Decision in cases of adolescents with serious illnesses

Clinical Case

Juan is 17 years old. Three years ago, at the age of 14, he was diagnosed with leukemia, treated and the results were satisfactory. However, when 4 months ago he began to feel very tired and lethargic and stopped practicing hobbies in his free time, his parents immediately consulted his hematologist. At the hospital, after suffering a relapse he was re-diagnosed with leukemia and informed of the different therapeutic alternatives. Juan refused all of them: he preferred to continue with conservative, symptomatic treatment and, if necessary, possible palliative care. He did not want to stop living his normal life, or condition his life around his illness. His parents did not agree. They agreed with the medical team, that he should be treated. Juan did not refuse a psychiatric exam. The psychiatrist concluded that he did not present any pathologies nor was he under any coercion or stress, thus considering him competent to understand his decision and its consequences. The medical team decided to bring the case to the Ethics Committee for Healthcare with the following question: in the case of a competent minor facing a serious illness, whose opinion should take precedence, the parents' or the minor's?

Ethical Analysis of This Case

We face the case of a 17 year old patient diagnosed with leukemia refusing treatment. His parents oppose this decision and agree with the medical team that this is not what is in the best interest of their son, and they prefer that he accepts new treatment. It is important that, to begin with, we verify the reasons why Juan is refusing treatment, and if the information he has received and his understanding of that information is adequate. It is entirely possible that initially he feels overwhelmed or burdened by the situation. This is why it would be reasonable to give Juan time to adjust to the news and its consequences.

If this method does not work, it is important to keep in mind that Juan is competent to make decisions (based on a psychiatric review), he is not under any pressure or stress and is fully aware of the consequences of his decision not to receive treatment. The patient is only willing to go through symptomatic treatment and receive hospice care, if and when that moment comes.

Possible Courses of Action

- ✓ Respect the opinion of the patient, which is against that of his parents and doctors: He is 17 years old and was determined by a psychiatrist to be competent of making decisions.
- ✓ Ensure that the information given and the understanding by the patient regarding treatment is appropriate: benefits, secondary effects, consequences of not receiving treatment, and therapeutic alternatives.
- ✓ Give the patient a reasonable amount of time to process the information and to reconsider the treatment options and their consequences.
- ✓ Look into why the patient is refusing treatment.
- ✓ Follow the opinion of the parents and, in this case, that of the medical team. Decide between them

the best treatment option to follow.

- ✓ Bring the case before the Juvenile Protection Services in order to protect the health of the minor and be able to make a decision against his will.
- ✓ Bring the case before the Juvenile Protection Services in order to decide if the patient can be emancipated so that he may make his own health decisions, since he is 17 years old and was found competent.
- ✓ Register the conflict and the respective decisions made in the clinical record.

Recommended Courses of Action

- ➢ The physicians in charge of the case must make sure that both Juan and his parents have all the necessary information in order to make a decision.
- ➢ Health Services should do everything possible to make sure that Juan understands the consequences of his decision. Likewise, it is necessary that they find out the reasons why he is refusing treatment despite its consequences. It might be beneficial to give Juan a reasonable amount of time to process the information and think about the various alternatives and their consequences.
- ➢ Similarly, the parents should be supported so that they may help their child make the right decision.
- ➢ If the parents make a decision in the best interest of Juan's health, then it is not necessary to contact the Juvenile Protection Services at the duty court. Only in the case that Juan is very reluctant and physically refuses the treatment (does not go to check-ups, prevents treatment from being performed, etc.) should the case then be brought to the attention of the Juvenile Protection Services in order to protect his health and treat him against his will.
- ➢ Faced with a serious vital risk, physicians should treat the patient in accordance with the decision made by the parents, at least until he turns 18.
- ➢ It is recommended to report the case to the hospital management.
- ➢ Each step taken must be registered in the medical records.

Discussion

In Spain, in 2022, law 41/2002 regulating the free will of a patient establishes in article 9.3.4 the following: *"When treating emancipated minors or minors of at least 16 years old […], consent cannot be given for representation. Notwithstanding the provision of the previous paragraph, in the case of a serious risk to the life or health of a minor, according to medical criteria, consent will be given by the legal representative of the minor, once the opinion of such minor is heard and taken into account".*

The conflict, in this case, arises because the patient is 17 years old and is facing a serious risk to his health. Given that he is under 18 years old, his parents/legal guardians are the ones who will make the decision to exercise their legal representation, as long as they are seeking what is in the best interest of the patient. Of course, the minor should be informed and their opinion should be taken into consideration. Therefore, the criterion that physicians should follow is the one expressed by the parents and, consequently, the patient should be treated for leukemia.

In general, any action that the doctor in charge of the case judges involves serious risk to the health or life of a patient between 16 or 17 years old requires consent by the representation of the parents or legal

guardians, all of which must be registered in the medical record. In the case that the parents do not choose what is best for the health of the minor, again in accordance with Law 41/2002, the case should be brought to the attention of Juvenile Protection Services or the appropriate judicial authority.

This case could be solved in different ways according to the specific laws of each country, as legal age limits can vary. For example, in countries in which the legal age for medical decision-making without requiring the consent of legal representatives is 16 years old, in this particular case, though the patient is just 17 years old, the conservative treatment would have to be followed, as he would be considered a competent patient.