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Original Article

Ethical considerations of transparency, informed consent, and nudging in a patient with paediatric aortic stenosis and symptomatic left ventricular endocardial fibroelastosis*

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Abstract A 9-year-old boy who was born with bicuspid aortic stenosis underwent two unsuccessful aortic valvuloplasty interventions, and by 2 years of age he developed restrictive cardiomyopathy caused by left ventricular endocardial fibroelastosis and diastolic dysfunction. The attending cardiologist referred the patient to a high-volume, high-profile congenital cardiac surgical programme 1000 miles away that has a team with considerable experience with left ventricular endocardial fibroelastosis resection and a reputation of achieving good results. Owing to problems with insurance coverage, the parents sought other options for the care of their child in their home state. Dr George Miller is a well-respected local congenital and paediatric cardiac surgeon with considerable experience with the Ross operation as well as with right ventricular endocardial fibroelastosis resection. When talking with Dr Miller, he implied that there is little difference between right ventricular endocardial fibroelastosis and left ventricular endocardial fibroelastosis resection, and stated that he would perform the operation with low mortality based on his overall experience. Dr Miller stated that the local institution could provide an equivalent surgical procedure with comparable outcomes, without the patient and family having to travel out of state. A fundamental dilemma that often arises in clinical surgical practice concerns the conduct of assessing and performing new procedures, especially in rare cases, for which the collective global experience is scant. Although Dr Miller has performed right ventricular endocardial fibroelastosis resection, this procedure differs from left ventricular endocardial fibroelastosis resection, and he cannot be sure that he will indeed be able to perform the procedure better than the high-volume surgeon. This ethical situation is best understood in terms of the principles of respect for patient autonomy, beneficence, non-maleficence, and justice. The tension between the imperatives of beneficence and the obligation to respect the autonomy of the patient by acting only with the patient's best interest in mind is discussed.

Keywords: Medical ethics; patient rights; nudging; virtue; ethics

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Case presentation

A 9-year-old boy was born with bicuspid aortic stenosis, underwent two unsuccessful aortic valvuloplasty interventions, and eventually developed restrictive cardiomyopathy caused by left ventricular endocardial fibroelastosis and diastolic dysfunction by 2 years of age. The attending cardiologist referred the patient to a high-volume, high-profile CHD programme 1000 miles away that has vast experience with left ventricular endocardial fibroelastosis resection in a handful of patients with good results. The patient was evaluated there and thought to be a reasonable candidate for a Ross operation with concomitant left ventricular endocardial fibroelastosis resection. Owing to problems with insurance coverage, the parents sought other options for the care of their child, including paying out-of-pocket expenses to have the operation at the high-volume programme noted above as well as approaching local programmes in their home state for second opinions.

During this time, the parents interviewed a well-respected CHD surgeon for his opinion and operative experience. The surgeon, Dr George Miller, has considerable experience with the Ross operation, including superior results without mortality and with high freedom from re-operation. He has no experience with left ventricular endocardial fibroelastosis resection. When specifically asked about this part of the proposed procedure, he described his results with the Ross operation and volunteered that, although he had no experience with left ventricular endocardial fibroelastosis resection, he had considerable experience with right ventricular endocardial fibroelastosis resection owing to his expertise with arrhythmia surgery for tetralogy of Fallot, which requires right ventricular endocardial fibroelastosis resection for ventricular tachycardia. In making such a statement, the surgeon is implying that there is little difference between right ventricular endocardial fibroelastosis and left ventricular endocardial fibroelastosis resection. The surgeon is aware of the recommendation from the above-mentioned high-profile institution. He offers to perform the operation with low mortality on the basis of his overall experience. He engages in comprehensive informed consent by describing the nature, risks, and alternatives of the operation with special emphasis on the Ross procedure thinking that the difference between right ventricular endocardial fibroelastosis and left ventricular endocardial fibroelastosis is slight. He stresses that the local institution could provide an equivalent surgical procedure with comparable outcomes without having to travel. The surgeon then left the decision to the family.

Introduction

As the full discussion of this case and the ethical principles associated therewith are dependent on a proper understanding of the major bioethical principles, we will briefly review them now. These principles include respect for patient autonomy, beneficence, non-maleficence, and justice.[1] Each of these principles can be applied to the present case, although with some overlap. The principle of patient autonomy is perhaps the most important, as many of the issues involved with this case are inherent to the process of informed consent. The principles of beneficence and non-maleficence are often conflated. Acting in a patient's best interest and ensuring that no harm is caused are often one and the same. In this case, the surgeon's selectivity in emphasising his experience with certain aspects of the case and his ability to offer the same outcomes as the regional centre can be assessed in terms of these principles. The principle of justice concerns the equitable distribution of economic, emotional, and societal burdens and benefits. This principle can be applied to several aspects of our case that are not directly associated with the physician–patient interaction, but are, nonetheless, essential to understand the ethical issues in contention. Such components of this case might include the additional financial and emotional hardship that travelling for care might confer on the family, and how such potential hardships might interact with the additional bioethical principles that are in apposition.

A conscientious professional, Dr Miller, tries to adhere to the fundamental ethical principles that frame responsible medical practice. Sometimes, however, differing principles can make conflicting demands on the physician, and it is not always clear how these conflicting demands are to be reconciled.

For purposes of analysis and discussion, this case is best understood in terms of tension between the imperatives of beneficence and the obligation to respect the patient's autonomy[2] by acting only with the patient's free and informed consent.[3] The first of these principles tells Dr Miller that he should act in the best interest of his patient. The second principle tells him that he should provide the patient with as much information and explanation as needed in order to make an informed decision. As is often the case, these two principles are in some tension with each other.

Dr Miller has a clear conviction about what is in the patient's best interest. He is confident that he can perform the Ross procedure as well as anyone in the country – indeed, better than most – and he believes that his experience with right ventricular endocardial fibroelastosis resection will provide him the expertise

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to accomplish left ventricular endocardial fibroelastosis resection. He acknowledges to himself that performing the resection on the left side is perhaps more complex and more difficult than on the right side, but does not think that this will pose a problem. In addition, he considers that the family will be better off staying close to home rather than travelling a thousand miles to the more high-profile institution. The out-of-pocket costs to the young family will be reduced as well. All things considered, Dr Miller judges that it is in the patient's best interest that he performs the procedure at the local children's hospital.

As he has a clear concept of what would be best for the patient, he sees it as his obligation to encourage the family to stay locally and allow him to perform the operation. There are presumably various ways Dr Miller could influence the parents to agree, but not all of them would respect patient autonomy. The following are a few methods that he *could* use that might well succeed in persuading the parents to agree: he lies, he uses emotional blackmail, dabbles in willful obfuscation, or pressurises by fear-mongering. These methods might work, but they would clearly violate Dr Miller's obligation to respect patient autonomy, as they do not result in a truly informed, rational decision on the patient's part. Rather, these methods result in the patient or parents being manipulated by non-rational, in effect *coercive*, means to secure agreement. Why are these manipulating and underhanded techniques being mentioned at all? After all, if Dr Miller is correct, and if he is basing his judgement on rational considerations, the parents do not need to be manipulated into agreeing. They only need to be provided the relevant facts and allowed to draw the right conclusions. If the parents are provided with the same information that persuaded Dr Miller, and if they are helped to see this information in the same light that he sees it, then the parents will agree. The process therefore will have been an ideal case of informed consent, and thus maximal respect for patient autonomy. Rarely are these ideals actually fulfilled in practice, especially in complicated cases. The parents are informed individuals with internet skills and intellectual curiosity, but short of taking anatomy, embryology, and pathology courses, the nuances of anatomical and functional asymmetry of the two sides of the heart may be lost in translation. Except for the drawings that Dr Miller shows the parents, the Ross operation is an abstraction to them, and left ventricular endocardial fibroelastosis resection does not actually register understanding despite all the metaphors that can be used to explain the operation.

Therefore, herein lies the crux of this case. Dr Miller holds that his obligation to do what is in the best interest of the patient requires that he convince the parents to authorise him to perform the operation; however, the facts and evidence that convince him are not really available to the parents nor can he, with the very best of intentions, make these facts available to them. He does not want to be overtly manipulative or disrespectfully paternalistic, but he does want to encourage the parents to agree with him. How can he convince them to act in the best interests of their son while respecting their autonomy?

A digression on rhetoric, persuasion, and psychology

Ancient philosophers have thought about ways in which rational and non-rational factors can influence a person's health and decisions. Early teachers in classical Athens – often called non-pejoratively "Sophists" – claimed to be able to teach the art of persuasion and the art of convincing another to agree or to share one's beliefs. Sometimes this art of persuasion relies on strictly rational factors such as logic and evidence; however, non-rational factors can be brought to bear in the effort to persuade as well. In the ancient world, the art of persuasion was sometimes called *rhetoric*, and it was rightly thought to be of great importance in politics, education, commerce, and even family life. In Aristotle's study of the subject, *Rhetoric*,[4] he defines it as "the faculty of observing in any given case the available means of persuasion".

An interesting passage from Plato's *Gorgias*[5] highlights the importance of intense persuasion over informed consent. Gorgias uses his persuasion techniques to help his brother, who is a physician, convince his patient to lie down and undergo the knife for therapeutic reasons (*Gorgias*, 456b). Gorgias, when questioned, infers that his technique is applied not necessarily for the good of the patient but for Sophistic principles of persuasion.

Gorgias replies, "Ah, if only you knew all, Socrates, and realized that rhetoric includes practically all other faculties under her control. And I will give you good proof of this. I have often, along with my brother and with other physicians, visited one of their patients who refused to drink his medicine or submit to the surgeon's knife or cautery, and when the doctor was unable to persuade them, I did so, by no other art but rhetoric. And I claim too that, if a rhetorician and a doctor visited any city you like to name and they had to contend in argument before the Assembly or nay other gathering as to which of the two should be chosen as doctor, the doctor would be nowhere, but the man who could speak would be chosen, if he wished".[5]

In the modern world, volition, motivation, and cognition have been studied in great depth in order to

ascertain what factors play a role in influencing decision making and belief formation. Psychologists, sometimes in the spirit of pure research and sometimes in the service of high-paying advertisers or politicians, have studied how people can be persuaded to embrace a certain belief, buy a certain product, or vote for a certain candidate. Although this is hardly an exact science, significant progress has been made, and we have now a better understanding than ever before of the ways in which we can influence the beliefs of others and, in turn, how they can influence us.

Dr Miller's responsibility and psychological techniques of persuasion

After Dr Miller discussed the issues of informed consent, he asked his nurse practitioner to stay with the parents in his absence to answer further questions that the family might have. It was during this time that the nurse practitioner confirmed Dr Miller's expertise, emphasised his favourable reputation, and allowed the family to ask questions that perhaps they were uncomfortable asking Dr Miller. She also noted the long distance of 1000 miles to the high-profile institution and how their family support system and geographical familiarity would help their child during the recuperation period. The family confirmed that they liked Dr Miller and found comfort that a member of the team – namely, his nurse practitioner – thought so highly of him. They decided to have the operation at the local institution with Dr Miller.

Dr Miller knew that he had the support and loyalty of his nurse practitioner, who has witnessed his excellent results over a 5-year period. He was comfortable leaving his nurse practitioner alone with the family knowing that she would underscore the benefits of staying at the local institution. Of some interest, the nurse practitioner is also financially dependent on the continued clinical volume and well-being of the surgical programme. Many provocative ethical questions arise. Was the informed consent comprehensive enough? Was there selective emphasis on the Ross operation over the left ventricular endocardial fibroelastosis resection? Did Dr Miller consult the literature to explore the potential differences between left ventricular endocardial fibroelastosis and right ventricular endocardial fibroelastosis resection? Does he, in fact, have the expertise to perform this part of the operation? Was there willful or unwillful deception on the part of Dr Miller or his nurse practitioner? In Dr Miller's mind, perhaps he determined that too much information would confuse and scare the parents at a time when he sensed that they wanted confidence. What techniques of persuasion are permissible that do not step over the line into coercion and manipulation?

Selective emphasis

During the process of informed consent, Dr Miller does not give all aspects and every nuance equal weight. Certain conditions or potential complications seem more salient and are emphasised. Others are very rare[3] and are mentioned but not emphasised. There is no intention of concealment per se, but the intent is to give proper weight to the various factors at hand. In this case, Dr Miller believes that the more difficult part of the procedure is the Ross operation which will, in his mind, make the left ventricular endocardial fibroelastosis resection easier owing to the increased exposure after native aortic valve resection. He therefore stresses the former over the latter, even though he has no experience with left ventricular endocardial fibroelastosis resection. He truly believes that he is capable of performing this operation and has used persuasive measures to convince the parents to have the operation at his institution.

Beneficent persuasion

Beneficent persuasion permits physicians to use decision-making psychology to influence patient behaviour in a manner that will favour their long-term health.[6] Physicians have a moral duty to enhance and improve patient well-being while respecting patient autonomy. Beneficent persuasion is ethically justified under these circumstances. Swindell et al[6] note that beneficent persuasion through empathy, respect, and negotiation includes several techniques such as introducing vivid depictions of possible negative outcomes, providing default options to the patient, encouraging patients to think about regret for lost opportunities if medical recommendations are not followed, as well as framing and re-focussing. Framing is a technique that can be implemented by noting the benefits of the procedure first, then discussing the risks or side-effects, and finally concluding the interaction by once more repeating the benefits. Re-focussing reminds patients of past physical and emotional challenges that they have overcome by stressing the end result rather than the temporary effects of pain and suffering during the recuperation period.[6]

Nudging and informed consent

The process of informed consent is grounded on the principle of patient autonomy. Beneficence and non-maleficence often appear to be in tension with

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respect to patient autonomy when considering the promotion of ethical patient care. Recent reports have highlighted libertarian paternalism as a way of influencing individual decision making that "makes choosers better off while preserving freedom of choice",[7–10] and thereby concurrently merging patient autonomy and medical beneficence. Libertarian paternalism acts as a nudge, helping to "alter people's behaviour in a predictable way" and is "paternalistic in that it aims to influence people through means other than rational persuasion to make choices perceived as good for them without threatening their liberty".[7] On the basis of a report by Cohen,[8] prompting individual decision making or nudging allows the chooser to benefit without affecting his or her free choice. Nudging, if performed correctly and ethically, can bridge the gap between the duty to respect patient autonomy and beneficence. This posture resembles paternalism and can be appropriate as long as it is ethically legitimate.[10] Nudging, like libertarian paternalism, recruits the use of "choice architects"[9] who construct contexts in which people make decisions by changing the default choice. In the case of Dr Miller and the family, the default choice is to have the operation; the opt-out choice, which requires some destructive action, is not to have the operation or to have it at another institution. Either choice must be easy and transparent.[10] In reports by Cohen[8] and Thaler and Sunstein,[9] nudging must not be used to influence people into making decisions but rather must include three guiding principles: all nudging must be transparent and never misleading; it must be easy to opt out of the nudge; and nudging must be with the purpose to improve the welfare of those being nudged.[10]

Shared decision making

Decision making is profoundly influenced by an individual's sentiments, spirituality, personal beliefs, society's tenets, and the law.[2] Whether by lifelong learning, societal teaching, or providential influence, humans are capable of discerning moral choices by perceptual acuity, patterns of attention, capacity for affective resonance with others, and ingrained tendency to do what the individual knows to be the right thing to do.[2] Charles et al[11–13] crafted a context for shared treatment decision making with reference to the doctor–patient relationship. This was developed in the context of a "life-threatening disease where several treatment options were available with different possible outcomes" in a specialist oncology practice for early-stage breast cancer. The doctor–patient interaction model contained characteristics of paternalism and also left room for the three components of shared decision making: information exchange, deliberation, and negotiation with treatment plan implementation.[11–13]

Competency, transparency, and informed consent

A fundamental dilemma that often arises in clinical surgical practice concerns the conduct of assessing and performing new procedures, especially in rare cases, in which the collective global experience is scant. General principles dictate that when confronted with such a challenge, practitioners consult the known literature, visit other programmes with more experience, and prepare their proposed operation with forethought and comprehensive planning. The looming question in this case remains. Does Dr Miller have the expertise to perform left ventricular endocardial fibroelastosis resection based on his stellar experience with right ventricular endocardial fibroelastosis resection and has he adequately prepared? To make a comparison to another surgical subspecialty, does a board-certified general surgeon who has proven expertise in colon surgery provide the surgeon with the expertise to perform complex pancreas surgery? This is a common dilemma and is attended by surgeon age, clinical experience, and technical expertise. At some point, in order to attain surgical experience, one has to perform independent surgery. Our value system calls for board certification, peer-reviewed hospital privileges, outcomes analysis, and reputation to establish perceived competency. These achievements notwithstanding, the assessment of skill when it comes to rare lesions and previously not performed operations remains problematic.

At first blush, the right ventricle is thinner, expected to produce pulmonary pressure, not systemic pressure, and is probably amenable to reparative procedures if the right ventricular endocardial fibroelastosis resection proves to cause iatrogenic injury to papillary muscles, cords, valve leaflets, and the ventricular wall. The left ventricle, on the other hand, is thicker, expected to support the systemic circulation with higher pressures, and is less amenable to reparative procedures in the event of unwanted iatrogenic injuries that are noted for the right ventricular endocardial fibroelastosis resection.

As expected, a comprehensive review (PubMed) of the differences between right ventricular endocardial fibroelastosis and left ventricular endocardial fibroelastosis resection proved fleeting. Most literature citations concerning endocardial resection, other than what was published by the high-volume institution,[14,15] were found in relation to ventricular

tachycardia/fibrillation treatment in the left ventricle that sometimes required papillary muscle translocation, localised ventriculotomy, and localised cryoablation.[16] The approach to the left ventricle in these patients was transaortic and through the mitral valve. Both exposures are challenging for an extensive endocardial fibroelastosis resection and raise the possibility for unwanted complications. References to right ventricular endocardial fibroelastosis were mostly confined to postoperative tetralogy of Fallot patients with pulmonary regurgitation, right ventricular dysfunction, and ventricular tachycardia.[17] Recent studies[18] have abandoned right ventricular endocardial fibroelastosis resection in these patients preferring the selected cryoablation lesion between the ventricular septal defect patch and the pulmonary annulus. Some authors,[17] however, still perform the right ventricular endocardial fibroelastosis resection in addition to the cryoablation lesion, and under these circumstances it is performed through the existent right ventriculotomy with superior exposure making unwanted surgical mishaps less prevalent than those for the left ventricle. The surgeon therefore is left to review the comparative anatomy of the right and left ventricles, recognise the contrasting exposures, and be prepared to perform the left ventricular endocardial fibroelastosis resection, taking into consideration the team's experience with right ventricular endocardial fibroelastosis and make necessary adjustments to perform a successful left ventricular endocardial fibroelastosis resection.

This cursory literature review and the intuitive complexity of the left ventricular endocardial fibroelastosis resection over the right ventricular endocardial fibroelastosis resection would leave the surgeon with the idea that the left ventricular endocardial fibroelastosis resection will be a more difficult operation with the potential for far more serious complications. Dr Miller does not explain this difference to the family perhaps because he has not considered the possibilities, perhaps because he has not consulted the literature, or perhaps because he truly believes that there is no material difference between the two procedures. Is this hubris or is this confidence? Should he be more circumspect about the left ventricular endocardial fibroelastosis resection and offer epistemological modesty; after all, he could be wrong about how easy the procedure in the left ventricle will be. Let us not forget that the Ross procedure in which he has demonstrated expertise is probably the more difficult part of this combined procedure and affords very good exposure for the left ventricular endocardial fibroelastosis resection; however, unsubstantiated confidence while comforting to the patient and parents may not be appropriate. Overly cautious comments that emphasise all the differences in the procedures may erode patient confidence. In the end, is Dr Miller competent enough to perform the operation? The studied answer has to be "yes", but the potential complications were not explained sufficiently – no literature search, not enough informed consent, etc.

Autonomy and transparency

Clinical outcomes of paediatric cardiac surgery continue to improve.[19] Transparent public reporting of paediatric cardiac surgical results is becoming increasingly common.[20–23] The justification for this transparency is based on the following principles:

- Variations in paediatric cardiac surgical outcomes exist.[24,25]
- Patients and their families have the right to know the outcomes of the treatments that they will receive.[20–23]
- It is our professional responsibility to share this information with them in a format that they can understand.[20–23]

Dr Miller is faced with the unusual challenge of caring for a patient with a rare lesion. This challenge is associated with multiple conundrums, including the moral dilemma of how public reporting can help regarding an operation that is so rare that only a few people in the world have actually performed it. In other words, although public reporting and transparency are virtuous, these qualities are complicated in the setting of a rare diagnosis and avant-garde surgery. In order to address this moral dilemma, it is useful to consider the largest platform for the transparent public reporting of paediatric cardiac surgical outcomes in the world: The Society of Thoracic Surgeons Congenital Heart Surgery Database. Over 95% of paediatric cardiac surgical programmes in the United States of America participate in the Society of Thoracic Surgeons Congenital Heart Surgery Database, the largest database in the world for paediatric and congenital cardiac surgery. As of March 2016, 60% of programmes participating in the Society of Thoracic Surgeons Congenital Heart Surgery Database have agreed to publicly report their outcomes using the Society of Thoracic Surgeons Congenital Heart Surgery Database Mortality Risk Model,[26–28] through the Society of Thoracic Surgeons Public Reporting Online website (http://www.sts.org/quality-research-patient-safety/sts-public-reporting-online), where outcomes of paediatric and congenital cardiac surgery are publicly reported in multiple risk categories using The Society of Thoracic Surgeons – European Association for Cardio-Thoracic Surgery Congenital Heart Surgery Mortality Categories (STAT Mortality Categories). Information about outcomes is available for five levels of operative risk.

Surgeons are confronted with a moral dilemma when asked to transparently share their expected outcomes of a rare operation. The principles of honesty and transparency help solve this dilemma. The logical solution is to share with the parents and family the rare nature of the proposed operation and to then extrapolate the expected outcomes on the basis of the known outcomes of operations of similar complexity and expected risk. This approach capitalises on available data and respects the principles of honesty and transparency.

Clinical outcome

The patient was taken to the operating room with preoperative and intraoperative assessment that showed aortic stenosis/regurgitation, left ventricular restrictive cardiomyopathy (left ventricular end-diastolic pressure 37 Torr), and diminished systolic function. The preoperative plan was to perform a Ross operation in conjunction with left ventricular endocardial fibroelastosis resection. Preparations were made for transaortic and transmitral exposure, retrograde cardioplegia, and moderate systemic hypothermia. After aortic transection, the bicuspid aortic valve showed a well-formed raphe that was supported by a fused commissure and two deep and competent leaflets on either side of the raphe. The fused raphe was incised, thereby repairing the aortic stenosis and forming a trileaflet aortic valve that appeared competent. At this point, it was determined that a Ross operation would not be necessary and that a mild degree of postoperative stenosis and regurgitation would be preferable to a Ross operation. The index operation therefore was changed to left ventricular endocardial fibroelastosis resection. The left ventricular endocardial fibroelastosis resection was performed through the aortic valve and the mitral valve orifice after proper exposure was attained through the interatrial groove. The fibrous peel was approached at the apex of the left ventricle and carefully resected by deliberate and precise scissor dissection to delineate the plane between the fibrous peel and the viable myocardium. The resection was accomplished in stages with frequent changes of transaortic and transmitral operative exposure. The papillary muscles were preserved, the integrity of the ventricular wall was maintained, and the chordae were left undisturbed; nevertheless, the operation proved to be longer, more involved, and more challenging than any right ventricular endocardial fibroelastosis resection that Dr Miller had performed in the past. Postoperatively, ventricular function and the left ventricular end-diastolic pressure improved. The left ventricular end-diastolic pressure was measured to be 12 Torr and compared favourably with 37 Torr as measured preoperatively. Intraoperative transoesophageal echocardiography revealed minimal aortic stenosis and insufficiency, excellent relaxation of the left ventricle, and a considerably smaller left atrium. The patient had an uncomplicated postoperative course with significantly improved symptoms and functional status.

Conclusion

Informed consent in the context of complex congenital heart surgery involving rare lesions is a challenging interchange between patients/parents and the surgeon. Dr Miller was confronted with moral and scientific choices that were not altogether vetted and considered. It could be construed that Dr Miller acted in a moral manner without malice and without intent to deceive or coerce. He used selective emphasis, beneficent persuasion, nudging, and shared decision-making techniques to accomplish his goals – namely, to convince the parents to allow him to operate on their child. He may not have achieved what many critiques would have hoped for and expected – namely, comprehensive informed consent. He did not consult the literature on the differences between left ventricular endocardial fibroelastosis and right ventricular endocardial fibroelastosis resection; he did not enquire whether the family wanted to return to the high-profile institution and offer to help them; and he underestimated the difficulty and potential complications of left ventricular endocardial fibroelastosis resection compared with right ventricular endocardial fibroelastosis resection.

A heightened awareness of comprehensive informed consent in light of accumulated data from the Society of Thoracic Surgeons Congenital Heart Surgery Database, review of the available literature, and full disclosure should attend all operations. This posture is especially important when considering therapeutic interventions on rare lesions that may require conscientious preparation before operations that heretofore have not been performed by the surgical team.

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