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Developing household guidelines for individuals with nonprogressive chronic childhood encephalopathy

Desenvolvimento de aplicativo de orientações domiciliares para indivíduos com encefalopatia crônica não progressiva da infância

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RESUMO | INTRODUÇÃO: A Encefalopatia Crônica Não Progressiva da Infância (ECNPI) é uma condição de deficiência física não progressiva decorrente de uma lesão no sistema nervoso central em desenvolvimento. Ela apresenta desordens motoras, no tônus muscular e na postura, com isso provocando uma deficiência na coordenação da ação muscular e dos movimentos, incapacidade ou dificuldade na manutenção postural. Com o crescimento e desenvolvimento das crianças pode ocorrer um agravo do quadro de saúde, como aparecimento de deformidades e contraturas que afetam a funcionalidade, com isso, para minimizar esses efeitos são necessárias medidas preventivas. **OBJETIVOS:** Desenvolver um aplicativo de orientação familiar para o manejo de pacientes referente a posicionamento, transferências posturais e prevenção de contraturas. **MATERIAIS E MÉTODOS:** O estudo constituiu-se de uma pesquisa de produção tecnológica, visando o desenvolvimento de um aplicativo móvel para a plataforma Android. A produção do aplicativo dividiu-se em três etapas, pesquisa científica, através das bases de dados de acesso eletrônico como PUBMED, LILACS, MEDLINE e Scielo; elaboração de uma linguagem simplificada e desenvolvimento da aplicação Android. **RESULTADOS:** O resultado obtido foi um aplicativo móvel composto por 5 tópicos: informações gerais da ECNPI, alongamentos, transferências posturais, manuseio e referências bibliográficas **CONCLUSÃO:** Verificou-se a importância de adequar a assistência em saúde aos avanços tecnológicos para melhoria da qualidade de vida dos pacientes.

PALAVRAS-CHAVE: Paralisia cerebral. Aplicativos móveis. Serviços preventivos de saúde.

ABSTRACT | INTRODUCTION: Non-Progressive Chronic Childhood Encephalopathy (ECNPI) is a condition of non-progressive physical disability due to a developing central nervous system injury. It has motor disorders, muscle tone and posture, thus causing a deficiency in coordination of muscle action and movements, inability or difficulty in maintaining posture. With the growth and development of children may occur an aggravation of health, as the appearance of deformities and contractures that affect functionality, so to minimize these effects preventive measures are necessary. **OBJECTIVES:** To develop a family guidance application for patient management regarding positioning, transfers and prevention of contractures. **MATERIALS AND METHODS:** The study consisted of a technological production research, aiming at the development of a mobile application for the Android platform. The production of the application was divided into three stages, scientific research, through electronic access databases such as PUBMED, LILACS, MEDLINE and Scielo; elaboration of a simplified language and development of android application. **RESULTS:** The result was a mobile application consisting of 5 topics: general ECNPI information, stretching, postural transfers, handling and bibliographic references. **CONCLUSION:** The importance of adapting health care to technological advances to improve patients' quality of life was verified.

KEYWORDS: Cerebral palsy. Mobile applications. Preventive health services.

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Introduction

Non Progressive Chronic Childhood Palsy, also known as Cerebral Palsy (CP) is a condition of a non-progressive physical injury due to a developmental central nervous system lesion which may occur during the prenatal period. It presents motor disorders, without muscle bonus and posture, thus occasioning hindrance in coordinating muscle action and movements, dificulty or inability in maintaining posture[1].

Motor clinical manifestations are diverse and vary according to their degree, type of motor impairment and movement disorder. Thus, it is classified as spastic, atetosic, ataxic, hypotonic and mixed, and its body location is classified as hemiparetic, diparetic and quadriparetic. The severity of neuromotor impairment in individuals with IPNS may be characterized as mild, moderate or severe, based on the means of locomotion[2].

With the growth and development of children may worsen the health due to complications such as the appearance of atrophies, deformities, altered muscle tone and contractures. Associated with this, other factors may interfere and directly influence functional performance, such as the environment and the lack of stimulation by caregivers may make individuals not acquire greater functionality and independence[3].

These problems and factors hinder the comfortable positioning of the individual, impair the tasks of daily living, positioning, transfer and hygiene care among others. In this context, the prevention of these complications to provide well-being and health through guidance to caregivers is extremely important. Thus, these physiotherapeutic prescriptions are necessary to integrate and complement the treatment performed in the clinic to the patient's daily routine, since the home environment is the place where the individual spends most of the time[4].

An effective way to make educational, entertainment, health and other tools available today has been mobile software, so-called mobile apps. These tools demonstrate the ease of reaching the target audience, due to the rapid spread of mobile devices in the market, which has favored the insertion of this technology in healthcare, both in research and in care management and care. The apps used in healthcare have the advantages of reducing paper printing costs, the dissemination of material without the need for displacement and the reach of distant places[5,6].

Thus, associated with the benefits and the need to guide caregivers of children with NPE, the aim of this study was to develop a mobile app which contains information and guidance on pathology, postural transfers, prevention of contractures and deformities in individuals with NPE.

Material and methods

The study is a technological production research, characterized by the process of development and creation of a mobile app with home orientations for caregivers of individuals with NPE regarding postural transfers, positioning, prevention of contractures and deformities.

The first stage of mobile app development consists of scientific research on NPE and associated pathologies, deformities, contracts, positioning and postural transfers, to substantiate the proposed theme and to establish a guiding principle to indicate the main demands of the target audience.

Thus, the electronic access databases PUBMED, LILACS, MEDLINE and Scielo were used using the following HSD descriptors: (Health Science Descriptors) Cerebral Palsy, Education, Telemedicine and Caregivers in isolation and in association.

We searched original articles, dissertations and reviews of systematic, integrative or narrative literature available in full, with specific publication period from 2015 to 2019, in English and Portuguese. Duplicate articles, editorial studies, congress proceedings, case studies and reflection articles were excluded. The search took place from September to November 2018.

In the second stage, corrections were made by a physiotherapist who specializes in neurological rehabilitation according to the characteristics of the

target audience, in order to make it accessible. In the third stage occurred the development of the app, which were used tools for system development for Android platform, i.e libraries and tools in the Java programming language provided by the Android Software Development Kit (SDK). Because the creation of the application is only possible after preparing the desktop that occurs with the installation and configuration of Android SDK (containing SDK Tools, Build Tools and Platform Tools) and the IDE (Integrated Development Environment) programming Android Studio.

Results

For theoretical foundation of the theme, several studies were reviewed. The most relevant authors for this research are shown in Chart 1.

Chart 1. Basic studies for the theoretical foundation of the mobile app

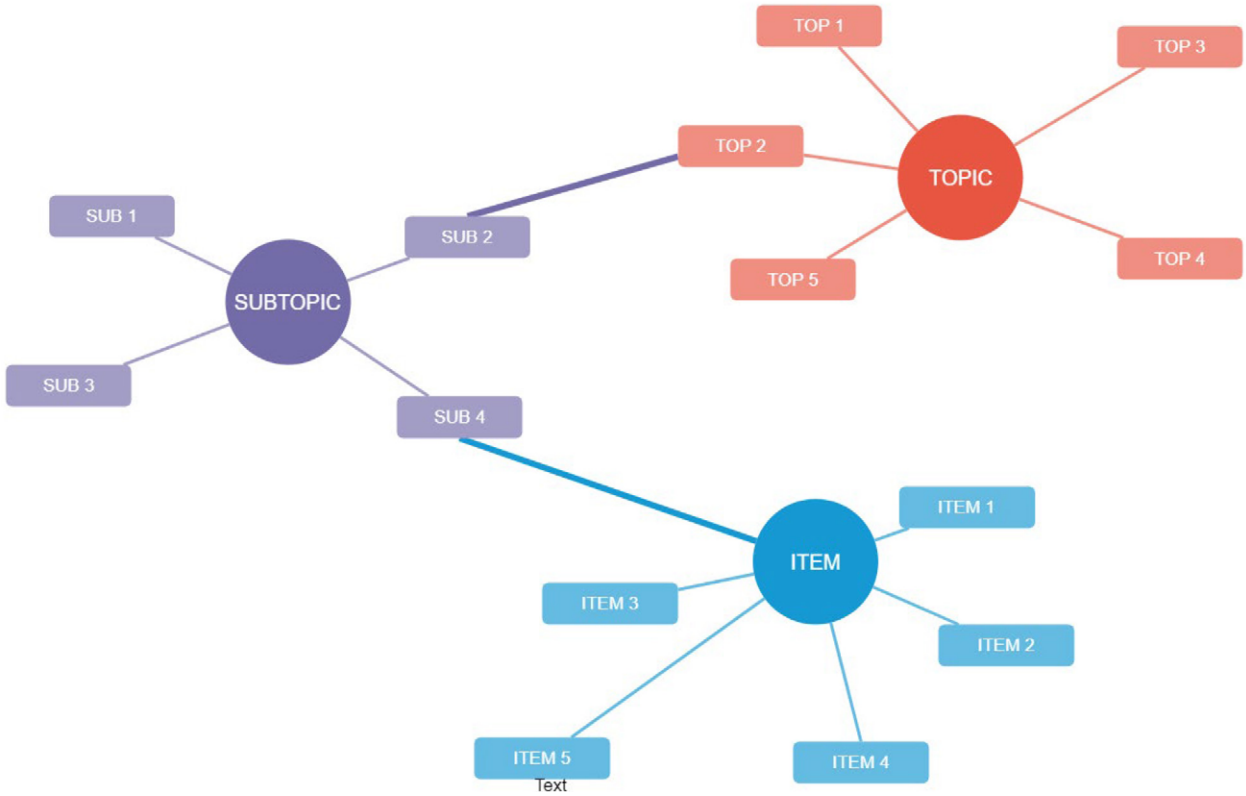
AUTHORS	TITLE OF THE STUDY	RESULTS
Santos GFL, Santos FF, Martins FPAA	Physical therapy in early stimulation in children with cerebral palsy	It was evidenced that physiotherapeutic techniques contribute to motor learning and should be performed in the first years of life, at the height of neuroplasticity to achieve more significant results, thus obtaining an effect as close as possible to typical development.
Alflen RA, Lima LD, Bussador A, Peres LW, Junior JA	Development of a platform to assist in the physiotherapy of patients with chronic non-progressive childhood encephalopathy- NPE	This paper presented the prototype developed in a partnership of Computer Science and Physiotherapy courses to assist in the treatment of children with cerebral palsy, incorporating in the sessions concepts of gametherapy
Barbosa JM	Guidelines on caring for children with cerebral palsy for caregivers and health professionals: a practical guide	This manual has two parts: the first one that discusses the meaning, types, causes and consequences of PC and the second one that presents suggestions to facilitate the feeding, clothing, hygiene, bath, added to the positioning orientations, stretching exercises and games
Souza JS, Knobel KAB.	Illustrated guide to caregivers of children with neuromotor disabilities.	This illustrated guide contains information regarding the care and management of children with neuromotor disabilities. It was made to encourage the reader to stimulate the neuropsychomotor development of children with neuromotor disabilities.
Pavão SL, Silva FPS, Rocha NAC.	Effect of home orientation without functional performance of children with special needs	It is suggested from the results that individualized home guidance to caregivers is effective in raising the level of functionality of children with special needs in areas of self-care and social function according to PEDI. Thus, a simple and efficient form of intervention with the family

The app was titled Move + and was developed for devices operating by Android type technology, the choice for this compatibility was due to the fact that this is the type of operating system compatible with most mobile devices, which makes the app accessible to more people.

The product acts as a digital booklet and as the app installation is completed it will also be available for offline use without the need for internet access to use it. As for the language used, it was distinguished by its simplicity and objectivity, making the contents more accessible to the target audience. About the design, light and clean design with a light color background was prioritized.

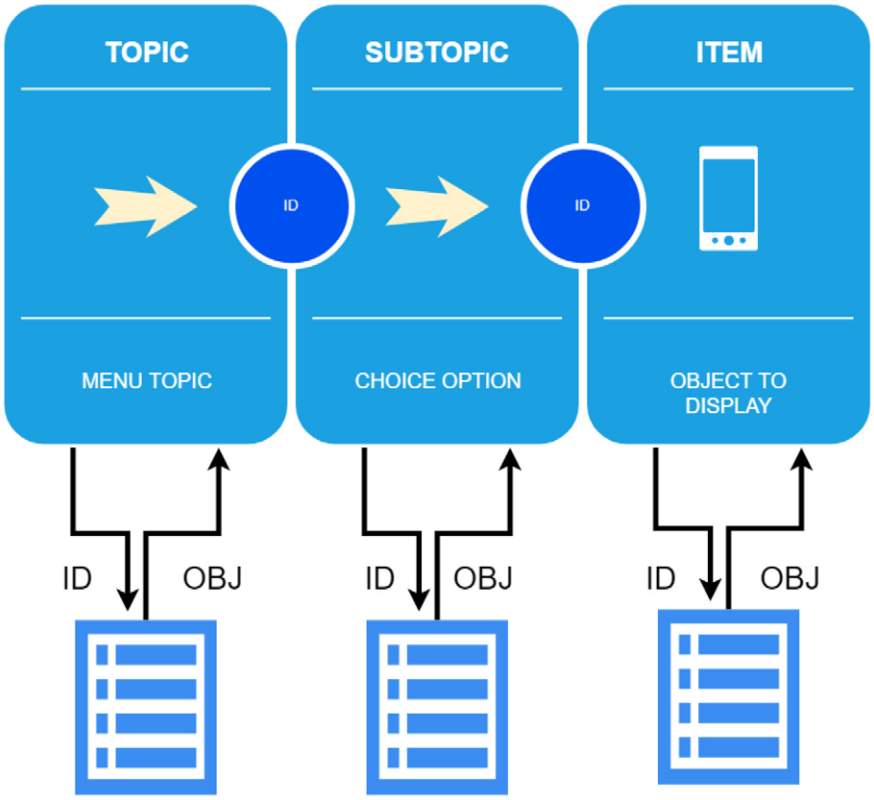
The data was organized in the structural tree concept to be accessed internally, the menus are closer to the root (main menu) and pages containing the information are on the sheets, thus having a more organized way of working with objects and displaying the information. Figure 1 represents the tree structure worked on the project.

Figure 1. Tree Structure



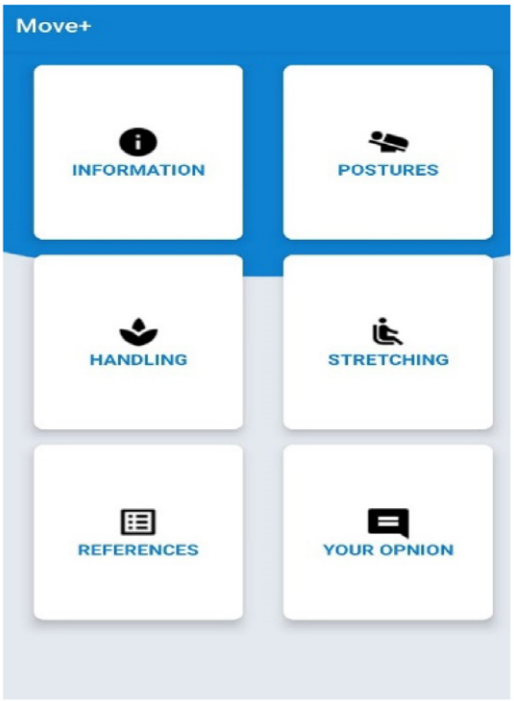
As such, the application has only 3 screens that are adjusted at run time, reducing the size of the application by avoiding over screens. All data is inserted into a HashMap used for more efficient queries than Lists and Arrays, as it works by implementing key-value through an ID for each object handled. Figure 2 demonstrates how information exchange occurs through ID mapping.

Figure 2. App info flow



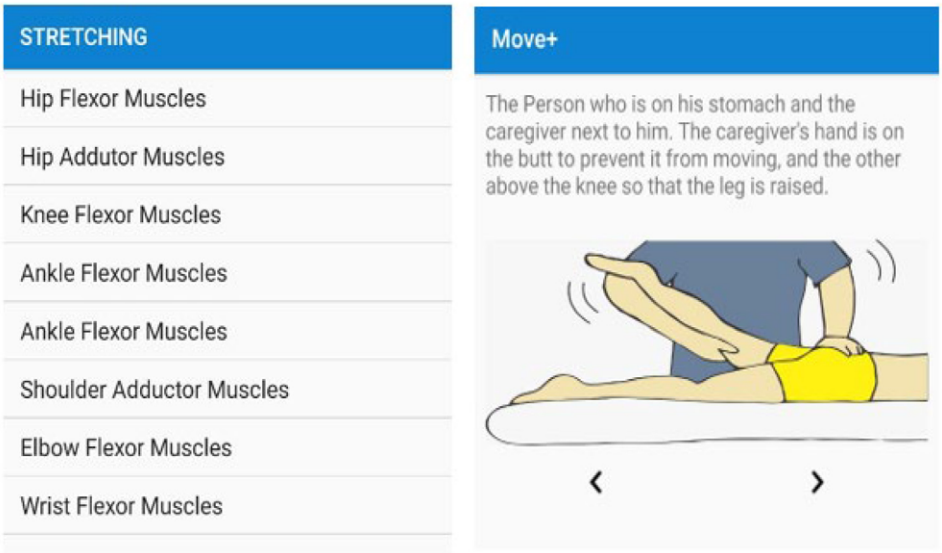
Each HashMap item consists of a key and an object as the value, the object has all the screen information that will be displayed, such as text and images. This form of implementation is characteristic of scalable systems because once implemented the update occurs with the insertion or removal of an object, and it is not necessary to create or remove new screens. The product consists of 6 topics, the first topic covers general information such as the definition of NPE, spasticity, tips on professionals who can assist in the treatment of individuals and clarification on the use of orthoses. Then the other topics are: Handling, Postures, Stretches, References used for the preparation of the product and Your Opinion for users to evaluate the application. Figure 3 shows the home screen with all access possibilities in the system.

Figure 3. App Home Overview



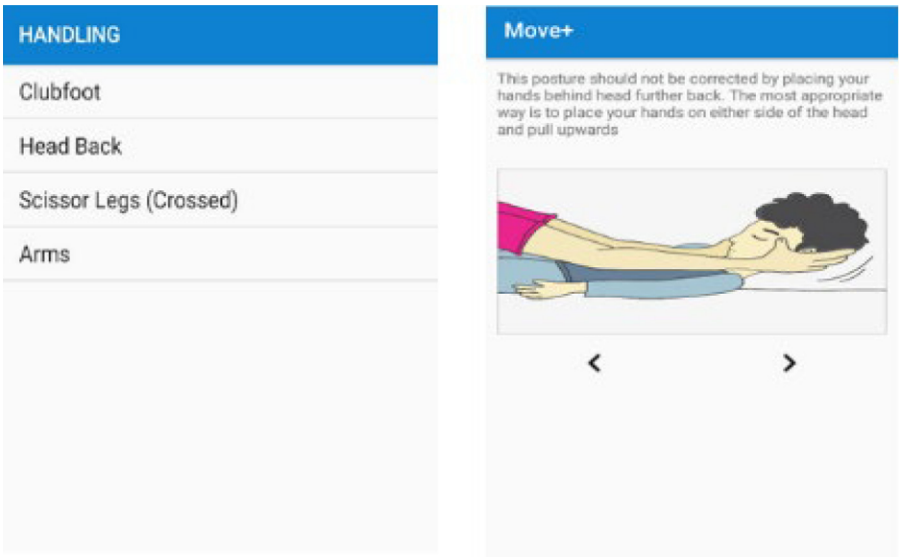
Each topic contains callouts and illustrative images. Figure 4 shows the main muscle groups that were chosen for stretching and the demonstration of how to perform stretching in order to prevent and reduce contractures and deformities.

Figure 4. Application topic regarding stretching. Authoral illustrative stretching image



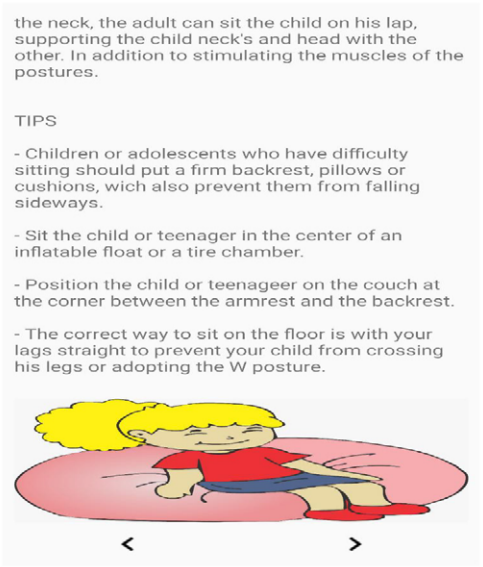
In figure 5, the topic handling demonstrates the correct way to manipulate the child, the approaches that are most susceptible to injury were chosen if not done properly.

Figure 5. Handling application topic and illustrated illustrative example of head handling



In the topic Posture, observed in figure 6, the tabs cover the general guidelines and the proper way to position the children in supine and prone position, to carry on their laps, sitting, standing and the care with pressure injuries.

Figure 6. Topic about proper posture. Author illustrative image



Topic 5 contains Bibliographical References used for the production of Move+, about which users are free to consult them if necessary. This prevents them from consulting additional information from unknown and unscientific sources.

Topic 6, designed for users' opinion, was designed to make it possible for the public to report whether the application was beneficial to them, offer suggestions for improvement, and ask questions relevant to the topic. This space for application feedback is very important for updates and improvements.

Discussion

The mobile app developed provides caregivers of children with NPE adequate instructions for home care to maximize the effects of treatment performed in a physical therapy outpatient clinic[7]. It offers users the possibility to consult whenever there is any doubt about the topics covered, as it offers the possibility to be consulted on mobile and offline[8].

One of the main advantages of the development of educational mobile applications is the reuse, because, through the availability on the Internet, they allow access and consultation of this information at any time, place and as often as needed[9].

Considering that one of the objectives of a mobile app is to facilitate the accomplishment of a specific task or to assist in some service, when dealing with health sciences, it can be stated that the availability of scientific knowledge at a click away increases the ability to empowerment of patients and their caregivers in their reality[10]. For this reason, the application developed obtained theoretical and practical grounding in reliable and secure databases, as well as providing guidance to caregivers through appropriate and simplified language[11].

Often the family is not guided by health services on how to perform care in the home environment, which points out that it is not recognized as the main unit of care. This implies greater functional risks for the patient due to inadequate management and scarcity of stimuli. The production of educational applications in the health area mitigates this failure in the health service and prepares the family for home care[12].

Orientation to caregivers of children with special needs, regarding home care, has a direct effect on increasing the child's functional performance in daily life activities, in the areas of self-care, mobility and social function. The application developed can broaden the child's relationship with the environment in which he finds himself, making the place a facilitating agent of functionality, rather than a limiting factor. Thus, home orientations extend the therapeutic process beyond outpatient care[13,14].

There is little knowledge about the understanding of the disease by caregivers, as well as aspects related to daily home care provided to children with NPE. The caregivers' difficulty in dealing with the child's limitations can promote situations that result in significant physical and emotional distress. The use of a mobile app with guidance for positioning management, postural transfers and prevention of contractures may benefit the child's rehabilitation process, as well as reducing overloads, reducing physical demands and preventing injuries due to caregivers' repetitive efforts[15,16].

In the study by Ghazisaeedi et al. (2016), we evaluated the effects of an Android application on the knowledge of caregivers of children with NPE before and after 2 months of using the app. This app included educational information about eating, bathing, playing, handling and movements. As an outcome, they obtained results that corroborate the increased knowledge of caregivers in all domains except playing[17].

In this sense, a positive result of the use of technologies to increase the knowledge of caregivers of children with NPE about the proper performance of daily activities stands out.

Although there are reports of the development of other mobile apps applicable to patients with NPE[17,18,19] it is still a small but growing field that has attracted the attention of researchers who reinforce the fundamental role of research about using health apps[20].

The limitations of the study are the development of the mobile app on the Android platform, which, although covering a larger number of possible users, the ideal is that such technology should also be suitable for other operating systems. The need to finalize the test phase and verify the impact of the app on the target audience, offer improvements and, finally, implement the app, which is a proposal for further studies.

Conclusion

This study was a record of the creation of a new technology, the "Move+" a mobile app for caregivers of individuals with NPE, which addresses how to perform postural transfers, positioning, prevention of contractures and deformities, using the Android platform. It is noteworthy that testing is still necessary to verify the need for further adjustments and updates.

Therefore, this research is expected to arouse the interest of other health researchers for the development of new technologies aligning the theoretical-practical knowledge of physical therapy and seeking to improve the quality of care to people with NPE and quality of life of caregivers and of the patients.

Author contributions

Dias ACL, Paz COC and Rocha LSO participated in the conception, design, search and analysis of research data, interpretation of results and writing of the scientific article. Carvalho IS participated in the conception and design of the study, product elaboration, data interpretation and writing of the scientific article. Gomes IF participated in the collection and analysis of research data, interpretation of results, writing of the scientific article. Costa CA and Moraes JBA participated in data analysis, study design and writing of the scientific article.

Competing interests

No financial, legal or political competing interests with third parties (government, commercial, private foundation, etc.) were disclosed for any aspect of the submitted work (including but not limited to grants, data monitoring board, study design, manuscript preparation, statistical analysis, etc.).

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