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**A qualitative study exploring risk perception in congenital cardiac surgery: the perceptions of UK surgeons**

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### Article

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## Abstract

**Introduction:** Managing risk is central to clinical care, yet most research focuses on patient perception, as opposed to how risk is enacted within the clinical setting by healthcare professionals. **Aim:** To explore how surgical risk is perceived, encountered and managed by congenital cardiac surgeons **Methods:** Semi-structured interviews were conducted with twenty congenital cardiac surgeons representing every unit across England and Wales. All interviews were transcribed verbatim, with analysis based on the constant comparative approach. **Findings:** Three themes were identified, reflecting the interactions between personal, institutional and political context in which risk is encountered and managed. First, '*communicating risk*' highlights the complexity and variability in methods employed by surgeons to balance legal/moral obligations with parental need and expectations. Universally, surgeons described the need for flexibility in their approach in order to meet the needs of individual patients. Second, '*scrutiny and accountability*' captures the spectrum of opinion arising from the binary nature of the outcomes collated, and the way in which they are perceived to be interpreted. Third, '*nature of the job*' highlights the personal and professional implications of conveying and managing risk, and the impact of recent policy changes on the way this is enacted. **Conclusion:** Variations in approaches to communicating risk demonstrate a lack of consensus, compounded by insufficient evidence to determine or monitor a 'best-care' approach. With current surgical outcomes suggesting little room for increasing survival rates, future care needs should shift to the 'soft skills' in order to continue to drive improvements in parental and patient experience.

## **Key words**

Congenital cardiac surgery, Qualitative, Congenital heart disease, Risk perception

## **Background**

Managing risk and uncertainty is a fundamental aspect of medical practice,<sup>1</sup> with effective risk communication central to non-directive care and informed choice. There are two distinct dimensions of risk; probability and effect.<sup>2</sup> These represent the 'chance' of an event occurring (probability), and the impact (effect). Within a clinical setting, these two dimensions heavily influence the information communicated between clinician and patient, as well as the data used for monitoring and scrutiny. Our understanding of the complex cognitive processes required to communicate and process risk and uncertainty have moved on from early assumption of rational decision making.<sup>3</sup> Much of our current knowledge has arisen from study of the interaction between two cognitive processes: a fast, intuitive reasoning; and a slower, analytical, but time and resource intense route.<sup>4</sup> The first involves adoption of heuristics, or mental shortcuts that base decisions on fewer predictors, but may introduce cognitive biases to decisions.<sup>3</sup> The second process reflects a more traditionally understood rational decision making process, deliberate and logical, but time consuming.<sup>4</sup> The interaction between these two processes is particularly complex when there are high levels of risk and uncertainty associated with the decision. Uncertainty may be generated through lack of knowledge or evidence<sup>5</sup>, differing values placed on risk between patient and clinician,<sup>5</sup>

uncertainty over what constitutes sufficient information,<sup>6</sup> as well as difficulties in communicating risk in a format that is understood by patients or families.<sup>7</sup>

Whilst the primary focus of much of the literature base explores the patients' perception of risk,<sup>8,9</sup> growing evidence suggests wide variations in perceptions of clinicians and patients,<sup>3</sup> highlights the need to examine risk from the clinician perspective.

The risks surgeons encounter has been exacerbated by the reporting and monitoring of outcomes, nationally and internationally. Several public investigations into the performance of cardiac surgeons or centres, has led to an unstoppable drive for increased transparency and scrutiny.<sup>10</sup> The Kennedy Review (2001) published following the deaths of 29 babies undergoing complex congenital cardiac surgery at the Bristol Royal Infirmary in the late 1980s and early 1990s, provided a blueprint for wider NHS reform.<sup>11</sup> Seven findings were identified related to congenital cardiac surgery including the need for national standards, and fewer centres to promote excellent surgical skills by centralising teams. Whilst the review did not focus on outcomes, the need for mandatory reporting of mortality following paediatric cardiac surgery was recommended.<sup>12</sup> Although voluntary, efforts to collate patient outcomes were already well established internationally, with the implementation of mandatory reporting well received, building on existing work and experience. A subsequent review in 2003<sup>13</sup> made similar recommendations for centralisation of services. By 2009, the status quo remained, and the 'Safe and Sustainable' review, was established.<sup>14</sup> A pre-consultation decision was made to close a number of units. However, the politicisation and subsequent scrutiny of the service created division, which in the most extreme, led to legal proceedings, with data used as weapons.<sup>15</sup> In an effort to move forward, and acknowledging the need for

collaboration between units, the New Congenital Cardiac Review was published, setting out standards of care. These are now reported against, and monitored to ensure consistent levels of care and practice.

Within this context of multiple reviews, our study explores how surgeons' perceive and manage risk and uncertainty. Focussing on the highly specialised field of congenital cardiac surgery, we explore the multi-contextual dimensions of risk, experienced during interactions with parents, in personal and institutional practice for the surgeon, against the backdrop of an increasingly scrutinous society.

## Methods

A qualitative approach was employed to explore the complex reality of risk perception amongst congenital cardiac surgeons. Twenty consultant congenital cardiac surgeons were recruited between May 2018 and September 2019. At least one surgeon was recruited from each of the ten tertiary referral centres that offer congenital cardiac surgery in England and Wales. The sample included consultant surgeons at all levels of experience and seniority.

Interviews were undertaken face to face, via internet or by phone. The interviews lasted between 15 and 55 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.<sup>16</sup> A '10+3' formula was used to establish data saturation,<sup>16</sup> where a minimum of ten interviews were 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.

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

## Analysis

All interviews were conducted by RL and HPH, audio-recorded and transcribed verbatim on an ongoing basis. A systematic and iterative approach of analysis based on the constant comparative method was used.<sup>17</sup> In practice, this involved an initial phase of 'open coding', where concepts were identified within the text and relations sought between them. Coding of all transcripts was undertaken individually by RL and SES. The open codes were 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, 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 and SES, which allowed further insight into the narrative gained. Data that did not support, or contradicted patterns or explanations from emerging data, were actively sought and discussed. This reduced the potential for bias associated with preconceptions of researchers during interpretation of the data, and created opportunities for researcher reflexivity.

## Findings

Three categories were identified, reflecting the interactions between the needs of parents and surgeons, and the personal, institutional and political context in which risk is encountered and managed. First, '*communicating risk*' highlights the difficulties faced by surgeons when balancing their legal/moral obligations to describe all potential outcomes of surgery with patient/parental need and expectations. Second, '*scrutiny and accountability*' captures the spectrum of opinion arising from how this is perceived to be interpreted by parents, colleagues and policy makers. Third, '*nature of the job*' highlights the personal and professional implications of conveying and managing risk, and the impact of recent policy changes.

### Communicating risk

The first category 'Communicating risk' highlights the difficulties and tensions encountered by surgeons as they explain the risks associated with surgery. Whilst conveying risk to parents is fundamental to their role, surgeons universally acknowledged the difficulties associated with effective communication of risk and uncertainty.

*There is no way of communicating risk to parents. Even the most articulate, well-read and empathetic doctor can only tell parents... a tiny miniscule idea of what is actually going to happen to their child, and what could happen. We know from talking to other doctors who are parents of*

*patients, that it is really difficult to communicate what the actual possible outcomes could be. C12*

Whilst the provision of balanced information was perceived as ideal, over-emphasis of risk was widely discussed as a potential self-protective mechanism in an era of growing defensive practice.

*you always try to be moderate and to achieve a balance..... we try to over-emphasise the risk in order to protect ourselves.... In the modern era of defensive practice, it's easy to over-emphasise risks and it's easy to over-scare parents about risk of dying.C01*

When defining risk, mortality was central, despite higher risk of other complications, suggesting that discussions were weighted around 'effect' rather than 'probability'.

*there are operations in cardiac surgery....where the risk of death...is so low that somebody might say, 'Well, why do you mention it?' Well, I think you should never lose sight of it....I've never taken a consent for a cardiac surgery that did not state death on the list. C06*

Emphasis on mortality led to a trade-off, diminishing discussions of lifelong morbidity. Furthermore, increased survival has rendered mortality meaningless as an outcome measure.



*we all get hung up on 30-day mortalities, and I think it's meaningless. It's also become less relevant, because in the past, what we did in intensive care wasn't quite so good. We can keep a lot of children alive in a very bad state these days, who are never going to leave hospital. We can keep them alive for several months, for a family that's a pretty devastating outcome.... I think we've got it wrong, C13*

But, mortality was simpler to define objectively whilst morbidities were interpreted differently by everyone.

*The perception of risk is very different.....We have to be factual, based on data. And ....mortality risk is fairly well defined. In terms of morbidity, what we perceive has complications and what the parents think of complications, we are very different. C03*

The difficulties encountered in effectively communicating this risk with parents was widely discussed, with the constant evolution of risk adding to the difficulties in communication, as it created an uncertainty that was often not portrayed to parents from the outset.

*It's a constant, evolving factor that if then the patient maybe gets an infection, and on top of that the kidney function goes down, then that patient is evolving into a higher risk patient, he can develop multi-organ failure. I think, actually, that is where we fail to say so C01*

## Summary

Clinicians highlighted many difficulties in effectively communicating risk. Mortality is an objective measure, and simple to convey. However, surgeons suggested that more emphasis on communicating risk associated with morbidity was needed. Nonetheless, defining these risks is difficult, as parents and clinicians had different understandings of what represented important morbidities. The evolving nature of risk in cardiac surgery, and the subsequent uncertainty it creates, further fuels the difficulties faced. Whilst surgeons acknowledge the distress felt by parents when managing uncertainty, they are conflicted as uncertainty provides professional protection, but risks damaging the parent-clinician relationship.

## Scrutiny and accountability

Whilst surgeons agreed mandatory reporting was required as: *we need to be accountable for what we do* (C03), many surgeons had an ongoing distrust of how the data was being used, and the direction this was taking.

*I think partly it's us to blame. We wanted to make this field of healthcare exceptional. So it's nice in one way. But we never set a pathway. So scrutiny, we thought is a good thing to do, but scrutiny has kind of deviated itself and it looks more like a microscope than a helpful strategy.*

C04

There were concerns about ranking individuals and centres rather than monitoring safety. Ranking ensures someone must always be 'worse', even if the care they provided was excellent.

*.....It seems to be more and more a discriminator between very good centres rather than a discriminator between complete outliers and very poor outcome versus appropriate outcome. Nowadays it is almost as if it trying to seek out who is the best rather than everyone is excellent, there has to be someone who is not good enough, and I don't think that is helpful. (C09)*

This was further compounded by the effects of previous national reviews, where this data was used as evidence in the decision making process to identify which units should be disbanded. This has also left a long-lasting impact on professional (personal and centre level) relationships.

*"Well there is no doubt that 'Safe and Sustainable' put a few centres against each other, in terms of surviving or referring patients or closing and being upsold by other centres..... Some relationships are broken, and I don't think it's going to be solved..... There's no doubt actually, everyone recognises that it's done more harm than good from that point of view"*

C01

A consequence of this external scrutiny was the risk of case selection, whereby high risk operations are potentially not accepted by individual centres. In the long term, this was seen to be detrimental to patients and their families.

*"If you have a death or complication from surgery ..... becoming risk averse in the way you behave clinically if you are worried about risk all the time. And that may be to the detriment of the patients, ultimately C07*

The need to balance accountability through mandatory reporting with 'excessive' scrutiny, whereby surgeons adopted a risk averse approach to case selection, was widely supported.

*it's getting the balance right between those extremes of scrutiny which... stop you from being potentially risk averse.....That doesn't help you, and especially doesn't help your patients (C16)*

However, with the emotive nature of the cardiac surgery, especially that involving children, it was widely acknowledged that external scrutiny was unlikely to change.

*The life of a child is the most emotive thing in human nature, so if you've got something you can count easily, something where there's a life or death risk, and it involves living children, it will be number one news story, public interest, and that's why paediatric cardiac surgery has attracted so much attention (C11)*

## Summary

Whilst the surgeons agreed that some level of benchmarking and scrutiny was essential to ensure the best outcomes for the patients, the degree of scrutiny was perceived, by many, to have gone too far.

## Nature of the job

Whilst the risk to patients was foremost in the surgeons' minds, the professional and personal risk to the surgeons themselves was also highlighted.

*when someone says... telling me about risks, you think about risk to the patient..... The operation, the risks are associated to the surgery and the risks of having a problem after surgery.....But there's also a professional, personal risk on the part of the surgeon. C05*

Risk to the surgeon was particularly pertinent within this speciality, due to the small numbers of procedures undertaken. Therefore, the death of one patient could impact on their 'ranking', potentially prompting a review into their practice.

*The professional risk in congenital cardiac surgery, the main issue is that numbers are so small that the difference between being an outlier and being an insidier [sic] is the loss of one patient in a year. That can make the difference. And the consequence of that as a professional are huge from suspension, losing your job C02*

Whilst this risk is carried by the surgeon, and has the potential to affect their reputation, the important contribution of the multidisciplinary team was widely discussed.

*a lot of them are not related to your performance but are related to the performance of the institution or the hospital or other professionals. But, at the end of the day, it will allocated to your risk..... You operate and you don't sleep for days until that patient goes home... you're responsible but you aren't in control .... Nobody is accountable except you C02*

Some risk could be mitigated through shared decision making, in relation to the approach to care. Nonetheless, the overall responsibility remains with the surgeon, as the outcome is attributed to them personally.

*The philosophy of CH surgery in this country is based on the team approach, and these are why the standards are there. Decisions about the appropriate or right procedure is taken by consensus by the entire team. So that responsibility, at least for the decision, is already a shared responsibility C07*

Many of the surgeons described the impact of a poor outcome on themselves, as well as the team.

*It is a cliché to say that, when we lose a patient or have a bad outcome the surgeon is the so called second victim. But that's not recognised..... Our care is very process driven, and a bad outcome will trigger a series of events, like...a child death review and audit. (and may result in) a report to the medical legal process. This can be quite traumatic C08*

This could include tarnishing of their professional and personal reputation.

*So the old analogy of being the captain of the ship, so theoretically you get the glory but you're the first one to go down, you have to take responsibility and I think that's always going to be true. You invest a lot of things, including your reputation... you do take it much more personally than everyone else C16*

Maintaining a balance between the risk to the patient and to themselves, came with a high personal cost. Many of the surgeons spoke about the potential burnout or depression.

*we are also human beings and two things can potentially happen: depression because other things don't happen as we always expect because we walk in such a delicate pathway..... So depression is common.... Or burn out syndrome C04*

The high risk nature of congenital cardiac surgery as a speciality was widely discussed. However, most felt that this was not acknowledged, or rewarded.

*There are other specialities where the level of risk professionally is pretty low, almost to the point of non-existent, but in cardiac surgery you carry an ultimate responsibility, and yet we all know that it's a team dynamics.... Well basically they're not paid more for taking an increasing level of risk.*

C06

Whilst acknowledging the rewards of the profession, the surgeons highlighted the price of choosing the speciality.

*really nice job and it's really satisfying and there are lots of good things, but it's not an easy job. There's a lot of stress, I can say that we need to be careful how to balance our private life and job, all expectations. I think that at this moment, it's not easy to be a cardiac surgeon in this country,*

C17

Parental perception of the surgeons themselves was seen to contribute to the stress of the role.

*to the public, because we wear this cape, we are this superhero* C05

Many spoke of the need for parents to have some insight into their role.

*for parents to understand our side because it is always one way traffic and the only way that it can come back well its understand what are the*



*professionals going through every time that they operate which is  
unpleasant C02*

The inherent stresses of performing surgery on a child are difficult to comprehend. However, risks to patient and to surgeon often do not receive appropriate and sufficient attention. The need to improve public awareness of risk was highlighted.

*More philosophically, I think understanding about public perception of risk  
is worth perhaps getting people to read around more, and understand  
more. ...it would be nice to be.... having sessions devoted to how you  
discuss risk and public perception of risk and so on. But we also need help  
raise people's awareness of it, I think C11*

All the surgeons expressed concern over the future of the speciality, and the need to plan.

*In the last five years, what have we had? We've had Leeds, we've had  
Leicester, we've had Liverpool, we've had, Bristol again, we've had the  
Evelina. There's an enormous risk, that's why nobody wants to go into  
congenital cardiac surgery anymore C10*

### **Summary**

Whilst patient risk was always central, surgeons identified a high risk to themselves, both professionally and personally. Many felt that they were disproportionately affected by risk;

without any acknowledgement. Levels of stress were reportedly high, and the risk of burnout was widely discussed. Many felt that societal perceptions of congenital cardiac surgeons, as heroes, exacerbated stress, creating unachievable expectations. As a result, concerns over the future of the speciality were raised, where surgeons highlighted the difficulties finding future consultants.

## Discussion

Our study explores the way in which congenital cardiac surgeons experience and manage risk. Surgery, in particular cardiac surgery, is viewed as a distinguished, high profile speciality, in part due to the 'heroic' perception of the intervention.<sup>18</sup> Surgeons are tasked with the complex balance of communicating risk and uncertainty to parents, whilst simultaneously managing their own personal and professional risk. Spurred on by the outcomes of several high profile scandals, congenital cardiac surgery has increasingly faced calls for transparency, and alongside, increase in public scrutiny. A technically demanding specialty, congenital cardiac surgery is "hard to do" but also "hard to get to do",<sup>19</sup> with the training of the next generation a major concern expressed by the participants. Yet, despite the pressures faced, congenital cardiac surgery was still considered "*the best job in the world*" (C01).

Difficulties in communicating risk with parents were universally reported within this study. Legal and clinical requirements for risk communication in relation to treatment consent are well established, where valid consent requires sufficient information provided objectively, for an informed pre-treatment decision to be made.<sup>20</sup> Different approaches to determining what

constitutes 'sufficient' include the *professional standard*, in which the provided information is based on agreement by a community of medical peers, or the *reasonable person standard*, in which the information that someone in the patient's position would expect is provided. Despite these guiding principles, the surgeons acknowledged that communicating risk is complex, and often not achievable. These difficulties are arguably exacerbated in a speciality such as congenital cardiac surgery, which carries one of the highest risks of any surgery.<sup>21</sup> Literature examining parental perspectives suggests that whilst information provision may create a sense of empowerment, it can quickly become overwhelming. In particular, where no other perceived option is available, some parents suggest clinicians' over-emphasise risk,<sup>22</sup> <sup>23</sup> with responsibility for deciding to operate or not perceived as unnecessarily placed on parents.<sup>23</sup> This is exacerbated by a situation of constant uncertainty intrinsic to surgery, and the immense psychological pressure of caring for, and making decisions on behalf of, a sick child.<sup>8,9</sup>

The importance of informing parents of the risk of mortality was universally agreed within this study, even when the risk was minimal. This was perceived as a mechanism to protect the surgeons themselves, in the context of increasingly defensive practice. However, the significance placed on this measure, and the subsequent impact of providing this information on parents, was questioned by the surgeons. Decisions made when emotional, and associated with high levels of uncertainty are particularly prone to influence from cognitive biases and heuristics. These can affect decision making by distorting our understanding of the choices and their subsequent consequences.<sup>24</sup> The way in which mortality data is presented, as well as the order in which information is given, is likely to have a significant impact on the way it

is understood by parents. Gain frame biases, where survival chances are expressed, as opposed to mortality, risk distorting parental understanding of the nature of the surgery, preventing them from understanding that a risk of death exists.<sup>25</sup> This phenomenon has been labelled as “putting on the blinders”, and creates a substantial threat to parents understanding the information provided.<sup>26</sup> The alternative, framing the outcome as risk of dying rather than survival is equally problematic. Parents are likely to have difficulties resolving the divide between emotions and rationality, resulting in a disproportionate anxiety reaction.<sup>25</sup> The surgeons similarly highlighted difficulties in conveying risks associated with morbidity. In particular, defining what constitutes a complication was perceived as problematic. Recent work has been undertaken to present a set of definitions of morbidity following congenital cardiac surgery. However, this assumes shared priorities between parents and clinicians, where individual values placed on the ‘effect’ or impact of a complication are not considered. Findings from this study suggest surgeons accept that their priorities are likely to differ, a finding further supported by previous work with parents.<sup>9</sup> This may be explained in part by ‘availability’ biases where cognitive processes apply recent vivid or ‘similar’ experiences to define the current experience.<sup>27</sup> For clinicians, this is likely to include recent cases, while parents may be left stranded with nothing concrete on which to ‘anchor’ their experiences.<sup>28</sup>

Communicating with parents has to be balanced with the increased personal risk to the surgeon in an increasingly scrutinous society. Transparency of outcomes potentially empowers parents to investigate and inform themselves about their child’s surgical team, and can foster trust, but is not without difficulties.<sup>29</sup> In particular the use of rankings and

comparisons of outcome data was perceived as problematic. Even when all care is excellent, someone still has to be ranked 'bottom'; an observation that is meaningless and may not be useful in the context of a small, collaborative specialty. This is problematic when considering outcomes such as mortality may not reflect the quality of care, or outcomes that matter to patients, and so may needlessly destroy future collaborative working by introducing unnecessary competition.<sup>30</sup>

In addition, findings from this study suggest that ranking in this way, has resulted in surgeons raising concerns over undertaking high risk surgeries. This is a common perspective within the adult cardiac surgery domain although evidence of risk avoidance remains conflicting.<sup>31</sup> However, concerns about risk adverse practice is perhaps more compelling within a small speciality such as congenital cardiac surgery, with low, but diverse, case numbers. This may lead to unintended risks for children unable to find willing surgeons.

Risk, to both patient and surgeon, provided the context for concerns for the future of the speciality which were expressed by many participants, in particular, the lack of trainees. Intense public scrutiny, risk to personal and professional reputations and in particular the lack of control where outcomes are attributed to surgeons rather than centres or institutions, and finally lack of recognition or financial incentive for these risks, were highlighted by the surgeons as contributing factors to the low number of trainees around the world.

The education, training and associated requirements for certification vary internationally, with the evolution and standardisation of education not keeping pace with the development

of the specialty.<sup>32</sup> At present, 70% of current consultant congenital cardiac surgeons in the UK have a non-UK primary qualification, making up 81% of new appointments in the last 10 years.<sup>33</sup> This has resulted in an internationally mobile workforce, with just under half of the consultant congenital cardiac surgeon workforce leaving the UK and moving abroad in the past 10 years. Of these 67% were UK graduates. Combined with an ‘aging’ workforce, with 35% qualifying over 30 years ago<sup>33</sup>, the need for a global approach to training within such a small speciality is paramount.<sup>32</sup>

Recent efforts by the Society of Cardiothoracic Surgery and the Joint Committee on Surgical Training, are seeking initiatives to improve both access to training and perception of the speciality. Insights from this study, suggest that while the focus of training is often technical, broader issues remain. The need for mentors, in the operating theatre and more broadly in all aspects of professional life, has previously been raised<sup>34</sup>. Unlike most specialities, congenital cardiac surgeons work in small groups. Standards developed following the latest review into congenital cardiac surgery, have highlighted the need to work in groups of a minimum of four, allowing sufficient exposure to operating, whilst ensuring support and cover.<sup>35</sup> However, small teams create issues, with the recent scandal at St George’s hospital demonstrating the importance of teams who can work together professionally and personally.<sup>36</sup> The negative impact of recent reviews on intra and inter centre relationships was highlighted by the participants. Recent work has explored ways in which psychometric profiling could explore the suitability of candidates prior to commencing training, as well as identifying “unsuitability tendencies” in candidates during selection.<sup>37</sup> The evidence for national or international mentoring system is growing. New consultants have less experience

and fewer first operator procedures completed. The existence of a learning curve for more complex operations is a surgical reality, which can be minimised but not abolished. The current intense professional and public scrutiny of cardiac surgeons provides a hostile learning environment.

As well as loss of surgeons abroad, and due to lack of trainees, we risk losing surgeons through workplace created stress and illness. Burnout is a significant issue within the physician community as a whole, and particularly affects surgeons whose practices can be characterized by long, unpredictable hours, high-stakes operations, and increasing administrative burden. With burnout reported to affect over 50% of surgeons, the added pressures on this small speciality requires urgent planning, not only in relation to their physical and mental health, but also patient safety, with burnout associated with increased medical errors.<sup>38</sup>

Despite these issues, the surgeons who participated were fiercely proud of their speciality, passionate about promoting and protecting the interests of patients and families, even to the point of personal upset and reputational damage.

### *Strengths/limitations*

Our sample is diverse in terms of location and seniority of the surgeons recruited, with a minimum of one participant from every tertiary centre in England and Wales. Analysis has been undertaken by two researchers, providing opportunity to verify findings. Our work was restricted to the UK, which operates a healthcare services free at the point of access (National

Health Service). However, these findings have relevance in other settings where consent taking, ranking of outcomes and similar working pressures are experienced.

### *Future work*

Our work has highlighted the need to 'future proof' congenital cardiac surgery. Serious issues exist in relation to attracting and retaining future generation of surgeons, as well as providing sufficient emersion and training. Whilst work around improving learning opportunities for technical skills through wet-labs and other simulation means is ongoing, there is a clear need to examine mechanisms through which softer skills such risk communication can be taught.

Work around support for existing clinicians should be further explored, particularly in light of the male gender bias within the subspecialty, and evidence to suggest this is a potential risk factor for burnout.

### **Conclusion**

Communicating risk forms the basis of many surgeon–parent interactions, and yet is one of the most complex. The evolving and ever changing nature of risk, results in a number of tensions between surgeon and parent. Whilst there is a clear need for transparency and honesty with families, surgeons highlighted the personal and professional impact of communicating and managing risk. In a world increasingly focussed on ranking and comparison of healthcare providers, the potential fallout for clinicians, both professionally and personally, needs to be better understood. Within a small speciality such as congenital



cardiac surgery, this is perceived to be particularly relevant, with surgeons suggesting that they are disproportionately affected. Risk of burnout was widely discussed, with many noting that societal perceptions of congenital cardiac surgeons, as heroes, added to these stresses, creating unachievable expectations of perfection. As a result, concerns over the future of the speciality were raised, where surgeons highlighted the difficulties in recruiting trainees.

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## Conflict of interest:

None declared

## Ethical standards

The authors assert that 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, and has been approved by North West - Greater Manchester South Research Ethics Committee (REC reference 16/NW/0730).

## References

- [1] Fox R. Medical uncertainty revisited. In: Bird C, Conrad P, Freemont A, (eds). *Handbook of Medical Sociology*. New Jersey: Prentice Hall., 2000:416.
- [2] Breakwell GM, Jodelet D, Vala J, et al *Societies under threat: A pluri-disciplinary approach*. 2020.
- [3] Slovic P. *The perception of risk*. Routledge, Oxford 2016.
- [4] Kahneman D, Tversky A. *Thinking Fast, Thinking Slow*. Macmillan, Germany 2011.
- [5] Bogardus Jr ST, Holmboe E, Jekel JF. *Perils, pitfalls, and possibilities in talking about medical risk*. JAMA 1999;**281**:1037-41.
- [6] Paton A, Armstrong N, Smith L, Lotto R. *Parents' decision-making following diagnosis of a severe congenital anomaly in pregnancy: practical, theoretical and ethical tensions*. Social Science & Medicine 2020:113362.
- [7] Spiegelhalter D, Pearson M, Short I. *Visualizing uncertainty about the future*. Science 2011;**333(6048)** 1393-1400.
- [8] Lotto R, Jones I, Seaton SE, et al. *Congenital Cardiac Surgery and Parental Perception of Risk: A Quantitative Analysis*. World J Pediatr Congenit Heart Surg 2019;**10**:669-77.
- [9] Lotto RR, Jones ID, Guerrero R, et al. *Congenital cardiac surgery and parental perception of risk: a qualitative study*. Cardiology in the Young 2019;**29**:1361-67.
- [10] Dixon-Woods M, Yeung K, Bosk CL. *Why is UK medicine no longer a self-regulating profession? The role of scandals involving "bad apple" doctors*. Social science & medicine 2011;**73**:1452-59.

- [11] Kennedy I. *Bristol Royal Infirmary Inquiry; Learning from Bristol: the Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995*. The Stationary Office, London 2001.
- [12] Pagel C, Utley M, Crowe S, Witter T, Anderson D, Samson R *et al.* *Real time monitoring of risk-adjusted paediatric cardiac surgery outcomes using variable life-adjusted display: implementation in three UK centres*. *Heart* 2013;**99**:1445-50.
- [13] Elliott M. *19 Lessons Learned from the Public Inquiry into Children's Heart*. *Pediatric and Congenital Cardiac Care: Volume 2: Quality Improvement and Patient Safety* 2014:243.
- [14] Elliott M. *Lessons Learned from the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary and the English Safe and Sustainable Cardiac Review*. *Pediatric and Congenital Cardiac Care*: Springer, 2015:243-59.
- [15] Dyer C. *Suspension of paediatric heart surgery in Leeds provokes controversy*. *BMJ: British Medical Journal (Online)* 2013;**346**: f2098.
- [16] Francis J, Johnston M, Robertson C, *et al.* *What is an adequate sample size? Operationalising data saturation for theory-based interview studies*. *Psychology & Health* 2010;**25**:1229-45.
- [17] Strauss A, Corbin J. *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, California: Sage., 1990.
- [18] Katz P. *The scalpel's edge: The culture of surgeons*. 1999.
- [19] Hussein N, Honjo O, Haller C, *et al.*, Hands-on surgical simulation in congenital heart surgery: literature review and future perspective. In: *Conference Hands-on surgical simulation in congenital heart surgery: literature review and future perspective*, 2020, pp. 98-105. Elsevier,

[20] Department of Health (DoH). *Reference guide to consent for examination or treatment*.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/138296/dh\\_103653\\_1.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138296/dh_103653_1.pdf) 20-01-2020).

[21] Haywood N, Kron IL. *Commentary: Litigation risk in congenital cardiac surgery*. Journal of Cardiac Surgery; **36(1)**: 143-4.

[22] Lotto R, Smith LK, Armstrong N. *Diagnosis of a severe congenital anomaly: A qualitative analysis of parental decision making and the implications for healthcare encounters*. Health Expectations 2018;**21**:678-84.

[23] Pfeil M. *Parents' experience of giving consent for their child to undergo surgery*. Journal of child health care : for professionals working with children in the hospital and community 2011;**15**:380-8.

[24] Blumenthal-Barby JS, Krieger H. *Cognitive biases and heuristics in medical decision making: a critical review using a systematic search strategy*. Medical Decision Making 2015;**35**:539-57.

[25] Redelmeier D, Rozin P, Kahneman D. *Understanding patients' decisions: Cognitive and emotional perspectives*. JAMA 1993;**270**(1) 72-76

[26] Faden RR, Beauchamp TL. *A history and theory of informed consent*. Oxford University Press, 1986.

[27] Mamede S, de Carvalho-Filho MA, de Faria RMD, Franci D, Nunes MdPT, Ribeiro LMC et al. *'Immunising' physicians against availability bias in diagnostic reasoning: a randomised controlled experiment*. BMJ quality & safety 2020;**29**:550-59.

- [28] Kahneman D, Lovallo D, Sibony O. *Before you make that big decision*. Harvard business review 2011;**89**:50-60, 137.
- [29] Exworthy M, Gabe J, Jones IR, Smith G. *Professional autonomy and surveillance: the case of public reporting in cardiac surgery*. Sociology of Health & Illness 2019;**41**:1040-55.
- [30] Lilford R, Pronovost P. *Using hospital mortality rates to judge hospital performance: a bad idea that just won't go away*. Bmj 2010;**340** c2016.
- [31] Hawkins RB, Mehaffey JH, Chancellor WZ, Fonner CE, Speir AM, Quader MA *et al*. *Risk aversion in cardiac surgery: 15-year trends in a statewide analysis*. The Annals of thoracic surgery 2020;**109**:1401-07.
- [32] Karl TR, Jacobs JP. *Paediatric cardiac surgical education: which are the important elements?* Cardiology in the Young 2016;**26**:1465-70.
- [33] Lotto A. *Congenital Cardiac Surgery Workforce*. Unpublished audit 2020.
- [34] Jonas RA. *Training fellows in paediatric cardiac surgery*. Cardiology in the Young 2016;**26**:1474-83.
- [35] NHS England. New Congenital Heart Disease Standards. 2015. Accessed 03-02-2021
- [36] Dyer C. *Shortcomings in cardiac unit at St George's hospital linked to 67 deaths*. BMJ 2020;**368**:m1281.
- [37] Hagelsteen K, Johansson B-M, Bergenfelz A, Mathieu C. *Identification of Warning Signs During Selection of Surgical Trainees*. Journal of Surgical Education 2019;**76**:684-93.
- [38] Dimou FM, Eckelbarger D, Riall TS. *Surgeon burnout: a systematic review*. Journal of the American College of Surgeons 2016;**222**:1230.

