Saúde e Pesquisa
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Validation and adherence to the use of the home exercise booklet - Duchenne muscular dystrophy

Validação e adesão ao uso de cartilha de exercícios domiciliares - distrofia muscular de Duchenne

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ABSTRACT

The present study aimed to validate the content and analyze adherence to the exercises presented in the booklet for children and adolescents with Duchenne muscular dystrophy (DMD). Nine expert judges evaluated the booklet using an adapted questionnaire for the content validation process. Fifteen children/adolescents with DMD and their caregivers reported on the quality of the material's content and adherence to its use (15 and 45 days after receiving the booklet). Twenty-two aspects addressed in the content validation received scores above the acceptable threshold. Most caregivers responded "I agree" or "I completely agree" to all items analyzed regarding the evaluation of the material. In the short term, the adherence rate was 33.3%, and in the long term, it was 13.3%. The booklet enriched the physiotherapeutic treatment of children and adolescents with DMD. However, moderate to low adherence was observed among participants.

Keywords: Children. Duchenne muscular dystrophy. Physical exercise. Teenagers.

RESUMO

O presente estudo objetivou validar o conteúdo e analisar a adesão aos exercícios contidos numa cartilha para crianças e adolescentes com distrofia muscular de Duchenne (DMD). Nove juízes especialistas avaliaram a cartilha usando um questionário adaptado no processo de validação de conteúdo. Quinze crianças/adolescentes com DMD e seus cuidadores reportaram sobre a qualidade do conteúdo do material e a adesão ao uso (15 e 45 dias após a entrega da cartilha). Vinte e dois aspectos abordados na validação do conteúdo receberam pontuação acima do índice aceitável. A maioria dos cuidadores responderam "concordo" ou "concordo totalmente" para todos os itens analisados referente à avaliação do material. Em curto prazo, a taxa de adesão foi 33,3% e em longo prazo de 13,3%. A cartilha revelou ser um instrumento benéfico para enriquecer o tratamento fisioterapêutico de crianças e adolescentes com DMD. No entanto, foi observada uma adesão "moderada/baixa" pelos participantes.

Palavras-chave: Palavras-Chave: Adolescentes. Crianças. Distrofia Muscular de Duchenne. Exercício físico.

INTRODUCTION

Duchenne muscular dystrophy (DMD) is a progressive hereditary disease with X-linked recessive inheritance[1]. It results from mutations in the gene that encodes the dystrophin protein, a structural protein responsible for maintaining the integrity and structure of muscle cells for effective muscle contraction[2]. In Duchenne muscular dystrophy, the protein is either absent or deficient, causing an imbalance in muscle functionality in DMD patients[3]. DMD is classified as the most common form of dystrophinopathy, affecting 1 in every 3,000-5,000 male children[4].

The clinical characteristics of DMD are related to the progressive reduction in overall muscle strength, starting in the lower limbs, progressing to the upper limbs, and then to the respiratory muscles . Gradual weakness and shortening lead patients to lose the ability to walk around the ages of 11-13 years-old and develop joint deformities that make daily activities difficult. This combination of factors restricts patients from participating in various social experiences, impairing their quality of life and socialization . Patients diagnosed with DMD have an average life expectancy of 23 years, with respiratory failure being the most frequent cause of death[,] .

DMD is a disease that currently remains incurable. Therefore, the treatment of these patients aims to delay the progression of the characteristic manifestations of DMD, such as loss of ambulation and deficits in respiratory muscles, as well as to seek resources that help reduce the disabling conditions of DMD, favoring the quality of life of patients and caregivers[1] . In muscular dystrophies, often due to pain, muscle weakness, and difficulties in performing motor activities, patients live a sedentary lifestyle[11]. In progressive muscle diseases, muscle weakness can be intensified by physical inactivity, leading to deformities and reduced efficiency of respiratory muscles . Given the complications caused by a sedentary lifestyle, interventions should be developed to promote physical activity, as specific exercises can increase muscle strength, consequently improving the motor capacity of patients with DMD[12], [13].

In 2018, Birnkrant et al. renewed considerations on DMD care. They emphasized that rehabilitation management should focus on range of motion, muscle flexibility, posture and alignment, muscle strength, individual functionality, quality of life, and participation in daily activities[14].

In 2018, the Brazilian consensus for DMD was published, and part of this document (part 2) specifically addresses the rehabilitation and systemic care of these patients. Within the scope of rehabilitation, two aspects should be addressed: assessment and intervention. The authors divide the approach into five stages: pre-symptomatic (birth to three years of age); early stage of disease symptoms (two to seven years); transition stage; early stage of ambulation loss; and advanced stage of the disease (late adolescence to adulthood)[1] .

In the first stage, pre-symptomatic, efforts should focus on maintaining the child's normal growth and development. In the second stage, the onset of disease symptoms, the focus is on maintaining joint range of motion through exercises and using orthoses to prevent deformities and preserve ambulation. In the transition stage – the third stage – there is a rapid loss of lower limb functionality; rehabilitation in this stage, besides focusing on range of motion, is aimed at considering and prescribing aids for ambulation and interventions for the respiratory system. In the fourth stage of the disease, early ambulation loss, children and adolescents with DMD begin using wheelchairs for mobility; the goal at this phase is to promote as much independence as possible, paying attention to upper limb functionality. In the last stage, the most advanced stage of the disease, the purpose of rehabilitation should be to maintain as much comfort and independence as possible for DMD patients[1] .

Given the patients' constant need for attention and care, caregivers must actively participate in the child's therapeutic process and access to information[16]. Including the family in treatment plans is extremely important as it facilitates family-professional co-participation at home care levels with the child during the development, implementation and evolution of therapeutic resources[17].

Considering these needs, educational methods for family members and caregivers are developed to provide the best guidance on information about the disease and patient management measures[18]. Printed materials such as booklets, leaflets and pamphlets support family members who will provide care when they are not in the presence of a healthcare professional. Printed material is of great importance in educating participants as it facilitates understanding, and patients' families can use it whenever questions arise[19,20]. In this context, to facilitate understanding and disseminate information about the disease, a guide for families of patients with Duchenne muscular dystrophy, focusing on diagnosing and managing these patients, was developed by the Muscular Dystrophy Association and collaborators in 2018. The guide provides accessible information about the signs and symptoms and forms of diagnosis, in addition to presenting possible recurring challenges and what care must be taken during each phase of the child and adolescent's development[21].

The exercises that make up the booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne" are similar to the guidelines presented in an international review on the Diagnosis and treatment of Duchenne Muscular Dystrophy, published in 2010[22], and in the Brazilian Consensus on Muscular Dystrophy of Duchenne part 2: rehabilitation and systemic care[15]. Both studies recommend physiotherapeutic and home management, aiming to maintain patients' flexibility, mobility and health. To the best of our knowledge, scientific literature regarding the development and validation of exercise books is scarce. Carvalho and collaborators (2010) published guidelines for performing stretching-type exercises at home[23] for patients with unspecified muscular dystrophy. Other types of exercises focused on patients with DMD and contained in a "booklet" document were not identified at national and international levels.

Pondering the facts reported above, members of the Physiotherapy Outpatient Clinic for Childhood Myopathies at Centro de Reabilitação of the Hospital das Clinicas of Faculdade de Ribeirão Preto – Universidade de São Paulo (CER-HC-FMRP-USP) and the team at the Fisioterapia Pediátrica Aplicada às Doenças Raras - Laboratório de Pesquisa Científica (FT-RARA) developed the booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne". The goal of this project was to support the participation of children/ adolescents, along with their families, in the rehabilitation process to improve the quality of life of this population. The booklet includes a brief overview of the disease definition, its progression, and the importance of physical therapy as well as an activity plan with descriptions of home exercises and useful information about orthotics and physical activities to maintain or improve heart, lung, and muscle function.

This material was finalized in September 2020, with illustrative figures for each task. The current project aimed to test its use in patients and caregivers to verify whether the language and appearance are effective and suitable for the target audience.

Through the production of the home exercise booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne", the study's objective was to conduct content validation through expert judges who evaluate the material (booklet) and analyze the adherence to the exercise guidelines contained in the booklet by DMD patients and their respective caregivers. Through this study and subsequent distribution, patients and caregivers can receive this material and benefit from being co-participants in rehabilitation.

METHODOLOGY

CHARACTERIZATION OF THE RESEARCH

In this quasi-experimental, before-and-after study, educational technology was evaluated, characterized as a booklet (Access here: https://drive.google.com/file/d/1T0-Ei_QtTEsd2crMWi7HL5H6iULe0x-5/view?usp=sharing), which was developed to guide patients and caregivers of children/adolescents with Duchenne muscular dystrophy undergoing treatment in outpatient rehabilitation centers. Participant assessments were carried out at the CER-HC-FMRP-USP, in person and remotely. The project was approved by the Research Ethics Committee of the Hospital das Clínicas of FMRP-USP under the CAAE no. 59926222.5.0000.5440. The study was carried out from September 2022 to September 2023.

SUBJECTS

Fifteen caregivers of children/adolescents with DMD undergoing treatment at the outpatient rehabilitation center participated in this research. The inclusion criteria were clinical diagnosis of DMD and age between 6 and 16 years. Non-inclusion criteria were recent fractures in the upper and lower limbs (6 months), factors that prevented physical effort, and illiteracy of caregivers.

PROCEDURE

Sample characterization

The caregivers and the children/adolescents selected according to the inclusion and exclusion criteria described above, respectively, were presented with the “Informed Consent Form addressed to the caregivers of children/adolescents with Duchenne Muscular Dystrophy” and the “Assent Form addressed to children/adolescents with Duchenne Muscular Dystrophy,” which were read and accepted in duplicate, with one copy returned to the researcher.

All participants initially underwent an interview with their caregivers, followed by a physical assessment to obtain anthropometric data (body weight and height/wingspan) along with the administration of the FMS (Functional Mobility Scale) and MFM (Motor Function Measure) scales. Additionally, participants were queried about their participation in physiotherapy sessions and other therapies.

Content validation by expert judges

Nine expert judges participated in content validation. For the selection of judges, training in physiotherapy and experience in pediatrics were considered. To validate the content of the booklet “Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne”, the nine selected expert judges received the booklet and answered the questionnaire adapted[20], which presents 27 items divided into 6 categories, which were: objective, organization, language, appearance, motivation and cultural suitability. The answers to the questionnaire items were rated from 1 to 4 by the expert judges, where 1 = non-equivalent item; 2 = item requiring major revision to assess equivalence; 3 = equivalent item requiring minor changes; and 4 = absolutely equivalent[12].

Delivery of the booklet

The booklet “Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne” was delivered and read together with the caregivers and children/adolescents selected for the study, training them to perform, at home, the exercises contained in the booklet (Figure 1). Children/adolescents and their caregivers verbally reported their understanding of the material presented. Any questions that arose during the training were promptly addressed and clarified, helping to ensure the effectiveness of the training. The research laboratory's landline and cell phone numbers (with WhatsApp) were also available. After 15 days of training, the participants returned to answer two questionnaires, as mentioned below, about performing the exercises at home (following a similar methodology – Martins et al., 2003)[26]. When the participant could not return in person, remote assistance was provided.

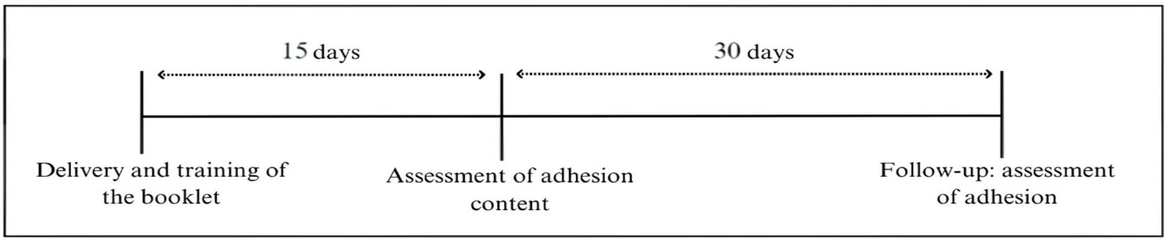

Figure 1. Schematic representation of the steps for evaluating and analyzing adherence to the use of the booklet.

Assessment of the material by caregivers

By having the material (booklet) evaluated by the study participants 15 days after delivery and initial training, we evaluated the clarity, ease of reading, understanding and the way the instrument was presented[27] (Figure 1).

For this, the questionnaire adapted, which was mentioned previously, was used. For caregivers, responses to these items were presented on a Likert scale with five levels (1 - completely disagree; 2 - disagree; 3 - neutral; 4 - agree; 5 - completely agree).

Analysis of adherence to the use of the booklet by caregivers

Fifteen days after the delivery of the booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne" (Figure 1), adherence to the exercise guidelines (here called "adherence to the use of the booklet") was assessed using the questionnaire adapted from Dalcin and collaborators[28]. This questionnaire addressed the following questions: 1) stretching exercises, 2) strengthening exercises, 3) balance exercises, and 4) all proposed exercises. The children/adolescents' caregiver answered the questions according to the frequency of performing the exercises: a) 3 days a week; b) 2 days a week; c) 1 day a week; d) no days in the week. The questions were scored three if the answer was "a," 2 if the answer was "b," 1 if the answer was "c," and 0 if the answer was "d." An adherence score was assigned based on the quotient between the number of points obtained and the number of points possible with the application of the questionnaire. If this score was greater than 0.70, it was considered high adherence to treatment; if the score was less than or equal to 0.70, it was classified as "moderate/low."

Follow-up on the booklet

Finally, 45 days after the delivery and initial training (Figure 1), the patient's caregiver again responded remotely to the adapted questionnaire from Dalcin and collaborators[28]. The objective of the follow-up was to analyze adherence to the use of the booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne" to perform exercises at home in the long term.

STATISTICAL ANALYSIS

An exploratory analysis of the data was carried out with subsequent descriptive statistical presentation of the variables age (mean and standard deviation), sex (absolute value), evaluation of the appearance and content of the booklet by caregivers, and adherence to the use of the home exercise booklet (absolute value and percentage).

The content validity index (CVI) was carried out for content validation. Considering that there is no specific statistical test for evaluating CVI, in this study, the proportion or percentage of judges in agreement on certain aspects of the material was calculated[29]. To calculate the CVI for each item in the questionnaire, responses 3 and 4 from the expert judges were added, and the result of this sum was divided by the total number of responses, according to the formula: CVI = number of responses 3 or 4 / total number of responses. The acceptable agreement index between the appointed expert judges is at least 0.80, preferably greater than 0.90[29].

Excel software was used for descriptive statistical analysis and content validation.

RESULTS

Seventeen booklets, "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne", were delivered to caregivers and children/adolescents with DMD receiving care at the outpatient center of CER-HC-FMRP-USP. Of these 17, 1 participant was excluded for not attending and not answering the telephone calls regarding the first return (15 days after delivery and training of the booklet), and 1 participant died during the study.

Table 1 presents the characterization of the sample, which comprises 15 children and adolescents with DMD, aged between 8 and 16 years, all male. As assessed by the FMS scale, most participants were wheelchair users. The MFM scale ranged from 19.7% to 84.3%, and 10 participants underwent physiotherapeutic treatment (Table 1).

Table 1. Sample characterization

Voluntary	Sex	Age (Years)	Body weight (kg)	Height/Wingspan (cm)	FMS	MFM total (%)	Performs physio-therapy?
1	M	8	23.5	120	5,5,5	84.3	Yes
2	M	9	42.0	142	c,1,1	35.4	Yes
3	M	11	28.0	158	4,1,1	59.0	Yes
4	M	11	52.0	123	1,1,1	38.5	Yes
5	M	11	51.4	138	1,1,1	63.5	Yes
6	M	12	44.0	131	1,1,1	58.3	No
7	M	12	38.7	165	1,1,1	54.1	No
8	M	13	29.6	114	1,1,1	42.7	No
9	M	14	86.0	149	1,1,1	60.4	Yes
10	M	15	31.1	131	1,1,1	28.1	Yes
11	M	15	44.5	155	5,4,1	56.2	Yes
12	M	16	71.1	149	1,1,1	40.6	No
13	M	16	37.8	121	1,1,1	53.1	Yes
14	M	16	52.2	141	1,1,1	19.7	No
15	M	16	35.0	121	1,1,1	56.2	Yes

Subtitle: FMS: Functional Mobility Scale; MFM: Motor Function Measure.

Regarding the caregivers' education, it was observed that 60% had completed high school, 33.3% had completed elementary school, and 6.6% had incomplete elementary school.

Based on the answers provided by the expert judges to the questionnaire, it was observed that, of the 27 aspects related to the booklet, 22 presented an agreement index greater than 0.90. At the same time, 5 obtained an acceptable index, ranging between 0.80 and 0.90 (Table 2).

Table 2. Expert judges answer to validate the booklet content

(Continued)

	n	Non-equivalent item		Item needs significant revision to assess equivalence		Equivalent item, needs minor changes		Equivalent item		CVI
		%	*n*	%	*n*	%	*n*	%		
Objective	1. Attends to the need of parents/caregivers regarding exercises at home.	0	0	0	0	2	22.2	7	77.8	1.00
	2. The booklet helps to take care of the child/adolescent.	0	0	0	0	3	33.3	6	66.7	1.00
	3. Can advise on the necessary care for the child/adolescent.	0	0	0	0	2	22.2	7	77.8	1.00
Organization	1. The cover of the educational booklet is attractive and indicates the material's content.	0	0	1	11.1	1	11.1	7	77.8	0.88
	2. The size of the title and contents in the topics is adequate.	0	0	0	0	1	11.1	8	88.9	1.00
	3. Topics have a logical sequence.	0	0	0	0	1	11.1	8	88. 9	1.00
	4. There is consistency between the cover information. presentation. and content of the booklet.	0	0	0	0	2	22.2	7	77.8	1.00
	5. The material paper is suitable.	0	0	0	0	0	0	9	100,0	1,00
	6. The number of pages is adequate.	0	0	1	11,1	0	0	8	88, 9	0,88
	7. The exercises portray important care for the child/adolescents.	0	0	0	0	1	11,1	8	88, 9	1,00

(Continued)

n		Non-equivalent item		Item needs significant revision to assess equivalence		Equivalent item, needs minor changes		Equivalent item		CVI
		%	*n*	%	*n*	%	*n*	%		
Language	1The text is clear and understandable.	0	0	0	0	1	11,1	8	88. 9	1.00
	2. The text is vivid and interesting. The tone is friendly.	0	0	0	0	0	0	9	100.0	1.00
	3.Vocabulary is accessible.	0	0	0	0	2	22.2	7	77.8	1.00
	4. All information is addressed clearly and objectively.	0	0	0	0	2	22.2	7	77.8	1.00
	5. There is an association between the figure of the exercises and the corresponding texts.	0	0	0	0	1	11.1	8	88. 9	1.00
Appearance	1. Illustrations are friendly.	0	0	0	0	1	11.1	8	88. 9	1.00
	2. Pages or sections look organized.	0	0	0	0	1	11.1	8	88. 9	1.00
	3. The number of figures is enough.	0	0	0	0	1	11.1	8	88. 9	1.00
	4. The figures are self-explanatory.	0	0	0	0	1	11.1	8	88. 9	1.00
	5. The figures provoke questions about the health condition of the child/adolescent.	1	11.1	0	0	1	11.1	7	77,8	0,88

(Conclusion)

	n	Non-equivalent item		Item needs significant revision to assess equivalence		Equivalent item, needs minor changes		Equivalent item		CVI
		%	*n*	%	*n*	%	*n*	%		
Motivation	1. The booklet is appropriate for this age, gender and culture.	0	0	0	0	1	11.1	8	88, 9	1,00
	2. The booklet arouses interest and curiosity.	0	0	1	11.1	1	11.1	7	77,8	0,88
	3. The booklet addresses issues needed by family members.	0	0	0	0	2	22.2	7	77.8	1.00
	4. The information contained in the booklet is important for the care of the child/adolescent.	0	0	0	0	1	11.1	8	88.9	1.00
	5. The booklet proposes to acquire knowledge to perform the care of the child/adolescent.	0	0	0	0	2	22.2	7	77.8	1.00
	6. Readers are encouraged to discuss problems and solutions. The booklet suggests actions.	1	11.1	0	0	2	22.2	6	66,7	0.88
Cultural Suitability	1. After reading the booklet, would you recommend it to family members of other children/ adolescents, considering the socioeconomic context of the population.	0	0	0	0	2	22.2	7	77,8	1.00

Legend: n: absolute frequency; % relative frequency; CVI: Content Validity Index.

When evaluating the material by caregivers and children/adolescents with DMD, it was observed that most participants responded "I agree" or "I completely agree" to all items analyzed. The "neutral" response was obtained in 3 items. The "disagree" response was obtained in only 1 item, and the "strongly disagree" response was not obtained in any item (Table 3).

Table 3. Frequency table of caregivers' responses for material evaluation.

n		Strongly disagree		Disagree		Neutral		Agree		Strongly agree		Total	
		%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	
Objective	1. Attends to the need of parents/caregivers regarding exercises at home.	0	0	0	0	1	6.7	1	6.7	13	86.7	15	100
	2. The booklet helps to take care of the child/adolescent.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	3. Can advise on the necessary care for the child/adolescent.	0	0	0	0	0	0	0	0	15	100.0	15	100
Organization	1. The cover of the educational booklet is attractive and indicates the material's content.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	2. The size of the title and content in the topics is adequate.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	3. Topics have a logical sequence	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	4. There is consistency between the cover information, presentation, and content of the booklet.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	5. The material paper is suitable.	0	0	0	0	0	0	2	13.3	13	86.7	15	100
	6. The number of pages is adequate.	0	0	1	6.7	0	0	3	20.0	11	73.3	15	100
	7. The exercises portray important care for child/adolescent.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
Language	1. The text is clear and understandable.	0	0	0	0	0	0	0	0	15	100.0	15	100
	2. The text is vivid and interesting. The tone is friendly.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	3.Vocabulary is accessible.	0	0	0	0	0	0	0	0	15	100.0	15	100
	4. All information is addressed clearly and objectively.	0	0	0	0	0	0	0	0	15	100.0	15	100
	5. There is an association between the figure of the exercises and the corresponding texts.	0	0	0	0	0	0	0	0	15	100.0	15	100
Appearance	1.Illustrations are friendly.	0	0	0	0	0	0	0	0	15	100.0	15	100
	2. Pages or sections look organized.	0	0	0	0	0	0	0	0	15	100.0	15	100
	3. The number of figures is enough.	0	0	0	0	1	6.7	1	6.7	13	86.7	15	100
	4. The figures are self-explanatory.	0	0	0	0	0	0	0	0	15	100.0	15	100
	5. The figures provoke questions about the health condition of the child/adolescent.	0	0	0	0	1	6.7	2	13.3	12	80.0	15	100

(Conclusão)

n		**Strongly disagree**		**Disagree**		**Neutral**		**Agree**		**Strongly agree**		**Total**	
		%	***n***	%	***n***	%	***n***	%	***n***	%	***n***	%	
Motivation	1. The booklet is appropriate for my age, gender and culture.	0	0	0	0	0	0	0	0	15	100.0	15	100
	2. The booklet arouses interest and curiosity.	0	0	0	0	0	0	0	0	15	100.0	15	100
	3. The booklet addresses issues needed by family members.	0	0	0	0	0	0	1	6.7	14	93.3	15	100
	4. The information contained in the booklet is important for the care of the child/adolescent.	0	0	0	0	0	0	0	0	15	100.0	15	100
	5. The booklet proposes to acquire knowledge to perform the care of the child/adolescent.	0	0	0	0	0	0	0	0	15	100.0	15	100
	6. Readers are encouraged to discuss problems and solutions. The booklet suggests actions	0	0	0	0	0	0	0	0	15	100.0	15	100
Cultural Suitability	1. After reading the booklet, would you recommend it to family members of other children/adolescents, considering the socioeconomic context of the population	0	0	0	0	0	0	0	0	15	100.0	15	100

Legend: n: absolute frequency; % relative frequency

The responses obtained from each participant about the questionnaire on treatment adherence were divided by the maximum number of points possible with the application of the questionnaire, thus obtaining the adherence score. This score was assigned to each study participant, allowing the classification of adherence to the use of the booklet as "high" or "moderate/low." Thus, 33.33% of study participants showed "high" adherence to using the home exercise booklet, while 66.66% showed "moderate/low" adherence to using the booklet in the short term (Figure 2).

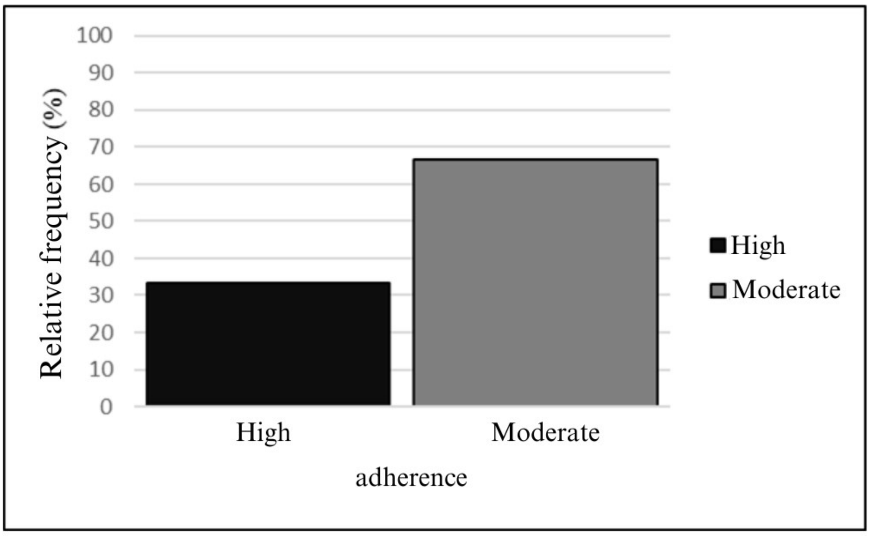

Figure 2. Adherence to the use of the Booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne" in the short term.

During the follow-up, it was observed that 13.33% of the study participants showed "high" adherence to using the home exercise booklet, while 86.66% showed "moderate/low" adherence to using the booklet (Figure 3).

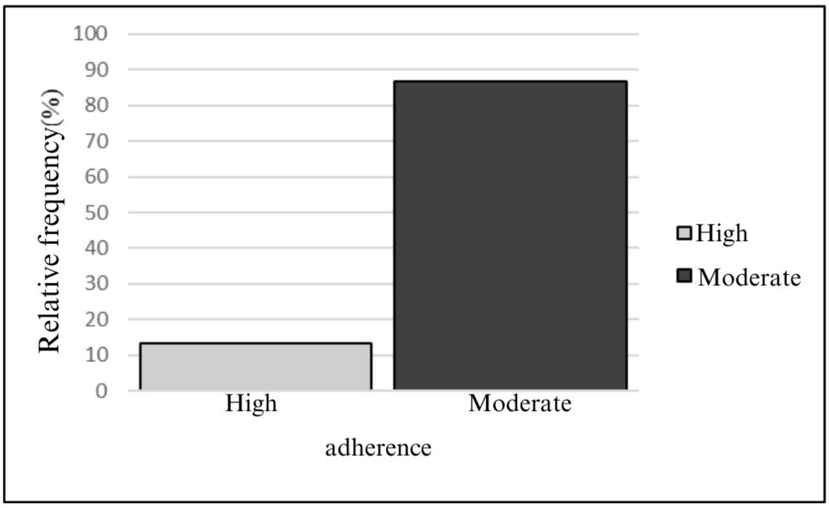

Figure 3. Adherence to the use of the Booklet "Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne" in the follow-up

DISCUSSION

By using an adapted questionnaire, this study showed that the booklet presents its contents clearly, being easy to read, understand and adequately presented. However, using the questionnaire adapted from Dalcin et al. [28], a "moderate/low" adherence to using the booklet was observed.

According to Moura et al.[30], health education is often related to the use of printed educational materials, as their application in conjunction with verbal guidance about what is written makes the method more effective and facilitates the subject's understanding, which promotes improvement in adapting to the sociocultural context in which it is integrated. The answers provided by caregivers and children/

adolescents with DMD demonstrated that the booklet “Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne” has clear items, it is easy to read and adequately understandable, thus having what is expected for a home exercise booklet.

According to Lewis et al.[31], self-care broadly refers to individuals’ actions to improve, restore or maintain health, prevent or limit diseases and preserve themselves. In addition, Sirari et al.[32] highlight that involving the patient in treating their illness is very promising, as the patient actively acts on their health. Furthermore, the patient’s adherence to the home exercise program is essential for the success of the therapy [33]. However, even with the encouragement for caregivers and children/adolescents with DMD to use the exercise booklet at home and follow the follow-up schedules, there needed to be better adherence to the booklet.

In 2022, the study carried out by Franco et al.[20] aimed to validate the content, evaluate the material, and analyze adherence to the exercises in the booklet for patients with spina bifida. Of the ten patients who participated in the study, the short-term adherence rate was 25%, and the long-term adherence rate was 12.5%, indicating that low adherence is a barrier observed in families of children and adolescents with chronic diseases. A study by Medina-Mirapeix et al.[34] highlighted that patients’ adherence to home exercises depends on individual characteristics, sociodemographic variables, motivation, social support, health condition, and environment.

In 2023, a study in Brazil sought to identify facilitators and barriers to adherence to a home exercise program in individuals with shoulder pain and investigate the influence of environmental barriers[35]. The authors observed that the most common barriers were lack of time/motivation for exercise, pain intensity and difficulties related to the environment[35]. Another study sought to characterize the caregiver’s profile in terms of burden and quality of life[36]. This study highlighted that the factors that exert the greatest influence on these aspects include ambulation status, total MFM score, general tension levels and disappointment[36]. Based on these data, in the context of our study that includes 86% of non-ambulatory patients with DMD, it is possible that daily demands, the quality of life of caregivers or other personal commitments have contributed to the children and adolescents and their caregivers having reduced time available to carry out the exercises in the booklet, which contributed to low adherence.

Despite the “moderate/low” adherence, the booklet was recognized as a valid instrument, providing potential benefits for children, adolescents and their caregivers. It can awaken the patient’s self-care and contribute to the family’s involvement in the physiotherapeutic process, offering guidance and facilitating the incorporation of exercises into the daily routine. Furthermore, carrying out home exercises helps to achieve therapeutic goals and functionality and improve quality of life.

The booklet also proves to be a valuable educational resource for healthcare professionals. It provides judge-validated exercises recommended for children/teens with DMD. Additionally, the booklet can be shared among professionals, representing a low-cost and easy-to-share tool. Thus, health professionals can use this resource to guide their patients and exchange knowledge with colleagues, considering the particularities of DMD.

The main limitation of this study is the small sample size. Secondarily, the availability of the material in printed format may have restricted its use, as there may have been home situations such as loss or damage.

For future investigations, we suggest making the content available online and creating an interactive version of the booklet (application), incorporating elements such as videos[37]. This approach could be especially beneficial to caregivers and children/adolescents with DMD when performing exercises at home in moments of doubt.

CONCLUSION

It was concluded that the exercise booklet “Orientações para a Manutenção da Qualidade de Vida – Distrofia Muscular de Duchenne” proved to be a beneficial instrument to enrich the physiotherapeutic treatment of children and adolescents with Duchenne Muscular Dystrophy by displaying its items clearly, being easy to read and adequately understandable according to the assessment of expert judges and caregivers of children and adolescents with DMD. However, the use of the booklet had a “moderate/low” adherence, making it necessary to look for alternatives that help and encourage children and adolescents to participate in self-care, and caregivers to encourage the autonomy of these patients.

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