Case Report
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The decision making process in a pediatric patient with Leukemia: ethical issues in Chilean case

Abstract

In health care, ethical issues coexist with generally inevitable clinical problems. It is necessary that health professionals have the tools to conduct proper analysis of these problems for accurate decision-making. A traditional therapeutic relationship is made up of two cooperative parts via the decision-making process, whose objectives are to cure and care. In the pediatric environment, due to the legal implications of the child, this process may be complicated because the parents have their own desires and values in relation to the health of their child, which may be in conflict with the wishes of the child themselves. Jonsen, Siegler and Winslade in their book Clinical Ethics developed a decision-making model to analyze cases of medical ethics known as the 'four quadrants'. This method has as a main function, to analyze the facts and values of a clinical situation with casuistic approach that considers relevant circumstances and the specific context in which decision-making is developed. This article will show a pediatric patient with acute lymphoblastic leukemia, posing the question, is it ethically correct to respect the decision of a teenager to abandon treatment, despite having possibility of cure?

Keywords: decision-making, childhood cancer, ethical issues, leukemia

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Introduction

Leukemia accounts for about one third of cases of childhood cancer, acute lymphoblastic leukemia (A.L.L) being the most common type.[1] From the time of diagnosis of A.L.L in pediatric patients various decisions should be taken throughout the disease process. The law states that parents should decide on the health care of their child, because as children they have no legal ability to choose. However a common practice today is that pediatric patients participate in decision-making regarding their health care.[2] The level of participation of children and adolescents is determined by age, cognitive development and previous experience.[3]

In health care, ethical issues coexist with generally inevitable clinical problems. It is necessary that health professionals have the tools to conduct proper analysis of these problems for accurate decision-making. In literature there are different models of decision-making,[4] the main rational for the use of these models is to try to improve the quality of decisions, encouraging doctors and nurses away from intuition and identifying the important factors of each case. This will give sustenance to justify and implement the decision taken.[4]

Jonsen, Siegler and Winslade in their book Clinical Ethics, developed a decision-making model to analyze cases of medical ethics known as the 'four quadrants': medical indicators, patient preferences, quality of life and contextual factors. In each quadrant there should be frequently raised questions, which the health professional should try to answer.[5] This method has as a main function, to analyse the facts and values of a clinical situation with casuistic approach that considers relevant circumstances and the specific context in which decision-making is developed, facilitating the resolution of ethical and clinical problems. The purpose of this model is to provide physicians and other professionals a structured framework as guidance for morally justified decision-making. This article will show the decision-making process through the four quadrant model, in a pediatric patient with A.L.L, posing the question, is it ethically correct to respect the decision of a teenager to abandon treatment, despite having possibility of cure?

Case report

The patient T.Q.P. is a 15 year old adolescent who is the eldest of four sisters in a single-parent family where the mother is the legal guardian who works as a supermarket cashier. She was diagnosed with A.L.L, standard risk, with an initially favourable prognosis. At diagnosis she presented with symptoms of depression. During the initial treatment of the underlying disease, she started in parallel with psychotherapy and pharmacological management for depression. Thanks to chemotherapy treatment, remission of the disease was achieved. During the following months the girl and her mother showed good adherence to the treatment. During the maintenance period T.Q.P. decides to stop the intake of the medicines needed to achieve the ultimate cure of the disease. After a short time the patient returns to hospital with serious life-threatening sepsis. During this hospitalization the patient required intensive care to preserve her life. Due to the clear symptoms of bone marrow failure, diagnostic tests were performed and an early relapse of the disease was diagnosed (before 18 months).

A relapse diagnosis is informed, new treatment options and prognosis of the disease is reported. At this time the patient refuses chemotherapy treatment for the relapse, despite this being a possible cure. The minor says she feels that the cure rate seems too low to submit her again to such an exhausting and painful treatment. The patient receives psychotherapy and during these sessions with medical advice, the course of the disease is explained, addressing also the dying process. The healthcare team disagrees with the decision of the patient to abandon treatment due to the consequences, as a cure treatment exists. Based on the medical urgency the patient receives the first cycle of chemotherapy while still being in intensive care.

In the weeks that follow the healthcare team decide to reassess the decision for treatment due to the determination of the patient, who clearly expressed her refusal for treatment, and who did not want to lose her hair or undergo painful procedures. The healthcare team devastated by the situation, believes that despite initiating treatment

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for disease relapse, with good response, that there is not the adherence and cooperation required from the patient and her family. The consistency and clarity with which the patient expresses her desire to abandon the treatment is also considered, a decision supported by the mother, who is her legal guardian.

Analysis four quadrants

Medical indicators

All clinical case analysis must begin contemplating the medical facts of the case, including diagnosis, prognosis, treatment options, involving a clinical objective with the benefits that can be offered to the patient. The patient was diagnosed with A.L.L, standard risk, with an initially favourable forecast, and a greater than 70% relative survival rate of 5 years.[6] Overall treatment for A.L.L consists of three stages; induction, intensification-consolidation and maintenance. The maintenance therapy in most protocols includes daily oral mercaptopurine (6-MP) and methotrexate, completing up to two years from the start of treatment.[6] When the initial treatment fails, the relapse occurs. In this situation there is a possibility to use an intensified protocol designed especially for this cases. There is also the possibility of Hematopoietic Stem Cell Transplantation (HSCT) in patients with very adverse factors, poor response to initial treatment or early relapse of the disease. The end result of treatment for relapsed patients depends on the duration of the first complete remission (CR1) and site of relapse.[6]

In a large percentage of patients (approximately 70%) the treatment of relapse consists in re-induction of chemotherapy to achieve a CR2, however, only 30-35% will remain in continuous CR. even with HSCT, the survival rate is less than 50%.[6] The patient T.Q.P suffers relapse of the disease and there is only one treatment option which is re-induction chemotherapy which aims to achieve a second remission which is essential to reach later instances; such as HSCT. Despite the above, under the premise of curing the disease, the treatment mentioned causes damage on a physical and psychological level. The consequences are varied and are present in the short, medium and long term. The possible side effects resulting from the use of combined chemotherapy include alterations in most systems. Some documented organic side effects can be; alterations in the process of growth and pubertal development, a decrease in cardiopulmonary and gonadal function; as well as secondary malignancies in up to 20% of cases.[7] However, intra-treatment adverse effects such as pain, fatigue, lack of energy to perform and enjoy the activities of daily living, as well as fear and uncertainty about the future seem to be those that affect quality of life (QoL).[8]

Patient preferences

This quadrant permits the setting of patient preferences, such as their choices regarding decisions about their health or medical treatment, respecting their values, beliefs and previous experiences. The patient, the one directly affected by the disease and treatment, their preferences have moral authority and should be considered at the moment of decision-making.[5] The pediatric patient can communicate their preferences but they are not legally able to make the decision. The laws of each country determine at what age people are competent to make their own decisions.[2]

In the medical scenario, the ability to choose refers to the ability to understand relevant information, assess the situation and its possible consequences, and communicate a decision and to deliberate rationally in terms of medical treatment options that are offered.[5] The Psycho-Oncologist evaluates the teen, validates her comprehensive ability and logical reasoning, she is able to make a comparison between her prior experience and current status, indicating she has understanding of her situation. The patient has made their own assessment and cost-benefit and has decided that the damages and costs associated with treatment seem to outweigh the potential benefits. She prefers to decide how and when to spend the last days of her life. She states to be prepared to accept the course of the disease and speaks of her desire to be happy; her concept of happiness is outside the hospital environment. It has been shown that there is cognitive development and moral sensitivity sufficient to make personal, voluntary decisions from the age of 14.[5] In Pediatrics this process is usually performed by parents because it is presumed that they do a better job. Parents care deeply for their children, they know their needs best, taking the moral and social responsibility to defend the best interests of their child.[9] It is important to consider that T.Q.P depends biologically, socially, ethically and legally on her mother.[5] The mother advises during the process that she does not want her daughter to die. However, she also does not want her to suffer, so she decides to support her daughter in her decision, respecting her preferences.

Quality of life (QoL)

The objectives of medical interventions are to maintain or improve QoL, which has been affected by the disease. In assessing the adequacy of treatment the patient's QoL should be taken into account and how likely it is to achieve the proposed objectives.[5] According to the World Health Organization (WHO) the term QoL refers to the degree of satisfaction that a person experiences and value about their life in general, as well as specific aspects such as physical health. The term health-related quality of life (HRQL) corresponds with QoL resulting from the medical interventions, which consider the wellbeing of patients during medical treatment and their effects on survival.[7]

The illness and the corresponding treatments cause changes in an adolescent's lifestyle, such as the interruption of their studies, plans for the future with regard to work, their partner, etc.; these changes can be as important as the possibility of death.[10] During the treatment period, patients (children and adolescents) may experience both physical and emotional side effects which could affect their self-esteem and thus their QoL.[8] According to the above, due to the subjective nature that is QoL, this will largely be determined by the preferences of the patient, which in turn are directly related to variability over time, that is, the stage of the life cycle and the time of the disease.[7] In this particular case it is essential to identify the specific elements that negatively influenced the QoL from the initial stages of treatment which have intensified during the relapse, as this could protect the welfare of the child, as well as prevent the abandonment of treatment.[11] Considerations for the quality of life were established from the onset of treatment, although these questions intensified when relapse of the disease occurred, because it was then that the patient expressed her deep dissatisfaction and low expectation of recovery. From the HRQL viewpoint, at receiving the proposed treatment, with intensified protocol, much more aggressive than at first, the patient experienced more secondary side effects which affected her QoL more acutely.[6,7]

Contextual features

All clinical situations occur in a much broader context. This should be considered because it is highly relevant to the ethical-

clinical analysis. In this fourth quadrant we consider contextual aspects of economics, religion and culture, confidentiality, impact of the decision within the family and the health team, etc.; as well as to establish what the relevance of these are in the ethical analyses.[5] The patient is a minor and therefore has no legal ability to choose. Her legal guardian is who must sign the consents and ultimately make the decisions. The mother of the patient was informed of the new clinical status of her daughter and the medical advice given was to continue with the treatment pertaining to a relapse with a curative objective. The mother refuses treatment on behalf of her daughter, arguing that T.Q.P. does not want to continue, and that she, the mother, will respect her daughter's wishes.

In this case the economic factor is not a deterrent in the decision-making as the patient is the beneficiary of FONASA (National Health Fund) and her treatment comes fully under its auspice, ensuring total coverage even in the case of relapse.[12]

Discussion

At the time of defining therapeutic alternatives in a case like this, it is important to ask whether to proceed with the treatment, or not, in the light of all the factors analysed. Likewise, it is not being considered in an abstract way if the patient is autonomous to make this decision, but more so in a concrete way of what the patient's preferences are or what is their ability to decide. In addition, the HRQH of children and adolescents with cancer should be remembered, as this will be affected by both the emotional status of the child, as well as by the treatments that seek to prolong their survival.[13] Knowledge about quality of life and its association with the uncertainty faced by people with their disease (caused by the nature of the diagnosis and the prompt commencement of treatment), allows nurses to look more deeply into the needs of patient care, using as a resource the large amount of time they spend with the patient and their parents, extending as well their clinical practice.[14] In considering this and supporting the role of the doctor, the Clinical Nurse Specialists (CNS) are an important pillar in the treatment of patients, developing and evaluating communication strategies and intervention to mitigate the emotional burden on patients and their families.[15]

The method used for making decisions places patient preferences at the fore, which remained constant over time. It also makes clear how chemotherapy decreases the patient's QoL in the short and long term, affecting their self-determination. In our case study we speak of a teenager diagnosed with A.L.L who presents a marrow relapse very early in the piece and faces an enormous challenge; accept the transitional stage where a cure is possible, to one where it is very unlikely. This is a complex process, however, a mature teenager who understands the course of the disease and treatment is in the best position to decide on whether to continue with treatment or not.[16] The evaluation by the patient was real and in good conscience, she is able to understand medical information, her main reasons for leaving treatment were the great suffering and the low probabilities of improvement. The close proximity of death makes her want a quiet end near her family. It is concluded that it is ethically correct that the teenager decide.

A traditional therapeutic relationship is made up of two cooperative parts via the decision-making process, whose objectives are to cure and care. In the pediatric environment, due to the legal implications of the child, this process may be complicated because the parents have their own desires and values in relation to the health of their child, which may be in conflict with the wishes of the child themselves. In relation to this, despite having consented to the treatment parents, on occasion, fail in their commitment to follow medical instruction, which creates an ethical problem.[5]

The four quadrants are aligned to clinical care so as to assist in solving ethical problems faced by the healthcare teams, helping them to pose relevant questions for the case in question. It starts from the concrete (medical indicators) and extends towards the contextual, achieving to see the problem as a whole and not just a part; expanding the clinical perspective that physicians and other health professionals have. This view of the specific to the more general of the factors that must be present at the time of decision-making, encourages the participation of other professionals such as nurses who have a holistic view of patient care and who may be able to contribute elements in quadrants of QoL and contextual factors that they are able to see because of their close proximity to the patient and their family. Moreover guiding professionals in their decisions, taking recourse to what Aristotle called practical wisdom or prudence being the virtue of the person who guides in their choice, to evaluate the existence 7of time and a proper place to do things, to judge depending on the context.[17] In other words to help those less experienced to be more virtuous. This model also encourages the active participation of the patient and/or family in making decisions, because the responsibility is shared with them.

Decision-making in the field of health is complex and must be justified by those who make them. Health professionals in clinical practice are constantly faced with different decisions, whose ethical implications are known: patient autonomy, beneficence and non-maleficence, values and preferences, among others. These implications require professionals to advocate for their patients, defend their interests, values and rights and include them in decisions that affect their health. To accomplish this work, professionals should be aware of the ethical elements and have been trained in understand that medical problems are not just biological, as they involve other dimensions in the lives of those who are in a vulnerable situation. This is the reason why ethics is inherent to the clinic. As Jonsen et al, noted, nurses have an "ethical tradition" and innate standards highlighting great loyalty towards patients, which makes them champion their preferences, participating collaboratively with the doctor.[5]

Children with cancer both physically and according to their abilities (cognitive level and moral development), are entitled to be respected in their dignity, with consent they can participate in the process, express their preferences after being informed and can accept or refuse treatment, as decisions taken in relation to their health will affect their future self. This is why they should be active participants in their own health care, regardless of who makes the final decision. However, in this process it is necessary to take into account variables such as the consequences of the decision, the complexities and medical emergency.

Conclusion

In cases where complex decisions are required, this method helps professionals to conduct proper analysis of the situation, distancing somewhat from the medical paternalism, where usually a greater reliance is given to the medical decision as opposed to the patient's, who is directly involved. Simply following a formula cannot solve an ethical-clinical problem; it must be addressed taking into account the contextual circumstances of each case. A structured model

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for decision-making does not guarantee ethical decisions because decision-making is not a mechanical process; however it helps guide those involved in this process and provides justification for the actions taken. Competencies in making ethical decisions become increasingly indispensable in current clinical practice, due to the growing diversity of individual value systems and the complexity of health systems, among others. The efforts should be allocated in the professionals to accompany the patients and their families in the clinical ethics decision–making process.

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Conflicts of interest

The authors report no conflicts of interest in this work.

References

1. OPS/OMS. El cáncer infantil en las américas.
2. Buchanan AE, Brock DW. Decidir por otros. Ética de la toma de decisiones subrogadas. *Dianoia*. 2009;56(6):406.
3. Coyne I, Amory A, Kiernan G, et al. Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs*. 2014;18(3):273–280.
4. Cooper RJ. Making the case for ethical decision-making models. *Nurse Prescribing*. 2012;10(12):607–611.
5. Jonsen AR, Siegler M, Winslade WJ. (2010). Clinical Ethics:A practical approaches to ethical decisions in clinical medicine. 8th ed. USA.
6. Health NCIatNIo. Childhood Acute Lymphoblastic Leukemia Treatment (PDQ®) health professionals. 2015.
7. Chiou SS, Jang RC, Liao YM, et al. Health-related quality of life and cognitive outcomes among child and adolescent survivors of leukemia. *Support Care Cancer*. 2010;18(12):1581–1587.
8. Castillo-Martínez ID, Juárez-Villegas LE, Palomo-Colli MÁ, et al. Calidad de vida en niños con leucemia linfoblástica aguda durante la inducción a la remisión mediante el PedsQL Cancer Module©. *Bol Med Hosp Infant Mex*. 2009;66(5):410–418.
9. Spriggs M, Caldwell PHY. The ethics of paediatric research. *J Paediatr Child Health*. 2011;47(9):664–667.
10. Lewis IJ. Cancer in adolescence. *Br Med Bull*. 1996;52(4):887–897.
11. Klünder-Klünder M, Miranda-Lora AL, Dorantes-Acosta E, et al. Frecuencia de abandono del tratamiento en pacientes pediátricos con leucemia linfoblástica aguda. *Bol Med Hosp Infant Mex*. 2012;69(3):226–232.
12. Salud Md. Guías Clínicas AUGE Leucemia en menores de 15 años. 2005. 26 p.
13. Landolt MA, Vollrath M, Niggli FK, et al. Health-related quality of life in children with newly diagnosed cancer: a one year follow-up study. *Health Qual Life Outcomes*. 2006;4(1):63.
14. Raile M, Marriner A. Modelos y teorías en enfermería. *España: Ed Mosby*. 2011. 616 p.
15. Pirie A. Pediatric Palliative Care Communication: Resources for the Clinical Nurse Specialist. *Clin Nurse Spec*. 2012;26(4):212–215.
16. Whitney SN, Ethier AM, Frugé E, et al. Decision making in pediatric oncology: who should take the lead? The decisional priority in pediatric oncology model. *J Clin Oncol*. 2006;24(1):160–165.
17. Aristóteles. *Ética a Nicómaco*. Madrid: Centro de Estudios Constitucionales; 1999. 348 p.

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