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Boundaries of Parental Consent: The Example of Hypospadias Surgery

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Abstract: Human rights organisations raise concerns about medical interventions on children with intersex variations, particularly when these interventions impinge on the child's bodily autonomy and are without a sound biomedical basis. Psychosocial literature and legal literature have made very different contributions to thinking about the healthcare of people with intersex variations, but both literatures pay attention to the process of informing patients about elective interventions and the workings of consent. The present paper addresses the absence of dialogue across medical, legal, and psychosocial literatures on the surgical treatment of children with intersex variations. The analysis presented in this paper focusses on the assumptions underpinning the practice of allowing parents to consent on behalf of their children to elective surgery in the instance of hypospadias. In this paper, we (i) introduce consent from a medico-legal perspective, (ii) analyse selected documents (including medical, psychosocial, and human rights documents) in relation to the concept of parental consent on behalf of a child, and (iii) reconsider the current practice of inviting parents to give consent for elective genital surgery on infants. What emerges from our analysis is a picture of long-term relationships and interactions over time within which the consent process is located. The focus is not whether *consent* is granted, but whether *free and informed consent* is granted. This picture allows us to expand the understanding of "informed consent," highlighting the importance of producing ethical interactions between health professionals and patients with the view that these relationships last for years. Understanding consent as a process, considering information as dynamic, partial, and negotiated, and understanding the doctor–patient interaction as relational might enable us to imagine the kind of informed consent process that genuinely works for everyone concerned. Our examination of selected legal, medical, and psychosocial texts raises doubt about whether current hospital practice meets the requirement of informed parental consent on behalf of children undergoing hypospadias surgery.



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1. Introduction

Human rights organisations have noted concerns about medical interventions on children with variations in sex characteristics (also known as intersex variations) (Amnesty International 2017; United Nations Human Rights Council 2013; United Nations Human Rights Office of the High Commissioner 2023). These concerns arise particularly when the intervention (hormonal, surgical, or diagnostic) impinges on the child's bodily autonomy and is carried out for reasons that do not strictly have a biomedical basis. Reasons for intervention are sometimes described as appearance-altering or functional and are often explained as being important for psychosocial reasons. It is striking that psychosocial research looking to substantiate those rationales has failed to find evidence that "normalising" interventions on children's sex characteristics reliably produce the hoped-for

psychosocial benefits for the child. Psychosocial research (e.g., [Lundberg 2017](#); [Roén 2019](#); [Steers et al. 2021](#)) and legal research (e.g., [Greenberg 2017](#); [McDonald 2015](#)) stand alongside human rights organisations in raising concerns about elective medical interventions on children with variations in sex characteristics.

Psychosocial literature and legal literature have made very different contributions to thinking about the healthcare of people with variations in sex characteristics, but both literatures pay attention to the relative roles of children and caregivers, the process of informing patients about elective interventions, and the workings of consent. These bodies of literature are not necessarily used at all by health professionals who draw up guidelines for medical practice. Instead, there is a chasm of understanding where medical, legal, and psychosocial literatures all address the same topic, and few authors work across these literatures.

The present paper addresses the absence of dialogue across medical, legal, and psychosocial literatures on the surgical treatment of children with variations in sex characteristics. We approach this collaboration as Aotearoa New Zealand researchers with expertise in human rights law (RS) and psychosocial research (KR). We undertake this work at a time when the United Nations Committee on the Rights of the Child is charging Aotearoa New Zealand and other countries with abusing children's human rights because surgeons perform elective genital surgery on infants born with variations in sex characteristics ([UNCRC 2016](#)). The surgery is presumed to be carried out on the basis of parental consent. This paper focuses principally on the most common variation, hypospadias, and it tackles questions about parental consent. Hypospadias is an anatomical variation where the urethral opening appears somewhere other than the tip of the penis, such as the underside or base of the penis. In this paper, we systematically work with medical, legal, and psychosocial research with the aim of contributing to the current dialogue about parental consent in the context of elective surgical interventions on the genital and reproductive organs of children with variations in sex characteristics.

What assumptions underpin the practice of allowing parents to consent on behalf of their children to elective surgery in the instance of hypospadias? To address this question, we (i) introduce consent from a medico-legal perspective, (ii) analyse selected documents (including medical, psychosocial, and human rights documents) in relation to the concept of parental consent on behalf of a child, and (iii) reconsider the current practice of inviting parents to give consent for elective genital surgery on infants.

Hypospadias surgery to move the urethral opening to the tip of the penis is driven by a popular belief that it brings psychosocial benefit to the child, but psychosocial research has failed to show the hoped-for benefits ([Schönbucher et al. 2008](#)). Although many surgeons argue for the continuation of hypospadias surgery ([Snodgrass and Bush 2016](#)), other surgeons have brought the evidence into question, pointing to research limitations and surgical failures ([Long and Canning 2016](#)). There are questions about the ethics of early surgery ([Weber et al. 2009](#)), in a context where parental regret rates are as high as 39% ([Ghidini et al. 2016](#)). Further, parents are affected in their decision to consent to surgery by framing effects that they are unaware of ([Streuli et al. 2013](#)). Psychosocial research shows that health professionals, whose role it is to support parents' consent process, seem to underestimate the framing effect they bring to the conversation ([Roén and Hegarty 2018](#)). We conclude that parents may be unintentionally set up to "agree" to surgery on behalf of their infant before they have genuinely weighed the pros and cons.

2. Consent

The legal doctrine of informed consent derives from [The Nuremberg Code \(\[1947\] 1996\)](#). This mechanism was introduced to move medicine from a paternalistic ('doctor knows best') model to a new model with respect for patient autonomy ([Katz 1998](#); [Skowron and Angelos 2017](#)). Although there is case law relating to consent, in Aotearoa New Zealand, consent in medical situations is based on the [New Zealand Public Health and Disability Act \(2000\)](#) and Right 7 of the [Health and Disability Commissioner \(Code of Health and Disability](#)

[Services Consumers' Rights\) Regulation \(1996\)](#). Medical informed consent is essential to the medical professional's ability to diagnose and treat patients as well as the patient's right to accept or reject clinical evaluation, treatment, or both ([Paterick et al. 2008](#)). The informed consent process puts in place a patient–doctor relationship where each partner understands and accepts the degree of autonomy the patient desires in the decision-making process ([Health and Disability Commissioner \(Code of Health and Disability Services Consumers' Rights\) Regulation 1996](#), Right 7; [Paterick et al. 2008](#)). Such a process should have a greater impact on patients with intersex variations than it has given the emphasis on respect for autonomy and beneficence towards patients ([Reis 2019](#)).

Informed consent is an interactive process whereby the patient is informed about all options, including not having the treatment and the possible benefits and possible negative effects ([Kumar 2013](#)). There is relativity in the practice of informed consent, that is, more intimate or invasive examinations require more explicit consent ([Kumar 2013](#)).

Informed consent indicates a right to choose whether to have a particular medical treatment (including the right to refuse or withdraw consent) rather than demanding a particular treatment ([Keenan and Dalziel 2016](#), p. 101). It implies that the patient knows what they are consenting to and the consequences of it. It strongly relies on the premise that patients are able to make treatment decisions based on a balanced and thorough understanding of the risks and benefits associated with available treatment alternatives ([Lorenzo et al. 2012](#)). The process of informed consent is meaningless unless consent is given on the basis of relevant information and advice ([Rogers v Whitaker 1992](#), para. 14). That is, the patient requires all information they deem relevant, whether or not the medical professional considers it relevant. The law indicates that the one giving consent is entitled to information even beyond the knowledge of a particular medical professional to enable the correct decision ([Rogers v Whitaker 1992](#), para. 14). This process involves an exchange of ideas where the patient indicates their situation and medical professionals answer their questions and provide information about risks and benefits connected with medical treatments ([Paterick et al. 2008](#)).

The decision must be voluntary and without duress; otherwise, consent is void ([Keenan and Dalziel 2016](#); [Skegg et al. 2015](#)). As Right 2 of the Code states, any decision must be free from coercion or discrimination ([Health and Disability Commissioner \(Code of Health and Disability Services Consumers' Rights\) Regulation 1996](#)). Informed consent infers agency or self-determination and upholding the patient's human rights ([Rogers v Whitaker 1992](#), para. 15). The law presumes competency unless proven otherwise. The test for incompetence involves the patient being unable to comprehend and retain the necessary information about the procedure or treatment and being unable to weigh the information, balancing risks, and needs to arrive at a choice ([Keenan and Dalziel 2016](#)). If the patient is deemed incompetent, a guardian gives or denies consent on their behalf. When it is in the child's best interests, it is assumed that the child's parent(s) or guardian can give or refuse consent on the child's behalf (refer to the [Health and Disability Commissioner \(Code of Health and Disability Services Consumers' Rights\) Regulation \(1996\)](#), for details).

Medical professionals must recognise that informed medical choice is an educational process, honestly providing all "necessary information that may influence treatment or advice" ([Paterson 2003](#), p. 1), and it has the potential to affect the patient–doctor alliance to their mutual benefit ([Paterick et al. 2008](#)). The consent process should be the foundation of the fiduciary relationship between a patient and a physician ([Paterick et al. 2008](#)). When medical professionals and patients take medical informed consent seriously, the patient–doctor relationship becomes a true partnership with shared decision-making authority and responsibility for outcomes ([Paterick et al. 2008](#)).

Although there is an established body of literature informing medico-legal understandings of consent, it is not clear how this literature informs current medical interventions on variations in sex characteristics.

3. Analysis of Selected Texts

The current paper is based on a body of literature selected with the aim of investigating questions of parental consent in the case of infant genital surgery. Our interest in drawing together psychosocial, medical, human rights, and legal approaches to this issue guided our selection of literature for analysis. We drew texts from our existing bibliographic databases and from literature searching. We selected texts that:

- Have implications for the process by which parents come to consent to elective genital surgery on behalf of children;
- Have broad relevance to variations in sex characteristics and/or specific relevance to hypospadias;
- Are published in English.

Our goal was not to undertake an exhaustive review but, rather, to draw together texts that might underpin a rigorous discussion across the disciplines of interest. For this purpose, we have included some texts written by surgeons, some written by psychologists, and some written with a human rights focus, as shown in Table 1.

Table 1. Body of texts for analysis.

Disciplinary Perspective	Selected Texts
Surgical/clinical perspectives	Dodds, P. R., Batter, S. J., Shield, D. E., Serels, S. R., Gavafalo, F. A., and Maloney, P. K. (2008). Adaptation of adults to uncorrected hypospadias. <i>Urology</i> , 71(4), 682-685. doi:10.1016/j.urology.2007.07.078
	Ghidini, F., Sekulovic, S., and Castagnetti, M. (2016). Parental Decisional Regret after Primary Distal Hypospadias Repair: Family and Surgery Variables, and Repair Outcomes. <i>The Journal of Urology</i> , 195(3), 720-724.
	Liao, L.-M., Wood, D., and Creighton, S. M. (2015). Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place. <i>BMJ (Online)</i> , 351, h5124. doi:10.1136/bmj.h5124
Psychosocial perspectives	Cools, M., Nordenström, A., Robeva, R., Hall, J., Westerveld, P., Flück, C., . . . on behalf of the Cost Action B. M. working group. (2018). Caring for individuals with a difference of sex development (DSD): a Consensus Statement. <i>Nature Reviews Endocrinology</i> , 14(7), 415-429. doi:10.1038/s41574-018-0010-8
	Roen, K., and Hegarty, P. (2018). Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. <i>British Journal of Health Psychology</i> , 23(4), 967-981. doi:10.1111/bjhp.12333
	Schönbucher, V. B., Weber, D. M., and Landolt, M. A. (2008). Psychosocial adjustment, health-related quality of life, and psychosexual development of boys with hypospadias: A systematic review. <i>Journal of Pediatric Psychology</i> , 33(5), 520-535. doi:10.1093/jpepsy/jsm098
	Streuli, J. C., Vayena, E., Cavicchia-Balmer, Y., and Huber, J. (2013). Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. <i>The Journal of Sexual Medicine</i> , 10(8), 1953-1960. doi:10.1111/jsm.12214
Legal and human rights perspectives	Mendez, J. E. (2013). <i>Report of the special rapporteur on torture, and other cruel, inhuman and degrading punishment</i> : 22nd Session of the UN Human Rights Council.
	Paterson, R. (2003). Informed consent in New Zealand: Medical myths. <i>New Zealand Medical Journal</i> , 116(1183).
	World Health Organisation. (2014). <i>Eliminating forced, coercive and otherwise involuntary sterilisation: An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO</i> .

In the first stage of analysis, we each independently read the selected texts, making detailed notes that were structured with a series of analytic questions. These analytic questions concerned (i) what is understood and assumed about consent and the legal framing of consent within the given text, and (ii) how children, parents, and health professionals are figured in the text in relation to their respective roles in the decision-making and consenting processes. We then combined our separate sets of notes, alongside each analytic question, in our analytic table. By reading our combined notes, we began to develop a shared interpretation. We each contributed to the writing of this interpretation, with RS leading the writing about the conceptual and legislative framing of consent, and KR leading the writing about how the various parties are figured in the consent process.

3.1. *How Consent Is Presented in the Selected Texts*

What is consent, and what are the assumptions made about consent, according to the selected texts? Although legal and human rights documents focus in detail on the concept of consent, this is not the case in medical and other health literature, where it is often assumed that a consent process takes place unproblematically.

Medical consent is intended to protect the patient (Paterson 2003). The consent process is not intended as a tick-box exercise that might protect the medical professional from potential disciplinary action (Paterson 2003). Health professionals have a “duty to inform and obtain informed consent” (Paterson 2003, p. 1), with the understanding that consent can only be given by an informed patient (Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation 1996, Rights 6, 7). It is envisaged that the informed consent process should be located in a context of trust and confidentiality between the patient and medical professionals (Cools et al. 2018).

Patients and/or parents/guardians should be thoroughly informed by the clinical team and, on the basis of being thoroughly informed, they may give consent (Cools et al. 2018). The person giving consent must consider that they understand the information (Paterson 2003). They must be “given the information that a reasonable patient, in that patient’s circumstances, would expect to receive” (Paterson 2003, p. 2), and patients can only consent of their own free will (Paterson 2003).

Informed consent procedures are based on trust and confidentiality. Cools et al. explained that, to “build a trustful relationship, an open discussion of all available relevant medical data, including progressive information on any hitherto insufficiently communicated aspects of the condition, is crucial” (Cools et al. 2018, p. 419). When intersex children undergo “cosmetic and other non-medically necessary surgery” (World Health Organisation 2014, p. 2), the validity of the consent process has been called into question. As a result, such surgical procedures have been “recognized as human rights violations by international human rights bodies and national courts” (World Health Organisation 2014, p. 2).

It is often assumed that “counselling by medical clinicians” is sufficient to enable parents to prepare for surgery (Ghidini et al. 2016, p. 723), but current information management concerning DSD and the medical framing of variations may produce biased decisions, as demonstrated by Streuli et al.’s study (Streuli et al. 2013). With regard to genital-normalising surgery, the Special Rapporteur on torture has stated that consent for surgery must be given by the person concerned (Mendez 2013), not solely by their parent/guardian.

Our initial analysis suggests that some complexities of parental consent may be underexamined, especially in relation to elective genital surgery on children. Our analysis so far raises questions about the process of informing parents so they can reasonably consent on behalf of their children. Given that the consent process involves relationships of trust, communication, and shared understandings, we are interested in the key parties involved in these relationships: parents, children, and health professionals.

3.2. Parents

Parents/caregivers become positioned in very particular and interesting ways when the possibility of infant genital surgery arises. This part of our analysis sheds light on the informed consent process by examining how parents are figured in the context of psychomedical, human rights, and legal literature.

In the texts we analysed, key ways that parents are figured relate to their emotional state, their understandings and beliefs, the information and support they may be given, the decisions they face, and the potential for regretting their decision afterwards. Each of these aspects involves uncertainties and tensions that have some bearing on their role in consenting (or not) to surgery on their child.

Parents may be understood as being “in the difficult situation of having to decide whether their young son should undergo an operation that is not strictly necessary and carries a risk of complications” (Ghidini et al. 2016, pp. 720–21). Of the parents who participated in one study, 78% “reported they wished they had had more information on the condition preoperatively” (Ghidini et al. 2016, p. 723). This study reported that parents strongly desired more knowledge before making decisions (Ghidini et al. 2016, p. 723). Medical professionals who took part in another study described parents as almost always wanting surgery to go ahead during infancy, yet non-medical professionals who took part in the same study described how a shift seemed to take place when they had conversations with parents about nonsurgical options (Roen and Hegarty 2018). Talking about non-surgical options was sometimes described as a relief to parents (Roen and Hegarty 2018). From this, we see some tensions inherent in what parents want and in what health professionals think parents want.

With regard to their emotional state, parents report that being told about their child’s diagnosis and treatment plans can be emotionally overwhelming (Cools et al. 2018). Clinical researchers point to the importance of providing parents with time and support, but this does not necessarily happen to a sufficient degree to offset the challenges parents face (Liao et al. 2015). Parents may feel “insurmountable pressure” in relation to social norms about genital appearance and may “find it impossible to delay surgery” (Liao et al. 2015, p. 2) because of the lack of a clear non-surgical pathway or protocol (Liao et al. 2015). Some psychomedical researchers argue that parents are not presented with real choices and are not given the time and psycho-educational input needed to properly engage with the information they are given (Liao et al. 2015). These statements about the psychological effect of norms and the absence of non-surgical healthcare options point to a situation where the possibility of meaningful parental consent is severely jeopardised.

One text describes various ways that parents might think about surgery and ways that they might engage in the consent process: they might be positioned to be responsible for deciding for or against a particular treatment; they might consider surgery as necessary and not requiring any decision at all; they often prefer not to wait until the child is old enough to contribute to the decision; they may be swayed by social pressures and norm-based attitudes; and they may be swayed by health professionals and the information they receive in healthcare contexts (Streuli et al. 2013). The focus of this paper is an empirical study demonstrating how the framing of healthcare information is likely to sway the decisions parents make about genital surgery.

The authors of one text explained that there is “no evidence that parents are given sufficient time to appreciate their child, effective psychosocial support to manage their emotional reactions, or help to slowly digest the highly complex medical information and implications” (Liao et al. 2015, p. 1). In the absence of this time and support, the consent process comes into doubt. Given that surgical techniques change and cannot be fully evaluated until adult outcomes are known, there is not a clear consensus about which surgical approaches work best, and most surgeons operate on children’s genitalia without the outcomes of their work being evaluated. This means that parents are effectively “opting for experimental surgery on their children” (Liao et al. 2015, p. 1) without realising that this is what they are doing. These authors point to the high levels of parental regret after such

surgery takes place, and they point to the parents' emotional state, suggesting that it "may not be optimal" for decision making (Liao et al. 2015). They also cite research showing that parents' decisions are likely to be influenced by the medicalised presentation of genital differences in ways they do not realise.

In this context, it is little surprise that follow-up studies after surgery find that a substantial number of parents express regret about their decision for the surgery to go ahead. Further, human rights literature raises the concern that surgery sometimes goes ahead without parental consent. This tallies with psychosocial literature, which reports instances of parents handing the decision over, not wanting to take responsibility for consenting to surgery and wanting this to be the responsibility of medical staff.

Reading across the different bodies of literature, we see a picture of parents that raises questions about the extent to which they are genuinely in a position to consent to surgery on behalf of their children. The way parents are figured across these texts suggests that they are not necessarily adequately informed, they do not necessarily feel sufficiently supported to take this responsibility on behalf of their children, and they are not routinely (if ever) given genuine options between at least two healthcare pathways, one of which involves surgery and the other of which does not.

3.3. Children

Children are central to the issue at hand. They are also, paradoxically, absent in the sense that their voice is absent, as adults make decisions on their behalf. This part of our analysis examines how children—particularly infants—are figured in the context of the selected psychomedical, human rights, and legal literature.

The tension running through these texts relates to whether it is advisable to carry out non-life-saving genital surgery as early as possible in the child's life, or whether it is advisable to wait until the child is old enough to be involved in any decision about a surgical intervention. That is, the absence of the child's voice is recognised as a problem.

Some explicitly advocate waiting until the child is old enough to be actively involved in treatment decisions whenever that is possible (Cools et al. 2018). The World Health Organisation also states, "if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision... and give full, free and informed consent" (World Health Organisation 2014, pp. 7–8).

Although some explicitly address urination issues that might be faced by a child growing up with a hypospadiac penis, there is also acknowledgement that no studies actually assess the urination/voiding issues experienced by children with unoperated hypospadias (Ghidini et al. 2016, p. 723). It would seem that an assumption is made about what children experience without that being evidenced in research.

Many of the references to children throughout these texts are speculative and future-oriented, focused on how to best promote the quality of life of the child and speculating about how penile appearance and urine spraying might affect the child's quality of life. However, one text asserts that children "born with atypical sex characteristics are often subject to... involuntary genital normalising surgery, performed without their informed consent, or that of their parents... Causing severe mental suffering." (Mendez 2013, pp. 18–19). A review of the research evidence base suggests, however, that there is no clear evidence of hypospadias surgery contributing positively to children's psychosocial well-being; these authors suggest that affected children "might profit from psychosocial support... to better accept their penis" (Schönbucher et al. 2008, p. 531).

In some texts, the child is clearly figured as a focus of detailed medical examination and testing. That is, the child is not a subject with desires or agency but is a body undergoing medical examination. Other texts point to the attempts that some non-medical staff make to talk with parents in a way that actively figures the child as happy and lovable (Roen and Hegarty 2018). This may be a strategic move to help the parents see their child in a non-medical light and understand that surgery is not a prerequisite for happiness, well-being, or being loved (Roen and Hegarty 2018). One study sought to show how children

can be figured variously as having a medical illness or as being part of a social world that can involve support (Streuli et al. 2013). This study suggests that different kinds of health professionals might foreground these different perspectives on the child (Streuli et al. 2013).

If one were to approach these texts naïvely and try to glean something about children through what is written, the resulting picture may well be quite patchy and unfocused. Just as the child does not clearly have a voice in this situation, they are not pictured as coherent subjects (agentic or otherwise) in the texts.

An interpretation that we could draw is that the very people at the centre of this work (i.e., children) are only understood in vague and partial terms. Each party involved in decision-making processes and healthcare has an idea about the child—an imagining, a speculation, and a wish—but no one knows the child yet. Not being able to clearly picture the subject at the centre of medical interventions raises questions about whether it might be possible for anyone to make decisions and give consent on behalf of this subject. Indeed, some argue that the child is a not-yet-subject in this context (Aspinall 2006; Roen 2009). Certainly, it is reasonable for adults to make life-saving decisions on behalf of the infant, but is it reasonable to make non-urgent decisions that presume knowledge of the child's own future experience of their body?

3.4. Health Professionals

Many of the texts we are examining have been written by health professionals, and the remainder of the texts comment on the work of health professionals. But how are health professionals figured in these texts? This question is important for examining health professionals' role in the informed consent process.

Across these texts, health professionals are featured as experts who work in multidisciplinary teams; as professionals who give one another advice about what is best practice; as people who have divergent views on infant genital surgery; as people who unwittingly sway parents' decisions through their medical framing of genital variations; and as professionals who are required to inform parents but who not legally required to ensure parents' understanding.

Clinicians undertake research and publish guidelines. They are also an intended audience for guidelines about the requirements of informed consent, such as the WHO statement that informs healthcare providers that any advice or information they give should enable individuals to make the best decisions for themselves and should be nondirective. "The guidelines that indicate the requirement of full, free and informed consent should be available and should be well understood by practitioners and the public" (World Health Organisation 2014, p. 9).

In some instances, health professionals themselves are the focus of research. Our sample of texts includes two studies addressing how health professionals might frame the information they give parents about infant genital surgery and the unintended consequences of this framing. This research opens up the possibility of different kinds of information-giving leading to different treatment decisions. Roen and Hegarty (2018), for example, distinguished between medical professionals who talk in ways that medicalise the child's body and psychologists who actively seek to demedicalise the child's genital variation. Health professionals who choose a demedicalising way of talking about genital variations might, for example, focus on the loving relationship between the parent and the child or other aspects of the social and support context that the child lives in. Streuli et al. (2013) demonstrated empirically how these different ways of talking can lead to different treatment decisions. The significant role that clinicians play when they talk with parents raises questions about the extent to which it is actually the parents making the decision. What does it actually mean to define infant genital surgery as occurring subject to "parental consent" (Roen and Hegarty 2018)?

It is interesting to read alongside one another the psychological texts, showing that medical professionals unwittingly influence parents' decisions due to the way they give "information", and the legal texts, pointing out that medical professionals' information-

giving role is so limited that they are not even required to ascertain how well parents have understood the information. Advice directed towards health professionals makes it clear that any information should be given in a spoken and written form (World Health Organisation 2014). “The doctor needs to inform the patient about the potential risks and benefits of the proposed treatment and let the patient to know that his or her welfare is the paramount concern.” (Paterson 2003, p. 1). In addition, “doctors are required to facilitate understanding [the law does not require them to] guarantee patient understanding” (Paterson 2003, p. 2). Psychology and Law both make an important contribution to our thinking about “informed consent” on behalf of infants, and reading these different texts alongside one another serves to highlight the chasm that opens up between them. It is in this chasm of possibility and uncertainty that health professionals are working. There is a great deal of flexibility around the actual practice of “informing” parents prior to them giving “consent.” In this context, it is, perhaps, not surprising that parents repeatedly express confusion and/or regret. Some texts consider regrettable medical interventions as a reasonable basis for apology. The WHO, for instance, states that it is important to recognise “past or present policies, patterns or practices of coercive sterilisation, and issue statements of regret or apology to victims” (World Health Organisation 2014, p. 15).

It is not only historical practices that might give rise to regret and apology. Researchers continue to raise uncertainties about the outcomes of childhood genital surgery. Liao et al. wrote that “Paediatricians’ confidence in the ability to construct genital anatomies is to meet cultural expectations of appearance and function has not been borne out” (Liao et al. 2015, p. 1). Researchers who have reviewed outcome studies similarly express concern that “there is no empirical evidence that corrective surgery at the youngest possible age leads to a better psychological development” and conclude that “empirical results do not support the early surgical interventions, which paediatric urologists recommend” (Schönbucher et al. 2008, p. 530). We see here that clinicians’ publications serve as a forum for expressing divergent perspectives on infant genital surgery. It must be understood that the very context for informing parents and engaging them in a consent process is a context of debate and uncertainty. It is not clear that parents are informed about these uncertainties before being invited to consent to surgery on behalf of their children.

4. Discussion

Hypospadias surgery is routinely performed in many countries and is most likely presented to parents as a routine surgery. Hypospadias is presented to parents as a common condition that can be corrected with surgery (Starship 2019). The routine discussion of this process produces an illusion in which both the medical professional and patient/caregiver believe that “all risks, benefits, and alternatives” have been discussed and agreed upon (Skowron and Angelos 2017, p. 1). This is despite there being little evidence for surgical urgency, except in the rare instance of urinary blockage.

There is relatively high trust in medical professionals in hospitals, putting them in a position of power. In such a high-trust environment, parents with little knowledge of the situation and why such procedures are performed rely on the advice given by medical professionals. They seldom have other information sources in such stressful times. Though it is couched in terms of parental consent, the decision may largely be “induced precipitately and unconsciously by a health professional rather than emerging from a balanced, comprehensive, and thought-out process” (Streuli et al. 2013, p. 1958). In the remainder of this paper, we consider consent as a relational process and as a legal duty.

4.1. Consent as a Relational Process

Although medical professionals and parents do not necessarily agree on the treatment of a child (McDougall et al. 2016), they are often engaged in a consent process. What emerges from our analysis is a picture of long-term relationships and interactions over time within which the consent process is located. This picture allows us to expand the understanding of “informed consent” so that it is no longer a matter of merely “giving

information” and “consenting”, but, instead, it is a matter of producing ethical interactions between health professionals and patients with the aim of healthcare relationships lasting for years. Understanding consent as a process, understanding information as dynamic, partial, and negotiated, and understanding the doctor–patient interaction as relational might enable us to imagine the kind of informed consent process that genuinely works for everyone concerned. This means imagining a future where parents do not come away from these interactions feeling confused and overwhelmed, where any consent that is given does not reliably lead to regret, and where the child concerned is figured as an agentic subject who is part of this relational dynamic that persists over time.

4.2. Legal Duty of Consent

Informed consent is a legal duty and affords medical professionals to avoid liability when performed in accordance with appropriate clinical standards (Keenan and Dalziel 2016; Skegg et al. 2015; World Health Organisation 2014).

Medical professionals would acknowledge, when suggesting treatments such as hypospadias surgery, that they have a legal duty to obtain informed consent (Paterson 2003). Although concerns are raised about surgery going ahead without consent (Frommer et al. 2021; Sterling 2018), it would be very difficult to find that hypospadias surgery has not had consent granted. It is also recognised that hypospadias surgery and associated treatments would follow standard protocols. The focus is not whether *consent* is granted, but whether such hypospadias surgery has *free and informed consent* granted. Moreover, is the consent granted by parents or guardians valid? Several cases have determined that parents cannot decide on cases affecting children’s ability to reproduce (Secretary 1992), yet this was held differently in the case of intersex surgery that was considered “therapeutic” (Re: Lesley (Special Medical Procedure) 2008, FamCA 1226).

Although, generally speaking, the law assumes that the person concerned is the one giving consent, when a person is under 16 years old, consent falls on the parent or guardian. This is a dwindling duty as the child’s competency increases, following the Gillick principle (Gillick v West Norfolk and Wisbech AHA 1985, UKHL 112, pp. 113–14). As the child’s understanding and intelligence develops, parental consent reduces, and it terminates when the young person has the capacity to make their own decisions (Gillick v West Norfolk and Wisbech AHA 1985). Therefore, with hypospadias surgery usually being carried out in infancy and sometimes in teenage years, parental consent can only be given when it is in the child’s best interest, as per the parents’ legal duty (Gillick v West Norfolk and Wisbech AHA 1985, p. 170; Care of Children Act 2004 (NZ)) or in teenage years with the child’s consent with parental support, in alignment with the Gillick principle. Does the treatment improve the child’s well-being, in particular given that hypospadias is not life-threatening (NHS Trust 2021)?

There are two critical components to be considered in consent for hypospadias surgery. The first is whether consent is freely given. The second is whether the person consenting is adequately informed. If either or both of these fail or are inhibited, then any consent becomes invalid. We address each of these components in turn.

When consent is freely given, this means there is no coercion or duress during the process of giving consent. This includes misrepresenting the necessity of the surgery. Stating that it “would be better off to have the operation than not to have it” does not meet the requirement of informed consent (Reibl v Hughes 1980, p. 925). Even if the medical professional may feel it is for the consumer’s own good, the medical professional must not “misinterpret the nature or necessity of a procedure, or resort to any attempt to put undue pressure on a consumer to accept it” (Keenan and Dalziel 2016, p. 104).

The second core aspect of the legal duty of consent in the medical context is that the person consenting is adequately informed (Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation 1996, Rights 6, 7). It is through being adequately informed and given time to contemplate and consult with others if desired that the person can give or refuse consent. Full disclosure concerning the

treatment suggested must include the “state of medical knowledge at that time” ([Rosenberg v Percival 2001](#), HCA 18, para. 67), recognising that knowledge is constantly evolving.

Being adequately informed legally indicates that a person has sufficient information to make a decision regarding whether or not to agree to a particular medical treatment ([Keenan and Dalziel 2016](#), p. 109). Although information may never be perfect, “fully informed” consent requires the disclosure of all expected risks, side effects, benefits, and costs of each option. The test for disclosure includes any information that “a reasonable person in the patient’s position would be likely to attach significance to” (*Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 2015*, para. 87). It also includes the likely consequence of not having treatment (*Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulation 1996*, Rights 6, 7; [Keenan and Dalziel 2016](#), p. 109). The patient is entitled to take into account all non-medical considerations when making decisions (*Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 2015*, para. 83). All risks, no matter how infrequent, must be disclosed ([Keenan and Dalziel 2016](#), p. 113; *Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 2015*, p. 89).

The test is not what significance the medical professional attaches to risks and benefits, but what significance the person concerned might attach to those risks and benefits. Even if a court is satisfied that a reasonable person in the patient’s position would be unlikely to attach significance to a particular risk, the fact that the patient may ask questions means there is some significance and relevance to the question ([Rogers v Whitaker 1992](#), para. 11).

5. Conclusions

Conversations between health professionals and parents have been presumed to provide the basis for the informed consent that underpins penile surgery on children with hypospadias. These conversations take place in a medical setting where parents are highly likely to trust medical professionals, perhaps to the extent that they may not consider that there is any option other than to go ahead with surgery. Psychosocial research demonstrates that parents’ interpretation of what they are told is strongly impacted by framing effects, which are likely to prompt them to opt for surgery when that course of action is presented to them by a medical professional. It is likely that non-surgical care pathways are not presented to parents and that non-medical professionals are not involved in talking with parents about their son’s healthcare, about penile variations, or about any concerns that might be relevant to parents soon after the birth of a child with hypospadias. In this context, it seems unlikely that conversations between medical professionals and parents can provide the basis for a valid consent process.

Human rights organisations have found the surgery carried out on children with variations in sex characteristics, including hypospadias, to be a breach of the rights of the child. Some medical professionals continue to argue for the benefits of this surgery on the assumption that it is consented to by parents or guardians. Psychosocial research brings into question the communication between medical professionals and parents that underpins the consent process. Our examination of selected legal, medical, and psychosocial texts raises significant doubt about whether current hospital practice meets the requirement of informed parental consent on behalf of children undergoing hypospadias surgery.

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References

- Amnesty International. 2017. *First Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany*. Available online: <https://www.amnesty.org/en/documents/eur01/6086/2017/en/> (accessed on 26 October 2023).
- Aspinall, Cassandra Louise. 2006. Do I make you uncomfortable: Reflections on using surgery to reduce the distress of others. In *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*. Edited by Erik Parens. Baltimore: Johns Hopkins University Press, pp. 13–28.
- Care of Children Act 2004 (N.Z.). 2004. Available online: <https://www.legislation.govt.nz/act/public/2004/0090/latest/DLM317233.html?src=qs> (accessed on 26 October 2023).
- Cools, Martine, Anna Nordenström, Ralitsa Robeva, Joanne Hall, Puck Westerveld, Christa Flück, Birgit Köhler, Marta Berra, Alexander Springer, Katinka Schweizer, and et al. 2018. Caring for individuals with a difference of sex development (DSD): A Consensus Statement. *Nature Reviews Endocrinology* 14: 415–29. [CrossRef]
- Frommer, Michael, John Howell, Edward Santow, Susan Cochrane, and Bruce Alston. 2021. *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics*. Available online: <https://humanrights.gov.au/intersex-report-2021> (accessed on 26 October 2023).
- Ghidini, Filippo, Sasa Sekulovic, and Marco Castagnetti. 2016. Parental decisional regret after primary distal hypospadias repair: Family and surgery variables, and repair outcomes. *The Journal of Urology* 195: 720–24. [CrossRef] [PubMed]
- Gillick v West Norfolk and Wisbech AHA. 1985. UKHL 112.
- Greenberg, Julie A. 2017. Legal, ethical, and human rights considerations for physicians treating children with atypical or ambiguous genitalia. *Seminars in Perinatology* 41: 252–55. [CrossRef] [PubMed]
- Regulation 1996) Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulation. 1996. (NZ). Available online: <https://www.legislation.govt.nz/regulation/public/1996/0078/latest/whole.html> (accessed on 26 October 2023).
- Katz, Jay. 1998. Reflections on informed consent: 40 years after its birth. *Journal of the American College of Surgeons* 186: 466–74. [CrossRef] [PubMed]
- Keenan, Rebecca, and Kathryn Dalziel. 2016. *Health Care and the Law*, 5th ed. Toronto: Thomson Reuters.
- Kumar, Nandini K. 2013. Informed consent: Past and present. *Perspectives in Clinical Research* 4: 21–25. [CrossRef]
- Liao, Lih-Mei, Dan Wood, and Sarah M. Creighton. 2015. Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place. *BMJ* 351: h5124. [CrossRef]
- Long, Christopher J., and Douglas A. Canning. 2016. Hypospadias: Are we as good as we think when we correct proximal hypospadias? *Journal of Pediatric Urology* 12: 196.e191–196.e195. [CrossRef]
- Lorenzo, Armando J., Luis H.P. Braga, Bozana Zlateska, Bruno Leslie, Walid A. Farhat, Darius J. Bägli, and Joao L. Pippi Salle. 2012. Analysis of decisional conflict among parents who consent to hypospadias repair: Single institution prospective study of 100 couples. *The Journal of Urology* 188: 571–75. [CrossRef]
- Lundberg, Tove Pernilla. 2017. *Knowing Bodies: Making Sense of Intersex/DSD a Decade Post-Consensus*. Doctoral thesis, University of Oslo, Representanten, Norway. Available online: <https://www.duo.uio.no/handle/10852/55654> (accessed on 26 October 2023).
- McDonald, Elisabeth. 2015. Intersex people in Aotearoa New Zealand: The challenges for law and social policy: Part I: Critiquing gender normalising surgery. *Victoria University of Wellington Law Review* 46: 705–24. [CrossRef]
- McDougall, Rosalind, Clare Delany, and Lynn Gillam. 2016. *When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion*. Alexandria: Federation Press.
- Mendez, Juan E. 2013. *Report of the Special Rapporteur on Torture, and Other Cruel, Inhuman and Degrading Punishment*. 22nd Session of the UN Human Rights Council. Available online: <https://digitallibrary.un.org/record/793910?ln=en> (accessed on 26 October 2023).
- Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland). 2015. UKSC 11. Available online: <https://www.supremecourt.uk/cases/docs/uksc-2013-0136-judgment.pdf> (accessed on 26 October 2023).
- New Zealand Public Health and Disability Act. 2000. Available online: <https://www.legislation.govt.nz/act/public/2000/0091/latest/DLM80051.html> (accessed on 26 October 2023).
- NHS Trust. 2021. Hypospadias Repair. NHS: The Leeds Teaching Hospitals. Available online: <https://www.leedsth.nhs.uk/a-z-of-services/childrens-surgery/childrens-day-surgery/about-your-procedure/hypospadias-repair/> (accessed on 26 October 2023).
- Paterick, Timothy J., Geoff V. Carson, Marjorie C. Allen, and Timothy E. Paterick. 2008. Medical informed consent: General considerations for physicians. *Mayo Clinic Proceedings* 83: 313–19. [CrossRef] [PubMed]
- Paterson, Ron. 2003. Informed consent in New Zealand: Medical myths. *New Zealand Medical Journal* 116: 1183.
- Re: Lesley (Special Medical Procedure). 2008. FamCA 1226; Unreported.
- Reibl v Hughes. 1980. 2 S.C.R. 880. Available online: <https://www.canlii.org/en/ca/scc/doc/1980/1980canlii23/1980canlii23.html> (accessed on 26 October 2023).
- Reis, Elizabeth. 2019. Did Bioethics Matter? A History of Autonomy, Consent, and Intersex Genital Surgery. *Medical Law Review* 27: 658–74. [CrossRef]

- Roen, Katrina. 2009. Clinical intervention and embodied subjectivity: Atypically sexed children and their parents. In *Critical Intersex*. Edited by Morgan Holmes. Farnham: Ashgate, pp. 15–40.
- Roen, Katrina. 2019. Intersex or diverse sex development: Critical review of psychosocial health care research and indications for practice. *The Journal of Sex Research* 56: 511–28. [CrossRef]
- Roen, Katrina, and Peter Hegarty. 2018. Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. *British Journal of Health Psychology* 23: 967–81. [CrossRef] [PubMed]
- Rogers v Whitaker*. 1992. HCA 58; 175 CLR 479 Available online: www.paci.com.au/downloads_public/court/12_Rogers_v_Whitaker.pdf (accessed on 19 November 1992).
- Rosenberg v Percival*. 2001. HCA 18, P44/2000. Available online: <http://eresources.hcourt.gov.au/showCase/2001/HCA/18> (accessed on 26 October 2023).
- Schönbucher, Verena B., Daniel M. Weber, and Markus A. Landolt. 2008. Psychosocial adjustment, health-related quality of life, and psychosexual development of boys with hypospadias: A systematic review. *Journal of Pediatric Psychology* 33: 520–35. [CrossRef]
- Secretary. 1992. Department of Health and Community Services v JMB and SMB (Marion's Case). *Family LR* 15: 392.
- Skegg, Peter. D. G., Ron Paterson, and Jo Manning. 2015. *Health Law in New Zealand*. Toronto: Thomson Reuters.
- Skowron, Kinga B., and Peter Angelos. 2017. Surgical Informed Consent Revisited: Time to Revise the Routine? *World Journal of Surgery* 41: 1–4. [CrossRef]
- Snodgrass, Warren, and Nicol Bush. 2016. Primary hypospadias repair techniques: A review of the evidence. *Urology Annals* 8: 403–8. [CrossRef]
- Starship. 2019. *Hypospadias*. Available online: <https://starship.org.nz/guidelines/hypospadias> (accessed on 1 August 2023).
- Steers, Denise M., Georgia L. Andrews, Esko J. Wiltshire, Angela J. Ballantyne, Sunny C. Collings, and Maria H. Stubbe. 2021. Young people with a variation in sex characteristics in Aotearoa/New Zealand: Identity, activism and healthcare decision-making. *Culture, Health & Sexuality* 23: 457–71. [CrossRef]
- Sterling, Rogena. 2018. Identity and Its Protection as the Aim and Purpose of International Human Rights Law: The Case of (Inter)Sex Identity and Its Protection. Doctoral thesis, The University of Waikato, Hamilton, New Zealand. Available online: <https://hdl.handle.net/10289/11891> (accessed on 26 October 2023).
- Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. 2013. Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *The Journal of Sexual Medicine* 10: 1953–60. [CrossRef] [PubMed]
- The Nuremberg Code. 1996. *BMJ* 313: 1448. First published 1947. [CrossRef]
- UNCRC. 2016. *Concluding Observations on the Fifth Periodic Report of New Zealand (CRC/C/NZL/CO/5)*; United Nations Human Rights Office. Available online: <https://www.ohchr.org/en/documents/concluding-observations/crcnzlco5-concluding-observations-fifth-periodic-report-new> (accessed on 26 October 2023).
- United Nations Human Rights Council. 2013. Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez (A/HRC/22/53). Available online: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf (accessed on 26 October 2023).
- United Nations Human Rights Office of the High Commissioner. 2023. *Human Rights Violations against Intersex People: A Background Note*; United Nations Human Rights Office. Available online: <https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf> (accessed on 26 October 2023).
- Weber, Daniel Max, Verena B. Schönbucher, Rita M. Gobet, Andreas Ch Gerber, and Markus A. Landolt. 2009. Is there an ideal age for hypospadias repair? A pilot study. *Journal of Pediatric Urology* 5: 345–50. [CrossRef] [PubMed]
- World Health Organisation. 2014. *Eliminating Forced, Coercive and Otherwise Involuntary Sterilisation: An Interagency Statement*; OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO. Available online: <https://www.who.int/publications/i/item/9789241507325> (accessed on 26 October 2023).

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