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Parental refusal: legal and ethical considerations

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Introduction

The Children's Act of 2005 was a watershed in establishing the rights of the child in South Africa. This legal document makes provision for the care and protection of children, and defines parental responsibilities and rights. It also defines who is a "parent," and what should be considered when requesting consent for anaesthesia and surgery prior to an operation. Current laws provide a balance of parents' wide discretionary authority in raising their children with the laws to protect children against abuse and neglect. There are two parts to this Act: the Children's Act 38 of 2005 and the Children's Amendment Act 41 of 2007, some of which came into force in 2007, and the associated regulations in 2010. The two acts have now been combined into one, called the Children's Act 38 of 2005 (as amended by Act 41 in 2007).[1-3]

Key principles

Decisions should always be made in the best interests of the child. What is the difference between "legal" and "ethical" considerations? Ethical means a set of moral principles which govern a person's behaviour. This may relate to or affirm a specific group, form or field of conduct, e.g. medicine. Legal pertains to the laws of the country; of, based on, or concerned with, the laws of the land.[4] Assent is an agreement to treatment without information about the procedure or the risks involved. Informed consent requires a description of the treatment, procedure or study, the indications for the proposed procedure, the risks involved, alternatives to this, the consequences of refusing treatment, and the ability of the person receiving the consent to evaluate the patient's or parent's understanding of the discussion.[5-7] A competent individual, having received the necessary information, adequately understood this information, and after due consideration, may arrive at a decision, without having been subjected to coercion, undue influence or intimidation, to consent to medical or surgical treatment.[8] Only patients and/or their parents with appropriate decisional capacity and legal empowerment can truly give informed consent.

By law in South Africa, consent must be given by a person legally capable of this responsibility. Valid consent for medical treatment, surgical procedures and/or research is just as necessary for children as it is for adults.[9] A child is a person who is 18 years of age or younger. This differs in many countries, and it is important that we familiarise ourselves with the laws and customs of any country that we may visit or where we may practise anaesthesia. Informed consent should be seen as a process of the exchange of information and discussion, not merely the signing of a piece of paper.

Consent for anaesthesia-related procedures should be recorded on the anaesthetic record. This is much more relevant than creating a special form and getting it signed. Any discussion about the procedure, insertion of rectal suppositories, invasive lines, regional anaesthesia, risks and benefits, and questions asked and answers provided, should be documented.

Age and consent

When can children give consent

Children can give consent in the following situations:[1-3,9]

- *Medical treatment:* If they are > 12 years of age, as long as they have the maturity "to understand the benefits, risks, social and other implications of the treatment". This is independent of parents' consent.
- *Surgical procedures:* > If they are 12 years of age and duly assisted by their parent or legal guardian (Form 34, or Form 35, if the child's parents themselves are aged 18 years and younger).
- *Research:* If they are < 18 years: Parental or guardian consent is required, plus the child's assent (once > 7 years of age).
- *Pregnancy:* Any female of any age may consent to the termination of her own pregnancy.
- *Virginity testing:* This is forbidden in children aged 16 years and younger. Virginity testing may only be performed in children aged 16 and older with their consent, together with appropriate and timeous counselling, and using a prescribed method. The results of this testing may not be disclosed without the consent of the child.
- *Circumcision:* Every male child has the right to refuse circumcision. Female circumcision is prohibited, regardless of age.
- *"Child parents":* If they are > 12 years old and have their own children, they may sign consent to medical treatment for

their own child, but require their own parent's assistance for surgical consent.

Who can give consent when children lack the capacity to do so

A parent or legal guardian may consent to a medical treatment and to a surgical procedure in children who are aged < 12 years or > 12 years, but who lack the maturity to make an informed decision.[1-3,9] A caregiver may not consent to surgery nor research, but may to consent to medical treatment.

Only when a person with parental responsibilities is unavailable in the case of an emergency (necessity plus urgency equals an emergency[3]) that is both life-threatening and urgent, may a medical superintendent or clinical manager provide consent for a surgical emergency to "preserve the child's life" or "to save the child from serious and lasting physical injury or disability". If neither a medical superintendent nor clinical manager is available, the Health Professions Council of South Africa guidance suggests that the healthcare practitioner may treat the child, providing that it is in the child's best interests.[10] This treatment should be limited to that which is reasonably necessary at this time (the emergency). Documentation of all of the events and attempts to locate the parents, as well as documentation of the clinical status of the patient, is crucial. Consultation with a multidisciplinary advisory group is recommended and is often very helpful.

Application should be made to the Minister of Social Development for non-emergency situations. This may be carried out through a social worker, but a doctor may approach the children's courts directly, e.g. over the weekend when social workers are unavailable. There is a magistrate on call for this eventuality, but most problems are addressed by the local provincial Department of Social Development. This department is also empowered to give consent in situations in which the parent or guardian unreasonably refuses to provide consent, is incapable of doing so, cannot easily be traced or is deceased.[3,9] This is often a time-consuming process, so it needs to be initiated as soon as the problem is detected.

Biomedical ethical principles of care

The biomedical ethical principles of care are as follows:

- *Autonomy:* The patient has free choice, e.g. the right to refuse.
- *Beneficence:* It is essential to act in the best interests of the patient.
- *Non-maleficenece:* In the first place, do no harm to the patient.
- *Justice:* Ensure that the benefits and burdens of treatment are distributed equitably.
- *Dignity:* The patient has the right to being treated with respect and to ethical treatment.
- *Truthfulness and honesty:* Information about what we know and what we don't know.

Who is a parent?

Parental responsibilities and rights may be regarded as "full" or "partial", and there are those persons who have no parental responsibilities or rights.[11]

Usually, full rights are held by the biological parents. This means the person has a duty to care for the child, maintain contact, act as a guardian, contribute to maintenance, and make decisions with or on behalf of the child with regard to consent to marriage, adoption, travelling overseas and outside the country, and applying for a passport. If a person with full rights chooses to share their rights and obligations with another, e.g. the grandparents of the child, partial rights are granted (legally) to those individuals. Day-to-day carers, who are there to safeguard the child's health, provide well-being and development, as well as protect the child from harm, have no legal rights or responsibilities.

Full responsibilities are afforded to a biological mother, a biological father (but not always), and a legal guardian. As the child's legal guardian, the biological mother has the authority to consent to all forms of medical treatment and research on behalf of her child, provided that she is > 18 years old or < 18 years old and married. If she is < 18 years and not married, she needs the assistance of her own parents to consent to a surgical procedure being performed on her child. The biological father must be > 18 years of age, must have been or be married to the biological mother during her pregnancy or after the birth, and then qualifies for joint guardianship, and has the authority to sign consent. If the father has parental responsibilities and rights, he can consent to all forms of health research.

When two people have full rights and responsibilities, either of them can sign consent for medical treatment, research or a surgical procedure without consulting each other. However, when major decisions are made, it is advisable for them to liaise with each other. Legally, this is not necessary, but it is the "right thing to do".[9,11]

At present, caregivers who factually care for the child may not sign consent for research or surgery, but may do so for medical treatment. In reality, in South African, approximately one third of children live with caregivers, of whom 80% are grandparents or relatives.[11]

Guardianship is an order of the High Court, and can be nominated on the death of a parent or on the adoption of a child.

Withholding consent

The child and the parents, together or independently, have the right to refuse to provide consent for medical treatment, surgery or research. If they refuse, it is necessary to determine if this is a reasonable or unreasonable reaction. Questions must be asked: "Why are they refusing this standard treatment or surgery?", "Has everything been explained satisfactorily?", "Do they understand the risks involved and the consequences of not having the treatment, and the possibility of increased pain and suffering for their child?" and "Is their decision likely to affect the child adversely?"

The child

Any minor with decisional capacity who refuses to consent to life-saving therapy, should have the case referred to the courts. Any decision to override this should not be made by the treating physician. Lifesaving action can only be taken in an emergency, when the treating clinician judges the treatment to be in the best interests of the child, but this requires consent from the medical superintendent or person in charge of the hospital. The documentation of all discussions, telephone calls and contact is essential. Parents may not override the child's decision.[1-3]

The parents

If parents withhold consent to surgical or medical treatment for a child who lacks the capacity to consent to it, and it is felt that this decision may adversely affect the child, either in the short or long-term, the matter must be reported to the social worker who will report this to the provincial Department of Social Development.

The same conditions apply, regardless of whether or not the child, parent or guardian refuses:[3]

- If reasonable, the health professional should respect that.
- If unreasonable, or purely on religious or cultural grounds, the health professional will need to go to the courts or Minister of Social Development to overrule the refusal by the parent or the child.
- If it is an emergency (i.e. urgent plus life threatening), the medical superintendent must be contacted.

Discussion

Do parents have the right to refuse what is seen to be standard treatment for their child, whether surgical or medical? Should the same apply to consent for research? In recent years, physician-directed decision-making has changed into increased shared decision-making between the physician, patient and the parents. This has moved the concept of care from a paternalistic approach whereby the doctor knew everything and had control, and the patient remained vulnerable and ignorant; to one of consultation and choice. Who is to determine "the child's best interests"? The parents may feel differently to the physician about what each thinks is in the child's best interests. A multidisciplinary meeting with the patient, parents and medical staff may clarify misunderstandings and defuse the situation, and thereby allow rational decisions to be made to facilitate the best way forward.[12-14]

More and more parents are looking at alternative or replacement therapies for their children, especially in patients with life-threatening or severely life-limiting illnesses. A holistic approach, using nutritional supplements, diet, stress reduction techniques and integrative medicine, is increasingly popular, and when therapies and surgical procedures are felt to cause more distress, pain and suffering, these options are understandably attractive.

Withholding treatment is a genuine ethical dilemma for medical caregivers, but if the parent or child's refusal is seen to place the child at risk, the case should be reported to the social worker, who will then report it to the provincial Department of Social Development. This may then proceed to the children's courts.

Grey areas

The maturity of the child, and the wishes and opinions, religious beliefs and customs of the parents; as well as the clinical circumstances, may seem to conflict. Decisional capacity is often difficult to evaluate in children. This is the ability to understand problems, risks, benefits, alternatives and the long-term consequences of both the illness and the therapeutic option. This links both to cognition and prior life experiences. The onus is on the health professional to communicate the information in a child-friendly manner, to involve the child in healthcare decision-making, to inform the child of the risks and benefits in a way that he or she will understand, allow the child to think, ask questions, express his or her views, and listen to his or her fears and concerns. An insightful decision can then be made with regard to the child's circumstances.

Conclusion

Children should be empowered to the full extent of their decisional capacity and emotional maturity so that they may make informed decisions about their own health and well-being. Good communication and understanding between parents and medical staff is crucial, but overall, the best interests of the child should be paramount.

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References

1. Department of Social Development, South Africa. Children's Act 38 of 2005 (as amended by the Children's Amendment Act 41 of 2007).
2. Department of Social Development. Children's Act, 2005. General regulations regarding children. Pretoria: Department of Social Development, 2010.
3. Department of Justice and Constitutional Development. Children's Act 2005. Regulations relating to Children's Court and international child abduction. Pretoria: Department of Justice and Constitutional Development, 2010.
4. Lake L, Proudlock P, editors. Child rights and child law for health professionals: a short course. Children's Institute, University of Cape Town; International Institute for Child Rights and Development, University of Victoria; 2013.
5. Oxford dictionary. Goodwood: Oxford University Press, 2013.
6. Informed consent, parental permission, and assent in pediatric practice. American Academy of Pediatrics Committee on Bioethics. Pediatrics. 1995;95(2):314-317.
7. Unguru Y, Coppes MJ, Kamani N. Rethinking pediatric assent: from requirement to ideal. Pediatr Clin North Am. 2008;55(1):211-222.
8. Unguru Y, Sill AM, Kamani N. The experiences of children enrolled in pediatric oncology research: implications for assent. Pediatrics. 2010;125(4):e876-e883.
9. De Roubaix M. Seeking patients' consent in anaesthesiology: consent in clinical practice. South Afr J Anaesth Analg. 2006;12(4):121.
10. Consent: children and young people. Medical Protection Society [homepage on the Internet]. 2001. Available from: www.medicalprotection.org
11. Booklet 15. Health Professions Council of South Africa.
12. Strode AE, Slack CM. Using the concept of "parental responsibilities and rights" to identify adults able to provide proxy consent to child research in South Africa. South African Journal of Bioethics and Law. 2011;4(2):152-161.
13. Angst DB, Deatrick JA. Involvement in health care decisions: parents and children with chronic illness. J Fam Nurs. 1996;2(2):174-194.
14. Rossi WC, Reynolds W, Nelson RM. Child assent and parental permission in pediatric research. Theor Med Bioeth. 2003;24(2):131-148.