CASE REPORT

Decision Making Status with Older Minors: An Ethical Dilemma

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Published: 28 February 2015
Ibnosina J Med BS 2015;7(1):27-30
Received: 10 April 2014
Accepted: 22 November 2014
This article is available from: http://www.ijmbs.org

Abstract
Clinical ethical issues arise on a daily basis for medical clinicians. We report and discuss a case of an older minor. A 16-year old female, with a complicated clinical history following a heart transplant, developed irreversible complications from her underlying medical condition that was largely attributed to noncompliance with recommendations from her medical team. Because of her minor status, she was ultimately unable to make healthcare decisions. The patient's healthcare team collectively agreed that she had minimal chances of surviving. We will discuss the ethical aspects of decision-making regarding her critical care.

Key words: decision making, older minor, clinical ethics.

Introduction

Decisional capacity and decisional status are two essential elements in decision-making and informed consent. (1). In the clinical arena we face these issues on a daily basis, and when the patient is a young child, the parents are the legal decision makers on behalf of the minor. This anonymous case arose from an ethics consult regarding a 16 year-old patient, expressed treatment desires that were contrary to medical evidence and her clinical team's judgment. The patient's mother was her legal surrogate decision maker, yet the mother's motives and substituted judgment (2) were called into question because she had not followed recommendations for care by the medical team in the past. The patient and her mother are citizens in a Western country where the legal age of majority is 18. We provide a discussion addressing the complex ethical challenges presented by this case (Table 1).

Case Report

Our case involved a 16 year-old female s/p heart transplant for long-standing heart failure from suspected viral cardiomyopathy. Her transplant is less than three years

Table 1. The complex ethical challenges presented by this case.
1. Who is the appropriate decision-maker? The patient, or her mother?
2. What is a suitable way to allow an older minor to contribute to health care decisions?
3. What principle should guide the patient's mother in making health care decisions?
4. What should be done if they disagree about resuscitation status?
5. Is it ethically permissible for the team to withdraw any of the medical technologies against the patient's directive?
6. Is a DNR order against the patient's directive ethically permissible?
7. If the patient loses consciousness, is it ethically permissible for the medical team to follow the mother's directive in making the patient DNR even though the mother is not using substituted judgment?
8. Would the answer to #6 change if the patient were 2 years older?
9. Would the answer to #6 change if the patient and/or her mother had been responsive to the medical team's treatment plan in the past?
DNR = "Do Not Resuscitate";

ago. She has become progressively ill from rejection and multiple complications (infection, kidney failure). Despite counseling by the medical team regarding compliance with medication and follow-up, the patient ignored her treatment plan, which ultimately contributed to her progressive deterioration. Her mother did not express any interest in her care nor encourage the patient to follow medical advice until this hospitalization.

The patient was admitted to the heart transplant ICU and is on multiple antimicrobials, inotropes, and vasopressors with increasing oxygen requirements, increasing leukocytosis, and worsening kidney failure. She did not require mechanical ventilation. The medical team has noted the patient's history of non-compliance. After 3 weeks in the ICU, the team came to the conclusion that she would not be likely to survive her current condition and that she was not a candidate for re-transplantation. She was placed on low dose opoid therapy and 2 antiemetics to control her severe nausea and dyspnea. She was on maximal doses of inotropes and vasopressors due to a decline in her condition. In the short term, her cardiac status was manageable with these life sustaining interventions. However, her cardiac function would have been unable to maintain her vital signs if these medications were held or decreasedher cardiac function is unable to maintain her vitals. Given her gradual functional decline with expectation that this would ultimately be refractory to medication and lead to her death within weeks, the team determined it was not feasible for her to continue on parenteral cardiac medications indefinitely. She was not expected to be able to return to her previous functional status and was expected to die within hours to days of stopping the IV medications. Although occasionally mildly sedated, she was awake, able to converse and desired that "everything be done." Often in conversations regarding her health, she closed her eyes and appeared to fall asleep. Her mother was continuously at her bedside and was her only known relative. She would answer for her daughter if her daughter did not respond to questions, and would take the lead in health related conversations.

The patient and her mother had both been told of the prognosis. The primary team discussed with the patient and mother the current treatment and resuscitation prognosis, indicating that they were unlikely to be effective. The patient stated that she wanted to live as long as possible and

that she desired aggressive treatment including attempted resuscitation, even if predicted to be ineffective. When the patient was not able to hear the conversation, her mother reassured the team that when her daughter loses consciousness she will make the daughter DNR (Do Not Resuscitate) since the mother understood that her daughter was dying. The mother expressed these these thoughts despite HT's wishes but in accordance with guidance from the healthcare providers.

Discussion

The team considered how to balance the wishes of the patient as an older minor against the wishes of her legal guardian and the medical team. They were uncomfortable with continued aggressive care, but also felt uncomfortable withdrawing care without the patient's agreement. Furthermore, the nursing staff was concerned about the mother's motives, stating that the patient was having graft rejection because the mother did not encourage sthe patient to take prescribed anti-rejection medications. They also noted that the mother had a history of incarceration and drug abuse. Despite the mother's history, it is unlikely that a court in this country would revoke the mother's guardianship. However, it is possible that a judge would order a psychiatric evaluation of the mother to determine the competency of her surrogate decision making The ramifications of this issue are significant as this is end of life decision.

Who is the legal decision maker? From a legal and policy perspective, this is the central issue. Assuming 18 is the age of legal majority and that no court has awarded this patient legal emancipation, the mother is the legal decision maker. The medical evidence provided by the primary team indicates this case is representative of physiologic futility (1), Without the IV medications, Miss HT would decompensate and die. Her life is only extended because of this intervention, and her condition is untreatable without expectation of meaningful recovery. Because of the physiologic futility, we maintain that it is ethically acceptable to withdraw care and implement a DNR order, which the mother indicated was acceptable. A DNR order, however, cannot be in place "only when the patient becomes unresponsive" as the mother has requested, and so until a solution can be found, a DNR order is not appropriate at this time.

The challenging issue is the patient's "older minor" status. Given the minor child will soon reach the age of legal decision making capacity, the patient's wishes should not be ignored or excluded—although from a legal standpoint it has no bearing. The ideal scenario would be to explore the patient's feelings about her condition and care and come to some resolution with her about the terminal nature of her illness. Has the patient been engaged in the conversation so that she has an understanding of the condition and lack of available treatment? Initiating that communication would be the sympathetic place to begin. We believe that over time, through compassionate communication, the patient may accept the mortality associated with her condition. The team could initially propose that should she have an acute event, the medications sustaining her life would not be increased but left at their current dosage. This would bridge to a conversation seeking veracity (3) about the futile nature of resuscitation for this critically ill young woman.

Conclusion

Given the possible suspect motives on the part of the mother as well as the patient's wishes as an older-minor, this case led to an ethics consult given the concern of the clinicians. From a clinical procedural standpoint, however, this case is legally clear that the patient does not have decision-making status. Because of the physiologic futility in this case, it is ethically permissible to enact a DNR order based on the mother's substituted judgment, but we recommend that this should coincide with supportive conversations with the young patient. At the time she can comprehend the gravity of her illness, it is also permissible to withdrawal parenteral cardiac support.

References

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