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Title

Congenital cardiac surgery and parental perception of risk; a quantitative analysis

Authors

Dr Robyn Lotto* PhD(1) r.r.lotto@ljmu.ac.uk

Prof Ian Jones PhD(1) i.d.jones@ljmu.ac.uk

Dr Sarah E Seaton PhD (2) sarah.seaton@leicester.ac.uk

Mr Ram Dhannapuneni (3) Ram.dhannapuneni@alderhey.nhs.uk

Mr Rafael Guerrero (3) Rafael.guerrero@alderhey.nhs.uk

Prof Attilio Lotto MD (1,3) Attilio.lotto@alderhey.nhs.uk

(1) Liverpool John Moores University, Webster Street, Liverpool

(2) University of Leicester, Department of Health Sciences

(3) Alder Hey Children's Hospital, East Prescot Road, Liverpool

*corresponding author

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Research Abstract

Introduction*:* Interpretation of risk by parents of children undergoing congenital cardiac surgery is poorly documented. The available evidence highlights a dichotomy, where clinicians suggest parents may not grasp the complexity and risk associated with procedures, whilst some parents suggest risk is unnecessarily over-emphasised. **Aim*:*** To quantify how risk is perceived by parents **Methods*:*** 106 parents of children undergoing cardiac surgery were recruited and completed a Likert scale from 1 (perceived low-risk) to 6 (perceived high-risk), at five points: arrival at pre-admission; post discussion with anaethetist/surgeon; day of surgery; discharge from intensive care; at outpatient follow up. The surgical sample was stratified according to risk adjustment in congenital heart surgery. **Analysis**: Data was analysed using Wilcoxon rank tests for differences in distributions of scores, and Krippendorff's Alpha to examine level of agreement. **Results:** Median parental risk scores varied over time, with no consistent risk scores observed. Maternal scores were consistently higher than paternal scores at every time point ($p<0.001$). Postoperative complications resulted in a persistent rise in risk perception at follow up ($p<0.001$). Analysis of parental risk scores, and objective measures of surgical risk highlighted poor agreement that was particularly marked at the extremes of risk.

Conclusions: Parents perceived higher risk scores than those reported by the clinical team. Mothers reported statistically significant higher scores than their partners, highlighting potential tensions. In addition, the changing perception of risk over time emphasizes the need for flexible levels of support and information as parents navigate uncertainty.

Keywords

Congenital cardiac surgery, risk perception, congenital heart disease, quantitative

1 Introduction

Around 8 in every 1000 babies are born with a cardiac anomaly [1], From diagnosis, their parents face multiple decisions. Each judgement requires the balancing of risk and uncertainty, in order for an informed choice to be made. The complexity of this task is often underestimated [2], with recent research highlighting the difficulties for both clinicians and parents when discussing risk [3]. However, the basis for these concerns appear to differ. Whilst clinicians expressed concerns that parents did not always appear to grasp the complexity of the risk scenarios, some parents felt that clinicians unnecessarily over-emphasised risk in situations where no other perceived option was available [4]. Similarly, findings from a study exploring parental views of the consent process in paediatric surgery, suggested that some parents felt that responsibility for the decision to operate or not should remain with the surgeon, not the parents [5]. Whilst this debate surrounding the manifestations of non-directive counselling and informed choice in care provision creates a theoretical framework in which the findings should be considered [6-9], this paper is primarily focussed on parental perceptions of risk. The aim of the paper is to explore the way in which parents of children with congenital cardiac anomalies navigate risk and uncertainty during the pre, peri and post-operative periods.

2 Methods

Ethical permission was granted by the North West - Greater Manchester South Research Ethics Committee (REC reference 16/NW/0730).

This study was undertaken in Alder Hey Children's Hospital, a large tertiary referral hospital in the North West of England. In line with current care pathways, patients are cared for by a congenital cardiologist. Where surgery is indicated, patient notes are

reviewed at a multidisciplinary meeting, and where appropriate, accepted and scheduled for surgery. Subsequently, they are referred to a surgical pre-admission clinic, where they first meet the surgical team. Families are invited to attend the 'one stop pre-admission clinic' several weeks before their surgery is scheduled. During the visit, they speak with the specialist cardiac nurses, undergo any necessary examination or lab work, and meet with the anaesthetic and surgical teams. The consent process is initiated, with information exchanged and opportunities provided to discuss surgery and post-operative care provision. A tour of the ward and intensive care areas is facilitated, with families then returning home until the scheduled surgery date. Written consent to participate in the study was formally recorded at this stage.

A Likert scale from 1 (perceived low risk) to 6 (perceived high risk), was completed by parents at five points: arrival at pre-admission; post discussion with both anaesthetist and surgeon; day of surgery; discharge from intensive care; at out-patient review. Time points one and two were recorded during the preadmission visit, with time points three and four recorded during the subsequent hospital stay. The final time point was documented between one and two months post discharge at a post-operative follow up clinic. Data from each participant was captured over a time frame ranging from 6 to 17 weeks. A small card and envelope was provided, and parents asked to document their perceived risk at the five different time points. The question posed was: "At this point in time, what is your perception of the level of risk to your child?" Parents were asked to document a number from 1-6. In addition, they were invited to qualify their response with free text. Couples were instructed to complete their card independently, without discussing their response with their partner. All responses were completed anonymously, with the card coded for subsequent analysis. Parents were invited to place their responses into a sealed envelope.

The Risk Adjustment in Congenital Heart Surgery (RACHS)-score[10] of each surgery was indicated by the surgeons according to the surgical procedure to be performed, and consent for the surgery obtained accordingly. These scores were recorded for the purpose of this study in order to provide a proxy objective measure of risk.

3 Data Analysis

The Likert scale provided a simple tool by which parental 'perception of risk' could be captured. Longitudinal changes in risk perception, are likely to be affected by changes in parental 'state' anxiety levels (reactions to an adverse situation in a specific moment). [11] Whilst the simplicity of the tool employed facilitated the collation of a large volume of data (over 500 individual data points), direct comparison between participants may be questionable, due to differences in baseline 'trait anxiety' (anxiety related to underlying personality characteristics).

Risk was classified based on complexity, as defined by RACHS. Scores were combined to create three categories of risk: low, medium or high (RACHS-Score 1 and 2 low, 3 and 4 medium, and 5 and 6 high).

Results are presented as descriptive statistics, with the median of scores presented throughout. First, a non-parametric Wilcoxon rank-sum test was applied to investigate differences in the distributions of the risk scores. Significance level was taken to be p=0.05.

Second, a measure of agreement between groups was sought. The median score across the five points for each individual parent was calculated and similarly grouped into categories represented as low, medium and high (1 and 2 on the Likert scale represented low; 3 and 4, medium; and 5 and 6, high). Comparison was made between the parents rating of risk versus the clinicians RACHS score. As the data

were ordered low to high risk, Krippendorff's Alpha testing [12, 13] was undertaken to demonstrate level of agreement between these different groups of ordinal data. Values range from 0 to 1, where 0 is perfect disagreement and 1 is perfect agreement. As no difference was being sought, level of significance were not calculated.

4 Results

One hundred and six parents of children undergoing elective cardiac surgery were recruited via preadmission clinic in the weeks prior to elective surgery. Data from the five time points: arrival at pre-admission (Time point 1); post discussion with anaesthetist and surgeon (Time point 2); day of surgery (Time point 3); discharge from intensive care (Time point 4); and at outpatient review (Time point 5), was collected by the research team. When a risk score was missing for one time point, the median of the other scores was used (n= 5 time points). In cases where more than one data point was missing, the participant was excluded (n=8 participants). In total, the data from 98 parents was included, couples n=44, mother only n=7 and father only n=3.

Three particular trends were identified: (1) changing perception of risk, highlighting the different longitudinal changes in risk perception between mothers and fathers; (2) changing perception of risk following complications, where the impact of complications was identified and (3) parental versus clinical risk perception, where maternal, paternal and clinical perspectives of risk were examined.

4.1 Changing perception of risk

Parental perception of risk was not static, peaking on the day of surgery for mothers, and after discharge from intensive care (see figure 1). By review in outpatients, the median maternal risk perception was lower than the pre-operative baseline. Fathers

presented a more static perception of risk throughout the pre and peri-operative phases, with their perception of risk lower at follow up. At all time points the distribution of maternal risk perception scores was higher than the associated paternal scores (Wilcoxon test for difference in distributions of risk scores between parents: $p<0.001$ at all time points, figure 2) although the difference was most marked on the day of surgery and post-surgery when there was a two point difference (median for mothers vs fathers: 5 vs 3, figure 1) ($p<0.001$).

Figure 1 – Median score by mothers and fathers at each time point

Figure 2 – Distribution of the parental scores at different time points

Subgroup analysis was undertaken to explore trends in responses between parents whose child had undergone surgery during a previous admission (n=6), and those whose child had not. Whilst numbers were small, trends were similar (Figure 3), suggesting that familiarity with hospital processes and procedures had little impact either in reducing or increasing perceived risk. However, small numbers precluded further formal data analysis.

Figure 3 – Median score of previous surgery versus first time surgery

4.2 Perception of risk following complications

Trends in responses following a complication during the post-operative period (n=12 parents) were also explored. Complications were defined as per the National Congenital Heart Disease Audit Database (NCHDA). [14] Whilst most complications occurred in the peri or early post-operative periods (captured in data points 3 and 4), parents of children with complications were ‘most anxious’ post discharge, reflected in significantly higher scores at this time point than the parents of children who did not experience a complication (median score at time point 5: 5 vs 3, $p<0.001$). No

significant difference was observed during the time points during which the complications occurred (Table 1: p=0.81 and p=0.21)

Table 1 – Impact of complications on risk perception

Time point	Complications	No complications	p-value*
Time point 1	3	4	0.03
Time point 2	3	3	0.11
Time point 3	4	4	0.81
Time point 4	4	4	0.21
Time point 5	5	3	<0.001

*This is the p-value for a difference in the distributions between parents of children with complications, and those with no complications, calculated using a Wilcoxon test

Whilst a rise in the perception of risk following a complication may be anticipated, these data highlighted that the timing of heightened parental risk perception may be delayed until the family is at home, suggesting a potential area for targeted care intervention.

4.3 Parental risk perception and RACHS

The third area examined was the impact of complexity of surgery (as defined by the RACHS score) on parental perception of risk.

Low risk

There were 37 parents in the low risk group. On the day of surgery, fathers reported their highest risk score (Figure 4). However, maternal scores peaked following discharge from intensive care, when the difference between parents was greatest (4.5 vs 2, $p<0.001$, Figure 4 and 5). This difference persisted following discharge ($p<0.001$, table 2).

Medium risk

Thirty one parents were included in the medium risk group. Maternal perception of risk was at the lowest following the appointment at preadmission clinic and at follow up following discharge. Their perception of risk increased on the day of surgery, remaining raised following discharge from PICU, before reducing post discharge. Median paternal scores were static throughout, finally reducing following discharge. Maternal perception of risk was significantly higher than that of the fathers on arrival at pre-admission (5 vs 3 $p<0.001$), day of surgery (5 vs 3 $p<0.001$), and in common with the low risk group, post discharge from PICU (5 vs 3 $p<0.001$, Figure 4 and 5).

High risk

30 parents were included in the high risk category. Perception of risk peaked for both parents on the day of surgery, with maternal risk remaining raised until after discharge home. The median score of the mothers were consistently higher than those of the fathers, with a $p<0.05$ at all time points, and $p<0.001$ at time point 4 (discharge from PICU).

Figure 4 – Maternal and paternal scores by surgical risk

Table 2 – Significance values between maternal and paternal scores at each time point

Time point	1	2	3	4	5
Low risk	0.02	0.01	0.006	<0.001	<0.001
Medium risk	<0.001	0.01	<0.001	<0.001	0.002
High risk	0.02	0.004	0.003	<0.001	0.001

*This is the p-value for a difference in the distributions between mothers and fathers, calculated using a Wilcoxon test

Figure 5 - Distribution of scores by complexity at each time point

Comparing Parental Scores with Complexity

The median score across all time points was calculated for each parent and categorised into low (median score: 1-2), medium (median score: 3-4) or high (median score: 4-5). This was compared to a score reflecting the complexity of surgery provided by the clinicians (RACHS 1 and 2 low, RACHS 3 and 4 medium, and RACHS 5 and 6 high). Parents and clinicians rated the same score 44.9% of the time (Table 3: low: 13, medium: 21, high: 10). Parents in the medium risk group agreed with clinicians 67.7% of the time (21/31). However, parents in the low and high risk groups reflected much lower agreement; low 13/37 (agreed 35% of the time) and high 10/30 (agreed 33% of the time). This equated to a low level of agreement between parents and clinicians, (Krippendorff Alpha: 0.368, table 3), indicating that parental perception of risk did not reflect the 'objective' measure of risk as represented by RACHS. Parents of children undergoing medium or high risk surgery scored their perception of risk higher than those whose child was undergoing low risk surgery.

Table 3 – Agreement in parental and RACHS scores

	Parents Low	Parents Medium	Parents high	Total
Low surgical risk	13	24	0	37
Medium risk	1	21	9	31
High surgical risk	4	16	10	30
Total	18	61	19	98

5 Discussion

Parents experience a rollercoaster of emotions when their child undergoes cardiac surgery.[15, 16] Critical time points in their journey have been explored within the literature. Some evidence suggests surgery and the immediate post-operative period illicit the greatest stress responses,[15] with reduced parental stress levels post extubation[17], discharge from intensive care [18, 19] and at home. [20] However, other studies highlight ongoing, or even exacerbation of stress symptoms post discharge [21, 22], with social support a strong predictor of coping. [23]

The data presented in this study, similarly highlights the ups and downs in the parental perception of risk and accompanying stress. However, subgroup analysis provides a more nuanced understanding of the impact of surgery on the parents, highlighting areas for targeted intervention.

5.1 Changing perception of risk

In the context of general paediatric surgery, maternal perception of risk, in particular, has been shown to be unrelated to the complexity, and therefore 'actual' risk of surgery. [24] This trend is reflected in these findings, with parental reported perception of risk higher than the objective measure of complexity. Low levels of agreement were particular apparent at the extremes of risk (low or high complexity surgery) with parents and clinicians only agreeing about the level of risk 35% and 33% of the time.

Significant differences in maternal and paternal risk scores were recorded throughout. Similarly, these differences in maternal and paternal experiences and responses to the stressors and demands of caring for a child with CHD are well documented [25]. Whilst these findings are reflective of the long term impact of parenting a child with CHD, the pattern of responses from mothers and fathers in this study suggest acute

events, such as surgery, illicit similar gender sensitive responses. At every time point (arrival at pre-admission; post discussion with anaesthetist and surgeon; day of surgery; discharge from intensive care; at outpatient review), the distribution of maternal risk perception scores was higher than the associated paternal scores. Within the psychology literature, similar findings have been observed, with higher maternal compared to paternal anxiety markers recorded pre paediatric surgery [20, 26, 27]. This difference appears to intensify when the speciality is deemed to be a high risk overall, such as cardiac or neurological surgery [26].

The implications of such variations on the wellbeing of the family unit are poorly documented. However, there is evidence to suggest that where expectations or perceptions of parents differ, family dynamics suffer, and there is a need to put preventative measures in place to protect the mental wellbeing of all family members.[28] In this instance, practical approaches to addressing this gap between maternal and paternal perceptions, could include formalising the consent process with both parents (by inviting both parents, if appropriate, to sign the consent form). Evidence from research examining decision-making following diagnosis of a severe fetal anomaly, suggests that formalising the consent process in this way provides some 'protection' to the parental relationship, where in the event of an undesirable outcome, blame is avoided, as responsibility was 'formally' shared on the consent form.[29]

5.2 Leaving PICU

Whilst the findings from this study highlights the raised perception of risk associated with surgery and an accompanying intensive care stay, mothers, unlike fathers, reported the highest perception of risk when leaving PICU (time point 4). This difference persisted in all subgroups when complexity of the surgery was taken into

consideration. The rationale for this is unclear. However, this may represent maternal anticipation of the start of the transition from hospital to home,[30] where the perceived responsibility for care provision shifts from healthcare professionals to parents (traditionally, although not always, the mother). There is growing literature base exploring the stresses associated with a PICU stay following cardiac surgery [15, 16]. However, little attention has been paid to the impact of leaving this protected environment. [31] Previous work exploring the impact of leaving the protected coronary care unit (CCU) environment, on adult patients who have suffered a myocardial infarction, highlighted similar stress patterns.[32] Structured educational programmes were found to be an effective intervention, formally preparing patients for the 'downgrading' of the care environment. These findings suggest this is an area that requires further examination, creating the opportunity for a targeted intervention aimed at reducing parental perception of risk.

Within this study, these heightened perception of risk experienced following discharge from PICU continued into the post discharge period for some parents. This was particularly evident in the maternal cohort caring for children following low risk surgery, and for those parents whose child suffered a complication. For those parents caring for a child undergoing low risk surgery, an assumption that perception of risk would reduce following discharge may be made, as surgery is predominantly curative as opposed to palliative, and future care requirements minimal. Unlike medium or high risk patient groups, the need for follow up is limited, and many of these families will be formally discharged. However, these data suggest that, following low risk surgery in particular, some form of ongoing support or reassurance is required.

5.3 Perception of risk following complications

For parents whose child suffered a complication, a significant difference in risk perception post discharge, compared to those parents whose child had a smooth recovery, was recorded. However, no difference was observed at the time of surgery and in the immediate post-operative period. Whilst the findings from this study only account for parental perception in the months between discharge and review in outpatients, the impact of complications was marked. The ongoing heightened levels of risk perception may perhaps go some way to explain the conflicting accounts reported in the wider literature. Further examination of the impact of complications may enable more targeted interventions for families in the future. Parental and child experiences are inextricably linked, with the potential for adverse parental experiences to impact negatively on the child's outcome [33].

Evidence examining parental stress following hospital admission of a child following an accident similarly highlighted heightened levels following discharge (particularly in mothers). Education on the normalcy of parental stress symptoms and reactions, and a routine follow up call following discharge, specifically to explore the potential impact of the symptoms on parents' ability to care for their child, was recommended .[34]

Whilst the unexpected nature of an accident differs from planned surgery, similarities in parental responses to the stressors of an unwell child, and in particular in the event of an unanticipated complication, suggests that the impact of such simple interventions should be evaluated within this cohort.

5.4 Information giving

Information giving is an essential element of the informed consent process.[35] However, determining what constitutes sufficient information, and the impact of that information on parental perception of risk is less clear. [36] Whilst information is likely to have been

sought by parents at varying times, and through multiple sources, a formal exchange of information occurred at time point 2, during discussion with the surgeon and anaesthetist. Quantitative studies exploring patient experiences of information exchange with clinicians present conflicting findings between information volume and patient satisfaction.[37] This apparent contradiction is explored in the qualitative literature where findings suggest a trusting clinician-parent/patient relationship forms the basis of ensuring patients feel that their information needs have been met.[37] A UK wide study, examining information requirements of parents whose children underwent cardiac surgery, highlighted that consistency of information giving was of primary importance in reducing anxiety; however, almost two-thirds of parents questioned suggested they had received different information from different people, leaving them confused and anxious. [38] The 'one stop shop' approach as experienced by this cohort, where a surgeon, anaesthetist and specialist nurse worked together to provide co-ordinated information, supported the delivery of a consistent message. Overall, the trend in responses from the parents reflected a drop in the median perception of risk and distribution of scores following discussions with surgeons and anaesthetists. Rather than assuming the information provided offered reassurance, evidence suggests that the opportunity to meet the surgeons prior to admission provided space to build the parent-surgeon relationship.

5.5 Working practices

Whilst relationships with the wider clinical team also warrant consideration, the surgeon carries ultimate responsibility for the outcome and thus for organization, surgical treatment and peri-operative care.[39] Variations in surgical working practices exist across units, from number of surgeons to the way in which the surgical team functions.[39] Some units have a clear hierarchy of surgeons, with senior surgeons

undertaking the most complex operations. Others have common surgical lists, where case load is distributed evenly across the surgical team. This could mean a staged procedure is performed by a number of surgeons. Little evidence exploring the impact of these different models of working, on parents or clinicians, was identified. However, discussions around the impact of working practices on surgeon burnout has been raised.[40] The findings presented in this study reflects the data collated from parents who were cared for in a unit that functioned with a common waiting list. The reduction in parental perception of risk following their introduction to the surgeon suggests an element of reassurance was achieved and a relationship established. The impact of a potential change in surgeon on the day of the operation is unclear, as is the impact of a change in surgeon for staged procedures. In units where patients are referred to a specific surgeon, other stressors, including potential difficulties in long term planning and risk of cancellation due to reliance on a single clinician, may arise. Optimising service configuration is complex, with the context in which the service is provided pivotal. The importance of the clinician-parent relationship cannot be underestimated. However, wider implications, including the impact of working practices on the surgeons themselves, require consideration. In the era of family centred care, engaging families in these discussions is important to help direct services.

Data for this study has been generated in a single, large tertiary referral centre. Staffed by three consultant surgeons and a team of 16 congenital cardiac anaesthetists and intensivists, parents engaged with a number of clinicians, and subsequently, different approaches to communicating risk. Nonetheless, the influence of hospital policy on the way in which the consent process (and other episodes of risk communication) is enacted, could impact on parental perception of risk. Whilst this is perhaps a limitation of the study, the findings provide a unique insight into parental perceptions during and

in the immediate post discharge period. However, further research is required to explore the rationale for these findings, along with potential solutions to address the issues raised.

6 Conclusions

Understanding how risk is encountered by clinicians and parents within this clinical setting is paramount in order to deliver effective and compassionate care that meets the needs of parents and clinicians alike. The changing perception of risk over time emphasizes the need for flexible levels of support and information as parents navigate uncertainty. When ranking perception of risk, mothers report significant higher scores than their partners, highlighting potential tensions. In the event of a complication, parental risk scores increased. Whilst perhaps unsurprising, what was notable was that the scores remained raised even following discharge. Similarly, mothers of children undergoing low risk surgery recorded a heightened perception of risk following discharge. Interventions to support these specific groups require exploration.

7 Declarations

7.1 Ethics approval and consent to participate

Ethical permission was granted by the North West - Greater Manchester South Research Ethics Committee (REC reference 16/NW/0730). Written consent was provided by all participants.

7.2 Consent for publication

Not applicable

7.3 Availability of data and material

The datasets analysed during the current study are available from the corresponding author on reasonable request.

7.4 Competing interests

The authors declare that they have no competing interests

7.5 Acknowledgements

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7.6 Authors' contributions

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	RRL, AAL, IDJ, RD, RG, SS
Involved in drafting the manuscript or revising it critically for important intellectual content;	RRL, AAL, IDJ, SS
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	RRL, AAL, IDJ, RD, RG, SS

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