AEBMedicine

Case study

False hope: a bioethics case study

Ariana Marie Martin[1,*]

[1] Tecnologico de Monterrey, School of Medicine and Health Sciences, Monterrey, Mexico
* Corresponding author: arianamariemartin@gmail.com

Keywords: gastroschisis, bioethics, parental autonomy, patient transfer

Abstract

This text portrays the case study of a newborn who was diagnosed with gastroschisis, a congenital structural defect of the abdominal wall. The narrative explores the ethical questions raised by the complications of this case, focusing on three key issues: the bioethics principle of beneficence, patient transfer guidelines and parent decision-making capacity. The conclusion highlights the tension between parental autonomy and the potential for harm to the child, citing the parens patriae doctrine and the Harm Principle as possible grounds for state intervention in the United States. Overall, the text highlights the complexity of ethical considerations in medical cases involving children and calls for individual analysis and collaboration among healthcare professionals to find optimal solutions.

Introduction

Immediately after being delivered by cesarean section via abdominal birth, weighing at 1.7 kilograms prematurely during 36 weeks of gestation, the pediatrician confirmed the newborn "Max's" ultrasound diagnosis of gastroschisis, a medical complication characterized by a congenital structural defect of the abdominal wall, through which the abdominal viscera protruded (1). The patient's mother had known of the defect due to previous ultrasounds, but she had yet to know what the future would hold for her son.

By itself, a patient born with gastroschisis has a favorable prognosis. This wasn't the case for Max. After his birth, he was rushed to the operating room where a surgery to reverse his condition was performed, and everything seemed to be going according to plan. The key word is "seemed". A few weeks later after the surgery he developed necrotizing enterocolitis, a rare complication of gastroschisis caused by bacteria invading the intestinal wall, that later perforated the intestines, requiring a surgery that resected from the rectum to the duodenum, attaching a bag to the duodenum and placing an orogastric tube to absorb the bile produced by the total parenteral nutrition (2).

Within 24 hours of his birth, Max's mother was informed that in fact, Max would have an unfavorable prognosis, contrary to what was discussed previously, and that from that point on, he would be on end-of-life palliative care since life was not possible with his condition and there was no cure.

In the beginning, Max's mother seemed to accept the diagnosis and his prognosis. And after two months of palliative care treatment for Max, she finally was at peace with her decision and with Max's prognosis. But then, something unexpected happened. A nurse led Max's mother to believe that they knew of a hospital that could perform a surgery to 'cure' Max. Suddenly, weeks of grief and acceptance were washed away and were replaced by a false hope. She would no longer listen to the doctors as she was convinced that they were not offering her son the optimal treatment, and she began to plan for an unauthorized hospital

Citation: Marie Martin A. False hope: a bioethics case study. *AEBMedicine*, 1(2), 1-4.

Received: 19/06/2023
Reviewed: 24/06/2023
Accepted: 18/07/2023
Published: 24/11/2023

Evidence level: case study.

DOI: 10.59706/aebmedicine.v1i2.7863

transfer, which was ultimately accepted, and Max was transferred to a different unit without future palliative care indicated.

Unfortunately, Max passed away a few weeks after his transfer due to a cardiac arrest.

Discussion

This case raises three key ethical questions in the medical field:

Issue 1: What bioethics principle did the nurse go against when she gave Max's mother false hope?

False hope in the medical setting goes against the principle of beneficence, which emphasizes the ethical obligation of healthcare professionals to act in the best interest of the patient, in order to promote the patient's well-being and provide realistic interventions. Providing false hope can be detrimental leading to unrealistic expectations, emotional distress, and a loss of trust in the healthcare system - all three which we are able to observe in the case discussed.

The False Hope Harms (FHH) argument is a new concept in healthcare that was established in 2020, when its' author, Marleen Eijkhol, from the University of Leiden, created this concept not to define what false hope is in the medical setting, but to outline the FHH argument in order to convince healthcare providers to avoid participating in a deceptive expectation. She outlined her argument with four points, emphasizing that consumer medicine and false hope are connected; providers and patients are very vulnerable in systems of consumer medicine: providers have the obligation and responsibility to stand up against false hope; and how her FHH argument could possibly affect how physicians view their contribution to the false hope dilemma (3).

Issue 2: Should the hospital have allowed Max's transfer?

According to the American College of Emergency Physicians (6), a hospital transfer is indicated when the optimal health and well-being of the patient is the principal goal of patient transfer and that if a "competent" patient requires transfer before the completion of the medical screening examination and stabilizing treatment, these services should be offered to the patient along with an informed refusal document.

In simpler terms, the answer is that yes, the hospital is legally obligated to transfer a patient that refuses treatment as long as the informed refusal document is signed. That being said, the following question arises: Is it ethically correct to transfer a patient in palliative care that is not stabilized even when an informed refusal document is signed? I propose that the answer is no. If the parent's argument is that the hospital where the patient is being transferred will provide a solution to a palliative care patient's situation, then the parent is misinformed because palliative care refers to end of life care in a patient whose diagnosis has no cure for.

Issue 3: Should a parent be able to make decisions for their child if due to their educational status they are not able to fully understand the diagnosis and treatment?

A parent's ability to make decisions for their child can be influenced by various external factors. These include their educational status, economical status, mental status, among others. In situations where a decision-making capacity is questioned, such as the lack of understanding of diagnosis and treatment options, the situation may be called into question.

In cases such as these, there are no legal doctrines that state what is the next step. Healthcare professionals are required to simplify the explanation of the diagnosis and treatment options, while using visual aids or interpreters to ensure understanding of the situation. However, in scenarios where despite a clear explanation is provided and the parent still does not understand the severity of the situation therefore refusing treatment, a clear risk is posed to the child's health and well-being.

In those cases, as healthcare professionals, we have the ethical obligation to ensure that our patient receives the necessary care, possibly seeking legal intervention to protect the child's well-being.

Since this situation clearly violates the parent's autonomy, each case must be analyzed individually on a case-by-case basis, with the end goal of protecting the child's health.

Conclusion

Under US law, parents have the authority to make medical decisions on behalf of their children (refuse or discontinue treatments), as long as their children are under the legal age.

However, according to the parens patriae doctrine in the United States, there are situations where the doctors can disagree with a parent's decision if presented with a medical dilemma. This doctrine can intervene with a parent's decision when the medical community is in agreement about the best treatment, if the child is at risk of serious harm, if the child would die without the treatment, or if a parent is refusing consent (4).

The Harm Principle, by Douglas Diekema, is described in the article titled "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention." He argues that the harm principle proposed by philosopher John Stuart Mill, can serve as a gateway for state intervention in the case of parental refusal of medical treatment. Much like the parens patriae doctrine, The Harm Principle suggests that if the parent's decision to refuse treatment poses a significant risk of harm to the child, the state may find a justifiable reason to override parental autonomy. He acknowledges that although there is much importance in respecting parental autonomy in medical decision-making, there are limits to parental authority when a child's well-being is at stake. Diekema proposes an individual evaluation of each case, while considering all contributing factors, and the likelihood of harm that may result from refusal of treatment (5).

Both the Harm Principle and the parens patriae doctrine propose that in the United States, the state intervenes in cases where the parent's decision results in harm to the child, albeit indirectly. While being plausible solutions, these principles hold no significance in other countries, where the state isn't allowed to intervene, and there is no solution to counteract a parent's decision.

Therefore, in countries other than the United States, a plausible solution is a combined decision between the doctors and the ethics committee that takes into consideration the decisions of the parents, while emphasizing the patient's best interest in the decision making process, in cases such as this one. The benefit of having an ethics committee weigh in on decisions as important as these ones are based on the multidisciplinary team of individuals who bring diverse perspectives and expertise to make such ethical decisions without bias. Not only is a hospital ethics community made up of healthcare professionals such as physicians, social workers, and psychologists, but it is also composed of ethicists, hospital administrators, legal representatives, and in some cases patient and family representatives. That being said, every case should be individually analyzed to find the perfect solution.

References

(1) Chuaire Noack L. (2021). New clues to understand gastroschisis. Embryology, pathogenesis and epidemiology. Colombia medica (Cali, Colombia), 52(3), e4004227. https://doi.org/10.25100/cm.v52i3.4227

(2) Ginglen, J. G., Butki, N. (2022). Necrotizing Enterocolitis. In StatPearls. StatPearls Publishing.

(3) Eijkholt M. (2020). Medicine's collision with false hope: The False Hope Harms (FHH) argument. Bioethics, 34(7), 703–711. https://doi.org/10.1111/bioe.12731

(4) Stern E. G. (2019). Parens Patriae and Parental Rights: When Should the State Override Parental Medical Decisions?. Journal of law and health, 33(1), 79–106.

(5) Diekema D. S. (2004). Parental refusals of medical treatment: the harm principle as threshold for state intervention. Theoretical medicine and bioethics, 25(4), 243–264. https://doi.org/10.1007/s11017-004-3146-6

(6) Appropriate Interfacility Patient Transfer. (2022). American College of Emergency Physicians. https://www.acep.org/siteassets/new-pdfs/policy-statements/appropriate-interfacility-patient-transfer.pdf