A Practical and Ethical Toolkit for Last-Minute Refusal of Anaesthetic in Children.

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Abstract
Children’s fear of a procedure, including the anaesthetic is a common issue that operating theatre staff face. This fear is generally mitigated by pre-aesthetic preparation and information sharing. Last minute refusal of a procedure creates unique difficulties for the anaesthetist and proceduralist. Refusal for a procedure raises issues of whether the dissent is binding, and if not, how best to get the child to theatre without creating moral injury. In this case review of a young adolescent who refuses to go to the operating theatre, we explore practical and ethical options to resolve the situation. We discuss respect for persons (including assent and consent), best interests, truth telling, harm minimisation and restraint. The importance of a post-event debrief is discussed. We also assess the value of a clinical ethics service with team members embedded in clinical teams.

Introduction
Children’s fear of peri-operative events is a problem that operating theatre staff in children’s hospitals deal with commonly. Careful planning, including age and developmentally appropriate involvement of the child in the process, is required. How much information parents and clinical staff share with children takes into account such things as
the urgency of the procedure, risks of the procedure, benefits to the child, previous experiences, age and developmental stage of the child. (1, 2) Parents and clinicians generally seek buy-in from the child, even if the child is appropriately reluctant, with some form of assent. (3-6) Every procedure needs to go well for the child since the experience can shape future approaches to healthcare.

Last minute refusal of a procedure creates specific difficulties for the anaesthetist and proceduralist. A practical response may be to separate the fear of anaesthesia from the fear of the procedure and negotiate the concerns. If the child continues to refuse to proceed, ethical issues are raised, such as how much weight should be given to a refusal and whether the child has ethical or legal status to countermand the consent which their parent has given. No one wants to force an unwilling child into the operating theatre, but staff must consider the harms that might result from delaying the procedure. If a child refuses a procedure that the medical team deem necessary, the parents can reasonably make a best-interest judgement to over-ride the preference of the child and consent to the procedure. (3, 7). Staff must then consider the risks and benefits of various strategies to facilitate the procedure which may include other psychological interventions, pharmacological agents or forms of restraint to carry out the procedure on the unwilling child.

In this paper we discuss a case of a young adolescent with last minute refusal of a procedure that, for his safety, could not be postponed. We evaluate the case from a practical and ethical perspective to determine the options for continuing with the procedure.

Case

‘Shane’ is a 12 year-old boy who presents for thoracic duct embolization. He was born with hypoplastic left heart syndrome and has a single ventricle Fontan circuit complicated by plastic bronchitis. He has had multiple episodes of life-threatening airway casts over many years. There is no evidence of protein losing enteropathy. The most helpful medical therapy for Shane has been hypertonic saline to induce coughing and cast
expectoration. Initial thoracic duct embolization at age nine years went well, with rapid resolution of airway casts, sustained for 18 months. Since then, he had gradual recurrence of plastic bronchitis with increasing frequency and severity of cast formation. Repeat MR lymphangiogram demonstrated a single thoracic duct running along the left paravertebral gutter. Repeat thoracic duct embolization was planned with respiratory and otorhinolaryngology support (to remove casts before and during the procedure).

On the day of procedure, Shane appeared relaxed and looking forward to having the procedure completed. In the pre-operative hold area, he became scared after overhearing possible complications of the procedure as consent was finalised since one of the three procedural disciplines had not had the opportunity to discuss the procedure with the family since the previous embolization. He developed a major epistaxis, requiring nasal packing. By the time the epistaxis was controlled he refused to be taken to the operating room. Owing to scheduling of multiple teams and likely prolonged procedure, acceding to his wish to return to the ward to calm down was not possible. Given the life-threatening nature of his casts it was not considered safe to reschedule the procedure for another day. Members of the anaesthetic team were not happy to proceed in the absence of assent. His mother (and father by phone) were very keen to proceed, even suggesting we tell Shane we would just cauterise the nose, but then proceeding to embolise the thoracic duct once he was anaesthetised. We were reluctant to deceive him in this way. While giving him time to calm down, he became cold and his bedding became wet with blood and melted ice, which had been used to control the epistaxis. We moved him into a fresh bed, placed him in a quiet corner of the pre-operative hold area and warmed him with heated blankets. Discussion with the chief of anaesthetics and the lead respiratory physician, both of whom sit on the clinical ethics response group, was helpful for the anaesthetic and interventional radiology service to consider the ethically important issues in order to decide whether or how to continue with the procedure. With time to reset Shane was given oral ketamine, which he willingly drank, and promptly fell asleep. He was taken to the operating theatre without waking. The procedure was prolonged but went well, with successful embolization of the thoracic duct. On waking from anaesthetic, he was pleased to hear the procedure had been done. A more substantial postoperative debrief was undertaken by the anaesthetic staff later in the day. Shane did not express hurt from the pre-operative events or experience.
Practical and Ethical issues Raised by the Case

This case raises issues with regard to last minute refusal for a procedure in an adolescent. We were forced to consider assent to treatment, the use of restraint and truth-telling. The practical issue was how to get Shane to the operating theatre. The ethical question was whether his refusal should be accepted. If his refusal could not be accepted the further ethical questions arose as to how to minimise psychological harm to Shane while doing the procedure despite his refusal. The following commentaries are based on our experiences working in a large tertiary referral hospital that practices patient-centred care.

The Anaesthetic Response: practical considerations to resolve last minute anaesthetic refusal

It is common for children to be afraid of an operation and the anaesthetic. There are well documented ways of mitigating this through pre-operative assessment with age-related and developmental stage-related techniques to create a smooth pathway from home to the operating theatre.(8-10) Smoothing the path to theatre generally falls to the anaesthetic team, but there are factors such as previous surgical experiences, earlier discussions about the surgery and parental management of the pre-operative experience that may work against a smooth pathway.(10) Shane’s refusal caught us off-guard as he was relaxed before arriving in pre-operative area and was well supported by his mother.

We needed to quickly consider Shane and the reason for his refusal. He was a developmentally appropriate 12 year-old boy who had previously, and repeatedly, expressed a wish to have the operation to alleviate life-threatening airway casts. He had a good experience with the previous procedure but had had three previous major cardiac procedures as an infant and young child that may have sensitised him.(11) The difficult to control epistaxis was likely a reaction to anxiety with elevated blood pressure but it frightened him. He was no longer able to engage in the sort of considered discussion that was usual for him, and further attempts at this proved counter-productive, heightening his fears. Verbally confirming with his mother in the pre-operative area was not in line with our usual best practice of completing this step before operating theatre booking. However, the time between attaining consent and the procedure can be weeks or months so that a final review of previously given written parental consent on the day is a common occurrence and, in this case, created a situation that could not be taken back by simple reassurance.
Ideally, at the point of refusal, we would have delayed the procedure, either putting him later on the list, or rescheduling for the next day, but neither option was possible, given the constraints of a busy tertiary hospital. It was, however, possible to comfort him with fresh linen, a warmed blanket, a quiet corner of the pre-operative hold area and (quiet) television for distraction. We were not prepared to take him to the operating theatre protesting, either from the point of view of his psychological well-being or staff safety. We did not wish to use physical restraint even for a brief period to deliver sedation. We wanted to avoid further discomfort or intrusive delivery that can be experienced with intranasal agents that could add to his negative experience. We decided to frame the oral ketamine as a drink “to make you feel good” and he took it without questioning.

The table sets out the practical considerations for last minute refusal of anaesthesia.

The Ethical Response: understanding the ethical basis for deciding how to resolve last-minute anaesthetic refusal

This commentary follows a sequence of ethical considerations that should be taken into account when trying to resolve last minute anaesthetic refusal.

Respect for Persons

Inherent in this discussion of last-minute anaesthetic refusal is the bioethical principle of respect for persons. (3, 12) Although sometimes narrowly understood as respect for autonomy, respect for persons is a wider account that allows us to consider and give weight to the whole child (in this case an adolescent) including their preferences and support for their emerging decision-making (3, 13, 14), even if they do not have full capacity for independent autonomous decision-making. This type of approach recognises that there is a continuum of decision-making for the child-patient, from being encouraged to express preferences on matters with no significant medical implications, for example, which arm to have an intravenous cannula or mode of induction of anaesthesia (gaseous or intravenous) through to more substantive decisions. This engagement model also grants enhanced locus of control that reduces anxiety and promotes trust. (14, 15) Such engagement may be considered in two ways, ‘instrumental’, that is purely for the purpose of facilitating the procedure going well and ‘intrinsic’, that is a as primary good that respects him as a person.
Children’s involvement in discussions actively supports their development as a decision-maker, and has moral significance in its own right. It is “a moral ideal, related to children’s participation in health care decision-making, that involves the cultivation of the child-patient’s awareness, understanding, and meaningful agreement with treatment.” (3)

On this basis, out of respect for him as a person, Shane had been involved in discussions and decision-making to date. During this process, he consistently expressed the view that he wanted the procedure done. That is, he assented to the procedure. When Shane overheard the risk information given to his mother in re-confirming her consent just prior to theatre, he became frightened and changed his mind. His dissent needed to be taken seriously but this does not mean that decisional authority should be ceded to him. His immediately stated wish was triggered by understandable fears aroused by information new to him about the remote risk of catastrophe during the procedure but was not consistent with his previously stated and stable agreement to have the procedure. Shane was not mature enough to weigh all this up. His dissent did not count as an autonomous independent refusal of the procedure, just as his assent had not counted as formal independent consent. It was his mother who gave consent on the basis of her considered weighing up of risks and benefits, and she had not withdrawn it.

Best Interests

Best-interests is a key principle in biomedical ethics and is the standard to which clinicians aspire for every patient.(7, 12) Best-interests is a broad term which takes into account the entirety of a person’s interests, physical, psychological and social. In this case, when we had to consider over-riding his dissent to surgery, we had to revisit what constituted Shane’s best-interests. Together with his mother, we considered it was in Shane’s physical interests to continue with the procedure as planned. Proceeding was the best chance of treating his plastic bronchitis, whereas delaying or rescheduling would put him at risk of further episodes of life-threatening airway casts. Fortunately, in this case, both medical staff and legal decision-maker (parent) were of the same opinion.

However, there was a divergence of opinion between the medical staff and his mother about how to achieve this shared aim of getting Shane to theatre. Both the medical staff
and Shane’s mother wanted to do the procedure without Shane being distressed, to protect his emotional as well as physical interests. However, his mother, being keen to just get on with it, wanted to use significant deception to get him to theatre as soon as possible. The medical staff were reluctant to take such a frankly deceptive approach as proposed by his mother. Deception can easily be seen as a pragmatic option, but in the longer term can also have negative impacts on a child’s psychological and emotional interests. All of these considerations have to be taken into account when determining Shane’s best interests.

Truth Telling
The suggestion of Shane’s mother that we deceive about what would be done in surgery in order to ‘get the job done’ made our staff uncomfortable. Such discomfort is often a flag that an ethical moment is happening. Truth-telling to children is supported by international and national guidelines and has instrumental and non-instrumental benefits in line with respect for persons. (16) Deception about a surgical procedure may have later consequences for Shane, as he will have many more encounters with medical staff and likely further procedures. Maintaining his trust is important to these endeavours. This position was quickly realised by Shane’s mother, whose initial reaction was well meaning, but not well thought through. We were still left with the problem of getting Shane to theatre, acknowledging it was in his overall best interests, but not wanting to do so over his protest. Reluctantly, we did engage in a more circumscribed deception by offering him liquid ketamine without disclosing exactly what it was. We felt this was ethically permissible because it involved much less deception than lying to a fully lucid, albeit highly distressed child about what surgical procedure would be done to him. Further, the postoperative debrief with Shane was a crucial piece in this regard, where we could explain to Shane what had happened and why. He did not give any indication that he felt he had been wrongly treated, simply expressing relief at getting the procedure that he had been wanting done successfully.

Harm Minimisation
At the time of refusal, we could not accede to his immediate wishes by calling off the procedure. Therefore, having arrived at the decision that the only option was to proceed,
the next consideration was how to do this with the least harm to Shane. Non-maleficence is a key biomedical principle that requires balancing benefits with minimising risks of harm to achieve the best balance of benefits over harms overall. (12)

The use of force must be seen as the worst option, even if it is what a family might ordinarily do to achieve its needs at home. It might even be worse for a child if parents allow strangers to engage forceful restraint. (17) Physical restraint is distressing to both child and staff. (18) No matter how well-meaning, force or restraint is likely to leave patients with psychological injury. (19) Restraint is also likely to make the next procedure more difficult for Shane to accede to and in the long run, not in his best interests.

Framing the problem this way increases our obligation to avoid physical restraint if at all possible. Staff should consider every other possibility to achieve the goal of getting the child to the operating theatre. Fortunately, there are a wide range of drugs and delivery options that can usually be used instead of restraint. Even this might be considered ‘chemical restraint’ and could be associated with psychological injury to the patient. However, it is usually the least harmful of options and if done sensitively, any potential harm can be mitigated after the event, as we describe below. We considered offering oral ketamine to be the least deceptive option to allow Shane to get to the operating theatre without protest. This was done with his mother’s consent. We assessed that detailed discussion with Shane about the contents of the ketamine drink might heighten his concerns and therefore be counter-productive. We were fortunate in this case that Shane drank the ketamine without question.

Clinical Ethics Support
One of the factors that helped recover the situation for this adolescent was the availability of staff who were involved in the hospital’s clinical ethics service. The Royal Children’s Hospital Clinical Ethics Service uses a group model to deliberate on challenging ethical cases. (20) (21) The Clinical Ethics Response Group includes trained ethicists and senior clinicians with clinical ethics experience, but also draws in members from the wider hospital community (medical, nursing, allied health and pastoral care). The advantage of this model is that Clinical Ethics Response Group members are embedded in various teams and often

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available to provide ethical input at short notice, as happened here. We were able to get Shane to the operating theatre to serve his best interests, in a way that minimised harm while still respecting his personhood. In essence, this was a practical endorsement of our model of ethics consultation.

**Conclusion**

In this paper we have offered a practical and ethical toolkit for dealing with last minute refusals of anaesthetic in an adolescent patient. We brought our patient to the operating theatre to achieve his best interests while minimising moral injury and respecting him as a person. Furthermore, Shane’s previous and consistently expressed view was that he wanted the procedure which lends ethical weight to the decision to over-ride his last-minute refusal.

**Data Statement:** Data sharing is not applicable to this article as no new data were created or analyzed in this study.

**References**


Table. Practical Considerations to Resolve last Minute Anaesthetic Refusal.

<table>
<thead>
<tr>
<th>Physical comfort:</th>
<th>warm bed, blankets, quiet environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Privacy:</td>
<td>quiet corner of hold area, private room</td>
</tr>
<tr>
<td>Parental support:</td>
<td>keep parents close</td>
</tr>
<tr>
<td>Distraction:</td>
<td>music, quiet game, television</td>
</tr>
<tr>
<td>Delay:</td>
<td>cool down period, re-establish trust and proceed later on the list</td>
</tr>
<tr>
<td>Reschedule:</td>
<td>re-establish trust, prepare more thoroughly</td>
</tr>
<tr>
<td>Medication:</td>
<td>select most acceptable and minimally distressing route.</td>
</tr>
<tr>
<td>Physical restraint:</td>
<td>avoid unless the only option is short term restraint to deliver anaesthesia</td>
</tr>
</tbody>
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