What doctors should know when working with surrogate decision-makers who disagree with their treatment plans

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Problems arise when a lawfully appointed surrogate decision-maker wishes to decide on a course of action on behalf of a mentally incompetent patient that is against the patient’s best interests. This may arise: (i) where there is no advance directive, and the decision is made by the surrogate decision-maker on religious grounds; (ii) where the medical practitioners are of the opinion that the surrogate decision-maker’s decision is not in the best interests of the patient; (iii) where the close relatives of the patient do not agree with the decision by the surrogate decision-maker; and (iv) where the surrogate decision-maker asks the medical practitioners to undertake treatment or a procedure on the patient that is unlawful or unethical. Suggestions are made regarding what doctors should do when faced with each of these situations.

What should medical practitioners do if a lawfully appointed surrogate decision-maker wishes to decide on a course of action for a mentally incompetent patient that is against the patient’s best interests? For instance, in the following situations:

(i) There is no advance directive, and a decision to withhold or undertake treatment is made by the surrogate decision-maker on religious grounds.

(ii) The medical practitioners are of the opinion that the surrogate decision-maker’s decision is not in the best interests of the patient.

(iii) The close relatives of the patient do not agree with the decision by the surrogate decision-maker.

(iv) The surrogate decision-maker asks the medical practitioners to undertake treatment or a procedure on the patient that is unlawful or unethical.

(i) There is no advance directive and the decision to withhold or withdraw treatment or a procedure is made by the surrogate decision-maker on religious grounds

In most cases, if the surrogate’s decision is based on full information as required by the National Health Act No. 61 of 2003,[5] and concerns treatment or an operation that is in line with good medical practice, and not life-threatening or will not cause serious bodily injury, the surrogate’s decision based on the patient’s and surrogate’s religious beliefs is likely to be accepted by the treating doctors without question.

However, caution must be exercised by treating doctors in situations where a decision based on religious grounds is made regarding the withdrawal or withholding of treatment that will result in death or serious bodily injury to the patient. Such caution is required, for example, in cases where a life-saving blood transfusion is refused because a patient who belongs to a religion that forbids blood transfusions may be prepared to accept blood in a life-threatening situation – but the surrogate is not – where no alternative substitutes for blood are available.[15] In such cases, the treating doctors should follow the ethical guidelines of the Health Professions Council of South Africa (HPCSA) regarding the withholding and withdrawing of treatment.[10] In addition, they should check with close family members to ascertain whether the patient had ever expressed a view on whether (s)he would refuse a blood transfusion in such a life-threatening situation (paragraph 8.2.2). In addition, such doctors should seek assistance from the biomedical ethical principles of non-maleficence (what can be done not to harm the patient); beneficence (what can be done that would be good for the patient); and justice or fairness (how can the patient be treated justly and fairly)?[20] In all instances where it is not clear what the patient’s wishes are, the doctors should decide what is in the patient’s best interests by conducting a risk-benefit analysis by applying the HPCSA guidelines on the withholding and withdrawing of treatment[10] (paragraph 2.4) and the biomedical ethical principles of non-maleficence, beneficence and justice or fairness.[21]

The law is, however, very clear where child patients are involved. The Children’s Act[3] provides that in the case of children, life-saving treatment may not be withdrawn or withheld solely on religious grounds (section 129(10)).[4]

(ii) The treating doctors are of the opinion that the surrogate decision-maker’s decision is not in the best interests of the patient

In deciding whether the surrogate decision-maker’s decision is, or is not, in the best interests of the patient, the treating doctors should again apply the biomedical ethical principles[6] and, where relevant, the HPCSA ethical guidelines on the withholding or withdrawal of treatment.[10] The HPCSA guidelines state that ‘a decision to withhold or withdraw life-prolonging treatment should be made only by the senior clinician in charge of a patient’s care, taking account of the views of the patient or those close to the patient’ (paragraph 3). The senior clinician must decide ‘what course of action would be in the patient’s best interests, by consulting the patient’s authorised representative, the health-care team, and wherever possible, those close
to the patient … [who] may be able to provide insights into the patient's preferences, and be able to offer an opinion on what would be in the patient's best interests[6] (paragraph 8.2.2).

In terms of the National Health Act,[7] the treating doctors should fully inform the surrogate decision-maker – termed the 'user' in the Act (section 1) – of the procedure and treatment options available, and the risks and benefits of each procedure or treatment option (section 6(1)). If, after the consultations, the surrogate decision-maker disagrees with the decision by the senior clinician, an attempt should be made to settle the matter amicably through negotiation or mediation.[8] Where, however, the matter still cannot be settled, the surrogate should be advised to approach the court for an order requiring the treating doctors to implement the surrogate's instructions. The court will then conduct a risk-benefit analysis of all the evidence to determine whether or not it agrees with the decision of the treating doctors or the surrogate decision-maker. The final word will lie with the court, not the treating doctors or the surrogate.[9]

(iii) Where the close relatives of the patient do not agree with the decision by the surrogate decision-maker

Where the close relatives of the patient do not agree with the decision by the surrogate decision-maker, the course of action to be adopted will depend on the particular situation. If the close relatives disagree with a decision by the surrogate that is in conflict with that of the treating doctors and healthcare team, the steps mentioned in paragraph 2 above should be followed.

Where the close relatives disagree with the decision of a surrogate who has accepted the recommendations of the treating doctors and healthcare team, an attempt should again be made to settle the dispute, using negotiation or mediation.[7] If such an attempt fails, the close relatives should be advised by the treating doctors to approach the court, so that the court can decide, after a risk-benefit analysis of all the evidence, which treatment or procedure is in the best interests of the patient.

(iv) Where the surrogate decision-maker asks the medical practitioners to undertake treatment or a procedure on the patient that is unlawful or unethical

Where the surrogate decision-maker requests the treating doctors to provide treatment or engage in a procedure, or withhold or withdraw treatment or a procedure that is unlawful or unethical, such doctors may not provide, withhold or withdraw such treatment or procedure.[4] Treating doctors must always provide palliative care to terminally ill patients, but where a surrogate asks the treating doctors to provide treatment that is futile with a hopeless prognosis, they must refuse to do so.[10] To provide treatment under such circumstances is a waste of resources and flies in the face of the biomedical ethical principles.[4]

In the case of a non-public sector patient, it would harm and not benefit the patient or their economic interests or those of their close relatives or any entity responsible for funding such treatment or procedure. It would also be unjust and unfair.[10] In the case of a public sector patient, futile treatment or procedures will not only harm the patient, but also other public sector patients seeking healthcare, who may not be able to access the necessary healthcare service because a shortage of resources.[10] Thus, the provision of such treatment or engaging in such procedures by doctors will again be in violation of the biomedical ethical principles of non-maleficence, beneficence and justice or fairness.[3]

Where such futile treatment or procedure is unlawful and causes the patient to suffer an injury, the treating doctors could be found guilty and sued for assault.[11] Furthermore, if such futile treatment or procedure unlawfully hastens the death of the patient, the doctors will be guilty of murder.[11] It would be no defence for them to state that they were carrying out the wishes of the surrogate decision-maker. The same would apply if the request for futile treatment was made by the patient himself or herself.[11]

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