

## Original Article

## Content validity and analysis of adherence to the use of the booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” in ambulator and non-ambulator children and adolescents with spina bifida

### *Validação de conteúdo e análise da adesão ao uso da cartilha “Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida” em crianças e adolescentes deambuladores e não deambuladores com espinha bífida*

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**ABSTRACT:** *Objective:* From the production of a booklet of home exercises “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*”, the aim was to validate the content, carry out the evaluation of the material (booklet) by caregivers, and analyze the adherence to the use of the booklet. *Methods:* For content validation, 8 expert judges evaluated the booklet through an adapted questionnaire, and the content validity index (CVI) was established for each aspect addressed. In the evaluation of the material carried out by the caregivers and in the analysis of adherence to the use of the booklet, 10 children and adolescents with spina bifida participated in this study. The booklet was read with the patients and their caregivers, who were trained to perform the exercises that are in the booklet at home. After delivery, a face-to-face return was scheduled, in 15 days, so that caregivers could report on the evaluation of the material as well as describe the

adherence of these participants to the use of the booklet. Finally, a second meeting was scheduled - follow-up - to analyze long-term adherence. *Results:* Of the 27 aspects addressed in the content validation, 24 of these received scores above the acceptable index (CVI = 1.00). Most caregivers answered “agree” or “strongly agree” to all items analyzed regarding the evaluation of the booklet. In the short term, there was an adherence rate of 25% of the participants, and in the long term, 12.5%. *Conclusion:* The booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” proved to be a great resource to increase the physical therapy treatment of children and adolescents with spina bifida, according to the evaluation of expert judges and caregivers, for presenting adequate content, language and appearance, but showed moderate/low adherence by the participants.

**Keywords:** Physical exercise; Children; Adolescent; Spina bifida.

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**RESUMO:** *Objetivo:* A partir da produção de uma cartilha de exercícios domiciliares “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*”, objetivou-se validar o conteúdo, realizar a avaliação do material (cartilha) pelos cuidadores, e analisar a adesão ao uso da cartilha. *Métodos:* Para validação do conteúdo, 8 juízes especialistas avaliaram a cartilha por meio de um questionário adaptado e foi estabelecido o índice de validade de conteúdo (IVC) para cada aspecto abordado. Na avaliação do material realizada pelos cuidadores e na análise da adesão ao uso da cartilha, participaram 10 crianças e adolescentes com espinha bífida e seus cuidadores. O pesquisador leu a cartilha e treinou os exercícios na presença do paciente e de seu cuidador, indicando como deveriam ser realizados em domicílio. Após a entrega foi marcado um retorno presencial, em 15 dias, para que os cuidadores pudessem relatar sobre a avaliação do material assim como, descrever sobre a adesão desses participantes ao uso da cartilha. Por fim, foi agendado um segundo encontro -*follow-*

*up* – para analisar a adesão em longo prazo. *Resultados:* Dos 27 aspectos abordados na validação do conteúdo, 24 destes receberam pontuação acima do índice aceitável (IVC = 1,00). A maior parte dos cuidadores responderam “concordo” ou “concordo totalmente” para todos os itens analisados referente à avaliação do material. Em curto prazo foi observada uma taxa de adesão de 25% dos participantes e em longo prazo de 12,5%. *Conclusão:* A cartilha “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” por apresentar clareza dos itens apresentados, facilidade de leitura e adequada compreensão, segundo a avaliação dos juízes especialistas e dos cuidadores, mostrou ser um ótimo recurso para incrementar o tratamento fisioterapêutico de criança e adolescentes com espinha bífida, porém evidenciou uma moderada/baixa adesão por parte dos participantes.

**Palavras-Chave:** Exercício físico; Crianças; Adolescentes; Espinha bífida.

## INTRODUCTION

Spina bifida is a congenital malformation of the neural tube that begins within the first 28 days of pregnancy<sup>1</sup>. This malformation involves tissues related to the spinal cord, vertebral arch, dorsal muscles, and skin<sup>2</sup>. It may affect the entire length of the neural tube or be limited to a small area<sup>2</sup>. Spina bifida is classified as occult (meningocele) when there is no extravasation of the spinal cord. The SB cystic (myelomeningocele) occurs when there is a protrusion of the nervous system structure. The last one is the more severe form of the disease<sup>2</sup>.

During pregnancy, congenital neural tube malformation is associated with several genetic and environmental factors such as folic acid deficiency, alcohol intake during the first three months of pregnancy, maternal diabetes, and zinc deficiency<sup>3</sup>. In addition, a study pointed out the use of specific drugs - carbamazepine and valproic acid - during the gestation period as possible causes of morbidity<sup>4</sup>.

SB patients face a set of physical and neurocognitive challenges, the latter related to hydrocephalus caused by Arnold Chiari malformation, including: decreased functional mobility, bowel and bladder control problems, muscle weakness, skeletal deformities, cognitive and sensory deficits, obesity, and unusual allergic reactions<sup>5</sup>. An integrated and multidisciplinary approach to health care has been associated with better psychosocial outcomes in these patients<sup>6</sup>. Therefore, health care for these children and adolescents is critical to improving their quality of life and interaction with the environment since all motor, and sensory changes impose physical and psychosocial barriers<sup>5</sup>.

Due to complications that accompanying the malformation, children and adolescents with SB tend to present a sedentary behavior and inactive lifestyle, leading to decreased muscle strength and endurance and increased body fat rates<sup>7</sup>. Physical activity is essential for development, covering physical and mental aspects to achieve ideal levels of body mass, bone growth, and cardiovascular fitness and proposing a healthier lifestyle and improved socio-emotional development<sup>8</sup>.

Macedo et al.<sup>9</sup> suggested interventions that alleviate the burden, promote access to information and equip mothers to monitor their children’s condition. Thus, it is possible to offer excellent care to family members, children, and adolescents with chronic diseases facilitated by the entire multidisciplinary team. Promoting family-centered care means that professionals incorporate into their practice the knowledge and conviction that the family is a constant in children’s lives. Betting on these relationships results in an increase in the quality of the care process<sup>10</sup>.

Printed materials stand out among family members’ educational and guidance technologies: leaflets, booklets, folders, or booklets. Printed material can have a positive impact on educating patients and being able to help them answer questions that may arise when they are not interacting with the healthcare professional<sup>11</sup>.

In the first half of 2021 to improve, optimize and assist the quality of life of children and adolescents with spina bifida was developed the booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” (supplementary material). These children/adolescents were being treated at the outpatient rehabilitation services of the *Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto - Universidade de São Paulo* (HCFMRP-

USP) and integrated hospitals.

The booklet has a succinct presentation of the definition of the disease, its development, and the importance of physical therapy; an activity plan with a description of home exercises; and helpful information about bracing and physical activities to maintain or improve the functioning of the heart, lungs, and muscles. In June 2021, this material was finalized, with illustrative figures for each task.

The exercises selected to integrate the booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” are similar to the international-guideline for SB patients published in 2020<sup>12</sup>. The authors point out that children aged 6 to 12 years should be educated about physical activity to maintain flexibility, strength, and health. Adolescents aged 13 to 17 should continue therapy or programs at home to maintain physical activity goals—mobility, flexibility, range of motion, and overall strength. There are no studies that used this type of material (booklet) for children and adolescents with spina bifida in the national and international literature.

The present study aimed to produce an exercise booklet-type material so that patients and caregivers could perform physical exercises at home as indicated and trained by their physical therapists. Because of that we created the instrument: “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*”. Then, expert judges performed the instrument content validity, and the caregivers analyzed the material evaluation and the patient’s adherence. The booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” was developed for ambulant and non-ambulant children and adolescents with spina bifida in attendance at the outpatient rehabilitation services HCFMRP-USP and integrated hospitals.

## MATERIALS AND METHODS

### *Study characterization*

In this quasi-experimental, before-and-after study, an educational technology, characterized as a booklet, developed to guide patients and caregivers of children and adolescents with spina bifida undergoing treatment in the outpatient rehabilitation services, was evaluated. The evaluations of the volunteers were carried out at the *Centro de Reabilitação Lucy Montoro* at the HCFMRP-USP, at the *Centro Integrado de Reabilitação* at the *Hospital Estadual de Ribeirão Preto* (CIR-HERibeirão) and by telephone. The Ethical Committee approved this study at the *Hospital das Clínicas da Faculdade de Medicina*

*de Ribeirão Preto - Universidade de São Paulo* (CAAE 49923821.2.0000.5440).

### *Subjects*

The study included ten caregivers of children or adolescents with spina bifida undergoing treatment at the outpatient rehabilitation services of HCRP and HERibeirão between August and November 2021. Inclusion criteria for all participants were: confirmed diagnosis of spina bifida and age between 6 and 16 years. Exclusion criteria were recent fractures in upper and lower limbs (6 months) and factors that prevented physical exertion.

### *Procedure*

#### *Content validation by expert judges*

The selection of expert judges considered training in physical therapy and dominance in pediatrics. To validate the booklet’s content, “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*”, the eight selected expert judges received the booklet and answered the questionnaire adapted by Ft. DC Petian-Alonso. The questionnaire presents 27 items divided into six categories: objective, organization, language, appearance, motivation, and cultural adequacy. For the expert judges, the answers to the questionnaire items were presented from 1 to 4, where: 1 = non-equivalent item; 2 = item needs significant revision to assess equivalence; 3 = equivalent item, needs minor changes; and 4 = equivalent item<sup>16</sup>.

#### *Booklet delivery*

Caregivers and children/adolescents selected according to the inclusion and exclusion criteria described above provided their written informed consent to participate in this study. Afterward, the booklet was delivered and read together with the patient and their caregiver, who were trained to perform the booklet exercises at home.

After 15 days of training to perform the exercises at home (following a similar methodology<sup>13</sup>), the patient returned to answer two questionnaires, shown below. Telephone assistance was provided when face-to-face feedback was not possible for the participant.

#### *Assessment of the material by caregivers*

In the booklet material evaluation by the caregivers of the children or adolescents participating in the study, the following items were evaluated: clarity of the items presented, ease of reading, understanding, and the form of presentation of the instrument<sup>14</sup>.

For this a questionnaire adapted by Ft. DC Petian-Alonso was used (quoted above). For caregivers, the responses to these items were presented on a Likert scale with five levels (1 - strongly disagree; 2 - disagree; 3 - neutral; 4 - agree; 5 - strongly agree).

#### *Analysis of adherence to the use of the booklet by caregivers*

Adherence to the use of the booklet "Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida" to perform exercises at home was assessed using a questionnaire adapted from Dalcin et al.<sup>15</sup>. This questionnaire addressed the following questions: 1) stretching exercises; 2) strengthening exercises; 3) balance exercises; 4) all the proposed exercises. The child or adolescent's caregiver answered the questions according to the frequency of performing the exercises: a) three days a week; b) twice a week; c) once a week; d) no day in the week. The questions were scored as 3 if the answer was "a," 2 if the answer was "b," 1 if the answer was "c," and 0 if the answer was "d."

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 adherence to treatment.

#### *Booklet Follow-up*

Finally, 30 days after the return, the caregiver answered the adapted questionnaire from Dalcin et al.<sup>15</sup> remotely (telemonitoring). The follow-up objective was to analyze the long-term adherence use of the booklet "Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida" to perform exercises at home.

## STATISTICAL ANALYSIS

It was performed an exploratory analysis of the data, with a subsequent descriptive statistical presentation of the variables age (median and 95% confidence interval), sex (absolute value), and assessment and adherence to the use of the booklet of home exercises by caregivers (absolute value and percentage).

For content validity, the content validity index (CVI) was performed. Considering that there is no specific statistical test for evaluating the CVI, the proportion or

percentage of judges in agreement on specific aspects of the material was calculated in this study<sup>16</sup>. The CVI of each questionnaire item was calculated considering the expert judges' answers 3 and 4. The sum of these answers was divided by the total number of answers. It is presented in the formula below:  $CVI = \text{number of answers 3 or 4} / \text{total number of answers}$ <sup>16</sup>. The acceptable index of agreement among the expert judges indicated is at least 0.80 and, preferably, greater than 0.90<sup>16</sup>.

## RESULT

In the content validity of the booklet 24 aspects related to the booklet presented an agreement index greater than 0.90, 2 aspects obtained an acceptable index between 0.80 and 0.90 and, 1 aspect did not reach the acceptable index (Table 1).

Ten booklets, "Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida" were delivered to caregivers and children/adolescents with spina bifida in attendance at the outpatient rehabilitation services of the HCFMRP-USP and integrated hospitals. Eight booklets were delivered to wheelchair users and two to ambulatory children/adolescents. Two caregivers and children/adolescents with spina bifida were excluded from the study because they did not attend the first return visit and did not even answer the phone calls. The median age of the eight participants was 13.0 (10.6-14.4) years, four were male, and in all participants, the level of the spinal lesion was lumbar.

In the step caregivers' material evaluation, it was observed that most of the participants answered "agree" or "totally agree" for all the items analyzed. The answer "neutral" was not obtained in any item. However, in question five ("Do the figures provoke questions about the health condition of the child/adolescent?") of the "Appearance" item, 87.5% of the participants answered, "strongly disagree," and another 12.5% answered "disagree" (Table 2).

Regarding adherence to the use of the booklet, 25% of the study participants showed "high" adherence, while 75% showed "moderate/low" adherence to the use of this treatment resource (Figure 1).

In the follow-up, it was observed that 12.5% of the study participants showed "high" adherence to the use of the home exercise booklet, while 87.5% showed "moderate/poor" adherence to the use of this treatment resource (Figure 2).

**Table 1.** Expert judges answer to validate the booklet content

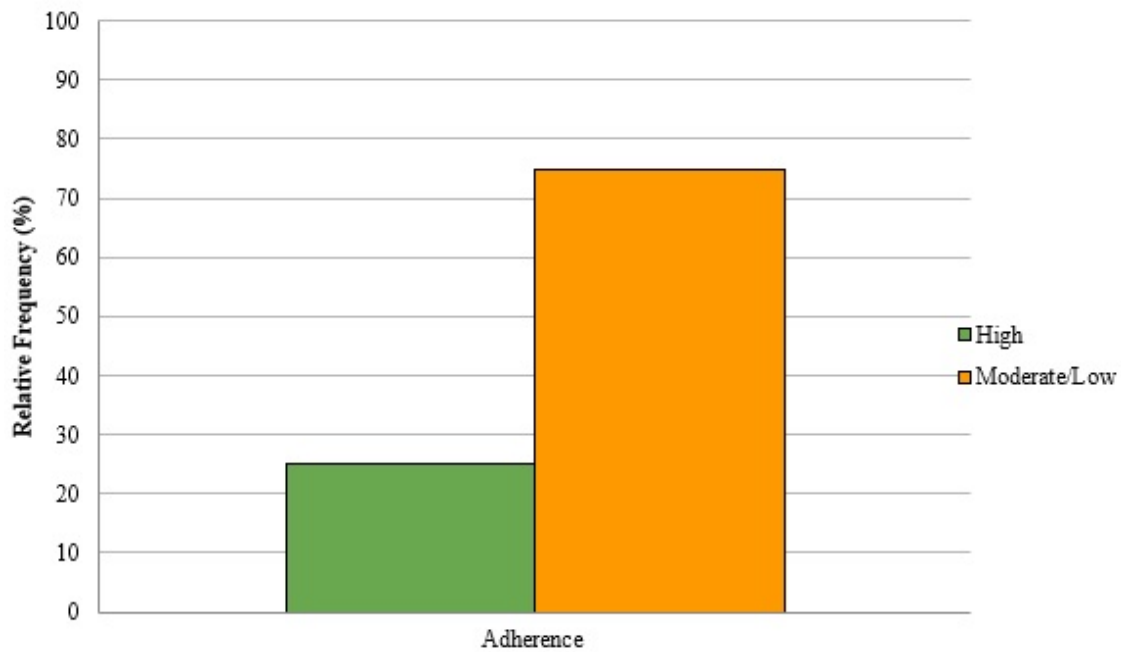
		Non-equivalent item		Item needs significant revision to assess equivalence		Equivalent item, needs minor changes		Equivalent item		CVI
		n	%	n	%	n	%	n	%	
Objective	1. Attends to the need of parents/caregivers regarding exercises at home.	0	0,00%	0	0,00%	3	37,50%	5	62,50%	1,00
	2. The booklet helps to take care of the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	3. Can advise on the necessary care for the child/adolescent.	0	0,00%	0	0,00%	2	25,00%	6	75,00%	1,00
Organization	1. The cover of the educational booklet is attractive and indicates the material's content.	0	0,00%	1	12,50%	2	25,00%	5	62,50%	0,87
	2. The size of the title and the contents in the topics are adequate.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	3. Topics have a logical sequence.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	4. There is consistency between the cover information, presentation, and content of the booklet.	0	0,00%	0	0,00%	2	25,00%	6	75,00%	1,00
	5. The material paper is suitable.	2	25,00%	0	0,00%	0	0,00%	6	75,00%	0,75
	6. The number of pages is adequate.	0	0,00%	0	0,00%	2	25,00%	6	75,00%	1,00
	7. The exercises portray important care for the child/adolescent.	0	0,00%	0	0,00%	1	12,50%	7	87,50%	1,00
Language	1. The text is clear and understandable.	0	0,00%	0	0,00%	1	12,50%	8	100,00%	1,00
	2. The text is vivid and interesting. The tone is friendly.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	3. Vocabulary is accessible.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	4. All information is addressed clearly and objectively.	0	0,00%	0	0,00%	2	25,00%	6	75,00%	1,00
	5. There is an association between the figure of the exercises and the corresponding texts.	0	0,00%	0	0,00%	2	25,00%	6	75,00%	1,00
Appearance	1. Illustrations are friendly.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	2. Pages or sessions look organized.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	3. The number of figures is enough.	0	0,00%	0	0,00%	1	12,5%	7	87,5%	1,00
	4. The figures are self-explanatory.	0	0,00%	0	0,00%	1	12,5%	7	87,5%	1,00
	5. The figures provoke questions about the health condition of the child/adolescent.	1	87,50%	0	12,50%	1	12,50%	6	75,00%	0,87
Motivation	1. The booklet is appropriate for my age, gender and culture.	0	0,00%	0	0,00%	1	12,50%	7	87,50%	1,00
	2. The booklet arouses interest and curiosity.	0	0,00%	0	0,00%	1	12,50%	7	87,50%	1,00
	3. The booklet addresses issues needed by family members.	0	0,00%	0	0,00%	1	12,50%	7	87,50%	1,00
	4. The information contained in the booklet is important for the care of the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	5. The booklet proposes to acquire knowledge to perform the care of the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00
	6. Readers are encouraged to discuss problems and solutions. The booklet suggests actions.	0	0,00%	0	0,00%	1	12,50%	7	87,50%	1,00
Cultural adequacy	1. After reading the booklet, would you recommend it to family members of other children/adolescents, considering the socioeconomic context of the population.	0	0,00%	0	0,00%	0	0,00%	8	100,00%	1,00

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

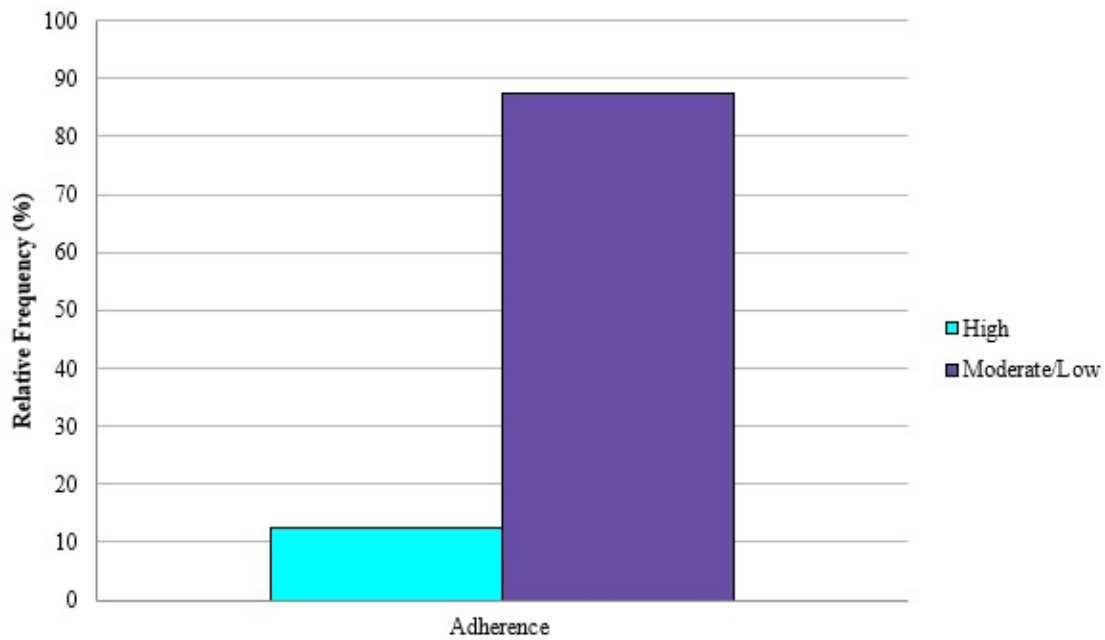
**Table 2.** Frequency table of caregivers’ responses for material evaluation

		Strongly disagree		Disagree		Neutral		Agree		Strongly agree		Total	
		n	%	n	%	n	%	n	%	n	%	n	%
Objective	1. Attends to the need of parents/ caregivers regarding exercises at home.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	2. The booklet helps to take care of the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	3. Can advise on the necessary care for the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
Organization	1. The cover of the educational booklet is attractive and indicates the material’s content.	0	0,00%	0	0,00%	0	0,00%	3	37,50%	5	62,50%	8	100%
	2. The size of the title and the contents in the topics are adequate.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	3. Topics have a logical sequence.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	4. There is consistency between the cover information, presentation, and content of the booklet.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	5. The material paper is suitable.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	6. The number of pages is adequate.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	7. The exercises portray important care for the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
Language	1. The text is clear and understandable.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	2. The text is vivid and interesting. The tone is friendly.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	3. Vocabulary is accessible.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	4. All information is addressed clearly and objectively.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	5. There is an association between the figure of the exercises and the corresponding texts.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
Appearance	1. Illustrations are friendly.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	2. Pages or sessions look organized.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	3. The number of figures is enough.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	4. The figures are self-explanatory.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	5. The figures provoke questions about the health condition of the child/adolescent.	7	87,50%	1	12,50%	0	0,00%	0	0,00%	0	0,00%	8	100%
Motivation	1. The booklet is appropriate for my age, gender and culture.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	2. The booklet arouses interest and curiosity.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	3. The booklet addresses issues needed by family members.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	4. The information contained in the booklet is important for the care of the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
	5. The booklet proposes to acquire knowledge to perform the care of the child/adolescent.	0	0,00%	0	0,00%	0	0,00%	0	0,00%	8	100,00%	8	100%
	6. Readers are encouraged to discuss problems and solutions. The booklet suggests actions.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%
Cultural adequacy	1. After reading the booklet, would you recommend it to family members of other children/adolescents, considering the socioeconomic context of the population.	0	0,00%	0	0,00%	0	0,00%	1	12,50%	7	87,50%	8	100%

**Legend:** n: absolute frequency; % relative frequency.



**Figure 1.** Adherence to the use of the booklet “Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida” in the short-term.



**Figure 2.** Adherence to the use of the booklet “Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida” in the follow-up.

**DISCUSSION**

The present study aimed to test the use of the booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” in children and adolescents with spina bifida and their caregivers. The application of an adapted instrument observed that the booklet presents clarity of the items presented, ease of reading, understanding, and acceptable form of presentation. However, through the adapted questionnaire from Dalcin et al.<sup>15</sup>, we found

moderate/low adherence to the use of the booklet.

According to Silva et al.<sup>17</sup>, the home exercise booklet allows the patient and their caregiver to consult the material for guidance whenever necessary, providing greater security, confidence, adherence, comfort, and family involvement and helping to ensure that the exercises are performed correctly. Through the answers given by patients and their caregivers, the booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” presented a pleasing appearance and content, thus enclosing

the expectations for an exercise booklet.

According to Copp et al.<sup>3</sup>, self-care can reduce the risk of complications and secondary conditions and can improve the results sought through treatment in populations with spina bifida. For children and adolescents with SB, the study by Peterson et al.<sup>18</sup> and the systematic review by Sawin et al.<sup>19</sup> showed that performing self-care behaviors helps in self-management of health, helps in social participation, and combats vulnerability, stigma, and discrimination. Our intention with the booklet was to promote self-care, improve quality of life and optimize and assist the participation of patients and their families in rehabilitation. Despite the scheduled returns and the encouragement to perform the exercises, the patients' and their caregiver's adherence was poor.

In 2019, de Damasceno et al.<sup>20</sup> assessed adherence to home exercises using a booklet. Twenty-two chronic hemiparetic patients were evaluated, and only two performed the exercises above the established rate. Therefore, these patients present low adherence to the use of the booklet. The authors argue that this finding may be related to the lack of family incentives, inadequate space for performing exercises, lack of understanding of the importance of home activities, and low exercise skills<sup>21</sup>.

In another study, Picorelli et al.<sup>21</sup> evaluated adherence to an unsupervised home program in 95 older women. An adherence rate of 33.09% was observed, confirming the study's hypothesis that the adherence rate to a home program is lower than recommended. The authors suggest that low adherence may be associated with the absence of social interactions and the lack of variability in the proposed program<sup>21</sup>.

The present study brought some benefits to patients and their families: 1) potential acquisition of independence

regarding the performance of home exercises; and 2) greater family involvement in the patient's habilitation/rehabilitation process. However, a moderate/low adherence was observed to the exercise booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*”, indicating that the health professional should encourage and guide more assertively caregivers and patients. Health professionals can use the booklet to guide their patients in home exercises. As well as disseminating knowledge to other professionals, as it is a low-cost instrument.

As specific limitations of the present study, we indicate: 1) the small number of participants that may have impacted the 2) low adherence of patients to the use of the booklet; 3) non-availability of the booklet on the internet, on the website of the *Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto - Universidade de São Paulo* and the association of parents of patients with spina bifida and, 4) non-development of an interactive version of the booklet with videos, so that patients and caregivers could consult in case of doubts, in the exercises performed at home, even after consulting the images of the material and previous explanations from the therapist.

We conclude that the exercise booklet “*Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida*” proved to be an excellent resource for increasing the physical therapy treatment of children and adolescents with spina bifida. The material presents clarity of the items presented, ease of reading, and adequate understanding according to the evaluation of expert judges and caregivers of children and adolescents with spina bifida. However, the use of the booklet showed moderate/low adherence, making it necessary to seek alternatives for children/adolescents to get involved in self-care and for caregivers to encourage the independence of these patients.

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### Supplementary material

### Booklet “Orientações para a Manutenção da Qualidade de Vida – Espinha Bífida”

