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Congenital cardiac surgery and parental perception of risk; a qualitative study

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Research Abstract

Introduction*:* The way risk is interpreted by parents of children undergoing congenital cardiac surgery is poorly documented. Literature suggests clinicians have concerns that parents may not understand the complexity of procedures. Conversely, some parents perceive an unnecessary over-emphasise of risks. **Aim*:*** To explore how risk is encountered by parents of children who are undergoing cardiac surgery, in order to deliver effective and compassionate care. **Methods*:*** A qualitative approach was adopted. Interviews were undertaken with eighteen parents (mothers n=10 fathers n=8). Recordings were transcribed verbatim and analyzed using a constant comparative based approach. **Findings:** Three themes emerged from the data: the nature of risk, reflecting the complexity of parental perception of risk and the influence of the doctor-parent relationship; presenting risk**,** highlighting the way in which risk is presented to and interpreted by parents; and risk and responsibility, examining the way in which parents engaged with risk and the impact of this on their relationship. **Conclusions:** The way in which risk is perceived by parents is complex and multifactorial. The doctor-parent relationship is key to parental engagement. However, parents manage risk and uncertainty through a number of mechanisms, including those perceived as being not rational. This can cause tension, particularly when required to engage in informed decision-making.

1 Background

There is an extensive literature base pertaining to decision-making, which focuses predominantly on the way individuals, groups and organisations arrive at judgements and decisions, particularly in situations involving risk and uncertainty.[1-3] Much of this evidence has been derived from simulation studies, undertaken in laboratory or artificial settings, and designed to explore decision-making in hypothetical scenarios. These studies highlight the use of short-cuts (or heuristics) that are applied in order to simplify the decision-making process, and the over-estimation / under-estimation of risk (or biases) that arise as a result.[3] However, the nature of risk, and how it is interpreted by patients and clinicians is less well documented,[4, 5] and it is unclear how much these simulation findings can be transferred to the clinical setting as they fail to account for the dynamics of time, high levels of stress,[6] the impact of inter-dependent patient characteristics (such as deprivation, education or cultural beliefs)[6-10] and the complexities of wider contextual factors.[11, 12]

Managing risk and uncertainty is central to clinical care, with a crucial part of non-directive care and informed choice revolving around the way in which risk is presented and understood. The general legal and clinical guidance on consent for treatment is well established. Valid consent must be obtained before commencing any treatment, with sufficient information given provided in a non-directive manner, for an informed decision to be made prior to treatment being accepted or rejected.[13] Non-directiveness, as a concept, has evolved from a narrow definition of what should not be done, to a broad definition that promotes active counselling skills in support of patient autonomy and informed decision-making.[14] Although initially a response to the abuses of human genetics in the early 20th century,[15] it also reflects

changes of power within the doctor-patient relationship, where a move away from a paternalistic view of medicine is being seen.[16]

Findings from a recent study highlighted the difficulties experienced by clinicians when discussing the concept of risk with parents following the diagnosis of a severe congenital anomaly, with parental views also reflecting the complexity of engaging with the concept of risk.[17] However, the rationale for these difficulties varied. Whilst clinicians expressed difficulties explaining risk, and concerns that parents did not always appear to understand the complexity of the procedures, some parents suggested that clinicians unnecessarily over-emphasised risk in situations where surgery was the only perceived available option.[18] This is further reflected in findings from a study exploring parental views of the consent process in general paediatric surgery, where some parents did not want to take responsibility, instead suggesting that the decision to operate or not should remain with the surgeon.[4]

Conflict and tensions that arise during consultation are frequently a result of conflicting needs and expectations of the two parties.[19] The high risk nature of congenital cardiac surgery, and the spotlight under which it has continued to operate since the Bristol Enquiry,[20] is likely to magnify such issues. 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 aim of this study is therefore to explore how risk is encountered by parents of children undergoing cardiac surgery.

2 Methods

A qualitative approach was employed in order to best understand the complex reality of risk perception amongst parents of children undergoing congenital cardiac surgery. Recruitment

took place in a large tertiary referral centre in England between May and December 2017. Eighteen parents (ten mothers, eight fathers) were recruited. Where possible, both mother and father were recruited (n=7 couples), with interviews undertaken separately. Participants were identified from a large dataset consisting of ninety parents of infants and children undergoing elective cardiac surgery. They had previously been asked to document their perception of risk using a Likert scale from 1 (perceived low risk) to 6 (perceived high risk). This was recorded at five time `points: arrival at pre-admission; post discussion with anaesthetist/surgeon; day of surgery; discharge from intensive care; post hospital discharge. Participant selection for this study was based on a maximum variation sampling principle,[21] with the data from the original dataset used to determine the criteria for sampling. The following criteria were applied: a spectrum of Risk Adjustment for Congenital Heart Surgery[22] (RACHS)-scores associated with child's surgery; large variation in scores between mother and father; some agreement between parental scores; and parents of children who experienced complications (as defined by the Central Cardiac Audit Database [23] (CCAD)). No parents suffered a bereavement as a result of the surgery. Whilst this was not an exclusion criteria, it is perhaps a limitation of the study. The views of this group of parents deserves further exploration. No parents approached declined to participate.

Demographics of patients identified reflected the range of surgical cases admitted. Six female and five male patients were included, ranging in age between neonate/infant to teenage years. The patients underwent a range of surgeries classified as RACHS-score 1-6. No RACHS-score 5 patients were recruited during the study period.

Whilst most parents were Caucasian, four were of South Asian heritage. Parental age ranged from 19 to 46 years, and represented a cross section of 'social class' (calculation based on the

index of multiple deprivation[24]). Interviews were undertaken at a time and place convenient to parents, with interviews conducted between 1 and 3 weeks post discharge. Interviews lasted between 25 and 90 minutes. Consistent with a naturalistic approach, the sample size was not pre-determined, with recruitment ending once 'data saturation' had been achieved and the data collection process no longer offered any new or relevant data.[25] Data from the final three participants provided no new themes, with the data derived from the interviews supporting the categories already established. This is supported by Francis *et al's* proposal for a '10+3' formula to establish data saturation.[25] This formula requires a minimum of ten interviews to be conducted followed by a further three to evaluate if any new insights are produced. The larger sample size in this study is likely to reflect the heterogeneity of the population, and no new themes or categories emerged following analysis of the data generated from the 15th interview. However, when seeking to demonstrate data saturation, the time expended on each participant, for example the length of interviews as opposed to simply the size of a sample, has been argued to be a more valuable reflection of the quality of the research.[26] In this instance, over 22 hours of interview data was generated.

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

3 Analysis

All interviews were conducted by RL, audio-recorded and transcribed verbatim on an ongoing basis. The interview schedule is available in appendix 1. A systematic and iterative approach of analysis based on the constant comparative method was used, assisted by NVIVO software to organise the data. This is a well-established method of qualitative data analysis, based on the grounded theory approach described by Corbin and Strauss in the 1990s.[27] It involves the

cyclical comparison of new data with existing findings. Each comparison is associated with inductive rather than deductive reasoning, and seeks to explore meaning rather than test an hypothesis.[28] In practice, this involved an initial phase of 'open coding', where concepts were identified within the text and relations sought between them.[29] The codes represented a mix of descriptive summary, commentary and second order constructs and were applied line by line to the data. Coding of all transcripts was undertaken by individually by RL and one other member of the research team. The open codes were then incrementally grouped into categories that reflected theoretical themes. These were discussed and agreed by the research team. The categories were organized into a coding scheme, programmed into QSR Nvivo software, and subsequently used to index the transcripts. These categories were modified continually as additional themes emerged from the data. A reflexive diary of the analysis was maintained by RL, which allowed further insight into the narrative gained.

4 Quality and Rigor

There is a growing call for medicine to embrace 'naturalistic inquiry', thereby giving a voice to patients and carers. [5, 30] Whilst clinical trials provide evidence of the relative effectiveness of interventions, qualitative research can provide insight into patient goals, values and priorities, whilst elucidating the meaning attributed to the risks and consequences of treatment.[5, 31] In line with this paradigm shift, the quality and rigor of qualitative research cannot be assessed in the same way as qualitative research, with a need to examine the 'credibility' and 'trustworthiness', rather than the 'validity' of the research.[32] Mechanisms through which qualitative research can be judged are well documented and established within the naturalistic paradigm.[33] In particular, Creswell's eight key strategies: prolonged engagement;

triangulation; peer review or debriefing; negative case analysis; clarifying researcher bias; member checks; thick description; and external audits; are commonly applied, with incorporation of at least two strategies suggestive of a 'credible' study.[33]

In this study, data collection was undertaken over a period of eight months. 'Prolonged engagement' within the area of interest, provided the researchers the opportunity to develop relationship, and co-construct meanings with the parents.[34] The sample size, or as discussed above, the volume of rich data collated, maximised the chances that 'negative cases' were explored.[35] Data that did not support, or appeared to contradict patterns or explanations from emerging data, were actively sought and discussed.[36] This reduced the potential for bias associated with preconceptions of researchers during interpretation of the data, and created opportunities for researcher reflexivity. This was supported by extensive 'member checks' where parents were actively involved in discussions and confirmation of all interpretations attributed to data.[37] Similarly, 'external audit' was undertaken, with colleagues invited to critique methodological processes and decisions. Together, employment of these rigorous standards and clearly identified procedures, support the credibility of the account conveyed, and give a voice to the parents involved.

5 Findings

Three themes emerged from the data: the nature of risk, reflecting the complexity of parental perception of risk, and the influence of the doctor-parent relationship; presenting risk**,** highlighting the way in which risk is presented to and interpreted by parents; and risk and responsibility, examining the way in which parents engaged with risk, and the impact of this on their relationship.

The nature of risk

Most parents provided a generic definition of risk when asked:

"Yeah it's about the percentages and chance of dying mainly…." M02

While most parents were able to provide a standard definition, many parents appreciated that risk was more complex than encompassed by this definition.

A simple definition would be the chance of something happening…. But it's much more complicated….. F04

Difficulty in verbalising the complexity of risk was common. However, narratives suggested that parents understood risk to be a combination of many factors, punctuated by experience and a general 'gut feeling'.

"I'm not really sure, it's partly what we hear, and see but also just what we feel" M11

Factors such as faith, trust and hope were identified by many of the parents as playing an important role in their assessment of risk. Trust is an essential element of a successful clinician-patient relationship.[38] Parents highlighted a variety of mechanisms through which this was established in their encounters.

*He made us feel like we had known him forever…. That sort of made the risk go away because we felt we could **trust** him" F07*

Conversely, many parents identified barriers to establishing a trusting relationship. In particular the need for clinical teams to demonstrate specialist knowledge.

"There's no way that I'm taking her back there [local hospital], as soon as you say 'heart patient' they panic.

She's been admitted and had unnecessary blood tests and all sorts." M01

Whilst parents understood the difficulty clinical staff face when caring for highly specialised conditions, it was apparent that trust was of primary importance, and once lost, irrespective of treatment care, it was likely to be compromised.

"I need to know that they doing the right thing, and we just feel they're not. Maybe they are, I don't know, but I can't trust them and so it really doesn't matter what they say, it'll be wrong." M10

Parental perception of clinician competence was often related to perceived experience. Where clinicians were seen to be caring for similar patients on a regular basis, this created an environment conducive to a successful parent-doctor relationship.

"Some of it is knowing they do this stuff day in day out." M01

Parents were often very knowledgeable about their child's condition, particularly as the child grew. Many saw themselves as effective gatekeepers, a skill learned through experience and time. In turn, this provided them with a solid grounding on which they felt they could base their judgement of risk.

"After a few years, I think my instincts are good. I can smell bullshit a mile off!" M06

When asked about how this impacted on her perception of risk, the mother elaborated.

"Yeah of course [having good instincts] helps. I've learned who I can trust…… people I haven't come across before….. well that's easy. You just know. The second they start

making assumptions and tell me stuff that isn't right, well that's it!" M06

The importance of continuity of care and a single point of contact were also highlighted by parents. In this instance, cardiologists were frequently singled out as the anchor.

"Doctor [cardiologist] is my God. We've known him since before [child] was born, and he knows us. If he says it'll be ok, then I have every faith it will be" F07

Presenting risk

Risk associated with surgery was presented and discussed with parents by a number of members of the clinical team. This provided the chance for parents to engage with the information in different forms, as well as ensuring opportunities to reinforce key messages.

The way in which risk was presented, predominantly in percentages, was broadly accepted as the primary mechanism to communicate risk.

"Well the numbers are important….. 'cause we need to know what the risk is" M07

However, further into the interview, the narrative of the parents highlighted some of the difficulties encountered when engaging with numerical descriptors of risk. In particular, the lack of a shared understanding or use of terminology, made interpretation of risk more complicated.

"Well in [hospital one] they said she had like a 99% chance that she wasn't going to make it. I guess we prepared ourselves to say goodbye at that point. But then suddenly it was 50/50 and then when we got here it was

only 25% risk of her dying. We knew then that she was
going to make it." M08

This quote encapsulates the issues that arise from the multiple meanings or interpretations attributable to the presentation of risk. For a Risk Adjustment for Congenital Heart Surgery (RACHS)-score of 6 (highest risk of mortality in congenital cardiac surgery) the associated risk of mortality is between 20-25%. However, in this instance, the parents have interpreted the percentages as indicative of a high chance of survival.

For some parents, the use of percentages to communicate risk was a consequence of an increasing litigious society, where processes were put in place to protect clinicians rather than inform parents.

"I sometimes feel we have to listen stuff so they can say
'We told you about that' if something goes wrong" M05

Two children within this study suffered complications following surgery. For their parents, perception of risk increased, and remained high even once the child had recovered and was discharged.

"I can't help worrying. I know it's irrational, but things
just keep popping into my head" M03

Some parents were unable to verbalise their concerns, but suggested that complications may be reflective of a previously underestimated risk.

"She was more poorly than they thought. It just makes
me worry about what else could happen" M02

With evidence suggesting that parents of 'cardiac children' are hyper vigilant,[39] these findings suggest that following a complication, parents may be particularly at risk.

Whilst the provision of risk information provided a starting point, some parents questioned whether it was possible to have a shared perspective on what actually constitutes a risk. These parents had recorded a raised score post-surgery, which continued into the discharge period. This was despite no 'official' complication being recorded. When this scoring was raised in an interview, the parent suggested that parental expectations did not always reflect those determined by the medical team.

"(clinicians) can't tell us the risk of everything, so how do they decide what to tell us about? Are they the same things that are important to me?" F06

Risk and Responsibility

A dichotomy was noted between couples who had recorded large variations in their levels of risk perception, and those who reported similar levels. Amongst the couples where a variation existed, one partner often took full responsibility for the decision to proceed with the surgery. In this sample this was always the mother. However, the rationale given for this varied. In some instances this was a pragmatic decision, based on modern family life.

"My husband's got four kids, but she's my only child. It just works for us that I make the decisions for her, as he has all the others to sort." M04

However, for others, the decision-making fell to one partner as a result of the way the parents individually managed the information they received.

"Well, [husband] just can't deal with this sort of thing. He gets all uptight and stressed. Then he just switches off and doesn't hear anything. I have to stay calm so at least one of us knows what is going on!" M09

This was reflected in the way in which the parents managed the regulatory processes such as signing of the consent form.

"Well, yeah I signed it. I mean I had been the one who had had to listen!" F01

There is evidence to suggest that the formal process of signing the consent form is associated, by parents, as accepting responsibility.[40] Should a complication occur, the potential for attributing blame was raised.

"It's difficult. I mean I had signed the form, so I feel it was my decision really. I hope [husband] wouldn't blame me, but it's difficult to know, and I know I would feel responsible" M07

Other mothers within this cohort felt that they had an obligation to take responsibility.

"I talked to the nurses about organ donation. I know [child] will need one in the future, and I can't hope that someone will make that decision for us, if I can't make that decision myself" M11

When seeking the paternal perspective, some fathers suggested it was fear of the future that rendered them incapable of taking responsibility or ownership of the decision.

"I have to just support [mum], I can't think like that." F05

However, for the couples who reported a more unified perception of risk, the decision-making was perceived as a joint responsibility.

"We both try to come to the appointments, so we both know what's going on. I remember some things, and (wife) will remember others, but sharing the strain takes some of the pressure off" F06

6 Discussion

Risk is complex, and understanding risk even more so, particularly within the context of sensitive issues like survival or mortality in children's heart surgery.

Data derived from these interviews provide some insight into how parents interpret and manage risk. In particular, the application of strategies such as faith and trust, as mechanisms to manage risk and uncertainty is identified. These resources are often considered irrational, and conflict with the requirement for parents (or patients) to make rational decisions culminating in informed consent. [17] However, evidence around the use of alternate strategies such as these by patients is growing.[41] Labelled as 'in-between strategies', they are neither the 'rational' anticipated mechanisms whereby information is weighed up, nor 'irrational' whereby the decision-maker is exposed to scenarios where they neither have the knowledge or time to apply 'rational' processes.[42] As a result, it is essential to acknowledge and recognise their importance in parental management of risk and uncertainty. Within this study, many parents enacted 'in-between strategies', in particular that of trust. Consistency and familiarity were key components to developing trusting relationships between parents and clinicians. These relationships often took years to negotiate, with continuity of care was paramount. Once trust had been lost, it was difficult to rebuild. Narratives of parents within this study suggest that this led to a further heightening of hypervigilance and anxiety levels, issues commonly associated with parents of children with a CHD. [39, 43, 44 45]

The findings from this study suggest that parents all expected risk of surgery to be presented in a 'standard' statistical form. Whilst some perceived this to be a mechanism to divert legal responsibility from clinicians to parents, others accepted the process as a mechanism to engage with clinicians, as the gatekeepers to expert knowledge.

One particular barrier to this exchange was the interchangeability of lay and expert understanding or use of data representation terminology. Whilst clinicians supported parents by providing information on risk in different formats, these findings suggest that this does not necessarily result in a shared understanding of the risks. This was perhaps most clearly illustrated by the excerpt from M08, where clinicians and mother held conflicting perceptions of the associated risk of surgery. In part, this may be attributable to the way in which 'risk' was presented to the parents as the baby was transferred between local and specialist services. Whilst the subjective 'risk' of death would not have changed, the risk figures provided are likely to have been presented as an expression of concern, rather than a calculated risk, thus confounding 'lay' and 'clinical' presentation and interpretation of risk.

This can lead to miscommunication and differing expectations between parents and clinicians. Much work is being undertaken by research teams exploring the communication of risk to the public.[46-51] Recent findings from a study exploring public understanding of the data presented around the quality and safety of the congenital cardiac surgical units around the UK, highlighted the difficulties encountered by the public when engaging with such data.[46] Whilst participants found comparisons easier than interpreting absolute data, parents within this study highlighted their concerns over receiving relative data, where they were saw their child as unique. This dichotomy will need to be addressed, if we are to improve the way in which parents are presented with data.

Complications during or after congenital cardiac surgery are well documented. These are universally recorded and monitored, with national data published and accessible to the public.[23] However, parents within this study raised the issue that expectations of clinicians and parents, in relation to what constitutes a complication, were not always aligned. Whilst it is clear that all eventualities cannot be accounted for during the informed consent process, differing expectations risk damaging the parent-clinician relationship. Complications following surgery are reported as having a long term impact on the psychosocial recovery of patients. [52, 53] However, the limited evidence exploring patient perception of the risks and benefits associated with surgery highlight that patients' interpretations frequently differ with those of their surgeons.[54] Whilst evidence examining this phenomenon in paediatric community is sparse, these findings raise the need to identify support mechanisms to meet the specific needs of this group of parents.

Whilst the main focus of this study was the way in which individual parents engaged with risk and uncertainty, differing intra family dynamics became apparent. Some family units shared responsibility, engaging as a collective, meanwhile others avoided facing uncertainty by delegating responsibility to their partner. The findings from this study suggest that this was unproblematic. However, a limitation of this study, is that the parents recruited had 'good outcomes' in that the child recovered (even if delayed by some complications). Previous studies exploring the decision-making processes of parents, has highlighted the potential for relationship breakdown, where responsibility is assumed by one party.[18] Consideration is therefore needed to identify the most effective way of supporting families, whilst taking individual needs and characteristics into consideration. Whilst this study has provided an insight into parental perception of risk, there remains a need to triangulate these findings

with the perceptions of clinicians. In turn this would provide the opportunity to identify shared recommendations for practice.

7 Conclusions

This study highlights the complexity around the way in which risk is perceived by parents of children with congenital heart defects. In particular, the impact of the parent-clinician relationship on the way in which parents perceive risk is highlighted. 'In between' strategies, such as trust were fundamental mechanisms applied by parents in order to manage risk and uncertainty. Consistency and familiarity were key to developing a successful relationship. Whilst development of trust took time, loss of trust was quick and continued to influence parental perception of risk in future care interactions. Statistical presentation of risk was accepted as a necessity. However, the confounding of lay and expert use or understanding of terminology often led to miscommunication. Both mechanisms to overcome this, and the implications of this on future care relationships require further consideration.

A greater understanding of the implications of differing family dynamics on the perception of risk is required, with targeted care interventions considered for those families whose child experienced complications during the operative or post-operative period.

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10 Conflicts of Interest

None

11 The Ethical Standards statement

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

All procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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