



Improving communication with families of patients undergoing pediatric cardiac surgery☆



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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.

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

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

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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

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