

## Original Article

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# Foetal cardiac intervention: an ethical perspective

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**Abstract** Although recent advances have helped identify cases where foetal cardiac surgery might reverse the development of certain lesions, the indications and measurement of success in these procedures have yet to be established. Thus, both patients and physicians have a “burden of knowledge”, whereby a diagnosis is made without a clear course of action. The profound issues raised by foetal intervention, specifically the question of how concepts such as “patient” and “success” can be used, complicate this burden further and test the limits of language and logic. Similar issues raised in postmodern philosophy are discussed and can be incorporated into foetal cardiac surgery dialogues to produce a multi-disciplinary approach that will elucidate, not obfuscate, these issues in the future.

Keywords: Congenital cardiac disease; neonates; philosophy; foetal surgery

## Foetal cardiac intervention: the burden of knowledge

THE PAST SEVERAL DECADES HAVE WITNESSED enormous progress in the surgical management of congenital malformations of the heart. Refinements in the techniques of surgery, anaesthesia, and cardiopulmonary bypass have brought us to a point where reparative cardiac surgery on neonates has been performed with technical success.<sup>1–3</sup> Conceptually, the next frontier is the repair or amelioration of critical features of abnormal cardiac anatomy while the heart is still developing. The possibility of foetal cardiac surgery has been explored extensively in the laboratory setting, using animal models, and most recently in the clinical realm. Despite decades of research evaluating the possible application of miniaturised heart–lung bypass circuitry for open foetal intervention, the very unique status of the foetal–placental circulation has limited the spectrum of foetal cardiac interventions that can be performed. Among these interventions are those that rely on transabdominal transuterine access under

ultrasound guidance, and techniques of catheter-balloon angioplasty to relieve critical obstruction(s) in the blood flow pathways of the heart.<sup>4,5</sup>

The clinical scenarios poised to benefit the most from foetal intervention are those where a singular feature of the anatomy causes an obstruction to the normal pattern of blood flow and where that obstruction is believed to be the basis for important secondary features of abnormal cardiac development.<sup>6</sup> One example is the circumstance where critical obstruction at the level of the aortic valve is believed to be associated with progressive maldevelopment of the left ventricular myocardium, leading in some cases to hypoplastic left heart syndrome with critical aortic stenosis. It is postulated that the relief of aortic valve obstruction sufficiently early in foetal development may be followed by birth of an infant with an adequately functioning left ventricle rather than one that is incapable of supporting the systemic circulation due to chronic subendocardial ischaemia throughout foetal life.<sup>7</sup>

Another example is the very rare circumstance of hypoplastic left heart syndrome with associated intact or severely restrictive atrial septum. The incidence of hypoplastic left heart syndrome is 0.016–0.036% of all live births, and this lesion represents roughly 1% of hypoplastic left heart syndrome cases.<sup>8</sup> These patients tend to do very

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poorly in the Norwood sequence of reconstructive surgeries, with survival after stage one at a dismal 33% compared with 70–80% in other aetiologies of hypoplastic left heart syndrome.<sup>9</sup> It is thought that these patients do worse than the others because the obstruction to left atrial outflow during gestation results in significantly abnormal development of the pulmonary vasculature, which decreases cardiac output in the reconstructed, single ventricle circulation.<sup>9,10</sup> The rationale for foetal intervention is the postulate that decompression of the left atrium by foetal atrial septal balloon septotomy may allow more normal development of the pulmonary vascular bed.<sup>11</sup>

Although the prospect of promoting more normal cardiac development by accomplishing a foetal intervention is attractive, it is often difficult to determine with a high degree of confidence which cases are most likely to be associated with unfavourable progression of the cardiac pathology without intervention. Owing to progressively higher morbidity and mortality with the aforementioned lesions, prenatal surgical intervention has been attempted. The purpose of such interventions is to relieve left heart pressure through balloon aortic valvuloplasty in the case of critical aortic stenosis, and through the creation of an atrial septal defect in the case of intact atrial septum. Thus far, interventions have not proven to be consistently successful in reducing morbidity and mortality compared with cases with no foetal surgical intervention. Furthermore, many of the cases that are technically successful by relieving left heart pressure and promoting biventricular circulation had circulatory function similar to those cases that had no foetal intervention.<sup>2,12</sup> Tworetzky and Marshall<sup>7</sup> argue that cases of foetal intervention that have been reported in the literature to date were performed during the third trimester, which may be too late in gestation to reverse the pathophysiologic progression of the lesions entirely. They go on further to suggest that foetal cardiac interventions, particularly those for critical aortic stenosis, might have better outcomes if they are done between 20 and 26 weeks. However, there are no data to suggest that earlier intervention would benefit cases of intact atrial septum.<sup>7</sup>

The purpose of this paper is not to debate the merits of foetal cardiac intervention; the rationale and methodology behind such procedures have been established. The preceding discussion is meant to show that there is a conflict of timing in the diagnosis and treatment of critical aortic stenosis and intact atrial septum. On the one hand, it seems logical that earlier foetal intervention could reverse pathophysiology, at least in cases of critical aortic

stenosis. On the other hand, the earlier the decision is made to intervene, the less confidence a physician has that the defect will ultimately progress to hypoplastic left heart syndrome. Foetal surgery brings with it many potential complications for the foetus, including prenatal death, foetal neurological injury, and pre-term delivery.<sup>13</sup> Similarly, the intervention is not without risk to the mother. The severity of potential complications to the foetus and mother requires compelling evidence that the lesion will progress to hypoplastic left heart syndrome in order to justify intervention.

Thus, there is a burden of knowledge that accompanies a diagnosis of a lesion that has the potential to progress to hypoplastic left heart syndrome. The technological advances of ultrasonography and foetal echocardiography have allowed for earlier diagnosis of certain congenital diseases. To be sure, these advances have done more good than harm. In the case of lesions that may progress to hypoplastic left heart syndrome, however, expecting parents and physicians can be put into a situation where there is a diagnosis without a clear course of action. One is burdened with the knowledge that there is a progressive cardiac defect without definite knowledge of the defect's natural course and of whether or not it will evolve into a life-threatening condition. The burden is complicated by the hypothesis that earlier intervention would better reverse the defect's pathophysiologic progression, because the indications for intervention are very difficult to identify earlier in gestation with the current state of diagnostic equipment and testing.

Owing to the fact that these procedures potentially expose two beings to the risks and benefits of surgical intervention, any proposed intervention needs to have a level of certainty for a positive outcome above that of other medical situations. In this unique medical and surgical situation, there is a burden of knowledge both for physicians and for patients in the interim period between the initial diagnosis and the subsequent tests that will indicate or contraindicate surgical intervention. What is worse, our set of current diagnostic criteria for determining which lesions will progress to hypoplastic left heart syndrome and which will not has neither a high positive predictive value, nor does it have high accuracy in predicting the extent of morbidity and mortality that a foetus may have if the lesion is left without surgical intervention. Thus, both physicians and patients have the burden of knowing that there is a progressive problem in utero, but that there is no established method to predict the extent of progression, nor is there a reliable way to reverse it effectively should it progress to a critical stage.

## The problem of language: throwing the proverbial baby out with the bath water?

The search for a cure for a disease is a burden that drives the majority of medical innovations. In this way, foetal cardiac surgery is no different from any other challenge that modern medicine faces. However, foetal cardiac intervention for hypoplastic left heart syndrome with critical aortic stenosis or intact atrial septum raises other issues that are unique. Chief among them is the relationship between mother and foetus and the threat that foetal surgery can pose to both. In addition to the obvious ethical issues raised by such a predicament – the details of which are beyond the scope of this paper – there are even fundamental issues of language raised in cases of foetal surgical intervention. The notion of a cure in these cases is troublesome, as the disease does not directly affect the patient who consults the physician. A pregnant woman is not ill during pregnancy with an affected foetus, nor can the diseased foetus be considered a disease in itself. Furthermore, because the foetus's viability is questionable during the mean age of diagnosis – around 20–22 weeks – it is difficult to say that the foetus has a disease that warrants intervention. Owing to the question of the foetus' viability, it is difficult to say that the foetus assumes any of the risks of the operative procedure, properly speaking. Thus, even though the pregnant patient is not “diseased” and does not stand to gain any direct, physical benefit from the proposed procedure, it is this patient who assumes all the risks associated therewith. Although there have been no reported cases of maternal mortality in foetal cardiac surgery, the general risk of mortality associated with surgical intervention remains, as do more specific morbidities such as pulmonary oedema, post-operative bleeding, and premature delivery.<sup>14</sup> Much has been written about the concept of a foetus as a separate patient; however, not one of these articles takes seriously the notion of putting aside maternal safety in favour of correcting a foetal lesion. Furthermore, because the methods of intervention are still being developed, the burden of knowledge also carries with it the question of whether or not the intervention is worth the risk to both the mother and the foetus.

The question of sufficiency in language and conventional terms in describing the complexities of foetal surgery has been addressed elsewhere in the literature. The most fundamental issue debated is that of *patienthood*. Chervenak and McCullough<sup>15</sup> argue that it is best to avoid terms such as *unborn child*, *mother*, *father*, and *baby* in discussing cases where the viability and thus the dependent moral status of the foetus is uncertain. Instead, they argue

that the foetus should be referred to as a patient. Rather than regarding the foetus as a fully separate patient with a separate autonomy and beneficence-based obligation to treat that accompanies such a classification, they argue that decisions of foetal health must be considered along with the autonomy and beneficence-based obligations that a physician has to the pregnant woman. In other words, the foetus is a patient insofar as its patienthood is considered along with its moral status, which is dependent on the pregnant woman until the foetus is fully viable. The authors further claim that words such as *treatment* and *therapy* should never be used during the informed consent process, as they are insufficient to describe the experimental nature of the interventions.<sup>15</sup>

Lyerly et al<sup>16</sup> challenged the work of Chervenak and McCullough<sup>15</sup> as to whether the term *patient* applies in cases of foetal intervention. They argue that the appeal to the dependent moral status of the foetus is not sufficient to counter the profound connotations that accompany referring to the foetus as a patient. *Patient*, as they argue, is more than a technical term, and any attempt to reduce the scope of such a broad word will foster misunderstandings between the physician and the patient. The authors fear that misunderstandings might cause pregnant women not to consider, or to consider too lightly, the risks associated with foetal surgery to look after a foetus that, by the connotation of its being a patient, is separate from the pregnant woman. Furthermore, they claim that no word in common usage is sufficient to describe the foetus in this situation and that one risks distortion and misunderstanding by implementing what they refer to as inherited words such as *person*, *patient*, *child*, and others.<sup>16</sup>

Another such inherited word not discussed by Lyerly et al<sup>16</sup> but certainly used throughout literature describing outcomes in foetal cardiac surgery is that of success. The question of what defines a successful outcome is a difficult one in any experimental field, as the procedure in question is a work in progress. The distinction that is made throughout these studies is that of *technical* success rate in foetal surgical interventions, which simply means whether the proposed intervention was able to be performed. This notion of success does not take into account the long-term outcome and whether the intervention was justified by the outcome. For example, recent data of balloon valvuloplasty in cases of hypoplastic left heart syndrome with critical aortic stenosis showed a *technical* success rate of 75–80%, indicating that the balloon dilatation technique was performed successfully without any major complications in the immediate post-operative period.<sup>1</sup> Of the 75% of cases that were deemed a *technical* success, only

30% had biventricular circulation at birth, which is the desired outcome of the intervention. Another 8% were successfully converted to biventricular circulation after initial univentricular palliation, however,<sup>1</sup> a significant discrepancy still exists between what is deemed a technical success and what is deemed an outcome that successfully achieves the objective for which the intervention was created. Even without delving in too deeply into what level of biventricular circulation determines a long-term, disease-free outcome, one can imagine the difficulties in obtaining informed consent for these operations. Words such as *success*, *patient*, and even *treatment* – fundamental words in describing outcomes – need to be qualified and the full extent of their meaning is often difficult to convey to patients in these situations.

The issues raised by foetal cardiac intervention go beyond the ethical and into the realm of linguistics. The problems presented seem to challenge the foundations of the physician–patient relationship by exposing the inadequacy of language. What constitutes a treatment? Who is a patient? What are the implications of language in ordinary discourse between physician and patient? Can there be effective communication on the subject of foetal cardiac surgery? Has language failed and have definitions become arbitrary in this situation? Must we throw the proverbial baby out with the bath water and give up attempts to converse about this very delicate issue? Who can help us understand these profound issues?

### Aporia and postmodernism: philosophical considerations

The turn towards language to address problems that seem to test the limits of our conventions and definitions is a characteristic theme throughout postmodern philosophical thought. The twentieth century ushered in profound revolutions in all aspects of life including society, culture, art, and thought. People such as Einstein, Heisenberg, Stravinsky, and Joyce introduced revolutionary concepts in their fields that questioned the very foundation of how humans perceive and understand the world. Such revolutions extended to the realm of philosophy as well; many thinkers started questioning whether the established truths, on which fields such as ethics and metaphysics were based, had any more objective validity than did Newtonian physics or classical rules of artistic expression. Ferdinand de Saussure<sup>17</sup> extended this line of reasoning to the subject of language. He argued that the signifier – or term used to describe something – and the signified – the thing itself – have no necessary connection in language. Further, he claimed that the definition or meaning of

a word can mean nothing outside the realm of language, as it is wholly contingent on the rules established within the system.<sup>17</sup> With this revolutionary line of thinking, Saussure questioned language's ability to represent concepts that defy the typical conventions. Owing to the fact that the meaning is dependent on differences that are established within the realm of language – subject different from object, man different from woman, alive different from dead – the concepts that exist between these conventions, he argued, cannot accurately be represented in language.<sup>17</sup> The present debate of how to refer to a foetus in cases of foetal surgery provides an analogous example. Because the foetus represents such a grey area between autonomy and dependence, viability and inviability, patient and condition, one can understand how language could fail to capture its meaning because of language's own dependence on conventions and differences.

Saussure's lectures reverberated throughout the philosophical community and helped to shape the burgeoning school of thinkers who would ultimately be referred to as "postmodern". Jean Francois Lyotard<sup>18</sup> defines the postmodern era as "incredulity toward metanarratives". What he means is that postmodern thinking is a rejection of the notion that meaning is somehow beyond the scope of language and conventions. He, like Saussure, argues that no concept has a meaning outside the system of conventions and opposites in language. Thinkers such as Jacques Derrida and Michel Foucault<sup>19</sup> extended this thinking and argued that concepts such as *reason*, *morality*, and even the subject, *I*, are nothing but conventional constructions without any external meaning. In questioning the foundations of language and meaning, these thinkers present their readers with a kind of *aporia*, or impasse. This impasse begs the question of how we, as humans, can continue debating philosophical issues in ethics and metaphysics if the language we use is wholly contingent on conventions and cannot express anything authentic. In doing so, they suggest that we recognise the contingency of all systems and that we abandon any hope of creating a kind of objective method of reference even to the simplest of concepts. In the present debate, their thinking would be consistent with the assertion of Lyerly et al<sup>16</sup> that no concept in language is sufficient to address the foetus in cases of foetal surgery.

Recognising the contingency of language and all the resulting ramifications is the primary burden of knowledge in postmodern thinking. This burden requires its proponents to shatter all notions of objectivity, meaning, and the hopes of ever achieving such concepts in discourse. In many ways, it is



against the entire *telos* of western philosophy, which can be characterised by the use of language to prove certain ideas about the natural world or about human interaction. Such a burden is stultifying, and is intended to be so insofar as it helps to challenge what we think we know. Foetal cardiac surgery presents us with the same kind of burden of knowledge. When language fails to elucidate a complex issue such as foetal surgery, physicians and patients are faced both with the burden of knowledge that accompanies the diagnosis of hypoplastic left heart syndrome with intact atrial septum or critical aortic stenosis and with the more general, postmodern burden of the inadequacy of language to express certain concepts. The combination of these two burdens leads to an *aporia* and serves as a significant barrier to clear communication between physician and patient at a time when it is most needed.

### Postmodernity and medicine?

One could argue that medicine cannot be postmodern in the way it has just been described. The problems that medical science seeks to solve are not open dialogues but, rather, are often binary variables filled with necessary conventions such as morbidity, mortality, disability, pain, distress, and suffering. These conventions are used in medicine to plot outcomes and are given precise meanings to that end. Such conventions cannot be subject to critical enquiry, as they are based on clinical realities and are vital to providing standards of care, which guide proper patient management. In this way, medicine is very “modern” in that the conventions it uses for its basis are seemingly immutable and immune to critical enquiry. Furthermore, these conventions are rooted in human physiology and pathophysiology and in the limited ways in which physicians can effect changes in these complex systems. Owing to the fact that the domain of medicine lies in clinical reality and the most basic realities of human science, is not any enquiry into its methods without a direct consideration of clinical utility simply a wasted effort?

The previous concern rightfully points out that medicine as a whole is incompatible with postmodern thinking, because the principles on which it is based need to be accepted in order to make decisions about patient care that are fundamental to the practice of medicine. That having been said, medicine is also a science and – like all sciences – it must have a method by which it addresses those concerns about which it cannot provide a certain course of action. The scientific method in medicine is the foundation for all such enquiry and is the essence of medical academia. However, when this

method of hypothesis testing fails to elucidate a proper course of action, the “modern” basis of medicine reaches its limit. Foetal cardiac surgery provides such an example of the scientific method failing to elucidate a clear course of action.

Such examples, one could argue, are part of the process of medical science, as these moments spur future studies that are designed to provide a better answer than those presently offered. This cannot be denied, but at the present moment – a moment of flux in both the standard of care for these lesions and in the very meaning of certain words that are used in the discourse between physician and patient in obtaining informed consent – one needs to consider an alternate method of enquiry. Owing to the fact that the postmodernists have dealt with similar problems, it is justifiable to apply their thoughts to the present debate. What is paradoxical about adopting postmodern thinking to any medical debate is that, ultimately, the answers derived will feed into medical science, the basis of which is incongruent with the postmodern insistence on questioning all foundations. This paradox need not preclude adopting parts of postmodern thinkers’ perspectives into such debates, because within postmodern philosophy there exist methods for building new systems of meaning and convention that can be used within other systems of convention such as medicine, as will be discussed below.

### The future of foetal cardiac surgery: gazing into the abyss

How, then, do we proceed in the debate on foetal cardiac intervention? We have reached a point in foetal surgery where we cannot revert back to the comfort and solace of always being able to rely on language to describe adequately the situation at hand, but how can we overcome the angst that accompanies such a lack of certainty? No one has deciphered a way to postulate oneself out of the angst of uncertainty in postmodern thought. For most postmodern thinkers, the constant questioning is more important than ever finding an answer. That having been said, many postmodern thinkers find comfort in liberating themselves from conventional thinking. The majority of Michel Foucault’s later work deals with how to embrace the freedom that comes with recognising that everything is based on conventions. He argues that removing the certainty of things like language, government, and rationality – which he argues are externally presented – one is free to focus on understanding oneself as being separate from these institutions.<sup>19</sup> However, developing oneself is not strictly self-centered, as such a process relies on interactions with others and sharing new experiences.

Habermas,<sup>20</sup> in a similar line of thought, argues that the way towards fostering understanding and the reestablishment of communication lies in discourse ethics. By “discourse ethics”, he does not mean ethics that derives from any ethical discourse; rather, he is referring to ethics being derived from a discourse about the foundations of discourse itself. Such a discourse is designed to expose the hidden assumptions and biases that tend to confound and complicate traditional ethical theories, and this method is his way of solving the fundamental issue of how traditions, cultures, and other biases affect ethical structure and reasoning. He argues that the subject has to create its normalcy out of itself and that only through discourse with others can this occur.<sup>20</sup> By insisting on discourse and development, Habermas is able to rebut claims that postmodernism provides truth and ethics only to individuals. Thus, the postmodern, by destroying the truth behind long-standing conventions in language, allows the possibility to establish one’s own way of communicating that will be free of the inadequacies and pitfalls of one’s inherited language.<sup>20</sup> In discourse with others, these new methods of communication can lead to advances in understanding for all who participate.

In many ways, Habermasian discourse ethics already exist in foetal surgery. At the 1982 inaugural meeting of the International Foetal Medicine and Surgery Society, members put forth a number of guidelines that included a cooperative exchange of information among institutions, a registry of all treated cases, and an establishment of guidelines for the indications of surgical intervention.<sup>21</sup> Further, they stated that there should be a multi-disciplinary team comprising at least a perinatal obstetrician, ultrasonographer, paediatric surgeon, and neonatologist, all of whom should concur before undertaking foetal intervention.<sup>22</sup> By insisting that many different specialists with different biases and viewpoints engage in discourse about cases, the International Foetal Medicine and Surgery Society is attempting to control for biases that can confound dialogues when they are not exposed by others, and is committing itself towards the kind of free, open dialogue that characterises discourse ethics. Although it may seem strange that some infighting appears in literature about the question of language in foetal surgery, such a debate is indicative of the kind of robust discussion that discourse ethics demands. Rather than being a sign of weakness, these challenging debates should be regarded as invigorating to foetal cardiac surgery professionals, because so many grey areas of medicine plague the field.

The burden of knowledge that accompanies the diagnosis of a lesion that may progress to hypoplastic left heart syndrome demands that foetal

cardiac surgery discourse ethics continue to be evaluated. A consensus needs to be formed on what constitutes *success* in foetal cardiac intervention, and this term should account for both technical and functional *success*. After all, it is not enough simply to restore biventricular circulation if the resulting cardiac function is worse than it would be in a corrected univentricular circulation. Owing to the fact that words such as *success* and *treatment* are so potentially equivocal in cases of foetal cardiac intervention, it is important to continue evaluating the language used in clinical and in ethical discourse in order to form clear definitions that will help the field make the most educated decisions on the future of the programme. These types of evaluations have already led to a cessation of performing foetal shunts for hydrocephalus because of its inefficacy.<sup>23</sup> To ameliorate concerns regarding timing and the resulting burden of knowledge in the diagnosis of hypoplastic left heart syndrome with critical aortic stenosis or intact atrial septum, researchers should continue to seek out other indicators that will better help physicians decide when it is appropriate to intervene. The purpose of this paper is not to argue for or against foetal cardiac surgery, but rather to remind us of the mindset necessary to move forward in ascertaining whether the uncertainty of foetal cardiac surgery will be looked upon as a necessary part of revolutionary treatment, or whether it will remain as a reminder of the limits of medicine, of ethical reasoning, or of language itself.

Foetal cardiac intervention, by the many uncertainties it raises, requires both patient and physician to gaze into a kind of abyss. The interventions are experimental, the outcomes are uncertain, and the ethical and medical issues involved are as complex as they are controversial. Further, the language currently in place to describe such interventions is not adequate to foster the best understanding between physician and patient. Looking into an abyss can be a terrifying experience. Nietzsche<sup>24</sup> famously wrote, “if you gaze for long into the abyss, the abyss gazes back into you”. Being at a loss, at an *aporia*, is normal for both the physician and the patient in cases of foetal cardiac surgery. Nietzsche understood the terror that can accompany being at a loss and staring into the abyss and in this aphorism is telling us not to dwell too much on the nothingness and frustration that the abyss presents. Rather, one must, as postmodern thinkers have done, form a way to live with the knowledge that conventions have no inherent meaning and that language cannot adequately represent reality. Perhaps Jancelewicz and Harrison<sup>21</sup> summed it up best when they wrote that the future motto for foetal surgery should be to “Proceed with Caution ... and Enthusiasm”. Whether

or not foetal cardiac surgery becomes a preferable option in the near future will depend as much on figuring out ways to confront the issues of communication and language as it will on technical advances. Until there is a clear understanding of concepts such as success, patienthood, and the indications for intervention, there will continue to be a burden of knowledge that will hinder further development in the field. Foetal surgery appears to have adopted discourse ethics as its *modus operandi* to combat the uncertainty that abounds within the field, and this marriage of medicine and postmodernity should be seen as a positive alliance, because the methods of postmodern discourse ethics encourage clear and open dialogue. Clear and open dialogue has always been essential to medical science's advancement and will continue to benefit this burgeoning field as these very difficult debates continue.

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