an adequate program for its purposes. This product has been endorsed by the results of the aspects that measure the formal and intrinsic quality of the program, the acceptance, adaptation and adequacy to the context and, in addition, allowed the attention to recommendations that enriched the proposal. In turn, the Phillips 66 technique is an alternative as a group method to be used in the evaluation by expert criteria, which confers greater scientificity to the research process developed.

REFERENCES

Barrera, J. M., Boceta, J., Benítez, J. M., Caballero, C., Camino, R., Díaz, P. et al. (2017). Documento de Consenso para la atención a los pacientes con Esclerosis Lateral Amiotrófica. Servicio Andaluz de Salud. Consejería de Salud y Bienestar Social. Junta de Andalucía, actualización 2017. http://www.elaandalucia.es/WP/wp-content/uploads/GUIA-ASISTENCIAL-ELA -revisi%C3%B3n.pdf.

Bello-Haas, V. D. (2018). Physical therapy for individuals with amyotrophic lateral sclerosis: Current insights.DegenerativeNeurological and Neuromuscular Disease, 8, 45-54. https://doi.org/10.2147/DNND.S146949

Cañadilla, Y. y Cañete, A. C. (2021). Abordaje rehabilitador en personas con esclerosis lateral amiotrófica. Revista Cubana de Medicina Física y Rehabilitación. 13(2):e585 http://revrehabilitacion.sld.cu/index.php/reh

Carvajal, A., Centeno, C., Watson, R., Martínez, M. y Sanz, A. (2011). ¿Cómo validar un instrumento de medida de la salud?; Anales del Sistema Sanitario deNavarra. 34 (1), 63-72. http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=s1137-66272011000100007&ing=es&ting=es

Escobar-Pérez. J. y Cuervo-Martínez, A. (2008). Validez de contenido y juicio de expertos: una aproximación a su utilización. Avances en Medición, 6, (1) 27-36 http://www.researchgate.net/publication/302438451

Fleitas, I., Mesa, M. y Guardo, M. (2013). Sobre algunos métodos cualimétricos en la Cultura Física: criterio de expertos, especialistas, peritos, jueces y árbitros, usuarios y evaluadores externos. *Efdeportes.* https://www.efdeportes.com/efd179/metodos-cualimetricos-en-la-cultura-fisica.htm

Jara, O. (2017). La concepción metodológica dialéctica, los métodos y las técnicas participativas en la Educación Popular. CEP Centro de Estudios y Publicaciones Alforja. https://trabajosocialsantafe.org/wp-content/uploads/2019/02/Jara-Sistematizacion.pdf

Jones, K. E., Berry, T. R., Merali, A. S. & Dal Bello-Haas, V. (2019). Intentions of Canadian health professionals towards recommending exercise for people living with ALS. BMC Neurology. 19:204. https://doi.org/10.1186/s12883-019-1426-z.

Mesa, M., I. Fleitas y R. Vidaurreta (2015). Sobre el tratamiento estadístico a los datos provenientes de las opiniones de los expertos en las investigaciones de la Cultura Física. *EFDeportes.com, Revista Digital*. Buenos Aires, 20, (210). https://www.efdeportes.com/efd210/tratamiento-estadistico-opiniones-de-expertos.htm

López, R., Crespo, E., Crespo, T. P., Fadul, J. S., García, M. B., Juca, F. X., Bastidas, M. I. y Palmero, D. E. (2016). Expertos y Prospectiva en la investigación pedagógica. Cienfuegos. Cuba; Universo Sur; ISBN: 978-959-257-464-9. https://www.researchgate.net/publication/324823076_Expertos_y_Prospectiva_en_la_investigacion_pedagogica

Robles Garrote, P. y Rojas, M. D. C. (2015). La validación por juicio de expertos: dos investigaciones cualitativas en Lingüística aplicada. Revista Nebrija de Lingüística Aplicada, 18. https://www.nebrija.com/revista-linguistica/files/articulosPDF/articulo5500aca89c37.pdf.

Tejedor, F.J. (2000). El diseño y los diseños en la evaluación de programas. Revista de Investigación Educativa, 18(2),319-339. https://revistas.um.es/rie/article/view/121021.

Vega, V., Comas, R., Morillo, J. R. y Sánchez, B. (2018). El método Delphi Fuzzy para la selección de expertos en el turismo. UNIANDES EPISTEME. Revista digital de Ciencia, Tecnología e Innovación. 5 (Especial) pp. 836-848. ISSN 1390-9150. http://45.238.216.13/ojs/index.php/EPISTEME/article/view/1548

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The authors declare not to have any interest conflicts.

Authors' contribution:

Yordán Cañadilla Barrios: Conception of the idea, literature search and review, instrument making, instrument application, compilation of information resulting from the instruments applied, database preparation, general advice on the topic addressed, drafting of the original (first version), review and final version of the article, article correction, authorship coordinator.

Magda Mesa Anoceto: Statistic análisis, review and final version of the article, article correction, review of the application of the applied bibliographic standard.

Jerry Bosque Jiménez: Instrument making, translation of terms or information obtained, review of the application of the applied bibliographic standard.

Rodolfo Ruvenio Vidaurreta Bueno: Statistic análisis, preparation of tables, graphs, and images.

Annia Caridad Cañete Rojas: Literature search and review, instrument making, compilation of information resulting from the instruments applied, database preparation, general advice on the topic addressed, review and final version of the article.