

# Instrument to assess educational programs for parents of children with congenital heart disease undergoing cardiac surgery

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## ABSTRACT

**Objective.** To design and validate an instrument to assess the relevance of educational programs for parents of children with congenital heart disease (CHD) undergoing cardiac surgery.

**Material and method.** In October 2011, an instrument was designed based on Kaufman's model and on the bibliography, and a survey was developed in the form of a checklist with 32 close-ended questions about received education and desired education, categorized into 5 items: educator, time, place, means, and content. The survey was reviewed by 4 academic professionals and 9 experts in the care of children with CHD, and the checklist was extended to include 42 close-ended questions and 5 open questions. The instrument was administered on the day before discharge to the parents of children with CHD undergoing cardiac surgery at the Department of Pediatrics between February and August 2013. The survey was self-administered by the first participants and administered by the investigator among the remaining participants.

**Results.** Fifty-five children met inclusion criteria; a total of 60 parents took part in the study. Agreement was observed between received education and desired education, which was statistically significant only in terms of education provided by a cardiologist ( $p=0.000$ ,  $K=0.659$ ) and in the hall ( $p=0.000$ ,  $K=0.655$ ). Statistically significant differences were observed between the 19 self-administered surveys and the 41 surveys administered by the investigator. Among the latter, a greater level of completion was observed for all items.

**Conclusion.** A validated instrument was developed to assess the relevance of educational programs for parents of children with CHD undergoing cardiac surgery. This survey should be administered by a health care provider for a better understanding of information.

**Key words:** surveys and questionnaires, training program, parents, congenital heart disease.

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## INTRODUCTION

At present, education about congenital heart disease (CHD), medical treatments, and cardiac surgery is provided by health care providers, generally in an incidental or informal manner. However, the bibliography shows that, to ensure patients' well-being following hospital discharge, it is critical for health care providers to plan relevant educational programs to make sure parents gain the minimum necessary knowledge about their child's heart disease, treatment, and measures to prevent complications.<sup>1</sup>

Based on Kaufman's hypothesis, for education to be relevant, it is necessary to assess educational needs and establish the difference between "received education" and "desired education" among users because once gaps in present educational programs are identified, more effective programs may be implemented, thus preventing users from failing to meet their educational needs with present programs.<sup>2</sup> For this reason, the first step to plan educational programs is to assess educational needs and understand that, according to this model, they account for "a gap between reality and what the investigator considers should be."<sup>2</sup>

However, no publications have been found in the bibliography that studied validated instruments to assess the relevance of educational programs for parents of children with CHD.

The objective of this study was to design and validate an instrument to assess the relevance of educational programs for parents of children with CHD undergoing cardiac surgery.

## MATERIAL AND METHOD

The process to design and validate the instrument was conducted by the Department of Pediatrics of the UC CHRISTUS Clinical Hospital in the period between October 2011 and October 2013. It consisted of three stages: instrument design, content validation, and pilot testing.

### Instrument design

According to Kaufman’s “problem solving” model (1973), educational needs may be assessed based on feedback or sensed needs or by means of specific empirical data, using different methods of interviews and questionnaires.<sup>2</sup> Instruments of choice should provide information that accounts for both polarities of “what is” and “what should be” to obtain information on results, not processes.<sup>2</sup> To this end, techniques and means should be selected, developed or created to assess needs taking into consideration three potential dimensions: nature of disease, nature of users, and nature of educators.<sup>2</sup> (Figure 1).

In this study, an instrument was developed based on Kaufman’s model to assess the relevance of an educational program using specific empirical data and considering “received education” (what it was) and “desired education” (what it should have been), and the five key elements found in system planning: educator, time, place, means, and content.<sup>2</sup>

The survey allowed to obtain data from study subjects, using a printed instrument aimed at collecting responses on the study problem; participants completed it themselves or had a

survey taker do it. The advantages of this method for data collection included its relatively low cost and ease to collect, analyze, and interpret data.<sup>3</sup>

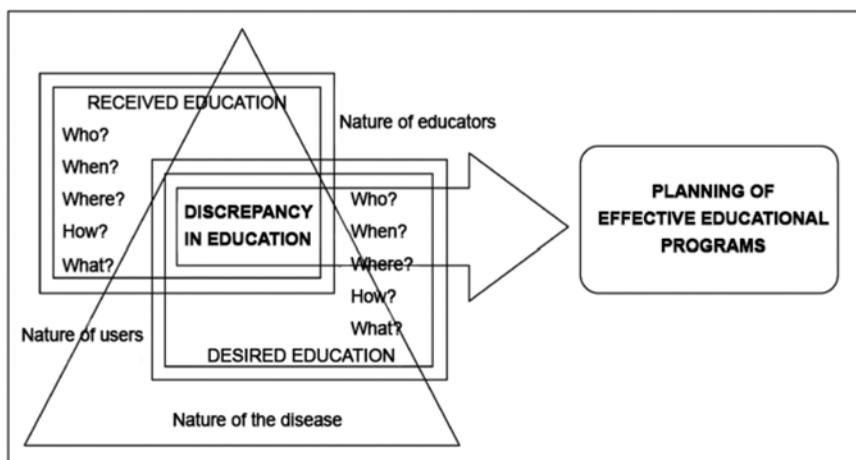
To collect information, close-ended questions with dichotomous options were used because they required less time and a lower level of skills for the survey taker, a minor effort for the surveyed participant, and simplified data tabulation, among other advantages.<sup>3</sup>

The instrument was developed based on a comprehensive bibliographic search that retrieved the elements currently recommended by international experts.

The search included the following databases: Medline / Pubmed, Lilacs, ProQuest, Cinhal, and Scielo, and was conducted between October 2011 and February 2012. Key words used were: knowledge, education, educational program, educational intervention, educational needs, parents, congenital heart disease, congenital cardiopathy. Thirty articles were selected for analysis that met the following inclusion criteria: original research and bibliographic reviews in Spanish, Portuguese, and English, and published up to 10 years ago.

Article analysis allowed to define four areas: nature of disease, nature of users, nature of educators worldwide, and the proposal of an educational program for parents of children with CHD based on the bibliography and on Kaufman’s model.<sup>4</sup> A survey was developed in the form of a checklist with 32 close-ended questions categorized into 5 items: educator, time, place, means, and content. Each question provided information that

FIGURE 1. Concept map for educational program planning based on Kaufman’s model<sup>2</sup>



accounted for the outcome measures “received education” and “desired education” among users so as to establish agreement between them.

**Item 1. Educator:**

1) Treating physician; 2) Cardiologist and heart surgeon; 3) Nurse; 4) Other member of the health care team (nutritionist, physical therapist, educational psychologist, psychologist).

**Item 2. Time:**

5) Upon admission to the referral hospital; 6) During hospitalization; 7) Upon discharge or transfer to the referring hospital.

**Item 3. Place:**

8) In the child’s room; 9) In a private room; 10) In the hall.

**Item 4. Means:**

11) Oral sessions; 12) Educational brochures; 13) Group workshops; 14) Indirect methods (videos, slides, hospital tours, Internet).

**Item 5. Content:**

*Topic 1. Overview of heart disease:*

15) Characteristics of the disease (course and prognosis); 16) Drug treatment (clinical use, dosing, adverse reactions, drug interactions); 17) Surgical treatment (type and number of surgeries required by the child).

*Topic 2. Characteristics of cardiac surgery:*

18) Preoperative assessment; 19) Type of anesthesia; 20) Potential consequences or complications of surgery; 21) Hospitalization in the intensive care unit (ICU); 22) Child’s appearance after the surgery.

*Topic 3. Care after cardiac surgery:* 23) Routine care provided by the hospital; 24) Duration of intubation and monitoring; 25) Presence of invasive devices (catheters, tubes, drainages, pacemaker leads); 26) Skin and surgical wound care; 27) Opportunity to accompany their child and become involved in his/her care (feeding, hygiene, recreational activities).

*Topic 4. Care after discharge:* 28) Return to daily living activities; 29) Prevention and detection of growth problems; 30) Prevention and detection of nutritional complications; 31) Prevention and detection of respiratory complications; 32) Prevention and detection of cardiovascular complications.

**Content validation**

During the development of the project four academic professionals (two experts in research methodology, an expert in education methodology, and an expert in the specialized

field) independently reviewed the survey.

In addition, the survey was reviewed by nine experts from different areas of care for children with CHD at a local level to establish if the checklist met its goals and whether questions were as clear as possible.<sup>3</sup>

The expert team consisted of a pediatric cardiologist, a pediatric heart surgeon, a pediatric intensivist, three nurses specialized in pediatric critical care, a nurse with a Master’s Degree in Bioethics, an educational psychologist, and a child and adolescent psychologist. Each health care provider received a printed copy of the survey together with the guidelines and instructions for carrying out the assessment. They were asked to rate each question based on theoretical adequacy and clarity, indicating a score of 0 if the question did not meet assessment criteria or 1 if it met all. In addition, they were asked to suggest changes in a clear and accurate manner. Recommendations were introduced in the survey. Finally, the survey included 42 close-ended questions; an open question was added at the end of each item to gather feedback on received education and desired education not included in the checklist, and the item “content” was moved to the first place for a better understanding of information (*Annex*).

**Pilot testing**

The instrument was administered one day prior to discharge to the parents of children with CHD undergoing cardiac surgery at the Department of Pediatrics between February and August 2013 who met the following inclusion criteria: children undergoing corrective or palliative cardiac surgery, without respiratory support, not receiving vasoactive drugs, and hemodynamically stable, and whose parents were interested in participating and had signed the informed consent. Patients with a length of stay of less than 48 hours and those transferred to another department following recovery in the unit of pediatric critical patients (UPCP) were excluded.

In the first stage, the instrument was tested in the first three participants, in the presence of the principal investigator, to verify questions’ quality in terms of understanding, individuals’ willingness to answer, time required to complete it, and clarity of instructions.<sup>3</sup>

The rest of the surveys were administered by two of the study investigators who were proficient in the project; this way, all participants

received the same instructions and explanations during the data collection period.

The survey was self-administered by the first 19 participants, who had no problems to complete it and had the chance to ask questions, as planned. However, the 20<sup>th</sup> participant required constant support to complete the survey, so the instrument was administered by the principal investigator, and difficulties in understanding the information were evidenced. Observations were discussed among investigators, who decided that the remaining surveys should be administered by the investigator. In the end, 41 participants completed the survey administered by the investigator, which indicated that they felt more comfortable and willing to answer with this modality.

The SPSS statistical software, version 17.0, was used for data analysis. A Kappa statistic was calculated to analyze agreement between the outcome measures "received education" and "desired education"; agreement was considered significant if the *p* value was <0.05 and the K value was >60. In addition, a  $\chi^2$  test was done to analyze differences between the 19 self-administered surveys and the 41 administered by the investigator, considering that a *p* value <0.05 was a significant difference.

This instrument does not require an analysis of psychometric properties to assess its reliability and validity nor an internal consistency analysis to assess homogeneity among items because it was designed to collect information on results, not processes, and it is not a measurement scale to obtain scores on the quality of received education.<sup>5,6</sup>

The study was approved by the Ethics Committee of the School of Nursing and of the School of Medicine of Pontificia Universidad Católica de Chile.

## RESULTS

A total of 122 children with CHD underwent cardiac surgery. Of these, 55 met the inclusion criteria; a total of 60 parents took part in the study.

Patients were mostly boys (52.7%), with a median age of 10 months (between 1 month old and 18 years old), referred from the public health sector (81.8%). There were no differences in the type of heart disease (52.7% had a simple heart disease, defined as a clinically relevant defect, whereas 47.3% had a complex heart disease, defined as a life-threatening defect);<sup>7</sup> most patients underwent cardiac surgery for the

first time (63%).

Participating parents were mostly mothers (81.7%), with an average age of 32.7 years (standard deviation [SD]:  $\pm 7.7$  years) and an average level of completed education of 11.8 years (SD:  $\pm 2.8$  years). There were no differences in terms of marital status (48.3% were single and 48.3% were married), number of children (33.3% had one child; 25%, two children; and 31.7%, three or more), or their occupation (45% were employed and 40% were stay-at-home parents), and most lived in an urban community (82.8%).

The instrument was administered before discharge, with a median of 1 day between the survey and actual hospital discharge (range: 0 and 37 days).

Agreement between the outcome measures "received education" and "desired education" among parents was analyzed using the Kappa statistic. A statistically significant agreement was observed only in the education provided by the cardiologist (*p*= 0.000, K= 0.659) and in the hall (*p*= 0.000, K= 0.655). However, significant results were obtained, although agreement was weaker, in relation to education provided by the pediatrician and the nurse, upon admission to the UC Clinical Hospital and during hospitalization, and regarding certain contents, such as drug treatment, surgical treatment, type of anesthesia and potential complications, potential surgery-related risks, hospitalization in the UPCP, physical appearance of the child after the surgery, routine care provided by the hospital, length of stay in the UPCP (days), and presence of invasive devices (Table 1).

In addition, differences were evidenced in the answers provided by the parents who completed the 19 self-administered surveys and the 41 surveys administered by the investigator, analyzed using the  $\chi^2$  test. Statistically significant differences were observed in questions corresponding to the 5 items for the outcome measure "received education" (Table 2) and in those corresponding to 3 items for the outcome measure "desired education" (Table 3). Besides, the rate of answers to open questions was compared between both groups; the group of parents who took the survey with the investigator provided more complete answers to all items (Table 4).

## DISCUSSION

This study describes the process to design and validate an instrument aimed at assessing the

relevance of educational programs for parents of children with CHD undergoing cardiac surgery. The instrument was strictly developed based on the minimum required information to ensure the

well-being of these patients after discharge, and was reviewed by four independent academic professionals and nine experts and pilot-tested in 60 parents.

TABLE 1. Agreement between the outcome measures "received education" and "desired education" (n= 60)

ITEMS	% DOES RECEIVE	% DOES DESIRE	KAPPA	CI (95%)
<b>EDUCATOR</b>				
Pediatrician*	91.7% (55)	98.3% (59)	p = 0.001 K = 0.314	-0.158 to 0.786
Cardiologist**	96.7% (58)	98.3% (59)	p = 0.000 K = 0.659	0.036 to 1.282
Nurse*	91.7% (55)	96.7% (58)	p = 0.030 K = 0.250	-0.191 to 0.691
Nutritionist	46.7% (28)	96.7% (58)	p = 0.923 K = -0.004	-0.090 to 0.082
Physical therapist	78.3% (47)	96.7% (58)	p = 0.323 K = 0.080	-0.134 to 0.294
Educational psychologist	18.3% (11)	88.3% (53)	p = 0.768 K = 0.013	-0.065 to 0.091
Psychologist	20% (12)	83.3% (50)	p = 0.386 K = 0.048	-0.044 to 0.140
<b>TIME</b>				
Upon admission to the UC Clinical Hospital* (lost-to-follow-up= 1)	96.6% (57)	94.9% (56)	p = 0.003 K = 0.375	-0.182 to 0.932
During hospitalization* (lost-to-follow-up= 1)	96.6% (57)	96.6% (57)	p = 0.000 K = 0.482	-0.131 to 1.095
Upon discharge or transfer to the referring hospital (lost-to-follow-up= 1)	39% (23)	96.6% (57)	p = 0.745 K = -0.012	-0.090 to 0.066
<b>PLACE</b>				
In the child's room (lost-to-follow-up= 2)	96.6% (56)	98.3% (57)	p = 0.849 K = -0.024	-0.057 to 0.009
In a private room* (lost-to-follow-up= 2)	19% (11)	56.9% (33)	p = 0.001 K = 0.301	0.136 to 0.466
In the hall** (lost-to-follow-up= 2)	29.3% (17)	37.9% (22)	p = 0.000 K = 0.655	0.453 to 0.857
<b>MEANS</b>				
Oral information	98.3% (59)	96.7% (58)	p = 0.851 K = -0.023	-0.054 to 0.008
Educational brochures	31.7% (19)	93.3% (56)	p = 0.767 K = 0.013	-0.071 to 0.097
Group workshops	11.7% (7)	78.3% (47)	p = 0.139 K = 0.070	0.009 to 0.131
Indirect methods	16.7% (10)	86.7% (52)	p = 0.734 K = 0.015	-0.063 to 0.093
<b>CONTENT</b>				
<b>Overview of heart disease</b>				
Characteristics of the heart defect	93.3% (56)	98.3% (59)	p = 0.788 K = 0.027	-0.016 to 0.070
Cause of the congenital heart disease	70% (42)	98.3% (59)	p = 0.509 K = -0.033	-0.096 to 0.030
Prognosis of congenital heart disease	70% (42)	100% (60)	p = 0.139 K = 0.071	-0.062 to 0.204
Drug treatment*	75% (45)	96.7% (58)	p = 0.013 K = 0.188	-0.039 to 0.415
Surgical treatment*	85% (51)	100% (60)	p = 0.024 K = 0.156	-0.116 to 0.428
<b>Characteristics of cardiac surgery</b>				
Preoperative assessment	96.7% (58)	96.7% (58)	p = 0.789 K = -0.034	-0.067 to -0.001
Type of anesthesia and potential complications*	68.3% (41)	96.7% (58)	p = 0.035 K = 0.139	-0.037 to 0.315
Potential risks or complications of surgery*	93.3% (56)	98.3% (59)	p = 0.000 K = 0.384	-0.151 to 0.919
Hospitalization in the UCP*	90% (54)	100% (60)	p = 0.006 K = 0.227	-0.145 to 0.599
Physical appearance of the child after the surgery* (lost-to-follow-up = 1)	79.7% (47)	96.6% (57)	p = 0.004 K = 0.242	0.214 to 0.270
<b>Care after cardiac surgery</b>				
Routine care provided by the department*	93.3% (56)	100% (60)	p = 0.001 K = 0.314	-0.158 to 0.786
Length of stay in the UCP (days)*	81.7% (49)	100% (60)	p = 0.044 K = 0.127	-0.100 to 0.354
Presence of invasive devices*	91.7% (55)	100% (60)	p = 0.002 K = 0.265	-0.152 to 0.682
Skin and surgical wound care	50% (30)	100% (60)	p = 0.329 K = 0.031	-0.030 to 0.092
Opportunity to accompany their child and become involved in his/her care	86.7% (52)	96.7% (58)	p = 0.573 K = -0.056	-0.009 to 0.121
<b>Care after discharge</b>				
Return to daily living activities	35% (21)	98.3% (59)	p = 0.169 K = -0.034	-0.101 to 0.033
Measures to prevent growth problems	36.7% (22)	98.3% (59)	p = 0.443 K = 0.019	-0.020 to 0.058
Measures to prevent nutritional problems	31.7% (19)	95% (57)	p = 0.949 K = -0.003	-0.081 to 0.075
Measures to prevent respiratory conditions	35% (21)	93.3% (56)	p = 0.664 K = 0.021	-0.069 to 0.111
Measures to prevent cardiovascular conditions	26.7% (16)	98.3% (59)	p = 0.094 K = -0.034	-0.101 to 0.033

\* Significant but weaker agreement (p < 0.05 and K < 60).

\*\* Statistically significant agreement (p < 0.05 and K > 60).

CI: confidence interval; UCP: unit of pediatric critical patients.

The results of the pilot test showed agreement only in the education provided by one educator and in one place, therefore it was established that the current educational program was not relevant. However, an even more relevant finding

in this stage was the great difference between results of the self-administered surveys and those administered by the investigator because of difficulties related to the amount and quality of data.

TABLE 2. Differences between self-administered surveys and those administered by the investigator in relation to the outcome measure "received education"

RECEIVED EDUCATION	% SELF-ADMINISTERED (n= 19)	% ADMINISTERED BY THE INVESTIGATOR (n= 41)	$\chi^2$
<b>EDUCATOR</b>			
Nutritionist	68.4%	36.6%	p = 0.021
Physical therapist	94.7%	70.7%	p = 0.036
Educational psychologist	36.8%	9.8%	p = 0.012
<b>TIME</b>			
Upon discharge or transfer to the referring hospital	78.9%	20%	p = 0.000
<b>PLACE</b>			
In the hall	56.6%	17.5%	p = 0.003
<b>MEANS</b>			
Educational brochures	57.9%	19.5%	p = 0.003
Group workshops	26.3%	4.9%	p = 0.028
Indirect methods	31.6%	9.8%	p = 0.035
<b>CONTENT</b>			
Overview of heart disease			
Cause of the congenital heart disease	89.5%	61%	p = 0.025
Care after cardiac surgery			
Skin and surgical wound care	73.7%	39%	p = 0.012
Opportunity to accompany their child and become involved in his/her care	100%	80.5%	p = 0.039
Care after discharge			
Return to daily living activities	68.4%	19.5%	p = 0.000
Measures to prevent nutritional problems	52.6%	22%	p = 0.017

TABLE 3. Differences between self-administered surveys and those administered by the investigator in relation to the outcome measure "desired education"

DESIRED EDUCATION	% SELF-ADMINISTERED (n= 19)	% ADMINISTERED BY THE INVESTIGATOR (n= 41)	$\chi^2$
<b>TIME</b>			
Upon admission to the UC Clinical Hospital	83.3%	100%	p = 0.025
<b>PLACE</b>			
In a private room	94.4%	40%	p = 0.000
In the hall	83.3%	17.5%	p = 0.000
<b>CONTENT</b>			
<b>Care after discharge</b>			
Measures to prevent nutritional problems	84.2%	100%	p = 0.028

TABLE 4. Differences between self-administered surveys and those administered by the investigator in relation to open questions

OPEN QUESTIONS	% OF ANSWERS IN THE SELF-ADMINISTERED SURVEYS (n= 19)	% OF ANSWERS IN THE SURVEYS ADMINISTERED BY THE INVESTIGATOR (n= 41)
Other contents	10.5%	68%
Other health care providers	10.5%	36.5%
Other time	0%	12.2%
Other places	0%	17%
Other means	0%	22%
Specify the indirect methods you received	10.5%	4.9%
Specify the indirect methods you desire	21%	90.2%

Although initially this instrument was planned to be self-administered to maintain participants' anonymity and remove any bias introduced by the survey taker,<sup>3</sup> the pilot test helped to establish the reality of this group of parents, who many times did not understand the information and preferred not to ask questions even though there was a health care provider willing to clear any doubts they had. For this reason, we suggest that the survey be administered by a trained survey taker because it makes it easier for participants to answer the questions and the data gathered is more complete, consistent, and easier to process.<sup>3</sup>

Users' understating of information is critical to ensure patients' well-being after discharge.<sup>1,8</sup> In this context, we find the concept of "health literacy," a social determinant defined as the skill "to understand instructions, adopt or disregard health beliefs, and practice self-care to improve care results and reduce treatment costs."<sup>9</sup> This concept becomes particularly relevant in pediatrics because health-related action outcomes are strongly associated with their parents' health literacy, who are completely responsible for their care at home once they are discharged.

In this group, health literacy poses a major challenge for the health team because these patients are referred from hospitals from different Chilean regions and therefore users have different education backgrounds. Although most participants come from the public health sector, have completed their education, are employed, and live in urban areas, there is a group of parents who have not completed their education, are stay-at-home parents, and live in rural areas, and there is even a small group who comes from the private health sector, have a higher level of education and, many times, ask to include their nanny in the educational program sessions.

Educational interventions aimed at parents and children with CHD should provide a higher level of understanding of this disease's nature, treatment, and potential complications, which will certainly have an impact on patients' follow-up, with a reduction in morbidity and mortality in this high-risk group.<sup>8,10</sup> This way, health care teams should use different strategies to convey information in a comprehensible manner to each user, also taking into account their specific characteristics so that they understand their

children's CHD, thus favoring home-based care practices, especially in relation to treatment adherence and the prevention of risk behaviors.<sup>8-12</sup>

## CONCLUSION

A validated instrument was developed to assess the relevance of educational programs for parents of children with CHD undergoing cardiac surgery. This survey should be administered by a health care provider for a better understanding of information among users. ■

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**ANNEX**  
**Instrument to assess the relevance of an educational program**

Read each question carefully and mark with an "X" the answer that best identifies you taking into account the education received by you during your child's hospitalization and the desired education.

**ITEM I: CONTENT**

**TOPIC 1: Overview of heart disease**

**a) Characteristics of the heart defect:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**b) Cause of the congenital heart disease:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**c) Prognosis of the congenital heart disease:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**d) Drug treatment (clinical use, dosing, adverse reactions, drug interactions):**

Yes  No

Do you wish you had received information about this content?

Yes  No

**e) Surgical treatment (type and number of heart surgeries that your child may require):**

Yes  No

Do you wish you had received information about this content?

Yes  No

**TOPIC 2: Characteristics of cardiac surgery**

**a) Preoperative assessment (venous line, tests, fasting, prior bath):**

Yes  No

Do you wish you had received information about this content?

Yes  No

**b) Type of anesthesia and potential complications:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**c) Potential risks or complications of surgery:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**d) Hospitalization in the unit of pediatric critical patients:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**e) Physical appearance of the child after the surgery:**

Yes  No

Do you wish you had received information about this content?

Yes  No

TOPIC 3: Care after cardiac surgery

**a)Routine care provided by the department (visiting hours, visits, standards):**

Yes  No

Do you wish you had received information about this content?

Yes  No

**b)Length of stay (days) in the unit of pediatric critical patients:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**c)Presence of invasive devices (catheters, tubes, drainages, leads):**

Yes  No

Do you wish you had received information about this content?

Yes  No

**d)Skin care and surgical wound care:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**e)Opportunity to accompany your child and become involved in his/her care (feeding, hygiene, recreational activities):**

Yes  No

Do you wish you had received information about this content?

Yes  No

TOPIC 4: Care after discharge

**a)Return to daily living activities:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**b)Measures to prevent growth problems:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**c)Measures to prevent nutritional problems:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**d)Measures to prevent respiratory conditions:**

Yes  No

Do you wish you had received information about this content?

Yes  No

**e)Measures to prevent cardiovascular conditions:**

Yes  No

Do you wish you had received information about this content?

Yes  No

Please indicate if you received information and you wished you had received information about some other content not included in this list:

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**ITEM 2: EDUCATORS**

**a) Pediatrician:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

**b) Cardiologist:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

**c) Nurse:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

**d) Nutritionist:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

**e) Physical therapist:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

**f) Educational psychologist:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

**g) Psychologist:**

Yes  No

Do you wish you had received information from this health care provider?

Yes  No

Please indicate if you received information and you wished you had received information from other health care provider not included in this list:

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**ITEM 3: TIME**

**a) Upon admission to the UC Clinical Hospital:**

Yes  No

Do you wish you had received information at this time?

Yes  No

**b) During hospitalization:**

Yes  No

Do you wish you had received information at this time?

Yes  No

**c) Upon discharge or transfer to the referring hospital:**

Yes  No

Do you wish you had received information at this time?

Yes  No

Please indicate if you received information and you wished you had received information at some other time not included in this list:

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**ITEM 4: PLACE**

**a)In the child's room:**

Yes  No

Do you wish you had received information in this place?

Yes  No

**b)In a private room:**

Yes  No

Do you wish you had received information in this place?

Yes  No

**c)In the hall:**

Yes  No

Do you wish you had received information in this place?

Yes  No

Please indicate if you received information and you wished you had received information in some other place not included in this list:

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**ITEM 5: MEANS**

**a)Oral information:**

Yes  No

Do you wish you had received information by this means?

Yes  No

**b)Educational brochures:**

Yes  No

Do you wish you had received information by this means?

Yes  No

**c)Group workshops:**

Yes  No

Do you wish you had received information by this means?

Yes  No

**d)Indirect methods (videos, slides, hospital tours, Internet):**

Yes  No

Please, specify.

Do you wish you had received information by this means?

Yes  No

Please, specify.

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Please indicate if you received information and you wished you had received information by some other means not included in this list:

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