


Validation of an exercise booklet for children with acute lymphoblastic leukemia

Validação de cartilha de orientação de exercícios para crianças com leucemia linfóide aguda

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Abstract

Introduction: Leukemia is the most common childhood cancer, and acute lymphoblastic leukemia (ALL) accounts for 75 to 80% of all such cases in this population. Survival has increased among children and adolescents due to advances in diagnosis and treatment, with a growing emphasis on the need for rehabilitation to improve functionality and quality of life, mitigating the long-term effects of treatment. **Objective:** To describe the process of compiling and validating an exercise booklet for children and adolescents during and after treatment for acute lymphoblastic leukemia. **Methods:** Methodological study using the Delphi technique for validation. The panel of experts consisted of seven healthcare professionals and three mothers of children without ALL. The booklet was evaluated using a form containing 15 items scored on a 5-point Likert scale, and by qualitative assessment. The frequency of the expert ratings, percentage agreement and content validity index (CVI) were presented for each item and the instrument as a whole. Analyses were performed in R 3.5.1 software. **Results:** The booklet containing stretching, aerobics, strength and relaxation exercises was validated in the second round, reaching 100% consensus. When assessed only by the mothers, 93.33% consensus was achieved in a single round. **Conclusion:** The exercises booklet was validated for use in the population studied.

Keywords: Acute lymphoblastic leukemia. Adolescents. Children. Physical exercise. Validation studies.

Resumo

Introdução: A leucemia é o tipo mais comum de neoplasia na população infantil, sendo que a leucemia linfóide aguda representa 75 a 80% de todos os casos de leucemia nessa população. O aumento da sobrevivência das crianças e adolescentes com câncer vem ocorrendo devido a avanços no diagnóstico e tratamento, destacando-se cada vez mais a necessidade de reabilitação para melhora da funcionalidade e qualidade de vida, reduzindo os impactos do tratamento a longo prazo. **Objetivo:** Descrever o processo de elaboração e validação de cartilha de orientação de exercícios em crianças e adolescentes durante e após tratamento de leucemia linfóide aguda. **Métodos:** Estudo metodológico, utilizando a técnica Delphi para validação. O painel de especialistas contou com sete profissionais da saúde e três mães de crianças sem leucemia linfóide aguda. A avaliação foi feita através de formulário composto por 15 itens, em escala tipo Likert, e avaliação qualitativa. Foram apresentadas as frequências das respostas dos avaliadores, a proporção de concordância e o índice de validade de conteúdo (IVC) para cada item e para o instrumento como um todo. As análises foram realizadas no software livre R 3.5.1. **Resultados:** A cartilha composta de exercícios de alongamento, aeróbicos, de força muscular e de relaxamento foi validada na segunda rodada, atingindo 100% de consenso. Na avaliação das mães, obteve-se consenso de 93,33% em única rodada. **Conclusão:** A cartilha de orientação de exercícios físicos foi considerada validada para utilização na população estudada.

Palavras-chave: Leucemia linfóide aguda. Adolescentes. Crianças. Exercício físico. Estudos de validação.

Introduction

Leukemia is the most common childhood cancer worldwide, representing 30% of all tumors that occur under the age of 15 years.¹ Acute lymphoblastic leukemia (ALL) accounts for 75 to 80% of all cases of leukemia in children and adolescents, with a wide range of clinical and biological aspects, and involves the proliferation, accumulation and infiltration of lymphoid blasts that overtake the bone marrow, lowering the number of red blood cells and resulting in complications such as anemia, hemorrhage and infections.^{2,3}

Although treatments for childhood cancer have been increasingly successful, there are significant long-term

complications. Physical impairments after cancer therapy contribute to a sedentary lifestyle and reduce cardiopulmonary and musculoskeletal function.⁴

Assessment of childhood cancer survivors (CCSs) five years after diagnosis and comparison of their physical performance with that of their siblings indicated that CCSs scored below their siblings in lower-extremity strength tests, timed up-and-go (TUG) and 6-minute walk tests (6MWT), despite reporting similar habitual levels and types of physical activity.⁴

In addition to reduced musculoskeletal and functional capacity, a study conducted in Turkey analyzed physical problems and symptoms in 91 children and adolescents after one to five years of treatment and identified the most common as being exercise intolerance (45.1%), pain (41.8%), respiratory system infections (40.7%), fatigue (29.7%), reduced bone mineral density (26.4%), urinary tract infection (19.8%) and obesity (18.7%).⁵

Survival has increased among children and adolescents with cancer due to advances in diagnosis and treatment, with a growing emphasis on the need for rehabilitation to improve functionality, independence, social inclusion and quality of life.⁶ Exercise and physical therapy can decrease critical impairments that generally develop during and after cancer treatment.⁷

Studies have shown the positive effects of exercise on the quality of life of these patients, as well as physical and psychological aspects.⁸⁻¹²

Despite its proven benefits, there is still no established exercise protocol for children and adolescents. Inconsistencies regarding the type, frequency and duration of exercise further hamper its prescription by healthcare professionals. Although physical activity cannot be standardized, guidelines and evidence are needed to improve collaboration between professionals in prescribing physical exercise for these patients, with a focus on improving quality of life and self-esteem.¹³

Given the importance of exercise as a form of rehabilitation, the difficulties involved in systematizing these activities as well as adherence and motivation, the use of printed educational material combined with verbal instructions has become an effective method to facilitate patient understanding and participation.¹⁴

In light of the above, this study aimed to describe the process of compiling and validating an exercise booklet for children and adolescents during and after treatment for acute lymphoblastic leukemia.

Methods

The methodological approach consisted of the following stages: literature review, compilation of the booklet, content validity assessment by experts using the Delphi technique, and evaluation by mothers of children without ALL on using the material.

The exercises included in the booklet were based on the recommendations of the South American Guidelines for Cardiovascular Disease Prevention and Rehabilitation¹⁵ and Brazilian Cardiology Society's Cardio-Oncology Pediatric Guidelines¹⁶, as well as scientific articles on physical exercise and pediatric oncology^{10,17-21}, used to establish the phases, intensity, duration, frequency and type of exercise.

The pictures were created by the authors on the Pixton® website and the exercises chosen based on the target population of children and adolescents and considering the chemotherapy phase and the first five years after treatment, as well as the main muscle groups targeted and total execution time.

The content was validated by a panel of experts consisting of healthcare professionals, using the Delphi technique^{22,23} and according to clinical knowledge in the field of pediatric oncology and in the areas of training exercise and rehabilitation.

The experts were identified by analyzing the resumes on the Lattes Platform, inserting the following terms into the "subject" field: pediatric oncology physiotherapy, physical training in pediatric oncology, physical education in pediatric oncology, and pediatric oncology. Selection was intentional, considering the fields of medicine, nursing, physical therapy and physical education, as well as academic experience and professional career in pediatric oncology. In physical therapy and physical education, experience in training, exercise physiology and cardiovascular rehabilitation in the field of pediatric oncology were deemed important. Twelve professionals were invited to participate by email and provided with information on the study and the purpose of the booklet, a consent form, and booklet assessment form.

The first section of the booklet assessment form contained sociodemographic data about the participants and the second consisted of 15 questions about the objective of the booklet, general theoretical information, organization, presentation, exercise descriptions, pictures and general layout. The items were rated on a 5-point Likert scale, with five possible scores: 1-completely adequate; 2-adequate; 3-somewhat adequate; 4-inadequate; 5-no opinion, as shown in Figure 1. The form was compiled by the researcher based on a model from a study that also assessed and validated an educational booklet.²⁴

Items	Rating				
	1	2	3	4	5
1. Are the guidelines regarding limitations and/or contraindications for exercise appropriate for children undergoing maintenance therapy?	1	2	3	4	5
2. Does the booklet achieve its objective of providing support and guidance for home exercises?	1	2	3	4	5
3. Is the booklet suitable for use by parents or guardians?	1	2	3	4	5
4. Is the booklet suitable for use by children and adolescents?	1	2	3	4	5
5. Is the wording used in the guidelines and picture descriptions clear and objective?	1	2	3	4	5
6. Do the exercises cover the main muscle groups?	1	2	3	4	5
7. Do the exercises follow a logical order?	1	2	3	4	5
8. Is the writing easy to understand?	1	2	3	4	5
9. Are the cover and title page visually appealing and is the provided information adequate?	1	2	3	4	5
10. Is the booklet well formatted (font, font size, general layout and appearance)?	1	2	3	4	5
11. Do the pictures accurately depict the correct position for the exercise?	1	2	3	4	5
12. Are the exercise descriptions easy to understand?	1	2	3	4	5
13. Is the order of the pictures (exercises) adequate?	1	2	3	4	5
14. In general, does the layout of the booklet achieve its objective simply and functionally?	1	2	3	4	5
15. Is the booklet relevant?	1	2	3	4	5

Figure 1 - Booklet assessment form. Source: research file.

Concomitantly to the expert assessment, three mothers were invited to evaluate the booklet and its applicability. They were chosen intentionally, based on the following inclusion criteria: mothers of children without ALL and who are not health workers. They evaluated the booklet using the same form as the experts and then gave it to their children to follow the proposed exercise program.

Mothers of children without ALL were selected because the initial objective of this stage of the assessment was to evaluate the applicability of the booklet and understanding of the exercises based on their execution and the language and pictures used, regardless of health status.

The characterization data for the experts are presented as absolute frequencies, means and standard deviations. The booklet assessment results were analyzed considering the frequencies of ratings for each item on the form and the total number of items, as well as percentage agreement between experts. The content validity index (CVI) was expressed as the ratio between the number of items rated "completely adequate" and "adequate" and the total number of assessments performed. The CVI was calculated for each item on the form (partial CVI) and the instrument as a whole (total CVI), with values greater than or equal to 80% considered for validation. Analyses were conducted using R 3.5.1 software.

The booklet validation process was part of a doctoral study for the Paulista School of Nursing entitled "Effects of an exercise program on the physical fitness and quality of life of children and adolescents with acute lymphoblastic leukemia", and was approved by the institutional Research Ethics Committee (CAAE: 58867116.3.0000.5505E) under protocol no. 1.751.878.

Results

The booklet contains 20 exercises, arranged as follows: A) eight stretching exercises to warm up; B) training phase: two aerobic exercises, with one also targeting balance, one balance exercise and six strength exercises; C) three stretching and relaxation exercises at a lower intensity than the previous stage. Before describing the exercises, the booklet provides guidance and information on how to do the exercises safely, including ideal locations, staying hydrated, appropriate clothing

and correct execution, as well as signs and symptoms that preclude children from exercising, as shown in the supplementary document [Exercise booklet](#).

Seven experts took part in the first round of the Delphi panel to assess the content validity of the booklet, but two were unavailable for the second round, which consisted of five experts.

Table 1 presents the characteristics of the panel. The experts were predominantly women and consisted of three physical therapists, two nurses, a physical education professional and a doctor. The majority had extensive professional experience and worked in clinical practice at the time of the study.

Table 1 - Characterization of the experts on the Delphi panel (Rio Branco, AC, Brazil, 2018)

Characteristics	Round 1 (*n=7)	Round 2 (*n=5)
Sex		
Women	6	5
Men	1	-
Age**	39.6 ± 10.3	40.8 ± 10.3
Time since graduation**	17.3 ± 11.8	19.2 ± 13.7
Career span**	15.9 ± 12.2	17.2 ± 14.5
Area of expertise		
Physical Therapy	3	2
Nursing	2	2
Physical education	1	-
Medicine	1	1
Academic Degree		
Doctorate	2	2
Master's	4	3
Specialization Course	1	-

Note: *n = sample size; **mean ± standard deviation, years. Source: the authors.

Table 2 shows the frequency of expert ratings, percentage of interrater agreement, total and partial CVIs for both assessment rounds.

None of the items were rated "inadequate" in either round. The CVI per item (partial) ranged from 57.1 to 100% in round 1, with all items obtaining 100% in the second round. The items with CVI < 80% (questions 4, 5, 6, 11 and 12) were related to language, particularly technical terminology, pictures that did not adequately illustrate

the exercises, questions regarding the execution of some exercises and execution time. The total CVI, considered the percentage of items rated "completely adequate" or "adequate", was 82.9% in round 1 and 100% in round 2, indicating group consensus for the booklet assessed.

The average age of the mothers who participated was 34 ± 1.73 years, with one working as a social educator, one psychologist and a housewife. They

asked their children (average age of 8.67 ± 3.21 years) to perform the exercises, initially using only the pictures without reading the instructions, and observed whether they understood and executed them correctly. The mother's assessments were positive and the pictures the children found most difficult to understand were the same as those identified by the experts, which were then modified for round two.

Table 2 - Absolute frequency of booklet ratings, interrater agreement (%) and content validity index (CVI) for each round of the Delphi panel (Rio Branco, AC, Brazil, 2018)

Item	Rating											
	Completely adequate		Adequate		Somewhat adequate		Inadequate		No opinion		§CVI (%)*	
	†R1	‡R2	†R1	‡R2	†R1	‡R2	†R1	‡R2	†R1	‡R2	†R1	‡R2
1	3 (42.9)	4 (80.0)	4 (57.1)	1 (20.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	100.0	100.0
2	3 (42.9)	4 (80.0)	3 (42.9)	1 (20.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	85.7	100.0
3	4 (57.1)	4 (80.0)	2 (28.6)	1 (20.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	85.7	100.0
4	2 (28.6)	3 (60.0)	2 (28.6)	2 (40.0)	3 (42.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	57.1	100.0
5	1 (14.3)	4 (80.0)	3 (42.9)	1 (20.0)	3 (42.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	57.1	100.0
6	4 (57.1)	3 (60.0)	1 (14.3)	2 (40.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	1 (14.3)	0 (0.0)	71.4	100.0
7	5 (71.4)	3 (60.0)	2 (28.6)	2 (40.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	100.0	100.0
8	2 (28.6)	3 (60.0)	5 (71.4)	2 (40.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	100.0	100.0
9	3 (42.9)	4 (80.0)	3 (42.9)	1 (20.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	85.7	100.0
10	5 (71.4)	4 (80.0)	2 (28.6)	1 (20.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	100.0	100.0
11	2 (28.6)	2 (40.0)	2 (28.6)	3 (60.0)	3 (42.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	57.1	100.0
12	2 (28.6)	3 (60.0)	3 (42.9)	2 (40.0)	2 (28.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	71.4	100.0
13	4 (57.1)	3 (60.0)	2 (28.6)	2 (40.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	85.7	100.0
14	5 (71.4)	4 (80.0)	2 (28.6)	1 (20.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	100.0	100.0
15	6 (85.7)	4 (80.0)	0 (0.0)	1 (20.0)	1 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	85.7	100.0
Total	51 (48.5)	52 (69.3)	36 (34.3)	23 (30.7)	17 (16.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.0)	0 (0.0)	82.9	100.0

Note: †R1 = round 1; ‡R2 = round 2; * The CVI was defined as the ratio between the number of items rated "completely adequate" and "adequate" and the total number of assessments performed. Source: the authors.

Discussion

The exercise booklet was compiled after the need for an educational instrument to support a program of home exercises for children and adolescents in the maintenance or post-treatment phases of ALL was identified in the research project entitled "Effects of physical exercise on the physical fitness and quality of life of children and adolescents with leukemia: a randomized controlled trial". Since chemotherapy sessions are less frequent in the maintenance phase, children can resume

their routine activities and begin a program of home-based physical exercise, as can those no longer being treated.

The booklet helps ensure that exercises are performed correctly and prepares both children and their families for a home-based program. The ability to continuously consult the material for guidance favors greater safety, confidence, adherence, comfort and family involvement in the activities, encouraging regular physical exercise.

Studies have used a home-based approach for physical exercise^{12,18,19,21} considering its long-term viability and maintenance, with more accessible exercise plans that do not require specialized equipment.

The types of exercise and execution stages were selected based on phase 2 and 3 of cardiac rehabilitation guidelines,^{15,16} studies with similar populations and topics,^{8-12,20,25} as well as the medications used during leukemia treatment and their adverse effects.

According to the recommendations of the World Health Organization (WHO), children and adolescents between the ages of five and 17 years should engage in at least 60 minutes of moderate-to-vigorous intensity physical activity a day, most of which should be aerobic, as well as high-intensity activities such as strengthening exercises three times a week. In addition to a planned exercise program, these activities include games, sports, recreation, walking or cycling to school, physical education classes, and community and home-based activities.²⁶

These recommendations are generally aimed at healthy children and adolescents, making it essential for adjustments to be made based on disease characteristics, clinical condition, medications used and possible complications in order to safely prescribe exercise for each population.

Authors recommend mild activities for children during the induction and consolidation phases of ALL treatment to help mitigate the negative effects of therapy. Moderate activities are permitted on some days during the maintenance phase, but daily exercise may not be viable, making a gradual progression in daily activities more recommended. As activities increase, the inclusion of strength and resistance exercises helps reduce fatigue, and the involvement of family members is important to ensure adherence regardless of the treatment phase.²⁵

In addition to exercises, the booklet analyzed here provides guidance on limitations and contraindications, important in determining when participants should stop exercising or postpone it. Although verbal instructions are more commonly used by healthcare professionals, written materials are important to reinforce these instructions and directly impact teaching effectiveness, facilitating the teaching-learning process and improving treatment adherence, by serving as a guide when questions arise later on, and helping in decision making.²⁷⁻³⁰

Once the booklet was compiled, its content validity was assessed by a panel of experts in the field of health.

The number of healthcare professionals varies between studies; however, a panel of five to ten experts in the instrument's area of knowledge is recommended for quantitative and qualitative assessment.^{31,32}

Studies use the content validity index (CVI), considering an index greater than or equal to 80% as indicative of consensus.^{28,33,34} The minimum acceptable interrater agreement adopted by researchers is 80%, although values above 90% are preferred.^{31,32,35}

Expert opinions are vital in adjusting educational material, improving its rigor and making it more comprehensive and effective, in order to standardize and formalize conduct with the participation of a multiprofessional team by valuing different viewpoints.^{33,36} Although the booklet was deemed validated in the first round, following suggestions and correction by the experts, it was modified and submitted to a second round of assessment.

Educational material should use simple wording with clear and precise information and visually appealing illustrations. When compiling the material, it is important to consider the content, language, organization, layout, illustrations, learning format and motivation.^{27,28,30} It should not be overly long, be objective, easy to understand, and it must meet the needs of the target population. Illustrations are also important, both to make the material more appealing and easily understood.³⁶

Suggestions made by the experts included language changes, in particular better communication of technical terminology, especially in the exercise descriptions. The pictures were designed so that parents and their children could immediately grasp the exercise, and accompanied by a description to ensure complete understanding.

It is important that educational material is easily understood by anyone, making it necessary to adjust scientific language to ensure understanding of the concept regardless of schooling level, since professionals often fail to notice the use of technical terminology.³⁶⁻³⁸

Another item highlighted for adjustment was the lack of standardized information on the execution time of the exercises, such as seconds for stretching and number of repetitions in the strength exercises.

This variation was considered when compiling the booklet, since intensity should be modified after two months of training. As a result, the change in intensity was maintained, but the number of repetitions before and after this time period was standardized. The number of repetitions used was based on studies that involve strength exercises with the same population.^{10,11}

For the stretching exercises, the experts suggested adhering to the standard 30 seconds recommended in the literature.³⁹ A time of 20 seconds was adopted in the booklet because longer stretching could deter children and distract them during exercise, potentially compromising adherence. Research varies in regard to the optimal frequency and duration of stretching. A study with children involving 20-second-long static stretching in physical education classes over 16 weeks showed an increase in flexibility.⁴⁰

Few changes were made to the exercises proposed in the booklet, with the exception of improving the positions depicted in the pictures (two exercises), replacing two exercises considered difficult to execute and altering the execution of one. In addition to the expert's opinions, the three children who assessed the booklet played a vital role in improving both the pictures and exercises by identifying positive and negative points during execution.

Illustrations are important in improving understanding of the text and should be clear, accompanied by a description, appropriate for the target audience and communicate a single idea.³⁰ Well-designed educational material can influence the reality of the target population, provided it meets their needs and that its contents are in line with what they consider important.³⁷

The booklet makes it possible to standardize information, provide guidance and encourage healthy habits through exercise based on the reality and abilities of the target population since, although exercise itself cannot be standardized, it is important to create guidelines and foster initiatives in the area of pediatric oncology.

Limitations of this study include the lack of research in pediatric oncology and physical exercise, particularly home-based programs, making it challenging to compile the exercises considering all the necessary criteria for proper execution. The scarcity of studies that use printed educational material for children or exercises booklets on a different topic limited comparison of the stages involved in compiling the material. Despite this limitation, several investigations^{28,33,34,41,42} provided the necessary support in compiling the booklet and a conceptual framework for its design and validation.^{30-32,35,36,43,44}

It is important to note that the goal of the booklet is to help children in the maintenance or post-treatment phase of ALL to perform physical exercise at home and promote a change in their daily habits, directly impacting their quality of life and self-esteem. The exercises should

be approved and monitored by the relevant healthcare team.

Conclusion

The present study compiled a booklet containing 20 home-based exercises aimed at children and adolescents in the maintenance or post-treatment phase of ALL, which, after validation of its content by experts, achieved 100% agreement in the second round of assessment based on the Delphi technique.

The objective of describing the process of compiling and validating the booklet was achieved, and its content was quantitative and qualitatively assessed by a panel of experts and considered valid.

Further research will include clinical validation of the booklet for children and adolescents in the maintenance or post-treatment phase of ALL in order to identify the impact of the home-based exercise program on their quality of life and physical fitness.

Authors' contributions

REGS was responsible for all stages of the article, namely: the literature review, conceiving and designing the study, data collection, statistical analysis, discussion of the results and conclusion. AFMA, advisor for the thesis that gave rise to the article, was responsible for conceiving and designing the study. Along with RPMS, co-advisor for the thesis, was also responsible for critically analyzing the manuscript, organizing the methodological process, correcting and analyzing all the different stages.

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