

Going home after a child's cardiac surgery: education for safe care

A volta para casa após a cirurgia cardíaca da criança: educação para cuidado seguro

La vuelta a casa tras la cirugía cardíaca infantil: educación para una atención segura

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ABSTRACT

Objectives: to validate the content and appearance of the booklet "Going home after a child's cardiac surgery" and assess family members' cognitive learning regarding its use. **Methods:** a methodological and quasi-experimental study of before and after type, with semi-structured interview, pre-test and reading of the booklet in a hospital; post-test and validation occurred after hospital discharge. Wilcoxon non-parametric statistics were used. **Results:** nineteen family members of children with heart disease participated. The average of correct answers increased 14 percentage points from pre- to post-test; most were medication errors. There was a significant difference ($p < 0.0001$) in the comparison between cognitive knowledge prior to using the booklet and learning acquired from its use. All items received a positive rating, except font size. **Conclusions:** the booklet helps family members to understand a child's needs after cardiac surgery, and can be used to prevent unwanted occurrences and enable safe care at home.

Descriptors: Validation Studies; Education Technology; Cardiac Surgery; Child Care; Health Education.

RESUMO

Objetivos: validar o conteúdo e aparência da cartilha "A volta para casa após a cirurgia cardíaca da criança" e avaliar a aprendizagem cognitiva de familiares em seu uso. **Métodos:** estudo metodológico e quase-experimental do tipo antes e depois, com entrevista semiestruturada, pré-teste e leitura da cartilha no hospital; pós-teste e validação ocorreu após alta hospitalar. Utilizou-se estatística não paramétrica Wilcoxon. **Resultados:** participaram 19 familiares de crianças cardiopatas. A média de acertos aumentou 14 pontos percentuais do pré para o pós-teste; maioria dos erros sobre medicamentos. Verificou-se diferença significativa ($p < 0,0001$) na comparação entre conhecimento cognitivo prévio ao uso da cartilha e aprendizagem adquirida no uso desta. Todos os itens da cartilha receberam avaliação positiva, exceto o tamanho da letra. **Conclusões:** a cartilha contribui para o familiar apreender as necessidades de atenção à criança após cirurgia cardíaca, podendo ser usada para evitar ocorrências indesejadas e possibilitar um cuidado seguro no domicílio.

Descritores: Estudos de Validação; Tecnologia Educacional; Cirurgia Cardíaca; Cuidado da Criança; Educação em Saúde.

RESUMEN

Objetivos: validar el contenido y apariencia del cuadernillo "El regreso a casa después de la cirugía cardíaca del niño" y evaluar el aprendizaje cognitivo de los familiares en su uso. **Métodos:** estudio metodológico y cuasi experimental del tipo antes y después, con entrevista semiestruturada, pretest y lectura del cuadernillo en el hospital; la prueba posterior y la validación se produjeron después del alta hospitalaria. Se utilizaron estadísticas no paramétricas de Wilcoxon. **Resultados:** participaron 19 familiares de niños con cardiopatías. El promedio de respuestas correctas aumentó 14 puntos porcentuales desde el preprueba hasta el posprueba; la mayoría de los errores de medicación. Hubo una diferencia significativa ($p < 0,0001$) en la comparación entre el conocimiento cognitivo previo al uso del cuadernillo y el aprendizaje adquirido al usarlo. Todos los elementos del folleto recibieron una evaluación positiva, excepto el tamaño de fuente. **Conclusiones:** el folleto ayuda al familiar a comprender las necesidades de cuidado del niño después de la cirugía cardíaca, lo que puede usarse para prevenir incidentes no deseados y permitir un cuidado seguro en el hogar.

Descriptor: Estudios de Validación; Tecnología Educacional; Cirugía Cardíaca; Cuidado del Niño; Educación en Salud.

INTRODUCTION

As they are malformations in the anatomical or functional structures of the heart, present before birth, congenital heart diseases must have their diagnosis made as early as possible⁽¹⁾. Since they can cause changes in the functioning of cardiovascular hemodynamics, if therapeutic control is not achieved with performance in maintaining children's clinical stability, surgical correction is indicated⁽¹⁻²⁾. Not only is diagnosis and treatment of this clinical condition important, health professionals should also take a close look at a child's family. When a child is diagnosed with congenital heart disease, either at birth or later, parents experience feelings of anxiety and fear, either through treatment or the possibility of the children's death⁽³⁻⁴⁾. Thus, the family needs time to adjust emotionally and understand the meaning of the disease⁽³⁻⁶⁾. Authors⁽⁷⁾ point out that parents' support systems also include the written information they receive; their needs are focused on having suitable verbal and written information at children's hospital discharge, but also when they are at home. There is also a desire to know from whom they can obtain clarification about children's heart condition. On the other hand, parents need to receive written guidelines to take home, knowing that they can help⁽⁷⁾.

After performing a cardiac defect correction procedure, it is important to provide information on hygiene, food⁽⁸⁻⁹⁾, physical activities⁽¹⁰⁻¹¹⁾ and others, which may still raise doubts for children's caregivers. To enhance positive responses in child care, educational practices are suggested, with the insertion of concepts of health promotion and empowerment of families of children with heart disease^(6-7,12-13). Health education activities for families in preparation for hospital discharge should be started as early as possible so that guardians can reduce uncertainties and feel capable of taking care of children at home as well as recognizing signs of worsening clinical condition and seeking care in health services^(7,12-13).

The absence of specific material in Brazilian Portuguese is a gap for this moment of experience of children and family. Considering that it allows the family to have appropriate knowledge and prior to children's hospital discharge so that the care experience after cardiac surgery is positive and that the care provided at home is safe, this study intends to offer educational material with suitable information to families of children with heart disease.

OBJECTIVES

To validate the content and appearance of the booklet "Going home after a child's cardiac surgery" and assess family members' cognitive learning regarding its use.

METHODS

Ethical aspects

In compliance with Resolution 466 of December 12, 2012 of the Brazilian National Health Council (*Conselho Nacional de Saúde*), this research was approved by the Research Ethics Committee of *Escola de Enfermagem de Ribeirão Preto* at *Universidade de*

São Paulo. After clarifying the research, participants signed the Informed Consent Form.

Study design, place, and period

This is a methodological⁽¹⁴⁾ and quasi-experimental research of before and after type to assess the cognitive knowledge of family members of children with heart disease using educational material.

The methodological research was developed in stages defined by reference⁽¹⁵⁾, including translation and validation of the booklet - created by *Fundación Menudos Corazones* in Spain - for Brazil, in a previous study⁽¹⁶⁾. Upon obtaining the translated and validated version by judges, now entitled "Going home after a child's cardiac surgery", for the present study, its content and appearance validation was carried out with family members of children with heart disease.

The booklet contains 14 illustrated front and back pages and ten chapters. The first, *Introduction*, highlights the relevance of educational material and for parents to seek health professionals in case of doubts. *Hospital consultations* has information about scheduling outpatient care to reassess children by the health team. *Medication* guides medication administration to children with tips that facilitate this process, avoiding forgetfulness or misunderstandings and errors. *Vaccines* encourages family members to resolve doubts with health professionals about whether or not children can receive a certain immunobiological product. *Care for the surgical scar* helps the family to take care of the surgical site with adequate hygiene, use of clothes, and sunscreen. *Nutrition* highlights food at home as important in the recovery of children and care with gastric or enteral tube. *Tooth care* of children is a chapter on the risks of bacterial endocarditis, teeth care and visits to the dentist. In *Signs and symptoms*, a list indicates the possibility of children's clinical worsening and the need to seek health care. The chapter *Children return to activities* highlights how parents can experience returning to school, the practice of physical activities and also how to stimulate children's motor, affective, social, communicative, perceptual and cognitive development. Finally, *Psychological considerations* deals with the importance of parents taking care of themselves and their health; it also describes how to interpret children's reactions and attitudes, in addition to their relationship with siblings and other family members⁽¹⁶⁾.

The field of study was a state public hospital, a reference in heart disease treatment in childhood, located in the countryside of the state of São Paulo. The Pediatric Intensive Care Center (PICU) has 10 beds active for immediate postoperative care of cardiac surgeries for newborns and children residing in the municipality and coming from surrounding cities or other regions of the country. With the potential to perform 200 child cardiac surgeries per year, the hospital has a monthly average of eight surgeries. Hospitalization at PICU takes seven to ten days. After clinical stabilization, children are transferred to the Pediatric Clinic to prepare for hospital discharge and subsequent outpatient follow-up. The Pediatric Clinic offers 56 beds for children and adolescents aged between 28 days and 18 years old, organized by specialties, allocating six beds for cardiology. Outpatient care for children with heart disease is done on Mondays, in the afternoon,

starting at 12:30 p.m. and on Fridays, in the morning, starting at 7:30 a.m. The booklet's content and appearance validation took place between May and August 2018, both at the pediatric and outpatient clinics.

Population, sample, and inclusion and exclusion criteria

Family members of hospitalized children with congenital heart disease participated; these were primarily responsible for caring for children at home (mother, father, grandmother, or other). For inclusion it was necessary: to be a family member of children in their first surgical procedure, justified by the interest in providing family members with information about care after the surgery, and those who had previously experienced such an experience could have already acquired knowledge; being a family member of children whose surgeries demanded devices to support life in the immediate postoperative period and complex care at home, based on the fact that major surgeries are performed for corrections of complex heart diseases; longer hospital stays and specific care for children at home. Family members of children with previous cardiac surgery and with less complex cardiac diseases in both surgical correction and home care were excluded.

Data collection and organization

To obtain the data, the main researcher attended the Pediatric Clinic twice a week, identified potential participants through contact with nurses in the sector who indicated the type of surgery performed in children, and the inclusion criteria were then applied. The choice to approach family members in this sector was due to the fact that children had already been discharged from the PICU and were clinically stable and in conditions of preparation for hospital discharge. The first stage of collection consisted of approaching each family member at the Pediatric Clinic. After consenting to their participation in writing, a semi-structured interview was carried out using a script, completed by the researcher, with closed- (family socioeconomic and demographic characterization) and open-ended questions (knowledge regarding children's disease), with an average time of five minutes. Then, for the quasi-experiment, family members answered a pre-test under the researcher's supervision, to assess their prior knowledge about caring for children with heart disease, containing 35 affirmative sentences extracted from the booklet itself; the relative was asked to mark an "X" for true or false. The pre-test time was 20 minutes. At the end, each participant received the booklet (Figure 1) printed in color on A4 paper and proceeded to read it together with the researcher, with an average time of 30 minutes. The booklet remained with the family member to allow its handling and reading when desired, in children's hospitalization and at home.

Family members were guaranteed the same time (15 days) between the information offered (delivery and reading of the educational booklet) and the completion of the third stage (post-test to assess the knowledge acquired after using the booklet). All participants were informed about a new meeting with the researcher, which took place on the (outpatient) post-operative return of children enrolled.



Figure 1- Booklet "Going home after a child's cardiac surgery"

The second stage took place at the Child Cardiology Outpatient Clinic in the same hospital and verified family members' knowledge after using the booklet. With the return date of enrolling children, the researcher approached each family member again; each family member received a form (post-test) with the same 35 affirmative sentences as pre-test to mark "X" in true or false. However, the order in which sentences were presented was changed to avoid memorizing the answers issued in pre-test and guaranteeing the same level of difficulty. This moment aimed to measure cognitive learning.

To validate the booklet's content and appearance, the adapted and widely used instrument in Brazil⁽¹⁷⁾, the Suitability Assessment of Materials (SAM), created to assess the difficulty and convenience of educational materials, was used with children's family members. This instrument uses the standard of the Likert scale (0 - not suitable, 1 - suitable, 2 - excellent), with attributes related to the organization, appearance, content, layout and presentation, motivation for learning and cultural adequacy. Participation time in this stage was approximately 30 minutes.

Data analysis, and statistics

The data were tabulated using the IBM Statistical Package for the Social Science (SPSS), version 22.0. Descriptive statistics described the characteristics of the study population. From pre- and post-test, the responses of each participant and the responses of everyone were calculated individually for each statement. The number of correct answers obtained in post-test was compared with those resulting from pre-test to assess knowledge acquisition about the care to be provided to children at home. Thus, for the learning test using the booklet, the scoring limits were from minimum 0 to maximum 35, with cognitive learning being the difference in score between

post- and pre-test. The Wilcoxon test (non-parametric test for related samples) was used to verify the significance of the correctness of the statements after reading the booklet. Significance level of 5% ($p < 0.05$) and 95% confidence interval were used.

For the material to be considered validated, the result of calculating the percentage of scores obtained should be equal to or greater than 60%⁽¹⁸⁾. The data for this stage were presented by distribution of absolute and relative frequency. Content Validity Index (CVI) was also calculated to assess the extent of agreement between family members, with responses classified as "strongly agree" and "agree" were grouped as agreement, and "strongly disagree" or "disagree", as disagreement. The CVI calculation was performed using the formula presented (Figure 2), and the coefficient of at least 0.8 was adopted as a relevant agreement among judges for validation⁽¹⁴⁾.

$$\text{CVI} = \frac{\text{Agreement}}{\text{Total of Family Members}}$$

(Content Validity Index)

Figure 2 - Content Validity Index Formula

RESULTS

During the study period, 20 family members were approached; 19 agreed to participate, all children's mothers had an average age of 32.9 years; most (63.1%) had more than 10 years of study; living with a partner (84.2%), who is the father of their children (78.9%) and with household activities (62.5%). They live in their own home (63.2%), with access to basic sanitation (84.2%). The average number of people in the household was 4.2, with an average of 2.2 adults and 2.0 children. Only one (5.3%) mother was unable to name the disease and 11 (57.9%) knew the name of surgery/treatment. Only four (21.1%) mothers indicated the type of surgery that children underwent.

When analyzing pre- and post-test of the 35 statements, the average of correct answers was different between the two moments, with an increase above 14 percentage points between them. Errors in the answers were mostly related to medication handling in situations such as children's vomiting, forgetting the time or dose. The Wilcoxon test indicated a significant difference in the comparison between the number of correct answers in pre- and post-phases (Table 1).

The assessment of caregivers' knowledge demonstrated that aspects of children's care were apprehended, with the exception of doubts about medications, a fact that reveals the urgency of working to teach safe medication administration at home even during hospitalization.

When validating the booklet, family members responded to the SAM with 100% positive assessment (suitable and excellent) for organization, appearance, writing style, content, and learning encouragement/motivation (Table 2), being considered validated with scores obtained above 60%. Only font size (layout and presentation) received a negative rating for 31.6% of the interviewees, indicating the need to increase the font used in the booklet. Although the item layout and presentation obtained positive scores above 60%, being considered validated, the font size printed in the booklet was later increased for better viewing and reading by the target audience.

DISCUSSION

The information in the booklet "Going home after a child's cardiac surgery" is extremely important for children's guardians, at home, after the surgical procedure, as it provides guidance on the care to be provided. Each chapter pays attention to children at this time in their lives, supporting studies that highlight aspects related to food, oral health, leisure and physical activity, care with medications and with the surgical wound, as well as the need to offer support to the families of these children^(6,19).

Such care has a close relationship with those offered by the nursing team while still in hospital as well as after discharge⁽⁶⁾. Nurses occupy an important place in this care, as they have direct contact with children and their caregivers and have greater opportunities to identify their needs both in the hospital and at home.

The first chapter highlights the importance of parents knowing the disease and its treatment, calling them to clarify their doubts about the necessary care at home. It still indicates that it is necessary to control the anxiety experienced at that moment, because, in some cases, children may be submitted to other surgical procedures; thus, further interventions will depend on children's good recovery.

These aspects are relevant to caregivers at home, as they allow them to understand how to provide effective care. Evidence⁽¹⁹⁾ points out that the explanations offered by the health team favor the feeling of security in those who will take care of children. Clear and accurate information is recognized by mothers, who also consider the availability of professionals to guide each identified need as a great help to empower them for care after hospital discharge⁽¹⁹⁾.

A specific chapter highlights scheduling children's *Return consultation* at the hospital to monitor their recovery. In *Medication*, attention is focused on the dose and time of medication administration to avoid forgetfulness or confusion between dosage and type of medication.

Table 1 - Score of family members of children with congenital heart disease in pre- and post-test of cognitive knowledge using the booklet, Ribeirão Preto, São Paulo, Brazil, 2018

Variables	Mean	Standard deviation	Minimum	Median	Maximum	p value*
Affirmative scores						< 0.0001
Pre-test score	29.0	2.3	24	29.0	33	
Post-test score	33.7	1.1	32	34.0	35	

Note: *Teste de Wilcoxon.

Table 2 - Assessment of the booklet "Going home after a child's cardiac surgery", Ribeirão Preto, São Paulo, Brazil, 2018

Factor to be classified ^a *	Not suitable n (%)	Suitable n (%)	Excellent n (%)	CVI ^b
Organization (how the booklet is organized)				
Cover is attractive		2 (10.5)	17 (89.5)	1
Cover indicates the contents of the booklet		2 (10.5)	17 (89.5)	1
There is a sequence in the content presented in the booklet		1 (5.3)	18 (94.7)	1
Size of content in topics (sentence size: long sentences/short sentences)	1 (5.3)	4 (21.0)	14 (73.7)	0.94
Appearance				
Illustrations are easy to understand		5 (26.3)	14 (73.7)	1
Illustrations serve to complement the text		4 (21.0)	15 (78.9)	1
Writing style (understanding/understanding of sentences)				
Writing is clear (sentences are easy to understand)		6 (31.6)	13 (68.4)	1
Words are easy to understand		6 (31.6)	13 (68.4)	1
Text is interesting (what is written is interesting)		5 (26.3)	14 (73.7)	1
Content				
The purpose of the booklet is clear (the booklet indicates care that should be taken)		2 (10.5)	17 (89.5)	1
Content is clear		3 (15.8)	16 (84.2)	1
Content is focused on the purpose (show care that should be taken)		3 (15.8)	16 (84.2)	1
Content highlights the main points (care that must be done)		3 (15.8)	16 (84.2)	1
Content helped in learning (taking care of children)		2 (10.5)	17 (89.5)	1
Layout and presentation				
Layout's characteristic (how figures and text are being shown)		3 (15.8)	16 (84.2)	1
Font size and font used	6 (31.6)	8 (42.1)	5 (26.3)	0.68
The booklet is attractive (colors, drawings, figures)		5 (26.3)	14 (73.7)	1
Learning encouragement/motivation				
The guidelines are specific and provide examples (in each item are the care that must be taken)		3 (15.8)	16 (84.2)	1
Motivation and self-efficacy (the booklet allows child care)		6 (31.6)	13 (68.4)	1
The booklet motivates reading until the end		7 (36.8)	12 (63.2)	1
Cultural fit				
The booklet is similar to its logic, language, experience			19 (100)	1
The booklet has cultural image and examples			19 (100)	1

Note: ^aAdapted from Sousa CS, Turrini RNT, Poveda VB. Translation and adaptation of the Suitability Assessment of Materials (SAM) into Brazilian Portuguese. *Rev enferm UFPE online.*, 2015; 9(5):7854-61; ^bContent Validity Index.

In a way, this care generates uncertainty for caregivers. Children are discharged using various medications, and because it is an age group with specificities and a pathology that requires full-time care, preparing and administering medications at home can become a complex action. It is possible for errors to occur in the preparation of the correct dosage, and still forget doses, schedules and what to do if children vomit the medication⁽²⁰⁻²¹⁾. This fact was identified both in the pre-test and in the post-test, with some participants mistakenly pointing out the alterations, which reveals the importance of providing caregivers with written material (booklet) that is capable of solving their doubts⁽⁷⁾.

Evidence⁽²⁰⁾ revealed that, at home, parents had doubts about storage, material they should use, correct handling, dilution, and application. Concerning time of administration, many did not report it correctly, demonstrating that they do not consider the regularity of medication administration to be important⁽²⁰⁾. This issue is also brought up by a study on the domestic stock of medicines and their use in children and adolescents⁽²²⁾. There was a high rate of inadequate storage, which puts children and adolescents at risk of intoxication. Guardians' level of education stood out, as 40.6% had high school education; 28.2% were classified as illiterate or with elementary school; 15.6% had elementary school and higher education⁽²²⁾.

The results of this study are similar to the authors⁽²⁾ and differ from others⁽²²⁾ regarding the study time of parents/caregivers. However, it is worth highlighting caregivers' level of education and the indication that medication administration by illiterate or uneducated guardians may represent a risk for children when

considering the complexity of dosages and care⁽²²⁾. These authors also recommend developing educational actions for health professionals and users, with encouragement to health education and the promotion of knowledge directed to the administration and stock of medications⁽²²⁾.

The guidelines in the *Vaccines* chapter value the fact that parents ask and have their doubts answered about whether or not children receive a certain immunobiological product. They indicate which ones will be administered, especially after the surgical procedure. Children with chronic health conditions are entitled to special immunobiological agents guaranteed by the Brazilian National Immunization Program (*Programa Nacional de Imunização*). Parents should know this right and which immunobiological agents their children will receive⁽²³⁾.

From *Scar*, the result of a surgery, in addition to the care shown, the booklet also indicates possible signs of the installation of an inflammatory process, type of clothing to be used and the importance of using sunscreen. Among the main nursing diagnoses of patients in immediate postoperative period of cardiac surgery, identified in a study⁽²⁴⁾ are some related to wound healing, such as Risk for infection, Fear and Impaired Comfort. Recognizing diagnoses allows care to be properly planned by establishing specific protocols⁽²⁴⁾. In this regard, the booklet is presented as material that assists health professionals, including nurses, in conveying the correct information to children's guardians, enhancing surgical scar care at home.

By proposing also to know the housing aspects of families of children with heart disease, the present study sought data that

would help to identify potentialities or weaknesses for child care. The findings revealed that most live in their own homes and have access to basic infrastructure, such as a water and sewage network. Unlike a study⁽²⁵⁾, which found families in situations of extreme vulnerability, with the potential to contribute to the worsening of the health status of children with heart disease. That said, the booklet's content emphasizes the importance of hygiene care for children after cardiac surgery and that they must be followed to achieve positive results, avoiding undesirable outcomes, such as infection of the surgical wound or other type of involvement with children's health.

Since *Nutrition*, as an indispensable aspect to be thought for children, has a positive impact on their recovery, for children who are discharged from hospital using a gastric or enteral tube, the booklet provides guidance on the care needed to offer diets by this way. The suitable supply of nutrients, as well as the restoration of nutritional status, is extremely important, as it reduces the risk of complications at this time of children's recovery⁽²⁶⁾. The diet should be followed according to the recommendations specified during hospitalization⁽²⁶⁻²⁷⁾, with the preparation for discharge being a moment to resolve possible doubts that may arise at home.

The authors⁽²⁸⁾, when assessing the weight-height evolution of children with congenital heart disease after surgical procedure, highlighted that, in up to one year, they recover their normal developmental state. Those who presented parameters below the normal range before surgery had a significant variation in weight, height and brachial perimeter, revealing that surgical correction helped in their weight-height recovery process⁽²⁸⁾, despite being slow.

Since there are risks for occurrence of bacterial endocarditis in these children, *Teeth care* is also included in the booklet. To rule out this possibility and safeguard children's oral health, it is necessary to increase vigilance in teeth care and regarding using prophylactic antibiotics, prior to any invasive dental procedure. The dentist needs to be aware of children's clinical condition⁽²⁹⁻³⁰⁾. The susceptibility of children with heart disease to bacterial endocarditis requires preventive antibiotic prophylaxis prior to interventions, as in the case of surgical correction of heart defect. Thus, identifying risk factors for such a clinical condition and managing it through established protocols, using antibiotic prophylaxis, prevents serious complications for these patients⁽²⁹⁻³⁰⁾.

After surgery, some signs and symptoms must be observed and, when identified, children need prompt medical attention. The chart in the booklet seeks to facilitate caregivers' understanding. The written information (the booklet) made available during the preparation for children's hospital discharge has the potential to strengthen caregivers' knowledge by ensuring a printed document to be consulted at any time at home and that, in the face of any clinical change in children, there may be recognition of urgency as well as the need to seek medical attention⁽⁷⁾.

The *Return of children to normal activities* can often be an uncertainty for caregivers. Thus, the booklet provides guidance on this topic to help recognize children's needs and reactions. School activities and physical exercise are conditioned to children's abilities⁽¹¹⁾; the necessary encouragement that the family must provide so that children have the opportunity to develop

in the motor, affective, social, communicative, perceptual and cognitive aspects is not left out of the booklet⁽³¹⁾.

The information about care after a surgical procedure and activities that children will be able to develop must be well clarified. In this case, education with empowerment of caregivers for promoting children's health is strong^(6,9,12).

Without forgetting to take care of caregivers, the booklet brings *Psychological considerations* that permeate this moment in families' lives. Thus, it is necessary that they pay attention to their own physical and mental health⁽³²⁾. There was a lot of repercussion among the participants, not only in pre- and post-test, but also in reading the booklet about the information to deal with children, to recognize behaviors and their relationship with other family members.

A study⁽¹⁹⁾ emphasizes that, for mothers, care priorities are focused on children with heart disease, concentrating efforts only around them. Thus, the guilt for what they feel is revealed in feelings such as tiredness, stress, fatigue and overload, negatively affecting other children. Such evidence indicates the urge to offer support to mothers to overcome these feelings and be able to exercise their care without feeling distressed; groups of parents can be good for allowing the sharing of similar experiences^(4,19).

Study limitations

The study presents as a limitation the number of caregivers and the approach in a single health service, in addition to being quasi-experimental, in which participants were in control of themselves, with no control group.

Contributions to nursing, health, and public policy

The contribution is in the provision of educational material, complete and that provide children's guardians with knowledge to reduce occurrences that lead to new episodes of hospitalization due to complications, or even the death of this child, for situations that could be avoided. It also meets the recommendations of national and international organizations regarding individuals' empowerment to practice safe health care, in the case of children, it is their caregivers. The relevance is that the information contained in the booklet can be used both by nurses and by other health professionals who care for children with heart disease, not only at the time of hospitalization, but also after discharge, so that they are entitled to a suitable care and may develop after correction of congenital heart defect.

CONCLUSIONS

The booklet "Going home after a child's cardiac surgery" was validated and demonstrated its contribution to a special moment in children's lives and that demands extreme attention.

The aspects of care were learned, demonstrated by the significant difference between knowledge before and after the use of educational material. However, doubts related to medications persisted, evidenced by the greater occurrence of wrong answers, which reveals the urgency to work better on medication preparation and administration even during a child's hospitalization. As professionals close to children and families, it is recommended

that nurses commit to this care action and facilitate this process, generating security for caregivers to minimize the potential risk of errors at home. In line with public policies for child care,

empowering caregivers to enable correct and safe home care will result in timely care, with the potential to reduce emotional, social and financial costs due to children's health complications.

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