






The eXpectations of Parents regarding Anesthesiology Study (XPAS) from a parental perspective: a two-phase observational cross-sectional cohort study

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Abstract

Background: Uncertainty concerning anesthetic procedures and risks in children requiring anesthesia may cause concerns in parents and caregivers.

Aims: To explore parental expectations and experiences regarding their child's anesthesia using questionnaires designed with parental input.

Methods: This observational cross-sectional cohort study included parents (including caregivers) of children undergoing anesthesia in a tertiary pediatric referral university hospital. The study consisted of two phases. In Phase 1, we developed three questionnaires with parental involvement through a focus group discussion and individual interviews. The questionnaires focused on parental satisfaction, knowledge, concerns, and need for preparation regarding their child's anesthesia. In Phase 2, independent samples of parents completed the questionnaires at three time points: before the preanesthesia assessment (T1), 2 days after the preanesthesia assessment (T2), and 4 days after the anesthetic procedure (T3).

Results: In Phase 1, 22 parents were involved in the development of the questionnaires. The three questionnaires contained 43 questions in total, of which 10 had been proposed by parents. In Phase 2, 78% (474 out of 934) parents participated at T1, 36% (610 out of 1705), at T2 and 34% (546 out of 1622) at T3. Parental satisfaction scores were rated on a visual analogue scale for the preanesthesia assessment with a median of 87/100, and with a median of 90/100 for the anesthetic procedure (0: not satisfied and 100: satisfied). Parental concerns were rated with a median of 50/100 (0: no concerns and 100: extremely concerned). Parental answers from the questionnaire at T2 revealed significant knowledge deficits, with only 73% reporting that the anesthesiologist was a physician. Parents preferred to receive more information about the procedure, especially regarding the intended effects and side effects of anesthesia.

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Conclusions: Overall, parental satisfaction scores regarding the pediatric anesthesiology procedure were high, with a minority expressing concerns. Parents indicated a preference for their child's anesthesiologist to visit them both before and after the anesthetic procedure. Parental expectations regarding anesthesia did not completely correspond with the information provided; more information from the clinician about the intended effects and side effects of anesthesia was desired.

KEYWORDS

anesthesiology, expectations, parents, patient satisfaction, pediatrics, preoperative care

1 | INTRODUCTION

Preanesthesia screening in the outpatient setting is an approach to improve clinical care. During this visit, the patients' health is assessed in relation to the risks of surgery and anesthesia, and informed consent is obtained from the patient.¹ An optimized perioperative plan and a risk inventory are made, based on the patient's medical records, clinical interviews, physical examination, and additional tests.²

A prerequisite for obtaining informed consent is that the patient fully understands the medical care provided by the anesthesiologist. In pediatric medical care, this concerns both the patient and their parents or caregivers.¹ The information provided during the preanesthesia assessment mainly involves the operative procedure and the induction of anesthesia, whereas other responsibilities of the anesthesiologist, such as monitoring the hemodynamic vital functions, are often not explained.¹ Previous research showed that many parents are unfamiliar with the responsibilities of the anesthesiologist.³⁻⁵

In terms of parental concerns, a previous study about parental perception of the effects of anesthesia on their child showed that 40% of the parents were concerned about their child's neurodevelopment after anesthesia.³ Indistinctness about the anesthetic procedures, the responsibilities of the anesthesiologists and the possible risks of anesthesia for children may lead to questions, uncertainty and anxiety among children and their parents.^{4,6-8} The latter is of importance, since preoperative parental anxiety is strongly associated with their child's anxiety.^{9,10}

Thus far, most research has assessed the expectations and experiences of parents from an anesthesiologist's point of view.³⁻⁸ To our knowledge, there is a lack of studies that have included the point of view of parents in the development of questionnaires regarding their expectations and experiences regarding pediatric anesthesia.¹¹ Insight into parental perspectives about pediatric anesthesia would enable the identification of areas of parental concerns which would allow for anxieties to be addressed and allayed proactively.¹²

The aim of our study was two-fold: first, we sought to explore parental expectations and experiences regarding their child's anesthesia. Second, we sought to quantify the prevalence of these expectations and experiences in a population of parents whose

children were undergoing anesthesia at a tertiary pediatric hospital. Post hoc, we analyzed the associations between parental concerns with age of the parents and patients, the education level of the parents, and the degree of severity of the medical procedure.

2 | METHOD

The study protocol was approved by the local Medical Ethics Committee of Erasmus Medical Center (MEC-2019-0240, Rotterdam, the Netherlands). Informed consent was obtained from the parents before the start of each questionnaire.

This observational cross-sectional cohort study was set up according to the Equator Network STROBE guidelines. In consecutive order, parents and caregivers of pediatric patients scheduled for anesthesia (hereafter referred to collectively as "parents") were invited to participate. The study had two phases. The aim of Phase 1 was to develop questionnaires using information from a focus group discussion and individual interviews with parents.¹³ In Phase 2, the XPAS (eXpectations of Parents regarding Anesthesiology Study) questionnaires developed in Phase 1 were distributed among a larger group of parents (Figure 1).^{12,14}

The study was conducted from March 2019 to January 2020 in a children's tertiary referral university hospital (Erasmus MC-Sophia Children's Hospital, University Medical Center, Rotterdam, The Netherlands), which serves the inhabitants of the southwest part of the Netherlands.

As standard care in our clinic, children and their parents visit with an attending anesthesiologist or anesthesiology resident at the preanesthesia outpatient clinic, within a maximum of 6 months before a scheduled medical procedure requiring anesthesia. All patients visit the outpatient clinic, except those undergoing an emergency surgery, patients who are bedridden, or patients who were screened less than 6 months beforehand for a similar procedure. The group who had recently undergone surgery is assessed through a telephonic consultation with the parents.

During the preanesthesia consultation, parents and patients receive information about the anesthetic procedure. At the end of the consultation, paper brochures with information about anesthesia, analgesia, side effects, and the role of the anesthesiologists are provided. Due to high case volumes, the anesthesiologist performing

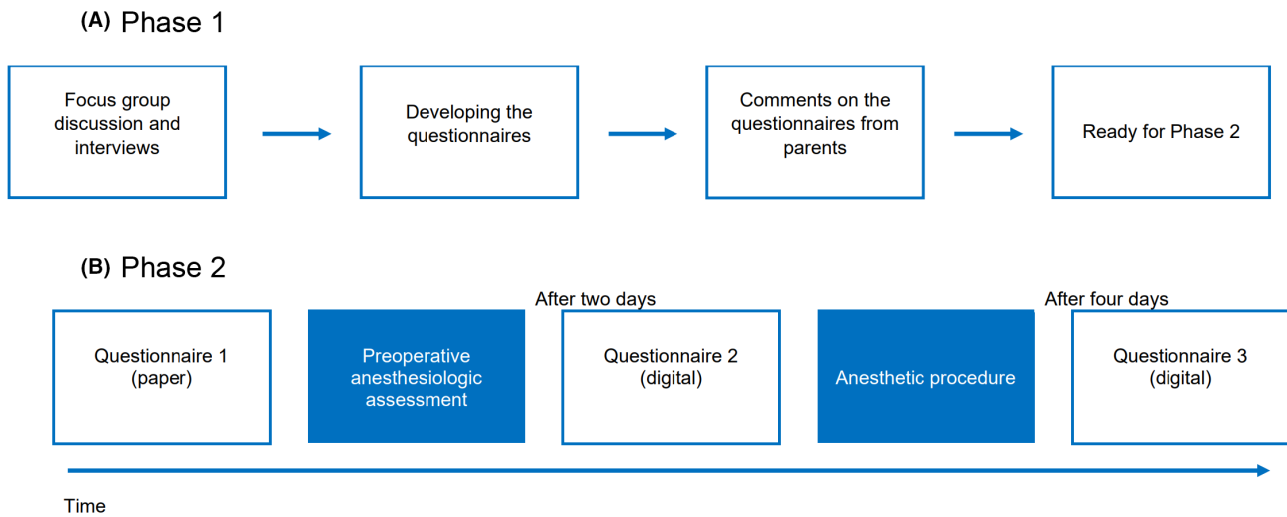


FIGURE 1 Flowchart study protocol for Phase 1 and Phase 2.

the consultation in the outpatient clinic is generally not the same provider performing the anesthetic procedure.¹⁵ On the day of the procedure, parents meet the attending anesthesiologist assigned to their child's case first at the holding area or in the operating room. One parent is allowed to be present during the induction of anesthesia. The anesthesiologist only visits or contacts the patient after the anesthetic procedure if complications occur, or out of personal preference.

2.1 | Phase 1: Development of the questionnaires

2.1.1 | Study population

From March 21, 2019 to May 10, 2019, during standard opening hours, one researcher (DS) invited all consecutive parents who visited the preanesthesia outpatient clinic or whose child had been hospitalized to participate in a focus group discussion or to be interviewed individually. As standard of care, parents had to complete a standardized questionnaire for the preanesthesia outpatient clinic, which contained questions on patient demographics and medical history. The standardized questionnaire was available only in the Dutch language at an intermediate level (B1).¹⁶ If parents experienced difficulties understanding or completing this questionnaire, the parent was deemed ineligible and excluded from the study.

2.1.2 | Study protocol

The focus group discussion was led by a psychologist (KD) in the presence of DS and a pediatric anesthesiologist (JdG) and was audio-recorded for offline analysis afterwards. The main purpose of the focus group discussion was to obtain information on parental satisfaction with pediatric anesthesiology, to understand if certain aspects of perioperative care were not clear, and to generate important

topics for subsequent questionnaire development. Parents were encouraged to share their feelings, thoughts, opinions, emotions, and concerns regarding anesthesia for their child. The discussion was structured into the following topics: knowledge and expectations of anesthesiology, concerns regarding pediatric anesthesia, and the need for information and preparation for anesthesia.

To increase the number of participants in Phase 1, one researcher (DS) approached parents consecutively whose children were admitted to the hospital surgical ward between April 25, 2019 and May 10, 2019 in individual semistructured interviews on the same topics discussed in the focus group (Figure 1A).

The audio-recorded focus group discussions and individual interviews were transcribed and analyzed by categorizing each statement. Subsequently, three questionnaires were designed based on the information acquired in the focus group discussion and individual interviews. The questionnaires were sent for feedback to parents who had participated in the focus group and individual interviews, as well as to other parents who were willing to comment. Parents could comment on the relevance and clarity of the questions and the desirability for more multiple-choice options. They were also invited to give feedback on the length of the questionnaires, the logical order of the questions, and to suggest topics that should be added. The comments were incorporated into the final version of the XPAS questionnaires (Figure 1A).

2.2 | Phase 2: Assessing the parent-reported questionnaires

The XPAS questionnaires 1, 2, and 3 of Phase 2 were delivered to separate cross-sectional samples at three distinct time points to the universe of parents of consecutive children undergoing anesthesia between July 2, 2019 and January 10, 2020. Though a child could have been accompanied by more than one parent, no more than one questionnaire at each time point was filled out for each child.

XPAS questionnaire 1 (Q1) was presented on paper to all parents in the waiting room of the preanesthesia outpatient clinic by a clinical assistant upon registration, prior to visiting with the pediatric anesthesiologist (T1). Prior to the consultation with the anesthesiologist, the completed questionnaires were collected by the same clinical assistant. This questionnaire was not emailed, since the preanesthesia outpatient clinic allows consultations without appointments and thus many consultations were not scheduled. XPAS questionnaire 2 (Q2) was emailed 2 days after the preanesthesia outpatient clinic visit (or after the telephonic consultation) to the parent registered as contact person of the patient (T2). XPAS questionnaire 3 (Q3) was emailed 4 days after the anesthetic procedure to the parent registered as the contact person of the patient (T3, Figure 1B). A reminder email was sent a week later for both digital questionnaires, which could be completed up to 2 weeks after the initial delivery. Parents received each XPAS questionnaire once, even if their child visited the preanesthesia outpatient clinic or had an anesthetic procedure more than once in the defined period. Since parents could be introduced into this study at different time points, not all parents received all three questionnaires. Parents who declined to fill in a questionnaire or could not complete the questionnaires because they could not read Dutch language at an intermediate level were excluded. For Q2 and Q3, parents whose personal email addresses were not available in the hospital electronic system were excluded.

Study data were managed using electronic data capture tools hosted at Erasmus Medical Center (Gemstracker¹⁷). The questionnaires were distributed using the online open-source software for online surveys LimeSurvey (<https://www.limesurvey.org>).

In addition, basic questions regarding parental demographics (age, sex, and highest education level), child's demographics (age and details of the medical procedure), and previous parental satisfaction with pediatric anesthesiology were included in the first questionnaire the parents received (see Appendices 1 and 2); this demographic data were then linked to responses to Q2 and Q3 via unique respondent identifiers.

In each of the three XPAS questionnaires, the last section contained the standardized questionnaire PROMIS v1.0 Anxiety Short Form 8a¹⁸ with eight questions regarding the level of anxiety parents had experienced for the past 7 days. The scores were translated into *T*-scores, with a mean of 50 and a standard deviation (SD) of 10. A *T*-score of 50 represents a normal anxiety state (not anxious). The higher the *T*-score, the higher the anxiety state.

The degree of severity for each medical procedure the patient underwent was based on the sum of scores of the duration (<1 h=1 point, ≥1 h=3 points, and unknown=0 points), postoperative admission (outpatient department=1 point, general hospital ward=2 points, intensive/high care unit=3 points, and unknown=0 points), and indication of emergency (no emergency=1 point, emergency=3 points, and unknown=0 points). The points were added up and classified into degrees (minor severity 0–3 points, intermediate severity 4–6 points and major severity 7–9 points). If a patient scored 3 points on at least one of

the items, they were automatically assigned a minimum degree of “intermediate severity”.

2.3 | Statistical analysis

All analyses were performed using the IBM SPSS statistical software (version 25). The collected data of each XPAS questionnaire (Q1, Q2, and Q3) were analyzed as separate cohorts. Descriptive analyses were used to analyze the quantitative data from the XPAS questionnaires. Data are presented as median and interquartile range [IQR]. Questions left unanswered were considered missing data.

For Q2, we performed statistical analyses using Spearman's correlation coefficient to determine the relationship between the VAS score of parental concerns with age of the parents and patients, the sex and education level of the parents, and the degree of severity of the medical procedure of the patients. The Wilcoxon/Mann-Whitney *U* test was used to compare the VAS scores of parental concerns between male and female parents. Nonparametric tests were selected because it was anticipated that the data would violate the assumptions of normality. A *p*-value of <0.05 was considered statistically significant.

3 | RESULTS

3.1 | Phase 1: Development of the questionnaires

Three out of approximately 250 invited parents participated in the focus group discussion and 16 parents were individually interviewed. Five parents—two of which had participated in the focus group discussion—reviewed the developed questionnaires. Three of these five parents had neither participated in the focus group discussion nor in individual interviews. The main reason for nonparticipation in Phase 1 was parental unwillingness to commute to the hospital for the purpose of research. Thirteen of all 22 parents (59%) who participated in Phase 1 were female (Table 1) with a median age of 41 (38–48) years. Their children were scheduled for medical procedures with the degree of severity of minor (2/15, 13%), intermediate (8/15, 50%), and major (5/15, 31%).

3.2 | Knowledge and expectations of general anesthesiology

Among parents whose child had anesthesia previously, most parents reported positive past experiences. Two couples without previous experience stated that they were nervous for their child's procedure and did not know what to expect. Parental knowledge of the anesthesiologist's responsibilities during a medical procedure varied, from only knowing about induction of anesthesia to the many needed requirements for maintaining hemodynamic stability.

TABLE 1 Parents and children demographics.

XPAS questionnaire	Parents involved in the development of the questionnaires	Parents who completed the questionnaires		
		Q1	Q2	Q3
N	22	374 one parent, 100 two parents	603	539
Focus group	3			
Interview	16			
Feedback	3 ^a			
Sex (missing)	(0)	(3)	(4)	(0)
F	13 (59%)	294 (79%, one parent), 100 (50%, two parents)	495 (82%)	442 (82%)
Age (years) ^b (missing)	41 [38–48] (0)	37 [32–43] (7) 37 [32–45] (1)	38 [33–44] (9)	38 [33–45] (17)
Education (missing)	(0)	(0)	(5)	(12)
Did not finish education	0 (0%)	11 (2%)	7 (1%)	3 (1%)
Primary School	0 (0%)	4 (1%)	7 (1%)	2 (0%)
High School	1 (5%)	41 (9%)	51 (8%)	41 (8%)
Middle Secondary Education	8 (36%)	201 (42%)	240 (40%)	209 (39%)
Upper Secondary Education	10 (45%)	146 (31%)	181 (30%)	178 (33%)
University	3 (14%)	61 (13%)	101 (17%)	86 (16%)
I prefer not to answer this question	0 (0%)	10 (2%)	11 (2%)	8 (2%)
Anxiety score ^c (missing)		49 (14) (0, one parent) 48 (15) (0, two parents)	52 (9) (24)	52 (9) (27)
XPAS questionnaire	Children of parents involved in the development of the questionnaires	Children of parents who completed the questionnaires		
		Q1	Q2	Q3
N	16	474	603	539
Age (years) ^b (missing)	6.5 [1–15] (0)	5 [1–10.25] (0)	6 [1–11] (4)	6 [1–12] (33)
Indication for anesthesia				
Abdominal surgery	2 (13%)	25 (5%)	34 (6%)	33 (6%)
Cardiothoracic surgery	2 (13%)	18 (4%)	22 (4%)	41 (8%)
Ear, nose, throat (ENT) Surgery	1 (6%)	79 (17%)	105 (17%)	75 (14%)
Eye surgery	1 (6%)	12 (3%)	9 (1%)	8 (1%)
General surgery	0 (0%)	45 (9%)	33 (5%)	52 (10%)
MRI/CT/other radiologic assessment	0 (0%)	55 (12%)	78 (13%)	62 (12%)
Neurosurgery	1 (6%)	17 (4%)	33 (5%)	28 (5%)
Oral and maxillofacial surgery	0 (0%)	16 (3%)	16 (3%)	21 (4%)
Orthopedic surgery	3 (19%)	74 (16%)	87 (14%)	71 (13%)
Plastic surgery	0 (0%)	51 (11%)	76 (13%)	65 (12%)
Urological surgery	5 (31%)	69 (15%)	76 (13%)	64 (12%)
Other	0 (0%)	12 (3%)	28 (5%)	17 (3%)
I prefer not to answer this question	1 (6%)	1 (0.2%)	6 (1%)	2 (0%)
Scheduled type of medical procedure (missing) ^d	(1)	(0)	(4)	(33)
Minor	2 (13%)	276 (58%)	325 (54%)	203 (38%)
Intermediate	8 (50%)	172 (36%)	232 (38%)	225 (42%)
Major	5 (31%)	26 (6%)	42 (7%)	78 (14%)

Note: Missings are represented as numbers (n).

^aTwo parents who participated in the focus group gave feedback as well. Thus, in total, 5 parents gave comments on the questionnaires.

^bMedian [IQR25–IQR75].

^cT-score (Standard Deviation), from PROMIS v1.0 Anxiety Short form 8a.

^dDuration (<1 h = 1 point, >1 h = 3 points, unknown = 0 points), postoperative admission (outpatient department = 1 point, general hospital ward = 2 points, intensive/high care unit = 3 points, unknown = 0 points) and indication of emergency (no emergency = 1 point, emergency = 3 points, unknown = 0 points). The points were added up and classified into degrees (minor severity 0–3 points, intermediate severity 4–6 points and major severity 7–9 points). If a patient scored 3 points on at least one of the items, they were automatically assigned a minimum degree of "intermediate".

3.3 | Concerns regarding pediatric anesthesia

Parental concerns varied from not being concerned at all to being very concerned. They proposed different options to reduce these concerns, which were used for the multiple-choice questions in the Phase 2 XPAS questionnaires (Appendix 3). Factors that had positively influenced their experiences were incorporated as multiple-choice answers in the Phase 2 XPAS questionnaires as well.

3.4 | The need for information and preparation of anesthesia

Parents reported that they received most information during the preanesthesia assessment or through brochures distributed by the Department of Pediatric Anesthesiology. Several parents stated they would like to receive information through other mediums as well. Their suggestions were incorporated in the multiple-choice answers in the Phase 2 XPAS questionnaires. Nevertheless, two couples stated that their questions before the procedure were left unanswered. Parents had different opinions on which topics to be discussed during the preanesthesia assessment.

3.5 | XPAS questionnaires

The three XPAS questionnaires contained 11 questions suggested by the researchers and two questions based on a review of the literature.^{7,19-21} The focus group discussion and individual interviews resulted in the development of seven additional questions and answer options of three multiple-choice questions. The questionnaires contained four types of questions: basic questions (parental demographics and satisfaction with pediatric anesthesia), knowledge and expectations of anesthesiology, concerns regarding their child receiving anesthesia, and need for information and preparation for anesthesia (Appendix 3). The researchers used a combination of dichotomous (yes/no), multiple-choice, and 10-centimeter visual analogue scales (VAS, with a score from 0 to 100) for the answer responses.

3.6 | Phase 2: Assessing the parent-reported questionnaires

3.6.1 | Demographics

The three questionnaires were completed by mostly women (ranging from 79% to 82% of the respondents), who had finished middle secondary education (range: 39% to 42%) and whose median age was 37 (Q1) and 38 (Q2, Q3) years. The median age of the child undergoing anesthesia was 5 years old in Q1 and 6 years old in Q2 and Q3. The degree of severity of the medical procedure was mostly

rated as minor in Q1 and Q2 (58% and 54%, respectively) and intermediate in Q3 (42%, Table 1).

3.6.2 | XPAS questionnaire 1

Parents of 86 of the 934 children scheduled at the preanesthesia outpatient clinic were excluded because the consultation was held by telephone, or they did not show up. Parents of 605 of the 848 children that visited the outpatient clinic for the preanesthesia assessment were invited to complete the questionnaire. Eventually, 474 parents completed the questionnaire: 374 were completed by one parent and 100 by two parents (response rate 78%, Appendix 4, Figure A1).

For parents who filled out the questionnaires alone, the mean parental anxiety *T*-score was 49 (SD 14); among parents who completed the questionnaire together, the mean *T*-score was 48 (SD 15, Table 1).

Almost all suggested topics to be discussed at the preanesthesia assessment were rated with a median score of 80 or higher, indicating a preference for these topics to be discussed (Figure 2; a score of 100 signified that the topic must be discussed). The one exception was the topic "responsibilities of an anesthesiologist during the medical procedure" (median score: 69).

3.6.3 | XPAS questionnaire 2

The response rate for Q2 was 36% (610/1705 parents, Appendix 4, Figure A2), and the data of 603 questionnaires were included for analysis. In total, 3% (57/1705) of the parents declined to participate, and 10% (206/2057) email addresses were missing in the patient registration system. The mean parental anxiety *T*-score was 52 (SD 9, Table 1).

The preanesthesia assessment satisfaction topic was rated with a median of 87 [75-100] (where 100 signified satisfied, Figure 3).

Seventy-three percent of the parents reported that an anesthesiologist was a physician, while 12% reported an anesthesiologist was a nurse (Figure 4). Ninety-two percent were aware that anesthesiologists provide and maintain anesthesia, while 41% knew that this includes intubation and 22% knew that this includes transfusing blood to the patient (Figure 5).

Parents rated their need for information about the responsibilities of an anesthesiologist with a median score of 52 [12-78] (where 100 signified that the parent felt that this information must be discussed) and preferred to receive this through informational brochures (55%), at the preanesthesia assessment (42%) and through the hospital's website (36%, Appendix 5, Figure A4).

The median score for parental concerns regarding their child receiving anesthesia was 50 [15-74] (where 100 signified extremely concerned, Table 2). There was a significant decrease in VAS for concerns with an increase in the age of the parent (Spearman's ρ -0.113, $p < 0.012$) and increase in the age of the child undergoing anesthesia

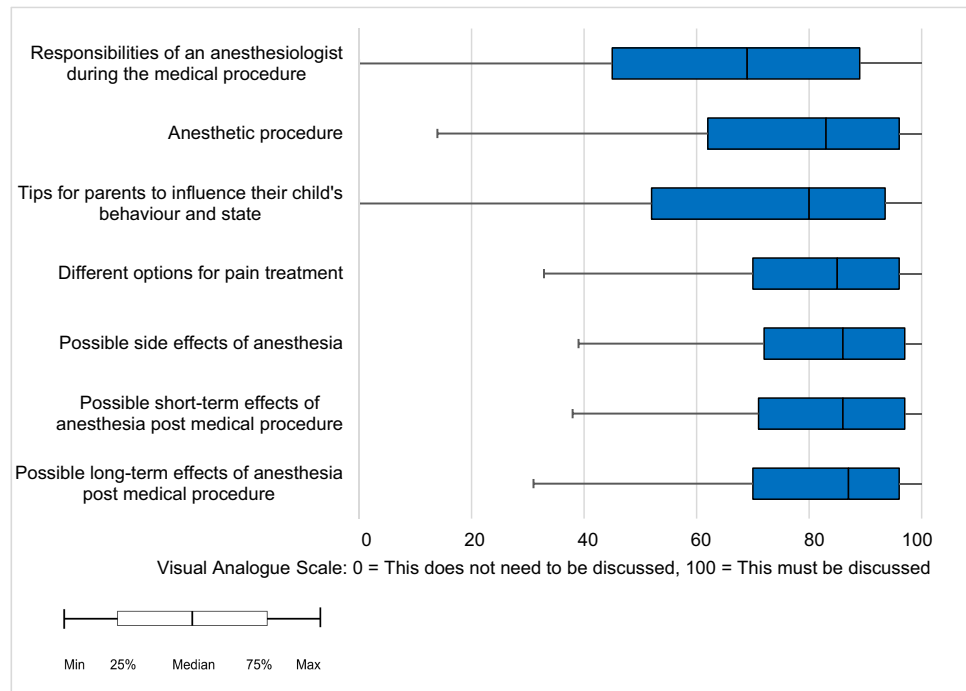


FIGURE 2 Boxplots of the visual analogue scale for subjects to discuss during the preanesthesia anesthesiology assessment with the pediatric anesthesiologist according to parents.

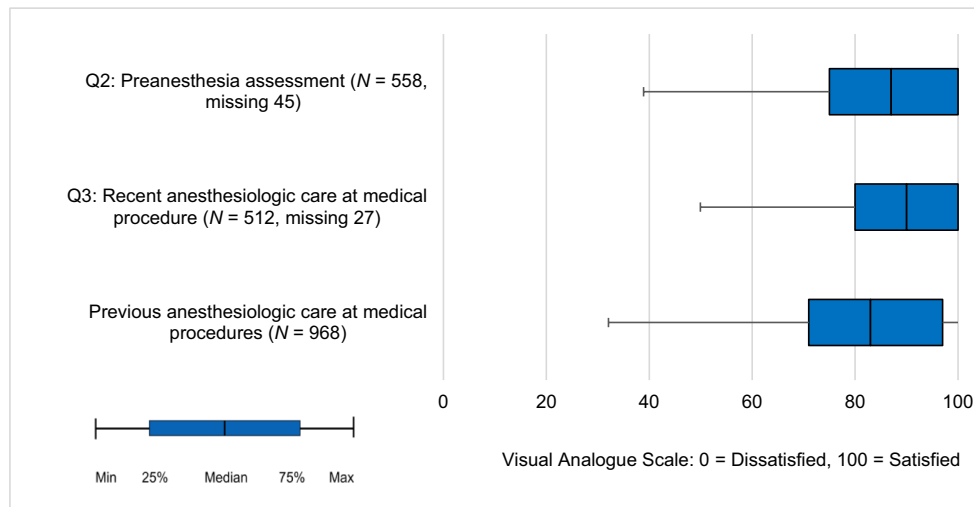


FIGURE 3 Boxplots of parents' satisfaction scores, rated on a visual analogue scale. Q2: XPAS questionnaire 2–2 days after the preanesthesia outpatient clinic visit or after the telephonic consultation. Q3: XPAS questionnaire 3–4 days after the anesthetic procedure. Previous anesthesiologic care at medical procedures was stated as from before the recent anesthesiologic care.

(Spearman's ρ -0.149 , $p < 0.001$). The VAS for concerns also had a significant increase with increase in degree of severity of the medical procedures of the patients (Spearman's ρ -0.093 , $p < 0.039$). There was no significant relationship between the sex and the education level of parents in relation to VAS concerns. Forty percent of the parents indicated that their concerns were related to the stress invoked by their child undergoing the anesthetic procedure and stated this was difficult to ease. Moreover, 17% would have liked to speak to the anesthesiologist assigned to their child just before and/or after the anesthetic procedure (Appendix 6).

More than a quarter of the parents stated they did not know whether anesthesia would cause short-term problems (28%), long-term problems (28%), or negatively affect neurodevelopment (34%, Table 2). Fifteen percent of the parents suspected that anesthesia has short-term consequences, such as nausea, fatigue, and anxiety. Five percent suspected long-term consequences of anesthesia, such as the child's fear for subsequent anesthetic procedures or problems with concentration or sleep. Only 3% of the parents thought that anesthesia could harm their child's neurodevelopment. Most of the parents would have liked to receive

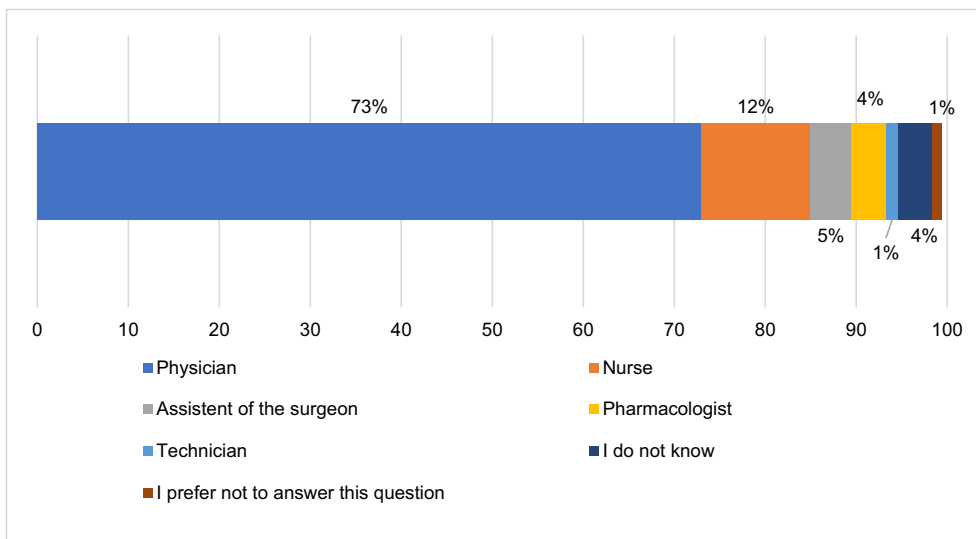


FIGURE 4 Descriptions of an anesthesiologist according to parents.

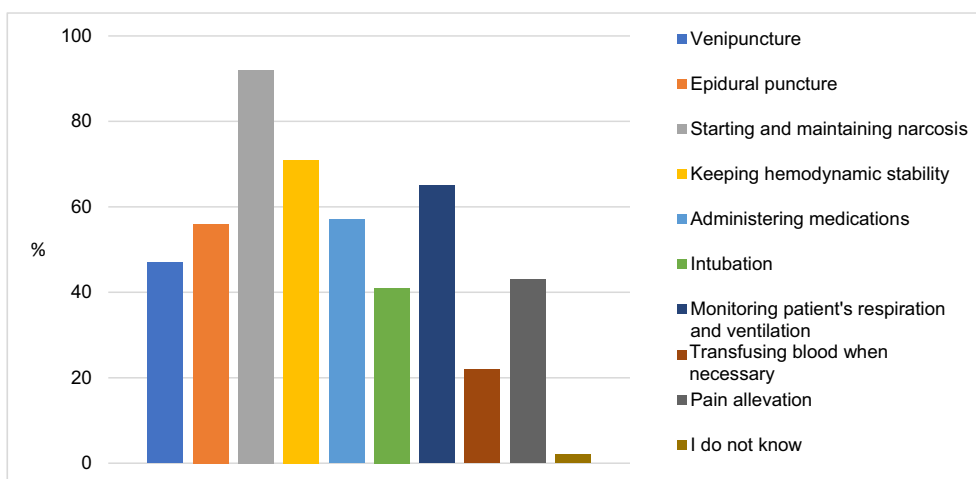


FIGURE 5 The responsibilities of an anesthesiologist according to parents. Multiple answers could be selected.

more information about the intended effects and side effects of anesthesia (median score 72 [19–90]). Those parents wished to receive it through informational brochures (61%), at the preanesthesia assessment (51%) and the hospital's website (32%, Appendix 5, Figure A4).

3.6.4 | XPAS questionnaire 3

The response rate for Q3 was 34% (546/1622 parents, Appendix 4, Figure A3); the data of 539 questionnaires were used for analysis. In total, 2% (37/1622) of the parents declined to participate, and 18% (438/2460) email addresses were missing in the patient registration system. The parental mean anxiety T-score was 52 (SD 9, Table 1).

Satisfaction with the anesthesiologic care during the recent medical procedure was rated with a median of 90 [80–100] (Figure 3). Those who had previous experience with pediatric anesthesiology rated the satisfaction with a median of 83 [71–97].

Parents reported multiple methods for preparing their child for anesthesia: including attending the preanesthesia assessment (69%), reading informational brochures (32%), and accessing the hospital's website (21%, Appendix 7). Sixteen percent of the parents did not prepare themselves; 69% of them stated they already had experiences with their child receiving anesthesia.

Most parents prepared their child for the anesthetic procedure by explaining the whole procedure to their child themselves (45%, Appendix 8), while 34% of the parents refrained from preparing their child; for instance, because the child was too young to understand or because the child had previous experiences with anesthesia.

TABLE 2 Parental concerns regarding the influence of anesthesia.

N = 500	Median (missing)	IQR25–IQR75
Parental concerns (VAS)	50 (103)	15–74
N = 591		Frequency
Short-term problems		
No		333 (55%)
Yes		88 (15%)
I do not know		163 (28%)
I prefer not to answer this question		6 (1%)
Long-term problems		
No		389 (66%)
Yes		29 (5%)
I do not know		167 (28%)
I prefer not to answer this question		5 (1%)
Negative influence on neurodevelopment		
No		370 (63%)
Yes		15 (3%)
I do not know		202 (34%)
I prefer not to answer this question		3 (1%)

4 | DISCUSSION

In this two-phase observational cross-sectional study among parents of children receiving anesthesia, parents were involved in the development of questionnaires containing items designed to assess potential concerns and experiences regarding anesthesia, and these questionnaires were distributed among a larger group of parents.

4.1 | Parental satisfaction

Overall, in our study, parental satisfaction around the pediatric anesthesiology procedure were positive, and participants expressed satisfaction with the pediatric anesthesiologic care. These results are comparable to other observational studies from the United States and Italy (both conducted at tertiary referral university hospitals), which showed similarly high parental satisfaction scores regarding pediatric anesthesiology, with a mean of 9.0 or higher out of 10 for every evaluated area.^{22,23}

4.2 | Parental knowledge and expectations of anesthesiology

We found that more than a quarter of the parents (27%) did not know that their anesthesiologist was a physician. We additionally found that parents were not fully aware of the responsibilities of an anesthesiologist. In a previous study at a University Hospital and Children's Hospital in Lithuania, 22% of the parents indicated

they did not know that anesthesiologists were physicians.¹⁹ Studies in adult patients exhibited similar results: a study from hospitals in Australia, Germany, and United States showed that a substantial percentage of patients did not know that an anesthesiologist was a physician (ranging from 17% to 42%).²¹ Another study in adult patients scheduled for elective surgery concluded that the patients' knowledge of the anesthesiologist's responsibilities was limited; 14% of the respondents did not know that anesthesiologists have medical degrees.²⁰ In spite of the documented lack of knowledge on the responsibilities of an anesthesiologist, the parents in our study were not very interested in receiving more information on the topic. We recommend that as a principle of informed consent, parents should be fully informed about the responsibilities of the anesthesiologist prior to consenting to their child's anesthetic procedure.

4.3 | Parental concerns regarding pediatric anesthesia

From the questionnaire results, we found that the parents were in general not very concerned nor anxious about their child's anesthetic procedure. This finding is in contrast to other studies, in which parents reported perioperative anxiety regarding the surgery, anesthesia, postoperative pain, and hospitalization.^{4,8,24} In a study from Great Britain's Royal Aberdeen Children's Hospital, 61 out of 100 parents stated they were anxious for their child receiving anesthesia; for nearly half of these parents, their anxiety was stated as quite or very anxious. These parents were approached as their child was admitted to the hospital for their surgery.⁴ The discrepancy with our findings could be due to the difference in assessment timing. Parents in our study did not complete the questionnaires on the day of the anesthetic procedure. Our questionnaires were sent after visiting the preanesthesia outpatient clinic (which was usually a few weeks before the procedure), and 4 days after the procedure. Parents who admitted being anxious preoperatively stated they would like to have a talk with the anesthesiologist just before or after the anesthetic procedure. Therefore, we encourage anesthesiologists to make contact before and after the procedure with parents to alleviate anxiety. In clinical practice, anesthesiologists evaluate the procedure at the end of surgery with the surgery and anesthetic team (as part of a sign-out of procedure). In this process, postoperative instructions for nurses and parents are recorded in the electronic health record keeping system before the patient is transferred to the recovery room. In most cases, the anesthesiologists do not have the opportunity to visit the patient and their parents after discharge from the recovery room, because they are occupied with the next procedure. Unfortunately, in this study we did not collect data regarding the frequency and content of postprocedural visits by anesthesiologists, nor rates of complications.

The present results show that only a low proportion of parents indicated being concerned about the effects on anesthesia

on short-term (15%) and long-term (5%) health outcomes, and on neurodevelopment (3%). By contrast, in a study at a Children's Hospital in Singapore, 20% of the parents were very concerned that general anesthesia would affect their child's neurodevelopment. These parents were approached on the same day of their child's surgical procedure, in the waiting room of the operating theater or in the recovery area.³

4.4 | Parental need for information and preparation for anesthesia

In the present study, parents overwhelmingly stated they would like to be informed during the preanesthetic assessment about all subjects that were mentioned in the questionnaire, though fewer reported wanting to know about the responsibilities of an anesthesiologist. Similar results were observed in a study from another university hospital in the Netherlands, where information about induction, side effects of anesthesia, emergence from anesthesia, and pain relief was desired 79% to 81% in parents.²⁵ A study about parental recall of anesthesia information found that most parents did not have a complete recall and understanding on the following topics: anesthesia plan (46%), its risks and benefits (11%), pain management (42%), and side effects of pain treatment (4%).⁵ Our results indicate that parents preferred to receive information through written informational brochures, rather than verbally. However, we did not ask parents if they would prefer to receive these brochures on paper or electronically. Of note, most parents considered themselves prepared for their child receiving anesthesia by attending the preanesthesia assessment, which underscores the importance of providing information to parents in that setting.

4.5 | Strengths and limitations

The primary strength of this study is the involvement of parents in the development of the questionnaires, in which we included the point of view of parents regarding their expectations and experiences regarding pediatric anesthesia. Furthermore, our study addressed parental experiences throughout the entire anesthesiology trajectory with multiple time points: from expectations beforehand, to the preanesthetic assessment, during the waiting time until the anesthetic procedure, and after the anesthetic procedure itself.

There were several limitations that should be addressed. Although we invited approximately 250 parents to participate in the focus group discussion, only three of them were willing to participate (Phase 1). This could have led to selection bias, since these three parents already had many experiences with pediatric anesthesia. To compensate for this, we conducted individual interviews with 16 additional parents with a varying range of

experiences with pediatric anesthesia. Therefore, the questionnaires were based on both the focus group and individual interviews of parents. Despite efforts to maximize participation, the low participation rate in Phase 1 undoubtedly led to bias in questionnaire development. However, we are unable to comment on the bias because we did not collect information on the parents who declined to participate. We would recommend offering incentives for participation in future studies to increase participation rates.²⁶

The questionnaires developed in this study were not previously validated in an external population, since the intention of this study was partially exploratory: to assess the needs of parents in order to improve information provision in pediatric anesthesia. To our knowledge, these are the first questionnaires focusing on the parental needs and concerns regarding pediatric anesthesia. Because we wished to limit redundant questions and were not able to test questions without exposing respondents to knowledge about anesthesia, it was not practical to validate questions in the context of this study. However, the methods by which the questions were developed ensured that they exhibited face validity. Future validation of the questionnaires is recommended.

In Phase 2, the response rates of the digital Q2 and Q3 (respectively, 36% and 34%) were much lower than the response rate of paper Q1 (78%). This nonresponse bias most likely contributes to biased estimates, but the direction of the bias is unknown. Parents were possibly more willing to complete a questionnaire when asked personally while waiting at the preanesthesia outpatient clinic. Q2 and Q3 could logistically not be administered in person and were therefore sent via email.²⁷ Since the parental educational level and the type and severity of the children's surgical procedures were similar among the three different cohorts, we assume that the different response rates were not a function of these demographic and procedural characteristics.

Furthermore, the questionnaires were mostly completed by women, which suggests that they are more involved with their child's medical care than men.^{4,28-30} Selection bias may have occurred in this study during recruitment. We excluded a minority of parents who were not able to read Dutch adequately (Q1: 10%), and we excluded additional parents without an email address registered in the electronic medical record (Q2: 10% and Q3: 18%). To ensure representativeness in future studies, other methods to minimize sample attrition should be explored.

Lastly, we caution that the results may not be generalizable to other institutions, as the results presented here are from one tertiary pediatric referral university hospital. Nevertheless, the results from our study are comparable to the results from other studies.

Future studies should explore experimental concepts to improve communication between anesthesia providers and parents. While the current research evaluated the expectations of parents, a further step would be to evaluate the children's expectations of and experiences with pediatric anesthesiology.

5 | CONCLUSION

In conclusion, this study provided new insights regarding parental experiences with pediatric anesthesiology through the development and fielding of questionnaires designed with parental input. Overall, parental satisfaction scores concerning the pediatric anesthesiologic procedure were high, with few notable concerns. Parents who completed the questionnaires were not well informed about the responsibilities of an anesthesiologist, though they reported less interest in learning about this compared to other aspects related to their child's anesthetic procedure. Nevertheless, parents stated that they would have liked more personal interaction with their child's anesthesiologist, which should be encouraged among anesthesiologists. Though this may be impractical on the day of the procedure due to scheduling constraints, we believe that increased personal interactions between anesthesia providers and parents or patients can serve to both increase understanding of the anesthesiologist's role and enhance the informed consent process.

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CONFLICT OF INTEREST STATEMENT

Dr. Jurgen de Graaff is an editor at *Pediatric Anesthesia*.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Ethical approval was obtained from the local ethics review board (MEC 2019-0240).

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APPENDIX 1

XPAS questionnaires, original Dutch version

XPAS questionnaire 1

Kunt u aangeven of u deze vragenlijst alleen of samen met uw partner heeft ingevuld? Als u het samen met uw partner invult, dan kunt u meer antwoorden per vraag geven (door meer vakjes aan te kruisen of meer streepjes te plaatsen).

1. Deze vragenlijst wordt ingevuld door:

- één ouder
- twee ouders

2. Wat is uw leeftijd? # jaar
(..... jaar)

3. Wat is uw geslacht? #

- Man
- Vrouw

4. Wat is uw hoogst afgeronde opleiding? #

- Ik heb geen opleiding afgemaakt
- Basisschool
- Middelbare school
- Ik geef hier liever geen antwoord op
- MBO
- HBO
- Universiteit

5. Wat is de leeftijd van uw kind dat een ingreep zal ondergaan? #

..... jaar

en maanden/..... weken (bij kinderen <1 jaar)

6. Bij welk specialisme zal uw kind anesthesie* krijgen? #

- MRI/CT/overig radiologisch onderzoek
- Algemene kindergeneeskunde (zoals ruggenprik (liquorpunctie), bloedafname)
- Cardiologie/cardiochirurgie
- Chirurgie
- Keel Neus Oor (KNO)
- Maag Darm Lever (MDL)
- Mond, kaak en aangezichtschirurgie (MKA)
- Neurochirurgie
- Oogheelkunde
- Orthopedie
- Plastische chirurgie

* Met **anesthesie** bedoelen wij onder andere:

- narcose: dat uw kind in slaap valt tijdens de ingreep,
- roesje: dat uw kind een wat verdovend middel toegediend krijgt maar nog wel bij bewustzijn is, of
- ruggenprik.

Questions that return in other questionnaires if they were not answered before

- Urologie
- Anders, namelijk...

- Ik geef hier liever geen antwoord op.

7. Wat voor ingreep zal uw kind ondergaan? #

- Ik geef hier liever geen antwoord op.

8. Hoe lang zal de ingreep van uw kind duren? #

- De ingreep zal naar verwachting korter dan 1 uur duren
- De ingreep zal naar verwachting 1 uur of langer duren
- Dit is nog onbekend
- Ik geef hier liever geen antwoord op.

9. Op welke afdeling zal uw kind na de ingreep worden opgenomen? #

- Afdeling Dagbehandeling
- Een gewone verpleegafdeling in het Erasmus MC-Sophia Kinderziekenhuis
- Afdeling Intensive Care Kinderen/Neonatologie
- Dit is nog onbekend
- Anders, namelijk...

- Ik geef hier liever geen antwoord op.

10. Op welk termijn zal uw kind de ingreep ondergaan? #

- Deze ingreep zal met (enige) spoed moeten worden uitgevoerd
- Deze ingreep was van tevoren gepland, zonder spoedindicatie
- Dit weet ik niet
- Ik geef hier liever geen antwoord op.

11. Heeft uw kind al eerder anesthesie* gehad? #

- Nee (ga naar vraag 14)
- Ja
- Ik geef hier liever geen antwoord op.

Questions that return in other questionnaires if they were not answered before

12. Hoe heeft u de anesthesie* bij uw kind toen ervaren? Plaats een streepje op de balk in de richting waar uw ervaring het meest mee overeenkomt: #

Ontevreden |-----| Tevreden

- Ik geef hier liever geen antwoord op.

Geef hier een toelichting van deze ervaring: #

- Ik geef hier liever geen antwoord op.

13. Heeft u andere kinderen die al eerder anesthesie* hebben gehad? #

- Nee (ga naar vraag 17)
 Ja
 Ik geef hier liever geen antwoord op.

14. Hoe heeft u de anesthesie* bij dit/deze kind(er) toen ervaren? (Mocht het om meer kinderen/ingrepen gaan, dan kunt u meer streepjes plaatsen.) Plaats een streepje op de balk in de richting waar uw ervaring het meest mee overeenkomt: #

Ontevreden |-----| Tevreden

- Ik geef hier liever geen antwoord op.

Geef hier een toelichting van deze ervaring(en): #

- Ik geef hier liever geen antwoord op.

15. Wat wilt u graag besproken hebben tijdens de preoperatieve screening? Plaats een streepje op de balk in de richting in hoeverre u vindt dat een onderwerp besproken moet worden.

- Ik geef hier liever geen antwoord op.

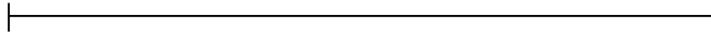
a. De taken en werkzaamheden van een anesthesioloog tijdens de ingreep.

Dit hoeft niet besproken te worden |-----| Dit moet besproken worden

Questions that return in other questionnaires if they were not answered before

b. Het plan van de anesthesiologische procedure (bijv. de manier van toedienen van de anesthesie, of wat hierna verder gebeurt).

Dit hoeft niet
besproken te
worden



Dit moet
besproken
worden

c. Tips voor ouders over hoe zij de gesteldheid of gedrag van het kind kunnen beïnvloeden voor en na de ingreep.

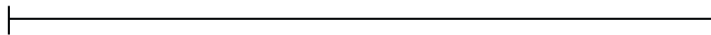
Dit hoeft niet
besproken te
worden



Dit moet
besproken
worden

d. De verschillende manieren van pijnstilling na de ingreep.

Dit hoeft niet
besproken te
worden



Dit moet
besproken
worden

e. De mogelijke bijwerkingen van de anesthesie*.

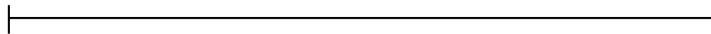
Dit hoeft niet
besproken te
worden



Dit moet
besproken
worden

f. De mogelijke korte termijneffecten van de anesthesie* na de ingreep.

Dit hoeft niet
besproken te
worden



Dit moet
besproken
worden

g. De mogelijke lange termijneffecten van de anesthesie* na de ingreep.

Dit hoeft niet
besproken te
worden



Dit moet
besproken
worden

Anders, namelijk...

16. Deze vraag dient vanuit uw perspectief, als ouder, ingevuld te worden. Geef een reactie op elke vraag of uitspraak door per rij één hokje aan te kruisen. Geef a.u.b. antwoord voor de afgelopen 7 dagen.

XPAS questionnaire 2

1. Hoe heeft u het spreekuur bij de preoperatieve screening met de kinderanesthesioloog ervaren?
Plaats een streepje op de balk in de richting waar uw ervaring het meest mee overeenkomt:

Ontevreden |—————| Tevreden

- Ik geef hier liever geen antwoord op.

Geef hier een toelichting van uw ervaring:

- Ik geef hier liever geen antwoord op.

2. Is het duidelijk wat de anesthesioloog bij uw kind gaat doen op de dag van de ingreep?

- Ja, het is mij helemaal duidelijk
- Ja, maar ik heb nog enkele vragen die niet beantwoord zijn, zoals...
- Nee, ik heb nog heel veel vragen, zoals...
- Nee, ik kreeg wel informatie van de anesthesioloog, maar deze begreep ik niet goed.

- Nee, maar ik wil dit ook niet weten
- Ik geef hier liever geen antwoord op.

3. Heeft u een voorstelling over hoe u uw kind na de ingreep zal aantreffen op de uitslaapkamer?
Plaats een streepje op de balk in de richting waar uw verwachting het meest mee overeenkomt:

Ik heb hier geen |—————| Ik denk te
beeld bij weten hoe dit
er uit gaat zien

- Ik geef hier liever geen antwoord op.

Geef hier een toelichting over:

- Ik geef hier liever geen antwoord op.

4. Welke omschrijving beschrijft volgens u het best een anesthesioloog?

- Een assistent van de chirurg
- Een verpleegkundige die gespecialiseerd is in anesthesie
- Een dokter die gespecialiseerd is in anesthesie

- Geen dokter of verpleegkundige, maar een verzorgende die zich bezighoudt met anesthesie
- Een medewerker die gespecialiseerd is in medicijnen (farmacoloog) die zich bezighoudt met anesthesie
- Een technicus die zich bezighoudt met anesthesie
- Geen idee
- Anders, namelijk...

- Ik geef hier liever geen antwoord op.

5. Wat zijn volgens u de taken van een anesthesioloog tijdens een ingreep?

- Infuus prikken
- Ruggenprik prikken
- Narcose geven (patiënt in slaap brengen) en patiënt in slaap houden
- De gezondheidsparameters (hartslag, bloeddruk etc.) in de gaten houden tijdens de ingreep
- Medicijnen toedienen en deze beheren tijdens de ingreep
- Een buisje (tube) plaatsen in de keel voor het ademen voor de ingreep
- De ademhaling van de patiënt tijdens de ingreep in de gaten houden en sturen
- Bloed geven als dit nodig is tijdens de ingreep
- Pijnvermindering na de ingreep
- Geen idee
- Anders, namelijk...

- Ik geef hier liever geen antwoord op.

6. Zou u meer willen weten over wat de specialisatie anesthesiologie precies inhoudt en wat een anesthesioloog nog meer doet? Plaats een streepje op de balk in de richting in welke mate u graag informatie over een onderwerp wilt ontvangen.

Dit hoef ik niet
te weten

Dit wil ik heel
graag weten


- Ik geef hier liever geen antwoord op.

7. Hoe zou u deze informatie willen ontvangen? Meerdere antwoorden zijn mogelijk.

- Via de anesthesioloog op het preoperatief spreekuur
- Via een andere dokter/specialist
- Via informatieboekjes over anesthesiologie vanuit het Erasmus MC-Sophia Kinderziekenhuis
- Via de website van het Erasmus MC-Sophia Kinderziekenhuis
- Via algemeen internet, boeken en/of tijdschriften
- Via een informatieavond georganiseerd vanuit de afdeling Kinderanesthesiologie
- Op een andere manier, namelijk...

- Ik geef hier liever geen antwoord op.

8. Maakt u zich zorgen over de anesthesie (narcose, roesje, ruggenprik etc.) bij uw kind? Plaats een streepje op de balk in de richting waar uw ervaring het meest mee overeenkomt:

Helemaal niet bezorgd  Heel erg bezorgd

- Ik geef hier liever geen antwoord op.

Waarover bent u bezorgd? (Indien u niet bezorgd bent, ga naar vraag 13)

- Ik geef hier liever geen antwoord op.

9. Hoe zouden wij u kunnen helpen om uw bezorgdheden te verminderen? Meerdere antwoorden zijn mogelijk.

- Niet zo veel, mijn bezorgdheid zal blijven
- Als ik met de anesthesioloog die mijn kind anesthesie geeft, korte tijd (een dag tot een week) voor de ingreep nog telefonisch kan spreken
- Als ik de anesthesioloog die de anesthesie bij mijn kind geeft, net voor de ingreep nog even spreek
- Als ik meer uitleg, een brochure of een bijsluiter krijg over de anesthesie medicijnen (zoals over de werking en bijwerkingen)
- Als ik meer uitleg of een brochure krijg over de anesthesie procedure
- Als ik de mogelijkheid krijg om in contact te komen met andere ouders die ervaring hebben met anesthesie bij hun kind
- Als ik deel kan nemen aan een informatieavond of bijeenkomst met andere ouders waarin ik mijn vragen kan stellen en mijn zorgen kan delen
- Als ik de anesthesioloog ook na de ingreep spreek over hoe de anesthesie is gegaan
- Anders, namelijk...

- Ik geef hier liever geen antwoord op.

10. Verwacht u dat de anesthesie (narcose, roesje, ruggenprik etc.) problemen zou kunnen geven op korte termijn (korter dan 1 week)?

- Nee
- Ja, namelijk...

- Ik geef hier liever geen antwoord op.

11. Verwacht u dat de anesthesie (narcose, roesje, ruggenprik etc.) problemen zou kunnen geven op lange termijn?

- Nee
 Ja, namelijk...

- Ik geef hier liever geen antwoord op.

12. Verwacht u dat anesthesie (narcose, roesje, ruggenprik etc.) schade zou kunnen geven op de ontwikkeling van de hersenen van uw kind op lange termijn?

- Nee
 Ja
 Ik geef hier liever geen antwoord op.

13. Zou u meer willen weten over de werking en bijwerkingen van de anesthesie medicijnen op uw kind? Plaats een streepje op de balk in de richting in welke mate u graag informatie over een onderwerp wilt ontvangen.

Dit hoef ik niet
te weten

Dit wil ik heel
graag weten

- Ik geef hier liever geen antwoord op.

14. Hoe zou u deze informatie willen ontvangen? Meerdere antwoorden zijn mogelijk.

- Via de anesthesioloog op het preoperatief spreekuur
 Via een andere dokter/specialist
 Via informatieboekjes of een soort bijsluiter specifiek over de anesthesie medicijnen vanuit het Erasmus MC-Sophia Kinderziekenhuis
 Via de website van het Erasmus MC-Sophia Kinderziekenhuis
 Via algemeen internet, boeken en/of tijdschriften
 Via een informatieavond georganiseerd vanuit de afdeling Kinderanesthesiologie
 Op een andere manier, namelijk...

- Ik geef hier liever geen antwoord op.

15. Deze vraag dient vanuit uw perspectief, als ouder, ingevuld te worden. Geef een reactie op elke vraag of uitspraak door per rij één hokje aan te kruisen. Geef a.u.b. antwoord voor de afgelopen 7 dagen.

XPAS questionnaire 3

1. Hoe heeft u de anesthesie (narcose, roesje, ruggenprik etc.) bij uw kind ervaren? Plaats een streepje op de balk in de richting waar uw ervaring het meest mee overeenkomt:

Ontevreden |-----| Tevreden

- Ik geef hier liever geen antwoord op.

Geef hier een toelichting van uw ervaring:

- Ik geef hier liever geen antwoord op.

2. Hoe heeft uw kind de anesthesie (narcose, roesje, ruggenprik etc.) ervaren? Plaats een streepje op de balk in de richting waar de ervaring van uw kind het meest mee overeenkomt:

Ontevreden |-----| Tevreden

- Ik geef hier liever geen antwoord op.

Geef hier een toelichting van deze ervaring:

- Ik geef hier liever geen antwoord op.

3. Heeft u zich voorbereid op de anesthesie (narcose, roesje, ruggenprik etc.) bij de ingreep van uw kind? Meerdere antwoorden zijn mogelijk.

- Nee
- Ja, via de anesthesioloog op het preoperatief spreekuur
- Ja, via een andere dokter/specialist
- Ja, via informatieboekjes over anesthesiologie vanuit het Erasmus MC-Sophia Kinderziekenhuis
- Ja, via de website van het Erasmus MC-Sophia Kinderziekenhuis
- Ja, via algemeen internet, boeken en/of tijdschriften algemeen
- Ja, via familie, vrienden en/of kennissen
- Ja, vanuit mijn eigen ervaring
- Ja, op een andere manier, namelijk...

- Ik geef hier liever geen antwoord op.

4. Heeft u uw kind voorbereid op de anesthesie (narcose, roesje, ruggenprik etc.) bij de ingreep? Meerdere antwoorden zijn mogelijk.
- Nee, ik heb mijn kind niet voorbereid
 - Nee, mijn kind heeft al eerder ervaring, dus extra voorbereiding was nu niet nodig
 - Ja, ik heb het mijn kind uitgelegd
 - Ja, familie, vrienden en/of kennissen hebben het mijn kind uitgelegd
 - Ja, de anesthesioloog/een andere dokter of specialist heeft het mijn kind uitgelegd
 - Ja, mijn kind heeft zichzelf voorbereid...
 - Ja, op een andere manier, namelijk...

- Ik geef hier liever geen antwoord op.

5. Heeft uw kind zich voorbereid op de anesthesie (narcose, roesje, ruggenprik etc.)? Meerdere antwoorden zijn mogelijk.
- Mijn kind heeft zichzelf niet voorbereid
 - Via de anesthesioloog op het preoperatief spreekuur
 - Via een andere dokter/specialist
 - Via informatieboekjes over anesthesiologie vanuit het Erasmus MC-Sophia Kinderziekenhuis
 - Via de website van het Erasmus MC-Sophia Kinderziekenhuis
 - Via algemeen internet, boeken en/of tijdschriften
 - Via familie, vrienden en/of kennissen
 - Op een andere manier, namelijk...

- Ik geef hier liever geen antwoord op.

6. Heeft u na de ingreep de anesthesioloog gesproken?
- Ja
 - Nee

7. Heeft u voldoende informatie ontvangen over het verloop van de anesthesie? Plaats een streepje op de balk in de richting waar uw ervaring het meest mee overeenkomt:

Onvoldoende |—————| Voldoende

- Ik geef hier liever geen antwoord op.

8. Uw kind heeft recent de ingreep ondergaan. Heeft u dingen tijdens deze periode opgemerkt, waar u eigenlijk meer informatie over zou willen ontvangen?

9. Heeft u nog suggesties hoe de zorg verbeterd kan worden vanuit de afdeling Kinderanesthesiologie richting u en uw kind?

10. Wat vond u goed gaan en zou voortaan zo door moeten blijven gaan?

11. Heeft u nog andere opmerkingen die u nog graag aan ons wilt doorgeven?

12. Deze vraag dient vanuit uw perspectief, als ouder, ingevuld te worden. Geef een reactie op elke vraag of uitspraak door per rij één hokje aan te kruisen. Geef a.u.b. antwoord voor de afgelopen 7 dagen.

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APPENDIX 2

XPAS questionnaires, English version

XPAS questionnaire 1

Please state whether you complete this questionnaire by yourself or together with your partner. If together with your partner, you can select more answer options/draw more lines for each question.

1. This questionnaire is completed by:

- one parent
 two parents

2. What is your age? # years
 (..... years)

3. What is your sex? #

- Male Female

4. What is your highest level of education? #

- I did not finish an education Middle Secondary Education
 Primary School Higher Secondary Education
 High School University
 I prefer not to answer this question

5. What is the age of your child undergoing the medical procedure in this hospital? #

..... years

and months/..... weeks (for children <1 year)

6. For which medical specialty will your child receive anesthesia*? #

- Abdominal surgery
 Cardiothoracic surgery
 Ear, nose, throat (ENT) surgery
 Eye surgery
 General surgery
 MRI/CT/other radiologic assessment
 Neurosurgery
 Oral and maxillofacial surgery
 Orthopedic surgery
 Plastic surgery
 Urological surgery
 Other, namely...

* With the term **anesthesia**, we refer to:

- narcosis: when your child will go to sleep during the medical procedure,
- mild sedation: when your child will receive a sedative (tranquillizer), but will still be conscious, or
- epidural or spinal puncture.

Questions that return in other questionnaires if they were not answered before

- I prefer not to answer this question.

7. What medical procedure will your child undergo? #

- I prefer not to answer this question.

8. How long will your child's medical procedure take? #

- Less than 1 hour
 Approximately take 1 hour or more
 Not known yet
 I prefer not to answer this question.

9. On what kind of ward will your child stay after the medical procedure? #

- Outpatient department
 General hospital ward
 Pediatric/neonatal intensive care unit
 Not known yet
 Other, namely...

- I prefer not to answer this question.

10. When will your child's medical procedure be scheduled? #

- This medical procedure is planned with urgency
 This medical procedure is not urgent and was scheduled a long time ago
 I do not know
 I prefer not to answer this question.

11. Has your child received anesthesia* before? #

- No (go to question 14)
 Yes
 I prefer not to answer this question.

Questions that return in other questionnaires if they were not answered before

12. How did **you** experience your child receiving anesthesia* the previous time? Please indicate on the line below the point that most closely matches your experience: #

Dissatisfied |-----| Satisfied

I prefer not to answer this question.

Please give an explanation of this experience: #

I prefer not to answer this question.

13. Do you have other children who have received anesthesia* before? #

- No (go to question 17)
- Yes
- I prefer not to answer this question.

14. How did **you** experience your child/children receiving anesthesia* the previous time? Please indicate on the line below the point that most closely matches your experience (you can draw more lines if there are more children or medical procedures): #

Dissatisfied |-----| Satisfied

I prefer not to answer this question.

Please give an explanation of this experience(s): #

I prefer not to answer this question.

15. What topics would you like to discuss during the preanesthesia assessment with the pediatric anesthesiologist? Please indicate on the line below the point that most closely matches your experience:

I prefer not to answer this question.

g. Responsibilities of an anesthesiologist during the medical procedure.

This does not need to be discussed |-----| This must be discussed

b. Anesthesia procedure.*

This does not
need to be
discussed

This must be
discussed

c. Tips for parents to influence their child's behaviour and state.

This does not
need to be
discussed

This must be
discussed

d. Different options for pain treatment.

This does not
need to be
discussed

This must be
discussed

e. Possible side effects of anesthesia.*

This does not
need to be
discussed

This must be
discussed

f. Possible short-term effects of anesthesia after the medical procedure.*

This does not
need to be
discussed

This must be
discussed

g. Possible long-term effects of anesthesia after the medical procedure.*

This does not
need to be
discussed

This must be
discussed

Other, namely...

16. The following questions must be completed from your perspective, as a parent. Please respond to each question or statement by marking one box per row.
In the past 7 days...

XPAS questionnaire 2

1. How did **you** experience the preanesthesia assessment with the pediatric anesthesiologist?
Please indicate on the line below the point that most closely matches your experience:

Dissatisfied |-----| Satisfied

- I prefer not to answer this question.

Please give an explanation of this experience:

- I prefer not to answer this question.

2. Is it clear for you what the anesthesiologist will do on the day your child will undergo the medical procedure?

- Yes, this is completely clear
 Yes, but I still have some questions unanswered, such as...
 No, I still have a lot of questions, such as...
 No, I received some information from the anesthesiologist, but I did not understand this information

- No, but I do not really need to know that
 I prefer not to answer this question.

3. Do you have an idea on how you will encounter your child at the recovery room after the medical procedure? Please indicate on the line below the point that most closely matches your experience:

I have no idea |-----| I think I know what to expect

- I prefer not to answer this question.

Please give an explanation of this expectation:

- I prefer not to answer this question.

4. Which of the following descriptions do you think best describes an anesthesiologist?

- A physician
- An assistant of the surgeon
- A technician
- A nurse
- A pharmacologist
- A caregiver
- I do not know
- Other, namely...

- I prefer not to answer this question.

5. What are the responsibilities of an anesthesiologist during the medical procedure? You can select more than one option.

- Venipuncture
- Epidural puncture
- Keeping hemodynamic stability
- Administering medications
- Intubation
- Monitoring the patient's respiration and ventilation (breathing)
- Administering blood when necessary
- Pain alleviation
- I do not know
- I prefer not to answer this question.

6. Would you like to receive more information about the responsibilities of an anesthesiologist? Please indicate on the line below the point that most closely matches your experience:

I do not need to
receive this
information

I really need to
receive this
information

- I prefer not to answer this question.

7. How would you like to receive this information? You can select more than one option.

- Through the anesthesiologist at the preanesthesia assessment
- Through another physician/specialist
- Through informational brochures of the hospital
- Through the hospital's website
- Through public internet, books and/or magazines
- Through an information evening organised by the department of Pediatric Anesthesiology
- Other, namely...

- I prefer not to answer this question.

8. Do you have concerns about your child receiving anesthesia (narcosis, mild sedation, epidural or spinal puncture)? Please indicate on the line below the point that most closely matches your experience:

I am not concerned |-----| I am very concerned

- I prefer not to answer this question.

What kind of concerns do you have? (If you are not concerned at all, go to question 13)

- I prefer not to answer this question.

9. How can we help to reduce your concerns? You can select more than one option.

- My concerns will not go away
- If I can speak by telephone to the anesthesiologist assigned to my child shortly before the medical procedure (a day to a week)
- If I can speak to the anesthesiologist assigned to my child just before the medical procedure
- If I receive more information about the anesthetics (about the effects and side effects)
- If I receive more information about the anesthetic procedure
- If I can get in contact with other parents who have experiences with pediatric anesthesia
- If I can join an information meeting with other parents to ask my questions and share my concerns
- If I can speak to the anesthesiologist after the medical procedure, to ask how the anesthetic procedure went
- Other, namely...

- I prefer not to answer this question.

10. Do you think anesthesia (narcosis, mild sedation, epidural or spinal puncture) could have short-term consequences (within 1 week)?

- No
- Yes, such as...

- I prefer not to answer this question.

11. Do you think anesthesia (narcosis, mild sedation, epidural or spinal puncture) could have long-term consequences?

- No
- Yes, such as...

- I prefer not to answer this question.

12. Do you think anesthesia (narcosis, mild sedation, epidural or spinal puncture) could harm your child's development on the long-term?

- No
- Yes
- I prefer not to answer this question.

13. Would you like to receive more information about the effects and side effects of anesthesia?

Please indicate on the line below the point that most closely matches your experience:

I do not need to receive this information |-----| I really need to receive this information

- I prefer not to answer this question.

14. How would you like to receive this information? You can select more than one option.

- Through the anesthesiologist at the preanesthesia assessment
- Through another physician/specialist
- Through informational brochures of the hospital
- Through the hospital's website
- Through public internet, books and/or magazines
- Through an information evening organised by the department of Pediatric Anesthesiology
- Other, namely...

- I prefer not to answer this question.

15. The following questions must be completed from your perspective, as a parent. Please respond to each question or statement by marking one box per row.

In the past 7 days...

PROMIS v1.0 Anxiety Short Form 8a

XPAS questionnaire 3

1. How did **you** experience your child receiving anesthesia (narcosis, mild sedation, epidural or spinal puncture)? Please indicate on the line below the point that most closely matches your experience:

Dissatisfied |-----| Satisfied

- I prefer not to answer this question.

Please give an explanation of this experience:

- I prefer not to answer this question.

2. How did **your child** experiences receives anesthesia (narcosis, mild sedation, epidural or spinal puncture)? Please indicate on the line below the point that most closely matches your experience:

Dissatisfied |-----| Satisfied

- I prefer not to answer this question.

Please give an explanation of this experience:

- I prefer not to answer this question.

3. Did you prepare yourself for your child receiving anesthesia (narcosis, mild sedation, epidural or spinal puncture) before the medical procedure? You can select more than one option.

- I did not prepare myself
- Yes, through the anesthesiologist at the preanesthesia assessment
- Yes, through another physician/specialist
- Yes, through informational brochures of the hospital
- Yes, through the hospital's website
- Yes, through public internet, books and/or magazines
- Yes, through family, friends and/or acquaintances
- Other, namely...

- I prefer not to answer this question.

4. Did you prepare your child for receiving anesthesia (narcosis, mild sedation, epidural or spinal puncture) before the medical procedure? You can select more than one option.
- No, I did not prepare my child
 - Yes, I explained the whole procedure to my child
 - Yes, the anesthesiologist/another physician or specialist explained my child
 - Yes, family, friends and/or acquaintances explained my child
 - Yes, my child prepared him/herself
 - Yes, in another way, namely...

- I prefer not to answer this question.

5. Did your child prepare him/herself for receiving anesthesia (narcosis, mild sedation, epidural or spinal puncture) before the medical procedure? You can select more than one option.
- No, my child did not prepare him/herself
 - Yes, through the anesthesiologist at the preanesthesia assessment
 - Yes, through another physician/specialist
 - Yes, through informational brochures of the hospital
 - Yes, through the hospital's website
 - Yes, through public internet, books and/or magazines
 - Yes, through family, friends and/or acquaintances
 - Yes, in another way, namely...

- I prefer not to answer this question.

6. Did you speak to the anesthesiologist after the medical procedure?
- Yes
 - No

7. Did you receive enough information about the anesthesia? Please indicate on the line below the point that most closely matches your experience:

Not enough |—————| Enough

- I prefer not to answer this question.

8. Your child just underwent the medical procedure. Did you experience anything during this period which you would have liked to have received more information about?

9. Do you have any more suggestions how we can improve the medical care from the department of Pediatric Anesthesiology for you and your child?

10. What went well and should be maintained?

11. Do you have other comments for us?

12. The following questions must be completed from your perspective, as a parent. Please respond to each question or statement by marking one box per row.
In the past 7 days...

PROMIS v1.0 Anxiety Short Form 8a

APPENDIX 3

Outline of the insertion of questions and type of questions of the final XPAS questionnaires

	Questionnaire 1	Questionnaire 2	Questionnaire 3
1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
4	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
5	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
6	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
7	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
8	<input type="checkbox"/> *	<input type="checkbox"/>	<input type="checkbox"/>
9	<input type="checkbox"/> *	<input type="checkbox"/>	<input type="checkbox"/>
10	<input type="checkbox"/> *	<input type="checkbox"/>	<input type="checkbox"/>
11	<input type="checkbox"/> *	<input type="checkbox"/>	<input type="checkbox"/>
12	<input type="checkbox"/> *	<input type="checkbox"/>	<input type="checkbox"/>
13	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	
14	<input type="checkbox"/> *	<input checked="" type="checkbox"/>	
15	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
16	<input type="checkbox"/>		

Legend

- Basic questions
 - Inserted primary by the researchers
 - Inserted after literature research
 - Inserted after the focus group meeting and interviews
 - Multiple choice answers originated from the focus group meeting and interviews
 - Inserted after receiving feedback
-
- Demographic questions and satisfaction with pediatric anesthesia
 - * Questions that return in other questionnaires if they were not answered before
 - Knowledge and expectations of anesthesiology
 - Concerns regarding their child receiving anesthesia
 - Need for information and preparation for anesthesia

APPENDIX 4

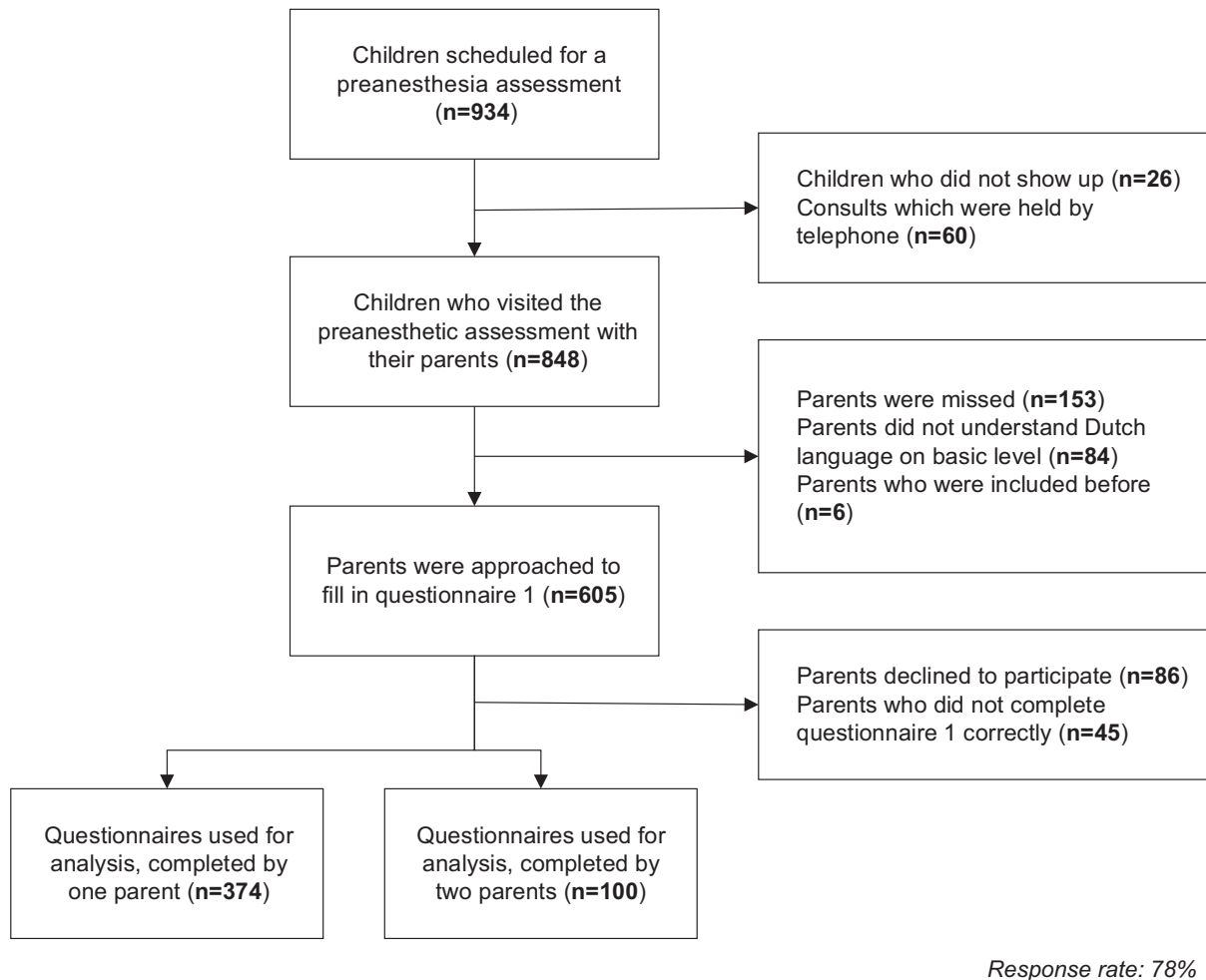


FIGURE A1 Flowchart XPAS questionnaire 1: on paper handout questionnaire before visiting the preanesthesia assessment outpatient clinic.

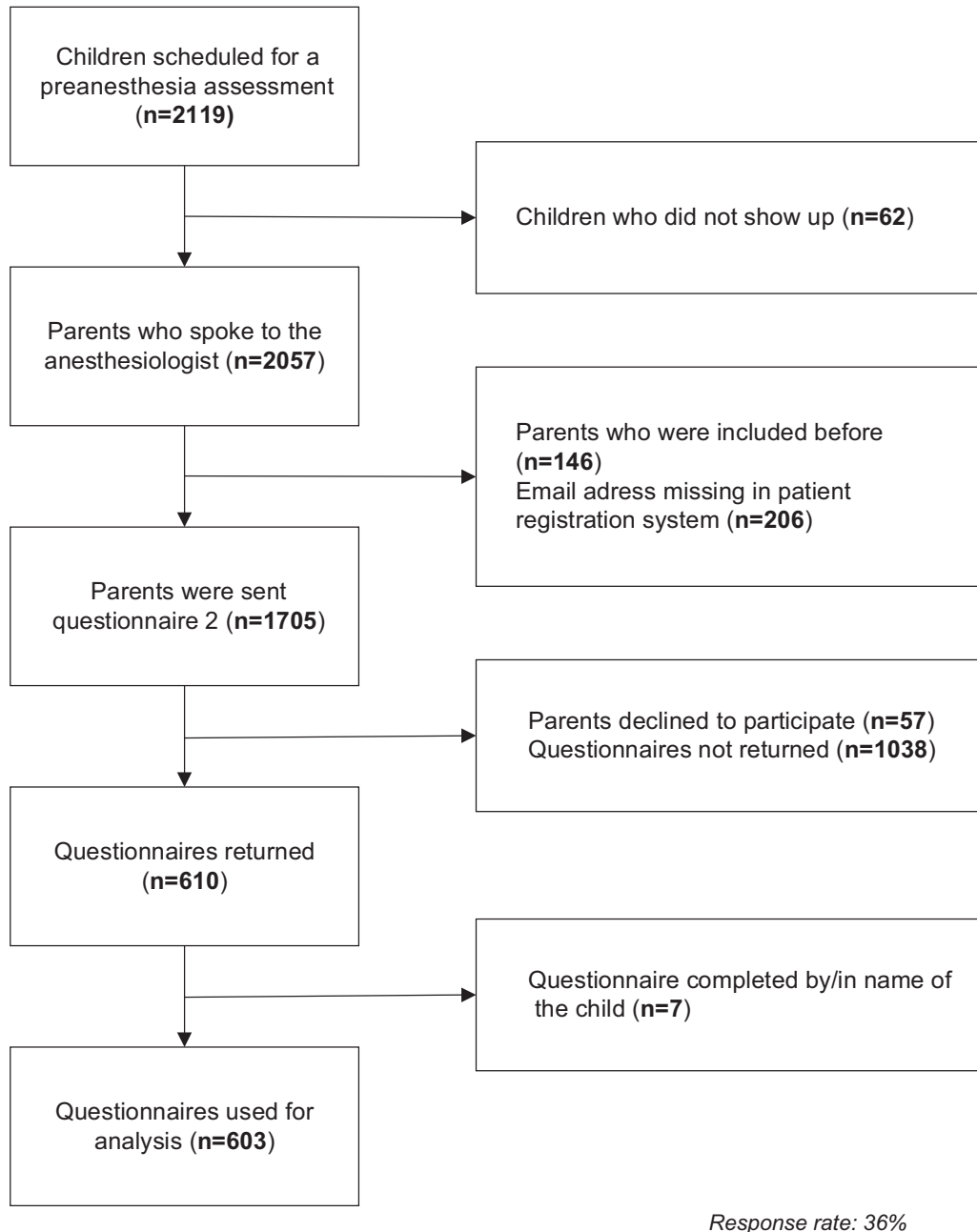


FIGURE A2 Flowchart XPAS questionnaire 2: 2 days after visiting the preanesthesia assessment outpatient clinic.

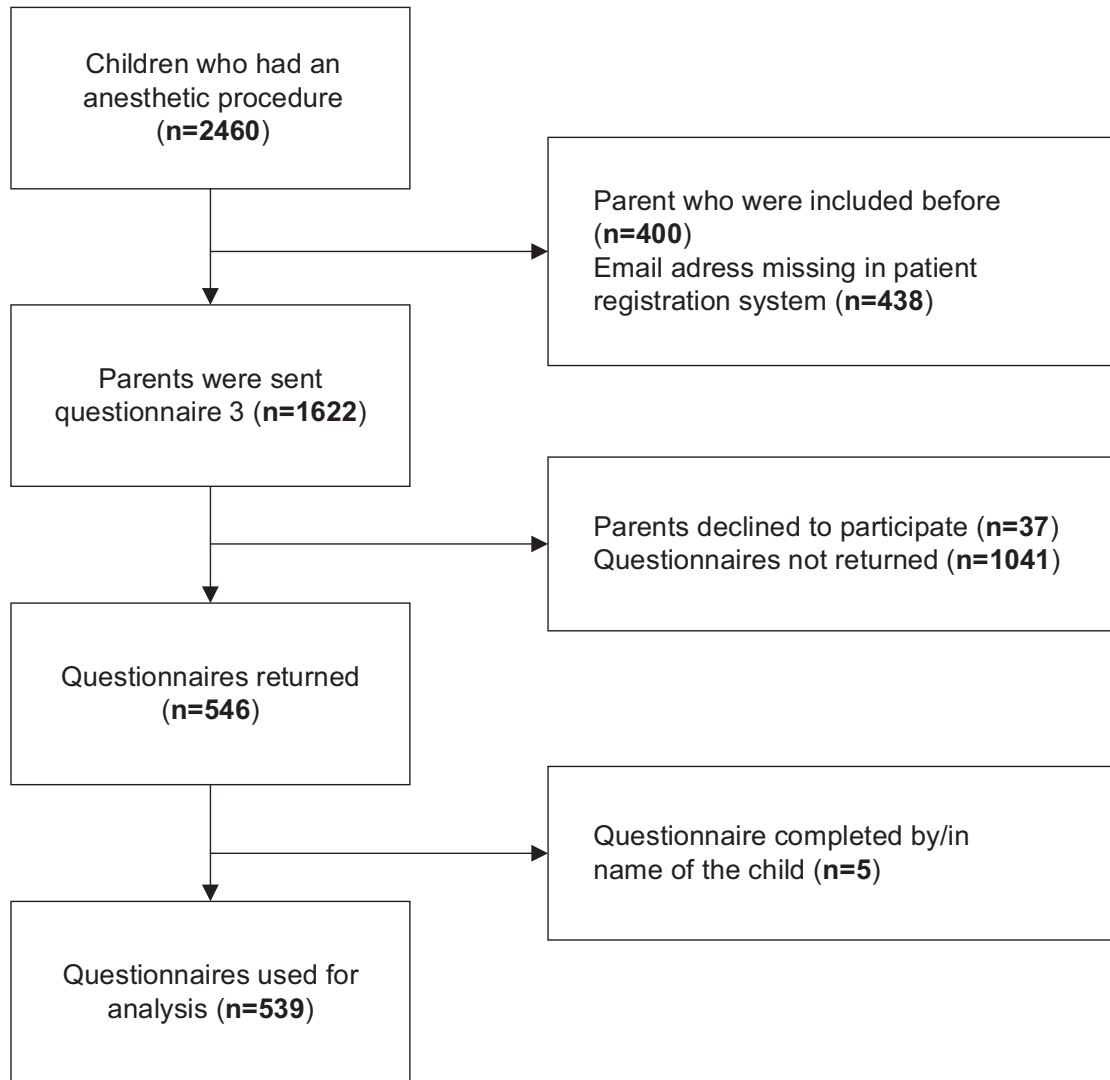


FIGURE A3 Flowchart XPAS questionnaire 3: 4 days after the medical procedure.

APPENDIX 5

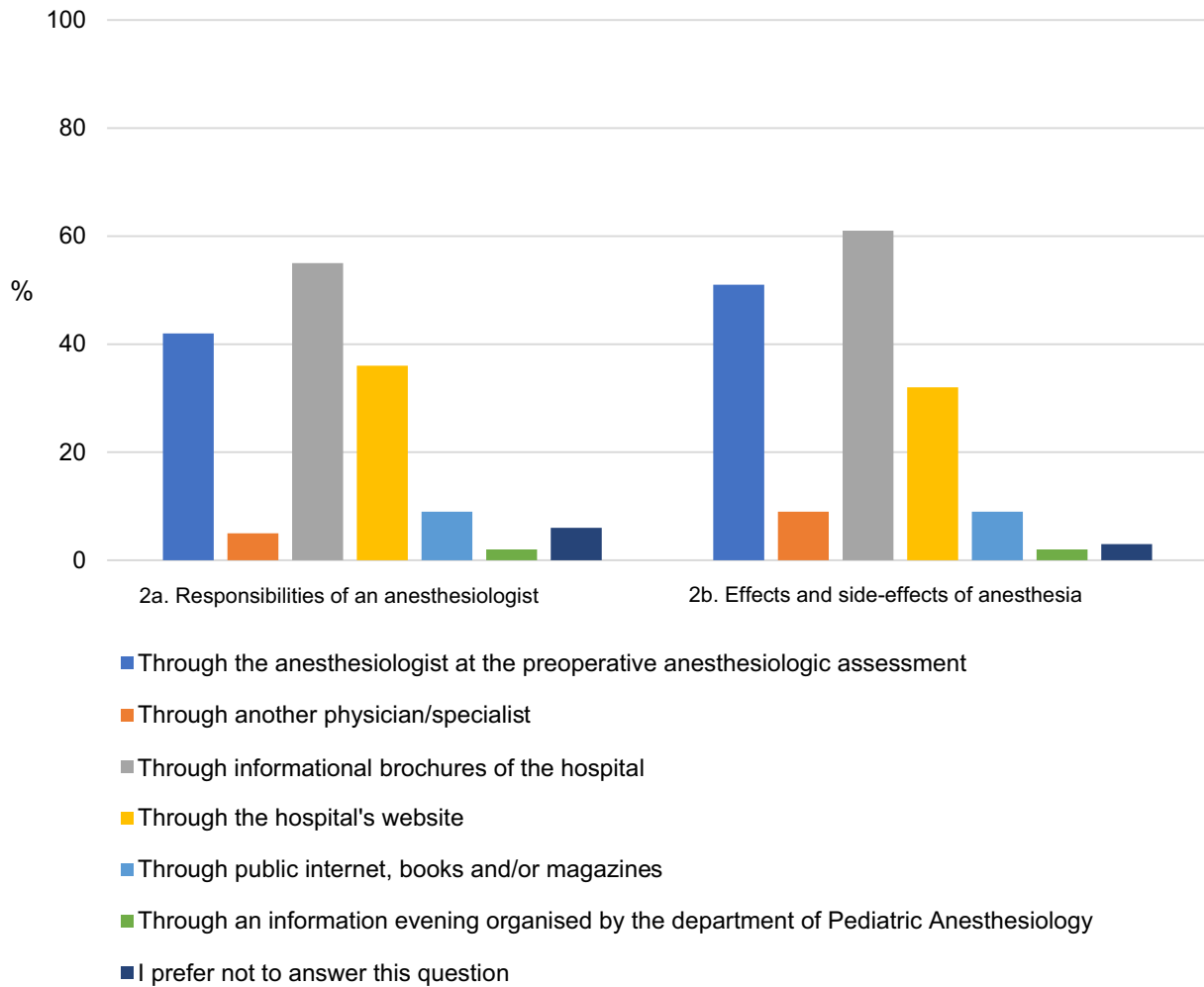
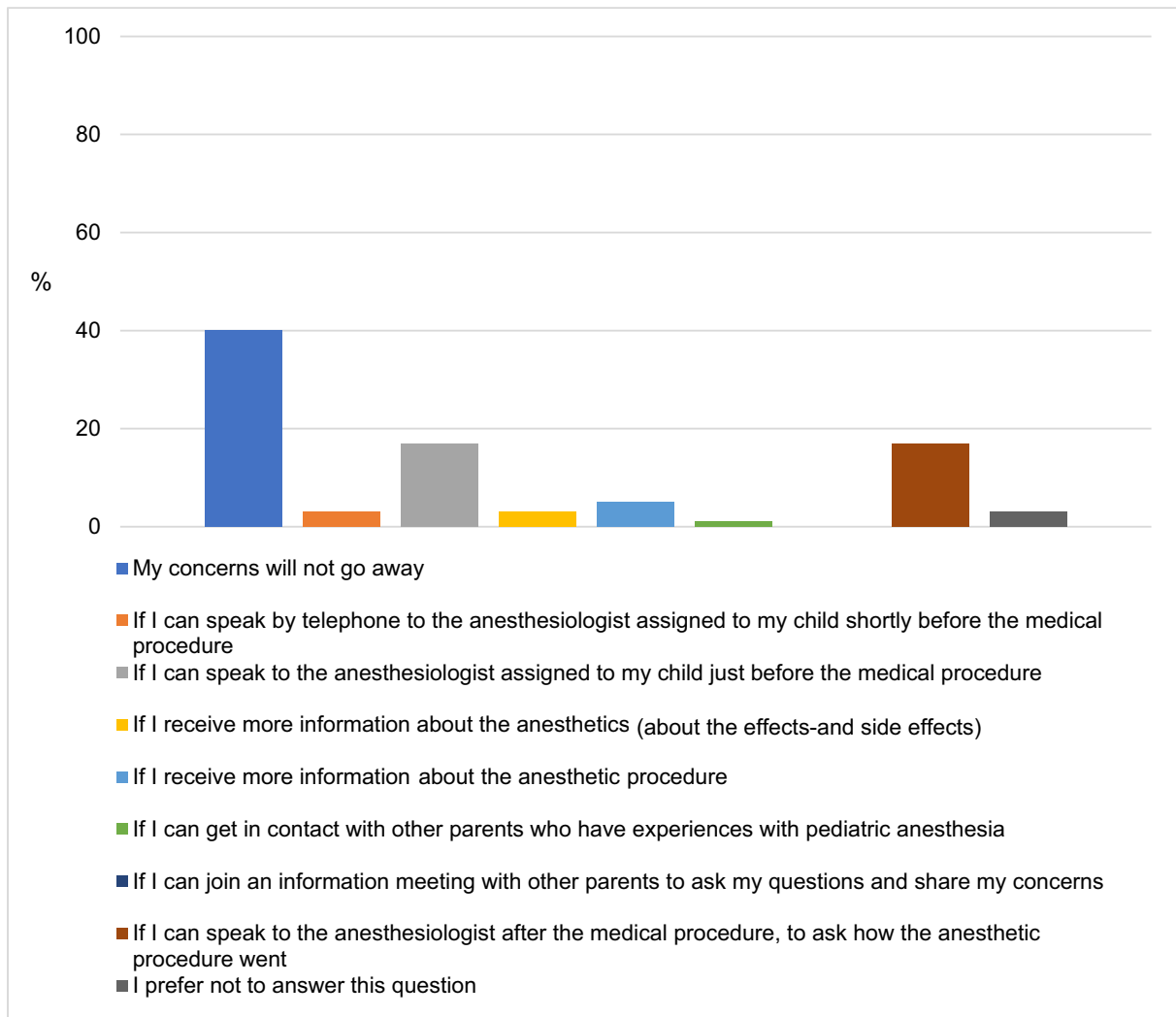


FIGURE A4 Preference of ways to receive information. Multiple answers could be selected.

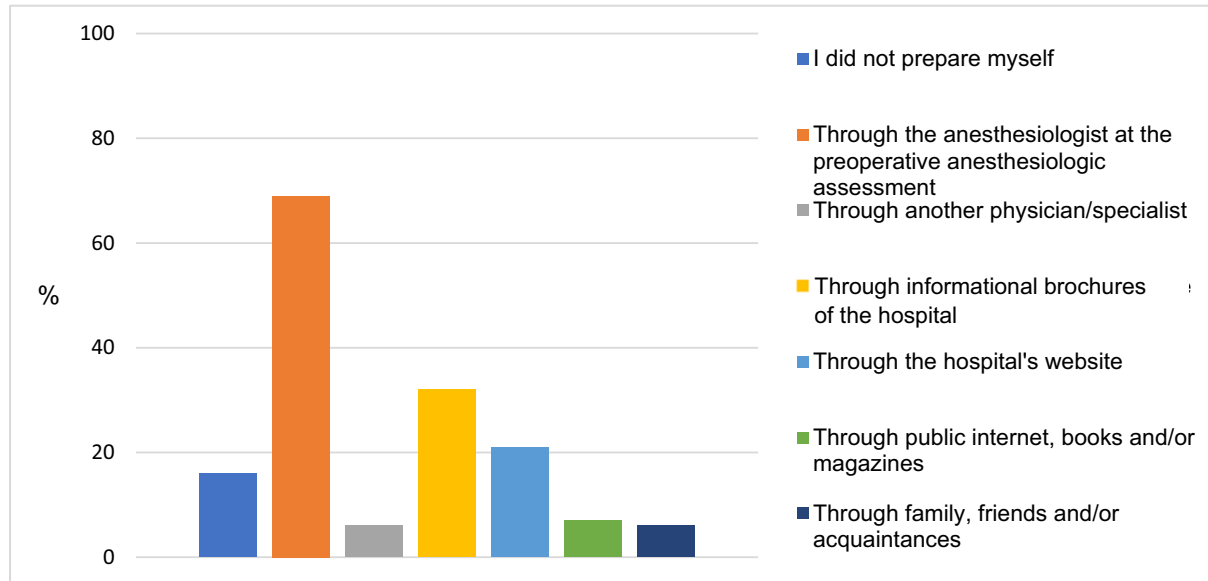
APPENDIX 6

Options to reduce parents' concerns. Multiple answers could be selected.



APPENDIX 7

Preparation of parents for their child receiving anesthesia before the medical procedure. Multiple answers could be selected.



APPENDIX 8

Child preparation for receiving anesthesia before the medical procedure by their parent(s). Multiple answers could be selected.

