CAN CHILDREN REFUSE MEDICAL TREATMENT?

Sharon Kling | Associate Professor
Mariana Kruger | Professor
Department of Paediatrics and Child Health, Stellenbosch University and Tygerberg Hospital
Email | sk@sun.ac.za

ABSTRACT
Children are increasingly recognised as being capable of making decisions regarding their own healthcare. This is reflected in international guidelines as well as South African legislation, where children as young as 12 years of age may consent to medical treatment. However, when it comes to treatment refusal, clinicians have a moral obligation to investigate and, if necessary, contest treatment refusal by the child and/or parents. Usually the best interests principle serves as guidance to clinicians in the choice of healthcare interventions, but in this case it is probably more apt to apply the harm principle.

INTRODUCTION
Current ethical guidelines and legislation recommend involving children in decision-making regarding their own medical care. Generally speaking, healthcare professionals are comfortable to respect children's decision-making when they give consent to medical treatment or procedures. However, treatment refusal often meets with a negative response, particularly when the treatment being refused is for a potentially life-threatening illness. A good example of this is where adolescents with eating disorders refuse healthcare interventions. This illustrates the everyday challenges clinicians face when caring for adolescents and young adults (AYA) in a culture that increasingly reflects the value of patient autonomy, even the developing and potentially inconsistent autonomy of an adolescent. Refusal of treatment by a child creates a tension between beneficence (what is in the child’s best interests) and respecting the evolving autonomy of the child. The best interests standard is the ‘highest net benefit among the available options that apply to any situation in which a decision has to be made regarding the health of the child’. The application of the best interests principle necessitates a risk–benefit and quality of life assessment. If the treatment promises significant benefit to the patient and poses a low risk, it is generally thought to be in that person’s interests. The ‘best interests’ standard has been criticised as being impracticable, narrow and difficult to apply, but the application thereof should be realistic rather than ideal. Kopelman explains that the best interests standard has three related meanings in that it can be:
• used as a threshold for intervention;
• used to establish prima facie duties such as respecting children’s rights to healthcare; and
• establishes a standard of reasonableness that also takes into account the availability of resources.

ETHICAL ISSUES IN PAEDIATRIC TREATMENT REFUSAL
In the past children were generally neither consulted nor involved in medical decision-making and all decisions were made by their parents, in consultation with their doctors. Currently, we recognise that children have the capacity to be involved in decision-making, depending on their age, maturity and experience of illness, such as in chronic diseases.

Refusal of treatment by a child creates a tension between beneficence (what is in the child’s best interests) and respecting the evolving autonomy of the child. The best interests standard is the ‘highest net benefit among the available options that apply to any situation in which a decision has to be made regarding the health of the child’. The application of the best interests principle necessitates a risk–benefit and quality of life assessment. If the treatment promises significant benefit to the patient and poses a low risk, it is generally thought to be in that person’s interests. The ‘best interests’ standard has been criticised as being impracticable, narrow and difficult to apply, but the application thereof should be realistic rather than ideal. Kopelman explains that the best interests standard has three related meanings in that it can be:
• used as a threshold for intervention;
• used to establish prima facie duties such as respecting children’s rights to healthcare; and
• establishes a standard of reasonableness that also takes into account the availability of resources.

A particular child’s best interests may also conflict with the interests of other children.

If a child and his/her parents refuse recommended medical treatment, the clinician cannot force them to accept it; only the state can do so. Diekema argues that the best interests standard is an inadequate guide to use when considering various treatment alternatives for children.
He proposes that a harm-based standard should rather be used in determining the appropriate threshold for intervention by a higher authority.\textsuperscript{10,11} The ‘Harm Principle’ originated in the powers granted to the state to protect the health and welfare of the public.\textsuperscript{11} Based on the liberty principle, John Stuart Mill wrote:

‘The only purpose for which power can rightfully be exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant.’\textsuperscript{12}

According to Joel Feinberg, any restriction on an individual’s freedom must be justified by the prevention of harm to that individual.\textsuperscript{13} Therefore a decision by a parent or child or both that is adjudged to potentially pose harm to the child can justify intervention by the state.\textsuperscript{10,11}

However, before any higher authority intervention in treatment refusal is considered, the child’s evolving autonomy must be respected and reasons for refusal investigated. This requires an assessment of the child’s decision-making capacity. Some of the factors to be considered are the child’s biological age, mental age, maturity compared to their peers, their cognitive ability, their participation in decision-making at school and whether they are easily influenced by others. What does the child understand, what do they want to know about their illness and the treatment options, and what information do they require in order to be involved in the decision-making process?\textsuperscript{14} Kenny et al make the point that, even if a child has not yet developed decisional maturity, information should be provided so that the child is able to express an opinion regarding the various treatment options.\textsuperscript{14}

According to the American Academy of Pediatrics (AAP), clinicians should assist the child patient to understand their illness or condition, inform them of what they can expect from tests and treatment, determine the child’s understanding of the condition and the factors influencing their response to the provided information and obtain assent or permission.\textsuperscript{1}

There are three different scenarios in paediatric treatment options. The most desirable one is when the child, parents and treating team agree on a course of action. If the child and parents agree about the treatment refusal and the treating team disagrees, the reasons for the differences of opinion should be explored and ongoing discussions held. If the situation is life-threatening and the prognosis is good, the healthcare team should take steps to institute life-saving treatment while negotiating with the family, based on the harm principle. It may be necessary to obtain state intervention via a court order to proceed with treatment. The situation where the child refuses treatment and is regarded as being a mature minor or having the capacity to make healthcare decisions, and the parents disagree with the child, is fraught with difficulties. This requires a careful exploration of the issues and values of the respective parties and why there is a difference of opinion. It is very difficult to force a child, who is regarded as competent to make decisions, to undergo treatment against their will, unless it is clearly in their best interests to do so and/or poses the least harm.\textsuperscript{1} According to Kenny et al:

‘The child’s interests must always be the basis for a decision to be followed by the healthcare team. This approach does not discount the parents’ concerns and authority but it does recognise the child (albeit as a member of a family) as the particular patient to whom the healthcare team has a primary duty of care.’\textsuperscript{14}

However, clinicians need to recognise that informed consent/assent/refusal is a process, which requires ongoing discussion and sharing of information or educating of families regarding healthcare interventions.\textsuperscript{1}

LEGAL ISSUES IN PAEDIATRIC TREATMENT REFUSAL

Medical treatment should be provided or withheld only if the patient has given legally valid consent for or refusal of such treatment. This implies that the consent or refusal is uncoerced, and the decision has been made by a person with decisional capacity and complete information regarding the treatment options. If the patient is a child and unable to make healthcare decisions, the parents or a legal guardian are the legally authorised decision-makers.\textsuperscript{14} If the healthcare professional believes that the parents or legal guardian are not acting in the child’s best interests, then they have recourse to child welfare authorities and/or the courts.

According to South African legislation a child is a person younger than 18 years. Section 10 of the Children’s Act 38 of 2005 states:

‘Every child that is of such an age, maturity, and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.’\textsuperscript{3,4}

Section 9 of the Children’s Act states that a child’s best interests are ‘of paramount importance’. It also states in section 11(3) that ‘a child with a disability or chronic illness has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his or her health, wellbeing or dignity’.\textsuperscript{3,4,15} It does not make mention of refusal of treatment by children, apart from section 11(3) above. ‘If a child unreasonably refuses to give consent to treatment,’ the Minister of Social Development may consent to that treatment (section 129(8)), using the best interests standard as a yardstick.\textsuperscript{15}
According to McQuoid-Mason, Section 6(1)(d) of the National Health Act No 61 of 2003 requires health providers to inform users (patients) about their right to refuse health services and to explain the implications, risks and obligations of such refusal. Children who have the mental capacity to consent to medical treatment therefore should also have the capacity to refuse treatment. Healthcare providers need to assess the child’s ability to understand the consequences of the refusal of consent so as to assess to what extent it should be respected.15

IS THERE A DIFFERENCE BETWEEN CONSENTING TO AND REFUSING MEDICAL TREATMENT?

John Harris discusses the case of Re W, a 16-year-old girl with anorexia nervosa.16,17 The court ordered W’s transfer from an adolescent unit to a hospital specialising in treatment disorders against her will. The judges argued that the characteristic of anorexia nervosa is that the patient does not want to be cured, and therefore the minor was able to consent to treatment but not to refuse it.17,18 Harris poses the question, ‘is it sensible to say that children or the mentally ill are competent to consent to treatment but not competent to refuse treatment?’16 He states: ‘The idea that a child (or anyone) might competently consent to a treatment but not be competent to refuse it is palpable nonsense.’ He argues that, in order to understand a proposed course of treatment sufficiently well to consent to it, also implies that the person is able to understand the consequences of a refusal and that therefore the refusal must also be competent. He concludes, if someone is ‘competent to choose to live they are competent to choose not to’.16

Manson describes the ‘asymmetry’ of consent and refusal of treatment by adolescents.19 If an adult consents to treatment it is rendered to them; if they refuse or do not consent, the treatment is withheld. For some types of treatment, particularly for life-saving treatment, the adolescent’s consent is considered to be as binding as that of adults, but refusal of consent is not respected and may be overridden by the courts. One of the explanations given for this asymmetry is that a patient may be considered competent to consent to an intervention, but not to refuse it. In other words: ‘The “bar” is set higher for refusal than for consent and the adolescent might reach the lower “bar” but not the higher.’19 There is justification for this as adolescents’ maturation of moral authority, autonomy and cognitive ability may not follow the same timeline.1 Brain development is an ongoing process until the third decade of life and impulse control, with executive functions in the prefrontal region the last to mature.

However, the limbic and paralimbic regions, with sensation-seeking and risk-taking regions develop during puberty, creating an imbalance between the two systems, as demonstrated through the risk-seeking behaviour noticed in adolescence. The supposition in the face of life-threatening illness is that adolescents will rely more on their limbic or socio-emotional system for decision – than on their risk-taking regions.1

Harris argues: ‘Competence is not an existential state, a state of being. It is not people who are competent but decisions. So the same person may be competent to make one decision but not another.’ If children are not competent to make decisions, then healthcare providers have to make decisions in their best interests, especially to minimise harm. They should involve children in the decision-making process to the extent of obtaining their opinion, but if they are prepared to override them in order to prevent harm, then they are not respecting their autonomy, but upholding beneficence. Instead the children’s ‘acquiescence’ rather than their consent is being sought.16

HOW SHOULD CLINICIANS MANAGE TREATMENT REFUSAL BY CHILDREN?

As far as possible the mature child’s views should be respected. Where disagreement exists between the child/family and the treating team, the clinician should explore the reason for the treatment refusal, and whether it may be related to a misunderstanding of the disease or the treatment. Differences of opinion between the child and parents should be discussed and elucidated with an attempt to reach consensus. The urgency and gravity of the situation influence the time available for negotiation. If the disease is life-threatening and the child’s prognosis is good, life-saving therapy should be instituted at the same time as negotiating with the child and family for continued treatment, as this would be in the child’s best interests and minimise harm. The best interests of the child or the potential of harm of non-treatment have to be weighed before overriding the child’s opinion regarding the treatment. Discussions about the child’s treatment goals are essential and, if necessary, a facilitator, perhaps a spiritual counsellor or a psychologist, should be involved.14 The information should be provided in layman’s terminology that is easily understandable and include the benefits with the potential risks or harms expected. As the decision-making capacity of the child is critical, it will be necessary for clinicians to be able to determine the child’s ability to understand the provided information. A trusting relationship between the healthcare professional, the child patient and the parents are crucial and should be actively fostered. It is especially how one shares the information that will foster this trust. The harm principle is probably a more realistic principle to use in treatment refusal as there is a need to determine the threshold before overriding the child’s autonomy. If treatment refusal poses significant risks, the questions should be asked whether the treatment poses significant benefits, whether there is another treatment option that is less invasive, and can state interference be justified in similar cases, as well as be deemed reasonable by the public?
CONCLUSION

Refusal of treatment by children creates a tension between beneficence and respecting the evolving autonomy of the child. The clinician’s response will depend on the disease and the prognosis of the child, as well as the assessment of the child’s maturity and understanding. We believe that a right to give consent also means that the person has the right to refuse treatment and that the mature minor’s views should be taken seriously and respected, even in the case of refusal of life-saving treatment. However, if the prognosis with treatment is good, beneficence and the harm principle may dictate overriding the child’s autonomy, especially if the parents and the treating team concur.18

Even then, the child’s acquiescence with treatment should be sought, and seeking legal advice is prudent.19

Treatment refusal is ethically challenging, especially in child/adolescent medicine. This is especially the case as clinicians need to determine the minor’s decision-making capacity, which is still evolving, and this requires a specific level of expertise and experience from the clinician. It is important in these scenarios to involve other healthcare expertise, such as social workers, ethicists, child-life experts and other specialists as part of an integrated team to address treatment refusal.1

REFERENCES