



Improving communication with families of patients undergoing pediatric cardiac surgery☆☆☆



Christina Lopez^a, Cherissa C Hanson^{b,*}, Diane Yorke^c, Julie K Johnson^d, Michael R Mill^e,
Karla J Brown^e, Paul Barach^f

^a Department of Pediatrics, Robert Wood Johnson University Hospital, New Brunswick, NJ, United States

^b WakeMed Physician Practices, WakeMed Children's Hospital, Raleigh, NC, United States

^c NC Children's Hospital, Chapel Hill, NC, United States

^d Department of Surgery, Center for Healthcare Studies, Institute for Public Health and Medicine, Feinberg School of Medicine, Northwestern University, Chicago, United States

^e Department of Surgery, University of North Carolina, Chapel Hill, NC, United States

^f Wayne State University, School of Medicine, Detroit, MI, United States

ARTICLE INFO

Article history:

Received 18 May 2016

Accepted 3 November 2016

Available online 17 November 2016

Keywords:

Pediatrics
Critical Illness
Pediatric Hospitals
Cardiac Surgery
Family
Communication
Patient-centered

ABSTRACT

Peri-operative communication between families and parents of children undergoing pediatric cardiac surgery remains uneven and is felt to contribute to variation in subjective perceptions and inclusion by parents. We conducted a series of structured interviews and surveys in a prospective mixed-method study at a 140 bed university-affiliated tertiary pediatric hospital with approximately 6300 annual admissions. All English speaking patients undergoing pediatric cardiac surgery were eligible for inclusion. The providers of the enrolled patients were divided into two groups: pediatric critical care, cardiothoracic, and subspecialty (anesthesia and cardiology) providers. Twenty-one pre and post-surgical interviews were conducted with parents ($n = 8$), and providers ($n = 13$) prior to, and following, the cardiac surgical intervention. We then worked with parents and staff to arrive at practical strategies to improve current system. A total of 4 areas across the process were identified where improvements could be introduced. These were: Mid Staffordshire NHS (Feb 2013) patient/family centered relationship, Dyer (2001) sources and locus of control, Committee on Hospital Care and Institute for Patient- and Family-Centered Care (2012) barriers to communication, and Hanson and Barach (2012) opportunities and timeliness for communication improvement. A number of potential failures in communicating results with families were identified, bedside rounds in the PICU that include patient families, use of modern technology methods to proactively communicate routine results to improve the expectations, subject knowledge, targeted training for family empowerment before and surgery. There remains an urgent need for further work to test these and other potential solutions.

© 2016 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

The Mid Staffordshire inquiry and the Bristol pediatric cardiac surgery inquiry highlight a widespread culture of denial and lack of attentiveness to pediatric patients and their caregiver's concerns [1–2]. Patient centered practices and system redesign around co-production are emerging as effective tools to increase patient compliance and

improve patient safety and outcomes [3–5]. Over the past decade an increasing body of pediatric literature supports family-centered care with the understanding that the family is the child's primary source of support and resilience. Despite improvements in care for children with congenital heart disease, outcomes vary widely. Heart failure is a chronic illness that requires a co-production model to improve patient-centered outcomes [5]. “Services” are fundamentally different from “products”; unlike goods, services are always “co-produced” [6]. Failure to recognize this difference may limit our success in collaborating with patients and families to improve care.

Furthermore, listening to the family's perspectives is important to improve clinical decision making and patient outcomes [3,4,7–9]. Family centered rounds can improve family confidence and trust in the provider team [7–12]. Effective partnership with families can lead to decreased healthcare costs and postoperative pain medication

Abbreviations: CC, critical care; CT, cardiothoracic; ICU, intensive care unit; P, patient family; PICU, pediatric intensive care unit; S, subspecialty.

☆ Clinical Trial Registration: ClinicalTrials.gov Identifier: NCT01371864 Study ID #: 10-1772.

☆☆ Authors declare there is no conflict of interest.

* Corresponding author at: WakeMed Physician Practices, 3024 New Bern Ave, Raleigh, NC 27610, United States.

E-mail address: chanson@wakemed.org (C.C. Hanson).

administration [3]. Optimizing peri-operative congenital heart disease management, including improving patients' and families' satisfaction and outcomes, requires a multidisciplinary teamwork approach [13].

Research in adult consent processes, suggests that patients often are not concerned about understanding the potential side effects and risks of surgery [14]. Research has found that providing parents with communication guidelines prior to consent can improve communication [15]. Additionally, it has been demonstrated that a large variation exists in how parents and families grasp the complexity and implications of the child's cardiac lesion [16]. This differs in each family based on age, level of education, and marital status. Significant gaps remain in parental understanding of the underlying condition even when a prenatal congenital heart disease diagnosis exists [17]. Family communication and involvement are critical to enhanced satisfaction and understanding of patient care and recovery [3,18–20]. Medical practitioners can build a trusting relationship with families by allowing parents to partake in the decision-making of their child. This partnership builds parental confidence in caring for their ill child at home [18] and decreases healthcare costs with more effective use of healthcare resources [3].

We could not find previous studies that evaluated the nature or impact of multidisciplinary team communications between nurses, physicians and children's families around perioperative time of the cardiac surgery on patient or family outcomes. We collate data from a series of discussions with patients and staff to assess strengths and weaknesses of current systems, and identify areas for improvement that account for patient preference, staff capabilities and logistical feasibility.

2. Methods

2.1. Patient Selection

We studied medical providers and families of children with congenital heart disease undergoing cardiac surgery at the University of North Carolina Children's Hospital. This 140 bed university-affiliated, tertiary pediatric hospital with approximately 6300 annual admissions provides medical and surgical services including emergency, outpatient, trauma, cardiac surgery, organ transplantation and extra corporeal life support. We conducted a prospective qualitative study consisting of structured interviews and surveys. All English speaking medical providers and families of children undergoing pediatric cardiac surgery from August – December 2011 were eligible for inclusion in the study.

The medical providers were divided into three groups: Pediatric critical care, cardiothoracic, and subspecialty (anesthesia and cardiology) providers. The study was approved by the Institutional Review Board (#10-1772). This study is registered with ClinicalTrials.gov (#10-1772).

2.2. Data Collection

Written informed consent was obtained from all study participants. Patient families and medical providers were interviewed before and after cardiac surgery was performed on children with congenital heart disease. A single interviewer, with substantial experience as a pediatric critical care nurse caring for children with congenital heart disease and their families performed all interviews. (D.Y.). Both mothers and fathers were invited to take part in the study during the pre-operative evaluation of their child either in clinic, or in the inpatient setting. If both parents of a child participated in the study they were interviewed jointly. Medical providers were invited to take part in the study on the day of surgery. The interviewer asked open-ended questions based on the interview protocol, followed up on participants' responses, pursued themes as they arose, and sought clarification or elaboration as required.

2.3. Number of Participants

The number of participants chosen was based on the criterion of data saturation, in that data were analyzed hand-in-hand with data

collection until no new themes were identified and met the purpose of the original inquiry [21]. We used a structured questionnaire in which socio-demographic data as well as satisfaction scores were collected from survey participants. Completion of the survey was optional and anonymous. The participants were given the survey at the end of the post-surgical intervention interview and they returned it in a sealed envelope to the interviewer. Demographic and clinical information was collected from the patient medical record including age, sex, diagnosis, and the peri-operative course.

2.4. Instruments

Self-assessment questionnaires (Appendix 1) were developed and piloted for this study to evaluate socio-demographic data, and satisfaction with both the interview process and the overall hospital experience. The questionnaires consisted of Likert-type questions that included 5 responses: strongly disagree, disagree, neither/nor, agree, and strongly agree. The face validity of the questionnaire and the structured interview form was piloted and refined by a sample of clinicians and researchers who were not otherwise involved in the development of the questionnaire. The interview pilot study demonstrated that participants had no difficulties completing the questionnaire and no changes were made.

The themes that guided the structured interview question development are the following:

- Communicating information and confidence
- Quantity and type of risk information disclosed
- Areas of delay and dissatisfaction in the communication process
- Negotiating responsibility and risk awareness
- Increasing patient and staff understanding of the process
- Managing expectations and fears of patients/families

2.5. Data Management and Analysis

All interviews were audiotaped and transcribed verbatim according to a standardized format. Each transcript was examined closely, and the findings analyzed thematically by CH, JKJ, PB, who met numerous times and agreed on emerging themes and the coding framework. Transcripts were analyzed along-side the field notes, using the constant comparative method to inductively generate a coding structure that outlined themes and subthemes. Coding is the interpretative process in which conceptual labels are given to the data [22–23]. After the researchers reached consensus on the coding structure, the codes were then applied to the entire set of interviews [24–25].

The interview data were summarized according to the four areas of inquiry and were analyzed using a thematic and iterative approach. Thematic analysis was used as a realist method, reporting the experiences and reality of participants [26]. Thematic analysis, in contrast to other qualitative methods, is not attached to any specific pre-existing theoretical framework.

3. Results

Ten pre-surgical interviews and eight post-surgical interviews and eight questionnaires were conducted with parents ($n = 10$). Thirteen pre-surgical interviews and twelve post-surgical intervention interviews and twelve questionnaires were conducted with medical providers ($n = 13$). One patient was discharged early and neither the parent nor the nursing caregiver was available for a post-surgical intervention interview to be performed. Additionally, one parent post-surgical intervention interview was lost due to technological error. To reduce respondent burden, each interview lasted between five and nineteen minutes. All interviewees were also asked to complete a survey during pre-surgery and post-surgery periods. [Table 1](#) summarizes the patient demographic data. The surgical procedures performed included Tetralogy of Fallot ($N = 2$), Coarctation of the Aorta ($N = 2$), Atrial Septal

Table 1
Patient characteristics (n = 9).

Patient	
Median age (range)	4mo (12 days–5 years)
Male (%)	n = 5 (56%)
Female (%)	n = 4 (44%)
Surgery	Median (range)
Cross-clamp, n = 9	38 (21–130 min)
Cardiopulmonary bypass, n = 7	84 (45–209 min)
Hospital course	Median (range)
Mechanical ventilation	<1 (<1–42 days)
Intensive care unit stay	3 (1–48 days)
Hospital length of stay	6 (1–63 days)

Defect/Ventricular Septal Defect (N = 2), Pacemaker placement (N = 1), Atrial Septal Defect (N = 1), and Rastelli (N = 1) procedures. Table 2 summarizes the participant demographic data. Appendix 1 includes the structured interview tools and the participant questionnaires.

All of the family participants strongly agreed “if given the choice and need, I would return to this hospital again for surgery”. Families responses to “overall, I am satisfied with the pediatric cardiac surgery team communication process” were evenly split between agree and strongly agree.

Four key themes emerged from the analysis where the process may fail in communication with the child's family: Patient/Family Centered Relationship, Sources of Control, Barriers to Communication, and Opportunities for Improvement.

4. Theme I: Patient/Family Centered Relationship

Interviewees discussed specific efforts to build a relationship of trust with the family, for example,

“It's not uncommon for me to say that I'll care for their child as if they were my own.” [S1 Subspecialty - Pre-surgical Interview] “I think it would be nice to meet all the families before surgery, just so that can familiarize themselves with our faces and who we are because I think that would help them to have less anxiety during the time that they're waiting knowing who's going to be caring for their child after surgery. They get a chance to meet the CT surgery team, they feel confident having a trusting relationship with them, but I'm sure they must feel some anxiety about who's caring for my child...until they're actually able to come into the room and meet you and establish a relationship. [CC 3 - Pre-surgical Interview]”

How information is communicated to the patients/families varies with the length of the relationship, as well as verbal and physical cues. For example, a family with a child who has undergone previous

Table 2
Medical provider Characteristics.

Families	
Median age (range)	27 (19–31 years)
Mother (%)	N = 9 (90%)
Father (%)	N = 1 (10%)
Physicians	
Median age (range)	44 (37–58 years)
Female	N = 2 (33%)
Male	N = 4 (66%)
Nurses/physician assistants	
Median age (range)	29 (19–46 years)
Female	N = 2 (29%)
Male	N = 5 (71%)

surgeries is more familiar with the care environment and the risks of the procedures.

“Ever since Jordan has been born, all the doctors...they know Jordan. They don't just know the congenital-heart-defect baby. They know her. Dr. X got to know her. And once she came to our house, she knows her by name.”

[[P2 Pre-surgical Interview]]

How information is conveyed also varies with the perceived level of health literacy, but the risks are conveyed regardless.

“I tailor the language I use or how I present it based on education level and understanding level – especially medical knowledge level.” [S1 Subspecialty Team - Post-surgical Interview]

“Regardless of who they are...regardless of how educated or not educated...you tell about the complications you face...you tell them... and make sure you understand that.” [CT3 Surgeon - Post-surgical Interview]

Family-centered rounds, bedside rounds in the PICU that include the families, are perceived as an important way to engage families in the care process.

5. Theme II: Sources and Locus of Control

There is a difference between how clinicians and families perceive control in decision-making as part of the care process. Effective communication around choices can allow the family to feel that they have a certain level of control in the care process.

“They're allowing me to help them move her. They showed me how to change her diaper and make sure I do it right without causing more pain to her and they allowed me to help them calm her down when they're doing different procedures . . . so they're letting us be involved in a lot of the stuff that's going on in there.” [P1 - Post-surgical Interview]

“Just ask me if it's okay...I'm not going to tell them no, not to do anything, but it's the point that they ask instead of saying, ‘We're going to do this’, [ask] ‘Is it all right if we try this?’ That kind of makes you feel a part of the decision-making instead of them just making all the decisions. [P1 - Post-surgical interview]

6. Theme III: Barriers to Communication

Although communication is perceived as good, interviewees identified several barriers to more effective communication, namely continuity of care, shortened resident work hours, and the multi-professional composition of the care team.

“I think one of the problems we that we have specifically in the intermediate unit is that because of other priorities we have very poor continuity on a day to day basis at the attending level so that there will be five days during the week, there may be five different attending physicians or at least certainly three different attending physicians during that week...Because of shortened resident work hours the residents have poor continuity just as we do and in fact frequently the attending physicians will have greater continuity as bad as it is...” [S3 Subspecialty - Post-surgical Interview]

The nature of the conversation – informed consent, conversations about the inherent risks of a complex surgical intervention – is a barrier for some families.

"I just try not to listen to all the bad stuff." [P2 – Pre-surgical Interview]

Other families require an in depth conversation on every possible complication.

"Just making me more informed and making sure I knew everything. That was important. The most things I was worried about is not knowing exactly what they were doing." [P1 – Pre-surgical Interview]

7. Theme IV: Opportunities for Process Improvement

Several interviewees offered feedback on the care process that suggests potential improvement opportunities. Families suggested being provided with educational materials such as video presentations and written information, having a scheduled a tour of the PICU prior to surgery, and being introduced to PICU staff that would be caring for their child after surgery. Frequent communication and encouraging families to ask questions was perceived by families as a way to alleviate anxiety and helped them feel more involved in the care provided.

"During her surgery, it would've been nice if somebody would have come out, maybe like halfway through it and just said, 'Everything is going good. She's doing fine.' Just give us an update because it was kind of nerve wracking sitting in the waiting room and not knowing nothing." [P1 – Post-surgical Interview]

Families and providers agreed that more communication can be provided to set expectations prior to surgery.

"I think the only other thing that we don't necessarily do or I haven't seen done here in a long time that other centers do is for the elective operations to actually have an opportunity to meet with the ICU nursing staff, potentially the ICU physician staff and to tour the facility to get a grasp of what they will be facing." [CC1 – Pre-surgical Interview]

8. Discussion

Our surveys found that parental and provider assessment of the content and nature of communications in the peri-operative time period suggest that communication is generally perceived as adequate and appropriate to address family concerns and desire for information but that communication could be improved. Many clinical services develop over a long period of time and in an ad hoc fashion. Such processes are accepted without question, and may even assume a kind of validation through use. Unlike evolution, however, there is no invisible narrative process to ensure that they undergo continuous adaptation and improvement. The study highlights the need for using specific tools, resources, and strategies to improve patient/family communication and to help set expectations with pediatric cardiac surgery patients and families.

Semi-structured interviews are an effective improvement strategy. Informed consent involves cultural diversity, language barriers, multiple psychosocial temperaments [27] and ultimately physician trust [19,28].

We found that most parents felt that the pre and post-operative communication was adequate but could be improved. Brochures, videos, a tour of the pediatric intensive care unit, and being introduced to the pediatric intensive care unit staff (who would care for their child after surgery) may have helped to prepare families more fully for the postoperative period. Families stated that they valued additional detail in their preoperative discussions and wanted to be aware of all the potential complications, no matter how severe. The medical providers relied on both verbal and physical cues from the family to determine the depth of discussion they needed to use in the peri-operative period.

We found significant variation in the extent of intraoperative communication with families'. Despite extensive preoperative conversation, lack of communication during the intraoperative period contributed to a more "nerve wrecking" period. Mothers of children with congenital cardiac disease have increased stress compared to fathers and are at an increased risk of post-traumatic stress disorder [29]. While prenatal diagnosis does appear to alleviate some of the stress during the perinatal period allowing for greater understanding of the lesion [17], efforts to alleviate stress may promote maternal and child health. The family members in the study valued regular updates from the cardiothoracic team during surgery and stated that they preferred additional communication as often as possible during the intraoperative period.

Congenital cardiac surgeries, as well as any congenital defect or complication, undermines the family's ability to parent [20]. The postoperative period overwhelms families, despite the pre-operative preparatory conversations. It is important for families to maintain a sense of semi-normal living, showering, eating, and being a parent. We found that the simple gesture of changing the baby's diaper was felt to be rewarding to the parent. In addition, families also felt more involved when addressed in question formation rather than using statements of intent. Providing the opportunity to ask and encourage questions helped alleviate anxiety and grow confidence and trust in the surgical team.

We have several suggestions for improving communication around pediatric cardiac surgery with patient parents and families. Coordination of care using a pre-operative multidisciplinary care conference that includes the cardiothoracic team, the cardiologist, and a member of the ICU team is essential to address family concerns and set expectations. Additionally, the use of brochures and videos to inform and answer families' questions may improve their understanding prior to surgery. Finally, a tour of the pediatric intensive care unit, including being introduced to the pediatric intensive care unit staff by name may help to more effectively prepare families for the postoperative period. We acknowledge that the suggested activities have not been tested for efficacy in improving patient and family outcomes.

9. Strengths and Limitations

Patient participants were drawn from those families with recent experience with exposure to pediatric cardiac surgery and the resultant communication process. Previous studies have found that the process for communicating with patients and parents is haphazard and that dissatisfaction with current practice is pervasive. Our study found that communication was perceived as adequate but with much room for improvement.

The study included a small group consisting of only English speaking families. As this study was limited to English speaking families, additional research is needed to determine what specific communication solutions will best benefit non-English speaking cultures. This may overlook the cultural and educational differences. In addition, this single pediatric center's procedures and care processes may differ from other institutions.

Despite the small number of interviews being relatively limited, this is within the range reported in existing literature, and both parents and staff repeatedly described similar experiences across our groups suggesting that we were approaching theoretical saturation.

The interviews were performed shortly after surgery during the inpatient time of hospitalization. If the interviews had been performed after the hospitalization was complete we may have found different results due to recall bias.

10. Conclusions

Communication with patients and their parents offers a number of opportunities for increasing patient safety, trust and satisfaction.

This study considerably advances our understanding of how patients perceive and experience care and the profound influence of the organizational culture on the families' perceptions. The families' understanding and satisfaction are key criteria for successful pediatric cardiac surgery, surgery beyond mortality and morbidity.

Our study highlights the need for more effective patient-centered specific tools, resources, and strategies to improve communication and improve family engagement and empowerment. Pediatric care can be improved by attending to suggested solutions by families and providers to improve communication practices and content. Improved communication decreases family uncertainty, improves family empowerment, and improves the understanding of the peri-operative hospital experience. The use of individual interviews provides valuable insights into the social behavior and the underlying shared values, beliefs, assumptions, and norms of families and health care providers. Further research is needed to investigate the impact of implementation of the interventions in this study.

Financial Disclosure

All authors have no financial relationships to disclose relevant to this article.

Funding Source

All phases of this study were supported by the Department of Anesthesiology, University of North Carolina School of Medicine.

Appendix 1

Provider # _____ Provider Survey

Date: _____

We are conducting this survey to improve patient care. Your opinion is important to us. This survey is confidential and will be used by quality improvement teams. This survey is **anonymous** and **optional**. Please do not write your name. By completing this survey you indicate that you are a willing participant.

Conflict of Interest

All authors have no conflicts of interest to disclose.

Contributor's Statement

Christina Lopez: Dr. Lopez drafted the initial manuscript, revised the manuscript, and approved the final manuscript as submitted.

Cherissa C Hanson: Dr. Hanson conceptualized and designed the study, designed the data collection instruments, obtained consent from study subjects, coordinated and supervised data collection, reviewed and revised the manuscript, and approved the final manuscript as submitted.

Diane Yorke: Dr. Yorke obtained consent from study subjects, collected data from study subjects, reviewed and revised the manuscript, and approved the final manuscript as submitted.

Julie K Johnson: Dr. Johnson carried out the initial data analyses, critically reviewed the manuscript, and approved the final manuscript as submitted.

Michael R Mill: Dr. Mill conceptualized and designed the study, critically reviewed the manuscript, and approved the final manuscript as submitted.

Karla J Brown: Ms. Brown assisted with study subject identification and enrollment, critically reviewed the manuscript, and approved the final manuscript as submitted.

Paul Barach: Dr. Barach conceptualized and designed the study, carried out the initial data analyses, critically reviewed the manuscript, and approved the final manuscript as submitted.

Please indicate the extent to which you agree or disagree with the following statements.		Strongly Disagree	Disagree	Neither/Nor	Agree	Strongly Agree
I was comfortable with the timing of the interviews performed.		SD	D	N/N	A	SA
I was comfortable with the topic of the interviews performed.		SD	D	N/N	A	SA
I was comfortable with the length of the interview process.		SD	D	N/N	A	SA
My patient's family understood why surgery was needed.		SD	D	N/N	A	SA
Overall, I am satisfied with the pediatric cardiac surgery team communication process.		SD	D	N/N	A	SA
Based on my experience with the pediatric cardiac surgery team, I would recommend this service to my family and friends.		SD	D	N/N	A	SA
If given the choice and need, I would choose this hospital for my child.		SD	D	N/N	A	SA
Please indicate the importance of the following...	Extremely Unimportant	Unimportant	Neither/Nor	Important	Extremely Important	
The parent's understanding of why my patient needed surgery.	EU	U	N/N	I	EI	
The parent's understanding of what complications may occur as a result of the surgery.	EU	U	N/N	I	EI	
The parent's understanding of what complications did occur as a result of the surgery.	EU	U	N/N	I	EI	
Communication by different team members was consistent.	EU	U	N/N	I	EI	

To help us better understand your responses please answer these confidential questions:

What is your medical position? How old are you? ____ Check One: Male ____ Female ____

Has your patient had surgery in the past?

If yes, was it performed by the NC Children's Hospital medical staff?

If yes, were there complications?

Family# _____ **Date:** _____

Family Survey

We are conducting this survey to improve patient care. Your opinion is important to us. This survey is confidential and will be used by quality improvement teams. This survey is **anonymous** and **optional**. Please do not write your name. By completing this survey you indicate that you are a willing participant.

Please indicate the extent to which you agree or disagree with the following statements.	Strongly Disagree	Disagree	Neither/Nor	Agree	Strongly Agree
I was comfortable with the timing of the interviews performed.	SD	D	N/N	A	SA
I was comfortable with the topic of the interviews performed.	SD	D	N/N	A	SA
I was comfortable with the length of the interview process.	SD	D	N/N	A	SA
I understood why my child needed surgery.	SD	D	N/N	A	SA
Overall, I am satisfied with the pediatric cardiac surgery team communication process.	SD	D	N/N	A	SA
Based on my experience with the pediatric cardiac surgery team, I would recommend this service to my family and friends.	SD	D	N/N	A	SA
If given the choice and need, I would return to this hospital again for surgery.	SD	D	N/N	A	SA
Please indicate the importance of the following...	Extremely Unimportant	Unimportant	/Nor Neither	Important	Extremely Important
My understanding of why my child needed surgery.	EU	U	N/N	I	EI
My understanding of what complications may occur as a result of the surgery.	EU	U	N/N	I	EI
My understanding of what complications did occur as a result of the surgery.	EU	U	N/N	I	EI
Communication by different team members was consistent.	EU	U	N/N	I	EI

To help us better understand your responses please answer these confidential questions:

What is your relationship to the patient? How old are you? ____.

Check One: Male ____ Female ____.

Has your child had surgery in the past? If yes, was it performed by the NC Children's Hospital medical staff? If yes, were there complications?

Provider # _____ Date: _____

Provider Perspectives on Team Communication before Pediatric Cardiac Surgery

I. Communicating Information and Confidence/Trust:

1. How would you describe the communication and contact with the patient's family up until now?
2. What demonstrates to you that the family understood both the content of the pre-operative consultation and your concerns?
3. What details do you remember about your pre-operative discussion with the family regarding:
 - a. What to expect?
 - b. What procedure will be performed?
 - c. How long the surgery will take to be completed?
 - d. Possible complications from this type of surgery?
 - i. Which possible complication most concerned your patient's family?
 - e. Who would be doing the surgery?
 - f. Who would be in the operating room?

II. Making Informed Decisions:

1. What details do you remember about what was discussed during the consent process?
2. How did you determine that all of the family's questions were answered?

III. Quantity and Type of Risk Information

1. In the pre-operative consultation how do you assess how much information to tell a family about potential complications during surgery?
2. What would cause you alter the discussion and include more detail?

IV. Negotiating Responsibility:

How did you involve the family in the health care decisions regarding your patient's care? Probe: What made you feel that the family was included or not included?

V. Managing Expectations and Fears:

1. How do you help alleviate the anxiety felt by your patient's family?
2. How do you help them feel in control of the decision to choose surgery for their child?

VI. We have talked about a lot here, are there other things that you would like us to know that went well or should be improved?

Provider # _____ Date: _____

Provider Perspectives on Team Communication after Pediatric Cardiac Surgery

I. Communicating Information and Confidence/Trust:

1. How would you describe the communication and contact with the patient's family up until now?
2. What demonstrates to you that the family understood both the content of the post-operative communication and your concerns?
3. What details do you remember about your post-operative communication with the family regarding:
 - a. What to expect?
 - b. Any additional procedures that will need to be performed?
 - c. How long it will take to recover from surgery?
4. What do you remember about your patient's family's concerns?

II. Quantity and Type of Risk Information

1. In the post-operative communication with the patient's family how do you assess how much information to discuss about actual complications that occurred during surgery?
Probe: What would cause you alter the discussion and include more detail?
2. If a complication occurred in the OR that will not result in lasting harm for your patient, how do you decide if you should discuss it with your patient?

III. Negotiating Responsibility:

How have you involved your patient's family in daily health care decisions?

IV. Managing Expectations and Fears:

1. How do you help alleviate the anxiety felt by your patient's family?
2. How do you help them feel in control of the daily health care decisions for their child?

V. We have talked about a lot here, are there other things that you would like us to know that went well or should be improved?

Family # _____ Date: _____

Parent Perspectives on Team Communication before Pediatric Cardiac Surgery

I. Communicating Information and Confidence/Trust:

1. How would you describe the communication and contact with the medical/surgical team up until now?
2. What demonstrates to you that the medical/surgical team heard your questions and concerns during the pre-operative consultation?
3. What details do you remember about the medical/surgical team's explanation regarding:

- a. What to expect?
- b. What procedure your child would be having?
- c. How long the surgery will take to be completed?
- d. Possible complications from this type of surgery?
 - i. Which of these complications are you most concerned with?

- e. Who would be doing the surgery?
- f. Who would be in the operating room?

II. Negotiating Responsibility:

How did the medical team involve you in the health care decisions regarding your child's care? Probe: Give me an example of how you felt that you were included or not included?

III. Making Informed Decisions:

1. What details do you remember about what was discussed during the consent process?
2. What questions did you have that were not answered?

IV. Quantity and Type of Risk Information

1. Prior to surgery, how much detail do you want to know about potential complications that may occur in the OR? Probe: Would you want to know about potential rare complications or only those that are more commonly encountered in the OR?
2. How much do you want to know about actual complications?
3. What detail would you want to know about a complication that occurred in the OR if it would not have any long term effect on your child?

V. Managing Expectations and Fears:

1. What did the medical/surgical team do to make you feel less anxious?
2. What did the medical/surgical team do to make you feel more in control of your child's care?

VI. We have talked about a lot here, are there other things that you would like us to know that went well or should be improved?

Provider # _____ Date: _____

Parent Perspectives on Team Communication after Pediatric Cardiac Surgery

I. Communicating Information and Confidence/Trust:

1. How would you describe the communication and contact with the medical/surgical team up until now?
2. What demonstrates to you that the medical/surgical team heard your questions and concerns during post-operative communications?

3. What details do you remember about your post-operative communication with the medical/surgical team regarding:

- a. What to expect?
- b. Any additional procedures that will need to be performed?
- c. How long it will take for your child to recover from surgery?

4. What do you remember about what you discussed with the medical/surgical team regarding your concerns?

II. Quantity and Type of Risk Information

5. In post-operative communications with the medical/surgical team what was discussed regarding complications that occurred during surgery?
6. If a complication occurred in the OR that will not result in lasting harm for your child, what detail would you want to know?

III. Negotiating Responsibility: How were you involved your child's daily health care decisions?

IV. Managing Expectations and Fears:

1. How did the medical/surgical team help alleviate the anxiety you felt after surgery?
2. How did the medical/surgical team help you to feel in control of the daily health decisions for your child?

V. We have talked about a lot here, are there other things that you would like us to know that went well or should be improved?

References

- [1] Mid Staffordshire NHS. Foundation trust public inquiry. Report of the mid staffordshire NHS foundation trust public Inquiry; Feb 2013.
- [2] Dyer C. Bristol inquiry condemns hospital's "club culture". *BMJ* 2001;323:181.
- [3] Committee on Hospital Care and Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics* 2012;129(2):394–404.
- [4] Hanson CC, Barach PR. Improving cardiac care quality and safety through partnerships with patients and their families. *Prog Pediatr Cardiol* 2012;33(1):73–9.
- [5] Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf* 2016(7):509–17 (Jul 25).
- [6] Fuchs V. The service economy. National Bureau of Economic Research: New York, NY; 1968.
- [7] Aronson PL, Yau J, Helfaer MA, Morrison W. Impact of family presence during pediatric intensive care unit rounds on the family and medical team. *Pediatrics* 2009;124(4):1119–25.
- [8] Kuo DZ, Sisterhen LL, Sigrest TE, Biazio JM, Aitken ME, Smith CE. Family experiences and pediatric health services use associated with family-centered rounds. *Pediatrics* 2012;130:299–305.
- [9] Landry MA, Lafrenaye S, Roy MC, Cyr C. A randomized, controlled trial of bedside versus conference-room case presentation in a pediatric intensive care unit. *Pediatrics* 2007;120(2):275–80.
- [10] Phipps LM, Bartke CN, Spear DA, et al. Assessment of parental presence during bedside pediatric intensive care unit rounds: effect on duration, teaching, and privacy. *Pediatr Crit Care Med* 2007;8(3):220–4.
- [11] Schor EL. Family pediatrics: report of the task force on the family. American Academy of Pediatrics Task Force on the Family. *Pediatrics* 2003;111:1541–71.
- [12] Kleiber C, Davenport T, Freyberger B. Open bedside rounds for families with children in pediatric intensive care units. *Am J Crit Care* 2006;15(5):492–6.
- [13] Zühlke L. Successes, failures, challenges and ground-breaking research: messages from the 6th World Congress of Paediatric Cardiology and Cardiac Surgery. *Cardiovasc J Afr* 2013;24(3):93–5.
- [14] Beresford N, Seymour L, Vincent C, Moat N. Risks of elective cardiac surgery: what do patients want to know? *Heart* 2001;86:626–31.
- [15] Cegala DJ, Chisolm DJ, Nwomeh BC. A communication skills intervention for parents of pediatric surgery patients. *Patient Educ Couns* 2013;93(1):34–9.
- [16] Kaden GG, McCarter RJ, Johnson SF, Ferencz C. Physician-patient communication. Understanding congenital heart disease. *JAMA* 1985;253:995–9.

- [17] Williams IA, Shaw R, Kleinman CS, et al. Parental understanding of neonatal congenital heart disease. *Pediatr Cardiol* 2008;29:1059–65.
- [18] Jacobs JP, Pasquali SK, Jeffries H, Jones SB, Cooper DS, Vincent R. Outcomes analysis and quality improvement for the treatment of patients with pediatric and congenital cardiac disease. *World J Pediatr Congenit Heart Surg* 2011;1(2):620–33, 4.
- [19] Rackley S, Bostwick JM. The pediatric surgeon-patient relationship. *Semin Pediatr Surg* 2013;22(3):124–8.
- [20] Salgado CL, Lamy ZC, Nina RV, de Melo LA, Lamy Filho F, Nina VJ. Pediatric cardiac surgery under the parents sight: a qualitative study. *Rev Bras Cir Cardiovasc* 2011;26(1):36–42.
- [21] Patton MQ. *Qualitative research & evaluation methods*. 4th ed. Thousand Oaks: Sage Publications, Inc.; 2015.
- [22] Corbin J, Strauss A. *Grounded theory research: procedures, canons, and evaluative criteria*. *Qual Sociol* 1990;133–21.
- [23] Hesselink G, Vernooij-Dassen M, Pijnenborg L, et al. Organizational culture: an important context for addressing and improving hospital to community patient discharge. *Med Care* 2013 Jan;51(1):90–8.
- [24] Strauss A, Corbin J. *Basics of qualitative research. Techniques and procedures for developing grounded theory*. Second edition. Thousand Oaks, CA: Sage Publications; September 1998.
- [25] Miles MB, Huberman AM. *Qualitative data analysis*. Thousand Oaks, CA: Sage; 1994.
- [26] Flink M, Hesselink G, Pijnenborg L, et al. The key actor: a qualitative study of patient participation in the handover process in Europe. *BMJ Qual Saf* 2012 Dec;21(Suppl. 1):i89–96.
- [27] Mavroudis C, Mavroudis C, Jacobs JP, et al. Procedure-based complications to guide informed consent: analysis of Society of Thoracic Surgeons-congenital heart surgery database. *Ann Thorac Surg* 2014;97(5):1838–49.
- [28] Schaufel MA, Nordrehaug JE, Malterud K. “So you think I’ll survive?” a qualitative study about doctor-patient dialogues preceding high-risk cardiac surgery or intervention. *Heart* 2009;95:1245–9.
- [29] Harvey KA, Kovalsky A, Woods RK, Loan LA. Experiences of mothers of infants with congenital heart disease before, during, and after complex cardiac surgery. *Heart Lung* 2013;42(6):399–406.