Case Report

Ethical analysis of a case of treatment refusal: respect for patients' autonomy in the context of the Iranian clinical environment

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Abstract

Refusal of treatment is a challenging issue in clinical ethics, especially in the context of pregnancy care. However, respect for patient autonomy remains a fundamental ethical principle, as outlined in codes of conduct and patient rights within healthcare services.

The aim of this case presentation was to critically analyze a clinical ethics case within the Iranian context using an ethical framework.

A theory-based framework was used that integrates the principlism approach, based on prima facie moral norms, with the moral development theories of Lawrence Kohlberg and James Rest to analyze this case. Mrs. M, a 38-year-old pregnant woman with acute myeloid leukemia, chose to continue her pregnancy until 32 weeks, despite medical advice, before starting her cancer treatment.

The decision, influenced by the significance of her first pregnancy after costly infertility treatments, presented a complex ethical dilemma. The patient's autonomy was respected by the medical team, and treatment was delayed until the pregnancy was terminated at 33 weeks, ensuring both maternal and fetal care. The case underscores the ethical challenges of balancing patient autonomy with medical beneficence, highlighting the importance of trust and informed consent.

Keywords: *Clinical ethics; Medical ethics; Personal autonomy; Treatment refusal; Pregnancy; Patients' Right*

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Introduction

Refusal of treatment is a challenging issue in pregnancy care, occurring when a pregnant patient declines proposed medical interventions and treatments to preserve her own well-being, the well-being of the fetus, or both (1). This situation becomes particularly significant when a cancer diagnosis occurs during pregnancy. The termination of pregnancy as an interventional option in these cases creates challenges for doctors, nurses, policymakers, ethicists, and lawyers, as the process of caring for and treating pregnant patients requires simultaneous attention to the health of both the patient and the fetus (2).

In this situation, the best interests of the fetus and the patient are in conflict (3). The management of treatment refusal and the establishment of a balance between the principles of autonomy and beneficence are required to be guided by a framework that consists of a principle-based approach and contextual factors, as the practice of autonomy can vary (4).

An innovative case analysis model was applied that utilizes the principle-based approach, based on prima facie moral duties and norms, combined with theoretical techniques from the fields of moral development and moral psychology. This model, primarily rooted in Lawrence Kohlberg's theory of moral development and James Rest's decision-making framework, creates a comprehensive framework for analyzing this clinical ethics problem. This framework, which transitions from theory to practice, is not only applicable to medical professionals but also valuable for analyzing more complex cases typically addressed by clinical ethicists (5, 6).

The clinical case

A 38-year-old pregnant woman with acute myeloid leukemia (AML) was admitted to the oncology department. The pregnancy had been achieved through infertility treatments, with significant financial investment to ensure its success. At the time of diagnosis, the gestational age was 26 weeks. As a result, protective treatments were initiated for the patient. To safeguard the fetus, chemotherapy and medications that could affect the fetus's health were postponed until 32 weeks. Although the gestational age reached 33 weeks, the pregnancy had not yet been terminated. Despite the doctor's recommendations, the patient refused to terminate the pregnancy and was unwilling to do so at any cost. While clinical symptoms were not

alarming, laboratory tests confirmed the definitive diagnosis of the disease. The attending physician recommended early treatment. In light of this case, several questions arise:

1. Can the patient refuse her own treatment?
2. In this case, is it necessary to obtain informed consent from the patient?
3. What would the morally appropriate action be in such cases?

Case analysis and Discussion

Step 1: Clarification of biomedical/anthropological context

At this stage, the nature of the disease, medical interventions, and potential outcomes are clarified, along with the family context and the patient's beliefs and values.

Cancer is diagnosed in 0.07% to 0.1% of pregnancies and is the second leading cause of death after vascular complications related to pregnancy. More than two-thirds of leukemia cases during pregnancy are acute myeloid leukemia (AML), with an incidence of 1 in 75,000 to 100,000 pregnancies. The disease is typically diagnosed in the second and third trimesters (3). Cancer is the second most common cause of death in women aged 25–34 years and the leading cause of death in women aged 35–65 years (7). Thirty-seven percent of cases are reported in the second trimester, and 40% in the third trimester of pregnancy, with an incidence of 23% in the first trimester (3). The treatment approach depends on various factors, including the gestational age at diagnosis, the clinical and laboratory characteristics of the disease, and the potential toxic effects of drugs on both the mother and fetus. A multidisciplinary team, including a medical oncologist, perinatologist, gynecologic oncologist, pediatrician, radiotherapist, psychologist or social worker, geneticist, and clinical pharmacologist, is essential for making informed decisions. Depending on the type of cancer, additional specialists such as a surgeon, hematologist, or others may be required (2). Evidence indicates that delaying treatment until after delivery significantly increases the patient's mortality (8).

The reliability and validity of the evidence, the severity of the expected outcomes, the burden or effort imposed on the patient, the patient's understanding of the severity of the situation and the associated risks, the urgency of the case, and finally, the patient's confidence that her request to refuse treatment will be respected are all critical factors (1). In the present case, the diagnosis was confirmed using accurate methods. Medical experts recommended terminating the pregnancy at

32 weeks via cesarean section to promptly initiate treatment and safeguard the patient’s health. In similar cases, pregnancy termination is typically performed between 32 to 35 weeks, with main treatments for the patient beginning one week after termination (8).

In some male-dominated societies, there is an unwritten rule that a husband's role influences his wife's decision-making (9). In Iran, requiring husbands’ authorization of married women’s informed consent for surgical interventions could be an issue (10). Therefore, exploring past experiences, power dynamics, and understanding the cultural context within the family should be carefully considered. However, the primary reason cancer patients refuse treatment is often rooted in their personal values and past experiences (11). Osamor and Grady state that in cases where decisions affect a child, both partners could typically make decisions together, using a joint decision-making approach (12). Although male-dominant decision-making was not explicitly evident in the present case, the consequences of the decision had a significant impact on the fetus. It is likely that the patient’s decision could be influenced by her husband.

Childbearing is highly valued among Iranian women, with most believing that becoming a mother is important (13). Sixty-two percent of women expressed the intention to have a child within two years of marriage (14). The decision to have a child is influenced by various social, economic and individual factors, as well as cultural considerations. Key factors include family policy, religiosity, the perceived value of children, and attitudes toward individualism (15). In Islam, whci is the religion of most of Iranians, childbearing and parenting are strongly emphasized, and motherhood is held in high regard (16). Therefore, the patient places great emphasis on maintaining the health of the fetus, and it appears that completing the pregnancy and delivering a healthy child are valued more highly than prioritizing her own health and starting treatment promptly. Individual and family counseling can be instrumental in identifying the personal values and beliefs influencing the patient's decisions; however, no evidence of such counseling sessions was found in the patient's medical records, either written or verbal. Given the patient's 15-year history of infertility, completing the pregnancy holds significant value for her. Motherhood is a pivotal event for many women's lives, and childbearing, pregnancy, and related experiences are deeply influenced by social structures and

cultural perceptions within both the individual and the family.

Infertility treatments are typically long-term and often require significant financial investment, particularly for patients. On average, infertility treatment in Iran ranges between US$1,500 and US$2,500 (17). If the treatment is unsuccessful, it can negatively impact the couple's mental health. As a result, couples undergoing these treatments are highly motivated to achieve a successful outcome (18). In Iran, the estimated prevalence of infertility is high, around 20%. Due to the high cost of infertility treatments and usually partial insurance coverage (19), families place significant importance on a successful pregnancy and the birth of a healthy child. This makes the successful completion of pregnancy and the delivery of a healthy baby extremely valuable and important to families.

Recently, the Family and Youth Protection Law of Iran was approved by the parliament with the aim of rejuvenating the population. According to this law, infertility treatments and diagnostics will be covered by insurance (Article 43). This law is relevant to the present case because it emphasizes that actions leading to the termination of pregnancy and endangering the fetus's health should be carried out with greater caution. Therefore, societal policies can influence the patient's decision (20).

Another important factor is the availability of facilities for the care of preterm infants. A cohort study by Akrami et al. showed that the survival rate of preterm infants in Iran increases with gestational age, from 5.7% at 23 weeks to 79.6% at 32 weeks, with an overall survival rate of 56.7% (21). Prematurity was the leading cause of mortality (44.14%) in NICUs in Iran (22). A prospective cohort study indicated that 71.3% of preterm and low birth weight infants who were hospitalized survived, with an overall survival rate of 70% (23). Therefore, the decision to terminate the pregnancy in this case strongly depends on the fetus's survival rate and the availability of facilities to care for the newborn. Building a trustworthy relationship between the family and healthcare providers is essential.

Step 2: Who is the moral agent in each case? (Who should decide?)

Beauchamp and Childress discussed the importance of moral agency in individuals. A person is considered a moral agent if they meet two conditions: first, the ability to make moral judgments about the correctness or incorrectness of actions, and second, having motivations that can be morally evaluated. These criteria imply that a

person can have immoral judgments and motivations but still be regarded as a moral agent (24).

In this case, the patient has the capacity and competence to make decisions, qualifying her as a moral agent who can make choices based on her interests and desires. According to the principle of respecting patient autonomy, her decision holds moral value.

The fetus could have different levels of moral status based on gestational age, lacking the capacity to make decisions, could be considered vulnerable, and mothers act as the main decision-makers. The mother, as one of the parents, faces a potential conflict due to her personal stakes in the decision, as she may prioritize her own interests over those of the fetus. The father, may also have concerns or preferences regarding the decision to continue or terminate the pregnancy.

Given these dynamics, when parental decisions influence the fetus's well-being, healthcare professionals may need to consider the well-being of the fetus. Initially, the medical team chose to continue the pregnancy until 32 weeks to avoid early interventions that might jeopardize the fetus's health. At 32 weeks, the medical team suggestion was to terminate the pregnancy and begin therapeutic interventions for the patient. This decision sought to balance the health of both the fetus and the mother

Step 3: Who should be protected?

At this stage, all individuals affected by the decision, as well as those who will influence or be impacted by the decision and its implementation, are identified. This includes a range of peoples including vulnerable individuals, family members, healthcare team members, and the community. In this case, the patient and the fetus are directly involved in the outcomes of the decision, as it impacts their health and well-being. Others such as the patient's spouse and members of the treatment team are indirectly affected by the decision's outcomes.

The patient directly benefits from starting treatments and would experience greater harm if treatment is delayed, as evidence indicates that mortality increases with delayed treatment. Preliminary reviews confirm that the patient has the capacity and competence to make decisions. Although the diagnosis has caused discomfort and concern, it does not necessitate psychiatric intervention or treatment by a psychiatrist. Therefore, the patient's decision-making capacity remains intact, enabling her to understand the situation and the treatment recommendations. The

nature of the disease requires timely treatment for the patient to gain the maximum benefit.

Regarding the fetus, at the time of diagnosis, the gestational age was 26 weeks. A 6-week window was allocated for pregnancy termination to increase fetal age, reduce the risks associated with premature termination, and improve fetal viability. The fetal age has now reached 33 weeks. The fetus lacks the capacity and competence to make decisions about its health and well-being. In such cases, mother can act as the main decision-maker for the fetus. The patient faces a conflict between her own well-being and the health of the fetus. Both the mother and father have stakes in the decision to continue or terminate the pregnancy.

Patient's Spouse: While the patient’s spouse may have a role in decision-making for the fetus, he cannot override the patient’s (mother’s) autonomous decision-making, as the patient is competent and capable of making decisions independently. Medical specialists are ethically obligated to provide high-quality, up-to-date care and treatment.

Healthcare Team Members

Team members are responsible for applying their expertise to ensure safe and stable conditions, avoiding life-threatening situations and potential risks to both the patient and fetus. They must be capable of making decisions in critical and uncertain situations, as identifying threats and providing optimal benefit based on the moral principles of harm and benefit is essential. Failure to make timely decisions that protect both the patient and fetus could result in moral accountability for the team.

Obstetrics Specialist: The obstetrics specialist plays a crucial role in managing the pregnancy process, including assessing fetal condition and viability. According to the Family and Youth Protection Law of Iran, any medical procedure involving abortion or posing a risk to the fetus requires careful consideration. If the specialist is not qualified, legal action may be pursued. Decision-making in the context of this law is highly sensitive, and the obstetrics specialist requires substantial support to navigate these challenges effectively.

Step 4: Determining moral versus practical (non-moral) dilemmas

Autonomy refers to respecting a patient’s right to make decisions regarding their own treatment. In this case, Mrs. M’s autonomous decisions is challenging because she has chosen not to terminate her pregnancy, even though this decision endangers her life. Doctors must navigate the

balance between respecting the patient's autonomy and the necessity of intervening to preserve her life. *Non-moral dilemmas* concern medical and practical issues, such as determining the appropriate timing for initiating chemotherapy or managing the disease based on clinical data, rather than ethical considerations. Therefore, the dilemmas in this case are fundamentally moral because they involve conflicts between ethical principles and their impact on medical decision-making. These conflicts and the need to reconcile them make this situation a moral dilemma rather than merely a practical or medical challenge.

Step 5: Specifying the moral standard at stake

Two principles, autonomy and beneficence, are mainly in conflict in this case. Primarily, respect for the patient's autonomy and beneficence/non-maleficence are at risk.

Step 6: Distinguishing moral obligations from supererogatory choices

Jonsen et al. introduced a logical model for addressing ethical dilemmas in clinical performance. In this clinical evaluation model, the patient's rights and preferences, the patient's quality of life, and external factors and context are the dimensions that physicians can use to identify conflicts between ethical principles and examine the value and balance between them (25).

According to this model, beneficence and non-maleficence can be evaluated through clinical assessment by considering the nature of the disease (acute, chronic, relapsing, or terminal), establishing therapeutic goals, selecting treatment options and evaluating their success probabilities, assessing the side effects of treatments relative to their benefits, and determining the effects of non-surgical and medical treatments. This evaluation also includes deciding whether to discontinue or cease treatment if it poses a threat.

Respect for the patient's autonomy is assessed by examining the patient's rights and preferences. The following questions are considered:

- *Is information about the benefits and risks of treatment provided?* Yes.
- *Has the patient understood and consented to the information?* The patient understood but did not agree.
- *Does the patient have mental capacity?* The patient appears to have full decision-making capacity.
- *If the patient has capacity, what is her preference?* Continued pregnancy.
- *If the patient does not have mental capacity, are her previous preferences known?* Not applicable (N/A).

- *Who is the most suitable alternative decision-maker if her preferences are unknown?* None identified.

Step 7: Balancing the various choices of action

The dilemma between respecting the patient's autonomy by delaying treatment and prioritizing her health by terminating the pregnancy is complex. Option one respects the patient's autonomy and avoids immediate harm to the fetus but risks deteriorating health and increased costs. Option two, involving early intervention, focuses on beneficence and non-maleficence but compromises the patient's autonomy and may induce emotional distress. Prioritizing patient autonomy is justified by honoring her values, maintaining emotional well-being, and enhancing satisfaction with healthcare. Given the emotional significance of the pregnancy and the non-urgent nature of immediate intervention, allowing more time for decision-making supports human dignity and fosters trust with the healthcare team.

Zhu et al. assessed 21 pregnant women with cancer and found that elective termination or induced delivery before starting chemotherapy could be a favorable choice for better maternal and fetal outcomes, particularly for patients diagnosed in early and late stages of pregnancy (>30 weeks). They also reported that four of the 21 patients died before starting chemotherapy (26).

Step 8: Checking the accuracy of the results: preparing the conditions for a better balance to avoid an unfair balance

This step evaluates the ethical principles of autonomy, beneficence, and non-maleficence to determine the best course of action in a medical scenario. Respecting patient autonomy involves recognizing the patient's right to self-determination, making informed decisions, and ensuring non-interference, especially when their choice does not pose an immediate threat to their life. However, autonomy may conflict with other ethical principles, particularly if the patient's decision could result in self-harm or harm to others. In cases where delaying treatment increases health risks, prioritizing autonomy requires more careful evaluation.

On the other hand, beneficence requires healthcare providers to act in the patient's best interest, while non-maleficence obligates them to avoid causing harm. These principles suggest that if the patient's condition is stable and delaying treatment does not pose an immediate threat, the urgency for immediate intervention is reduced.

In this specific case, respecting the patient's autonomy should take precedence, as her decision

does not immediately endanger her life. Moreover, forcing medical intervention, even when the patient's life is at risk, is neither applicable nor ethical. Acknowledging the patient's autonomy aligns with her personal values and choices, which are central to patient-centered care.

Step 9: Reflection, compensation, recovery and relief

In this case, the patient's autonomy was upheld, and the therapeutic intervention initially did not lead to the termination of the pregnancy. Eventually, the patient consented to the termination, which was performed via cesarean section. The baby was born a healthy girl at 33 weeks of gestation. The infant was transferred to the neonatal intensive care unit for care, while the patient was moved to the adult intensive care unit. A week after the pregnancy was terminated, the patient's condition stabilized, and the main treatments began for her.

Step 10: Motivation analysis and legal evaluation

At this stage, the resulted decision is examined to see what are possible barriers that could stop moral agents (healthcare professionals) from following the moral choice. One important issue could be legal evaluation in light of related laws, regulations and guidelines, including the Charter of Patients' Rights in Iran (Paragraph 3) (27), the Code of Ethics for Medical Professionals (28), and if available specific professional guidelines like that of The American College of Obstetricians and Gynecologists (ACOG) (1).

Respect for the patient's decision and will is upheld and accepted, as demonstrated by the following:

Considering the legal context of Iran, where laws must align with Shiite Islamic perspectives (29), such a case could be subject to jurisprudential evaluation. However, according to various rules of Islamic jurisprudence, forcing competent individuals to accept treatment is not justified and could be considered an unjustified intervention in their bodies (30).

On the contrary, building trust is a crucial component of the therapeutic relationship between doctor and patient. The greater the trust, the less likely the patient is to doubt the usefulness of the interventions suggested by the doctor. In the present case, it is clear that the patient desires to give birth to a healthy and viable baby. However, there is a conflict between the patient's preference and the explanations provided by the treating doctors regarding the current condition. Honest clarification of the situation, including a thorough discussion of the risks and benefits, strengthens trust and supports informed decision-making.

Conclusions

In this case, the healthcare team should provide the patient with comprehensive information about the risks and benefits of delaying treatment versus immediate intervention. They should emphasize the potential consequences of her decision on her health while also acknowledging her values and concerns. This approach aims to help her understand the significance of the situation and the rationale behind the recommended medical course, without undermining her right to make the final decision. By respecting the patient's autonomy, the team ensures that she feels supported and informed, rather than pressured, when making her healthcare choices. This case shows that in Iranian medical system, despite complex biopolitical context, deciding about termination of pregnancy in case of pregnant women's cancer diagnosis, the autonomy of women is respected.

Building trust and encouraging the patient to express her perceptions, values, and beliefs will help the treating doctors understand the situation from her point of view. This approach enables them to provide more detailed explanations to address her uncertainties and doubts.

Conflict of interest

The authors declare that they have no potential conflicts of interest.

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Ethical Considerations

Ethical approval for reporting this case is available at the Iran National Research Ethics Portal. Approval number: IR.RHC.REC.1403.041

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