



SPANISH ASSOCIATION OF PAEDIATRICS

Views of the Spanish Paediatric Association Bioethics Committee on the refusal of essential and non-essential treatment in minors[☆]



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Abstract The conflicts that arise when minors or their legal representatives refuse to receive medical treatment considered necessary by the paediatrician pose a serious ethical dilemma and also have a considerable emotional impact. In order to adequately tackle this rejection of medical treatment, there is to identify and attempt to understand the arguments of the people involved, to consider the context in each individual case and be conversant with the procedure to follow in life-threatening scenarios, taking into account bioethical considerations and the legal framework.

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PALABRAS CLAVE

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 Decisión por
 representación

Reflexiones del Comité de Bioética de la AEP sobre el rechazo de tratamientos vitales y no vitales en el menor

Resumen Los conflictos que se plantean al negarse el menor de edad o sus representantes a recibir un tratamiento considerado necesario por el pediatra suponen un importante problema ético y conllevan fuerte impacto emocional. Para afrontar el rechazo al tratamiento es necesario explorar y comprender las razones que aducen los implicados, considerar los factores contextuales de cada caso y conocer la conducta a seguir teniendo en cuenta consideraciones bioéticas y el fundamento legal.

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Introduction

As doctors we should try to comply with the maxim ‘‘cure sometimes, relieve often and comfort always’’. When we cannot cure, because a patient refuses a beneficial treatment, it produces an emotional impact, which is not only distressing but presents us with serious problems with regard to patients’ rights and their limits and to the competence of children and adolescents and of their representatives. There is often an underlying failure of communication or misunderstandings for cultural or other reasons.¹

The problem becomes more acute when the refusal of treatment entails a risk of death and when, in addition, the decision is taken by patients’ legal representatives or by medical professionals.

Such situations arise both at hospital level and in primary care in relation to treatments or preventive measures, such as vaccinations.²

The reasons for refusing a treatment may be based on doubts about the success of the treatment and its risks, religious beliefs³ or lack of confidence in the doctor. Moreover, a growing tendency to question traditional medicine can be observed, combined with the upsurge of alternative forms of medicine,⁴ indicating that the cause is failure to satisfy the patient’s desire for information. Anti-science feeling in certain sectors of society is not merely an expression of post-modernism, but also of the fact that within the context of these alternative forms of medicine the patient is treated as a person.⁵

All this is connected with problems of legal nature in relation to the possession and exercise of the rights of minors.

Cases such as those set out below raise ethical problems that can be analysed using the deliberative method proposed by Diego Gracia.⁶

Clinical scenarios

1. Refusal of growth hormone (GH) therapy. Iván was aged 4 years 6 months and was referred from primary care (PC) to endocrinology for a short stature examination (–2.6

SDs). The only salient point was that as a neonate he had been small for his gestational age. At the conclusion of the study, the parents were informed that GH therapy was indicated and they signed the informed consent (IC) form and the treatment request. Once the treatment was approved, the parents were instructed in administration of GH, but they were very late in attending the appointment and it was observed that the child had not grown as expected. The parents admitted that they had not applied the treatment because ‘‘taking hormones is bad for you’’. They were informed again in detail of the benefits of the treatment, but despite this the parents held firm to their decision, as they did not see any problem in the fact that the child was short.

2. Lucía was 4 years old when she was diagnosed with standard-risk B-cell acute lymphoblastic leukaemia (ALL). The treatment protocol consisted of remission induction chemotherapy (CT), followed by a consolidation phase, a reinduction phase and maintenance for 2 years with low-dose oral CT.

Having been informed of the remission of the disease at the end of induction, the parents considered that their daughter was ‘‘cured’’ and refused to administer further treatment.

Remission induction is insufficient to cure ALL, and if the treatment is halted at such an early stage, the disease reappears in almost 100% of cases. After a relapse, the prognosis worsens, since the delay in treatment promotes the emergence of resistances. The haematologist, being aware of this serious risk, did not know how to deal with the case.

3. Rebeca was 13 years old when she attended PC with her grandmother because she was very aggressive and ‘‘they couldn’t cope with her’’. She was eating very little and was believed to be starting to suffer from an eating disorder (ED). The family had the impression that they were wasting their time and suspected purging behaviours. Rebeca said that ‘‘she had no problems, except that her parents were pestering her all day to eat’’ and that ‘‘she argued with her mother all the time’’. Mild malnutrition was observed and an urgent appointment was requested with the child psychiatric service. The problem was that Rebeca refused to see any medical professional.

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