

Maya Kowalski's Story: do no harm

La historia de Maya Kowalski: no hacer el mal

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Abstract

Johns Hopkins Hospital was ordered to pay \$261 million to the Kowalski family (1) following a lawsuit revealing ethical and systemic failures in medical care. The story follows Maya, diagnosed with complex regional pain syndrome (CRPS). Ketamine treatment turns into tragedy when misunderstandings lead to false accusations against the mother. Maya is separated from her parents, facing devastating consequences. This case highlights medical gaslighting. Lack of communication, institutional accountability, poor patient-physician relationships and non-maleficence contributed to this tragedy and raises ethical questions about the use of experimental treatments. The story underscores the importance of a doctor-patient relationship based on trust and empathy, as well as the need for ongoing ethical training for health professionals. Bioethics must be fundamental in medical care to avoid tragedies such as that of the Kowalski family.

Keywords: gaslighting, non-maleficence, malpractice, pediatrics.

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1. Introduction

The diagnosis of an illness will always be accompanied by a process of family and personal adjustment. The way in which the health care environment behaves with respect to it can generate fatal and permanent consequences in the dynamics of a family. It is increasingly common to encounter the struggles of patients and their families against medical disbelief, lack of answers and a healthcare system that, instead of providing support, contributes to their despair, reflecting the devastating consequences of the lack of empathy and understanding in the doctor-patient relationship; however, such stories highlight the urgent importance of addressing ethical and systemic failures in health care, emphasizing the critical need for ongoing ethics training for health care professionals and a reevaluation of how bioethics can be more effectively integrated into clinical decision making.

2. The story of Maya and her family

Recently, Johns Hopkins Hospital was ordered to pay 261 million dollars to the Kowalski family after they filed a lawsuit related to the case of their daughter, Maya (1). As a result of this news, I decided to address the documentary that details this case.

In the documentary *Take Care of Maya* presented on the Netflix platform (2), the story of the Kowalski family is told, composed of a married couple where the mother is a nurse and the father a firefighter, along with their two young children, Maya, and her younger brother. The plot centers on Maya, a little girl affected by generalized pain, loss of strength in her legs, coughing and other symptoms. At the time, the parents sought help from doctors of all specialties, always encountering skepticism, doubts, and lack of answers. Eventually, one of these pain specialists diagnosed CRPS (3).

CRPS is a medical entity characterized by persistent pain that is disproportionate to the original injury and usually affects one extremity. Although its exact etiology is not fully established (4), it is thought to involve an interaction of neuroinflammatory factors, alterations in the autonomic nervous system, and changes in pain perception. Diagnosis is based on specific clinical criteria, with the presence of constant pain, changes in skin temperature and color, as well as alterations in sweating of the affected area. It tends to affect women in a much higher proportion, presenting a peak in prepubertal girls and premenopausal women (5).

Table 1 shows the proposed and validated Budapest criteria, which are widely used to diagnose CRPS (6) and incorporate the evaluation of clinical symptoms and not only instrumental tests.

Table 1. Budapest Criteria

<i>1) Continuous pain, disproportionate to any triggering event.</i>
<i>2) The patient must report at least one symptom in 3 of the following 4 categories.</i>
Sensory: reports of hyperalgesia and/or allodynia.
Vasomotor: reports of temperature asymmetry and/or changes in skin color and/or skin color asymmetry.
Sweating/Edema: reports of edema and/or sweating, changes and/or sweating, asymmetry.
Motor/trophic: reports of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nails, skin).
<i>3) Must show at least one sign at the time of evaluation in 2 or more of the following categories.</i>
Sensory: evidence of hyperalgesia (to pinprick) and/or allodynia (to light touch and/or deep somatic pressure and/or joint movement).
Vasomotor: evidence of temperature asymmetry and/or skin color changes and/or asymmetry.

Sudomotor/Edema: evidence of edema and/or sweating, changes and/or sweating, asymmetry.
Motor/trophic: evidence of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nails, skin).
4) <i>There is no other diagnosis that better explains the signs and symptoms.</i>

Source: (7).

The therapeutic approach is multidisciplinary and aimed at improving the patient's quality of life. Pharmacological strategies, such as analgesics and nervous system modulating drugs, are included, along with non-pharmacological interventions such as physical therapy and occupational therapy. Physical therapy seeks to restore function and reduce disability, while occupational therapy focuses on improving participation in daily activities. It is crucial to highlight the variability in response to treatment, emphasizing the need for an individualized approach. Early detection and appropriate treatment can positively influence long-term prognosis, highlighting the importance of early intervention to prevent disease progression.

Maya's physician recommends initiating treatment with ketamine to address her disease. Ketamine is an anesthetic drug commonly used in medical practice. Although originally developed for anesthetic purposes, it has been observed to possess remarkable analgesic properties, which has led to its research and application in pain management. Ketamine has demonstrated efficacy in acute and chronic pain situations, as part of perioperative analgesia management and in patients with neuropathic pain. Its unique mechanism of action involves modulation of N-methyl-D-aspartate (NMDA) receptors in the central nervous system, providing pain relief that differs from other conventional analgesics. However, its use in the treatment of pain is still in an active phase of research and evaluation, as considerations persist regarding possible side effects and potential risk of abuse (8).

Treatment was started with low doses, but when a favorable response was not observed, ketamine-induced coma for five days was recommended in Monterrey, since such a procedure would not be feasible in the United States. The therapy proved effective, allowing Maya to experience a significant improvement in her quality of life through the daily use of ketamine. However, several months later, Maya suffered a seizure and was rushed to Johns Hopkins Hospital, where doctors were unaware of her medical history. Mistakenly, it was suspected that the mother was causing harm to the daughter by administering high doses of ketamine. As a result, Maya was taken into state custody, separated from her parents, and remained in the hospital for months without receiving the necessary treatment or contact with her parents.

Throughout this difficult situation, the mother persisted in her struggle to reunite with her daughter and secure the treatment that had previously been effective. Facing resistance from the system and the hospital, Beata, the mother, continued the legal battle. This situation progressively weakened her mental health as she dealt with the legal and emotional challenges associated with the separation from her daughter, receiving a diagnosis of adjustment disorder and depression. After three months of separation, Beata attempts to take her own life. Subsequently, another doctor confirms Maya's diagnosis, and she is released from the hospital into her father's custody. The Kowalski family is taking legal action, suing the hospital and the people involved in this tragic episode.

3. Impact of the doctor-patient relationship in the case of Maya Kowalski

The patient-physician relationship is an essential component of the healthcare process, fundamental to the achievement of positive patient health outcomes. This connection goes beyond the simple transmission of medical information. The physician-patient relationship is characterized by building trust, empathy, and effective communi-

cation between both parties. Empathy, another key pillar in this relationship, allows the physician to understand the patient's concerns and needs, contributing to shared decision-making and greater patient satisfaction. Effective communication, based on clear and understandable language, is essential to avoid misunderstandings and strengthen the doctor-patient relationship.

Maya Kowalski's story highlights the critical importance of this relationship to the quality and outcomes of care. Although medical care initially improved with the diagnosis of CRPS by a pain specialist, the subsequent lack of understanding and medical coordination led to devastating consequences for the Kowalski family. The pain physician played a pivotal role in recommending an innovative and investigational approach to address Maya's symptoms. However, the lack of widespread knowledge about the use of ketamine in pain management and the medical establishment's reluctance to accept unconventional approaches contributed to misunderstandings and errors later on.

Maya's subsequent crisis at the hospital highlights the importance of effective communication and a thorough understanding of the patient's medical history. Physicians' unfamiliarity with her diagnosis led to misplaced suspicions about treatment, resulting in Maya's separation from her parents and inadequate medical care. At this point, the physician-patient relationship was compromised, directly affecting the family's trust in the health care system.

This case exemplifies the critical need for a physician-patient relationship based on empathy, open communication, and a comprehensive understanding of the patient. Reluctance to accept innovative treatments and lack of coordination between healthcare professionals can have tragic consequences, affecting not only the patient's physical health, but also his or her emotional well-being and family unity.

4. Medical gaslighting and its terrible consequences

This case is not isolated, the medical habit of not believing in patients or in the intentions of family members is becoming more and

more frequent where doctors end up deciding on the realities and ailments of each person and family instead of considering the needs that result from the difficulties represented by an illness. This case undoubtedly raises a bioethical problem with several nuances that we will address in this text.

First, it is necessary to denounce the deep-rooted paternalistic habit of some physicians who distrust the patient, believing that, if it cannot be quantified, it is not real. This attitude places the burden on the patient to prove his or her illness rather than on the physician to strive to discover the causes of the symptoms. Patients with subjective symptoms, such as pain, fatigue, or weakness, are particularly susceptible to medical gaslighting (9), which minimizes the person and places an enormous emotional and physical burden on someone who is already at a disadvantage and in a state of vulnerability. This is a practice that undermines the patient and affects every principle of principlism bioethics, as we will discuss below.

Medical gaslighting constitutes a form of emotional abuse where the validity of the patient's feelings is questioned, and the patient's condition is minimized. It delays diagnosis, delays timely treatment, and alienates the relationship between doctor and patient, creating a vicious circle that, in the case of pediatric medicine, even causes legal problems, as was the case of the Kowalski family. Not only does it cause maleficence in the minor, but it can harm the health of others, as was the case with the mother.

We do not assume that ignoring warning signs of child abuse is reasonable, but certainly the evidence showed time and time again that the mother presented a genuine concern for her daughter's welfare and that her attitudes were only signs to be expected of a person desperate for both the medical and legal situation. It makes us wonder what attitude a parent concerned about her child's health should have to be considered acceptable by medical personnel. From a bioethical perspective, we can examine the human capacity to experience emotions that transcend what we might consider reasonable. It is precisely this capacity that defines us as human beings and that empowers love for others, particularly our family.

5. Adaptive mechanisms and their relevance in and out of health care

The mother, being a nurse, is expected to develop an adaptive mechanism focused on the attempt to control the situation, which analyzed in the light of psychology has foundations and can be understood in this context. The adaptive means that each person can develop to cope with a stressful situation should no longer be seen as a distant part of the overall health problem or as a problem remote from the person and the health care provider. As with any situation that is difficult to manage, the emotional side will be affected and it does not mean that it is directly associated with the disease, but it will influence the way in which we as family members and patients will approach the problem.

Sometimes, physicians can anticipate a specific response on the part of patients when faced with difficult situations. When the patient does not react as expected, the physician may develop defense mechanisms that, unfortunately, can be detrimental to the patient-physician relationship or, in extreme cases, affect the quality of care provided. It is imperative that, as health care professionals, we are aware of our own biases regarding the reactions of others and are prepared to respond appropriately to whatever way the patient handles the situation. If we lack that capacity, it is crucial to recognize it and seek the collaboration of additional specialists who can offer a broader perspective, transcending our own vision.

Beata Kowalski was diagnosed with depression and adaptive disorder by other professionals, ruling out some other disorder associated with child maltreatment. However, health care staff stigmatized the primary caregiver's (entirely expected) diagnosis. Not only that, but they completely dismissed the medical diagnosis given to Maya despite multiple pieces of evidence for it. And like a vicious cycle, the more the doctors refused to believe Maya and her mother, the more this sense of hopelessness was fed and the more the mental health of both deteriorated, which was used by the doctors to justify that the problem was psychogenic.

6. The pediatric patient and his vulnerability

When dealing with pediatric patients, we face a situation in which the family context becomes a key part of the problem or the solution. Illnesses always influence a family, and even more so when it is a minor who suffers from them. Parents develop different adaptive mechanisms that require psychosocial support, which can affect their well-being and family dynamics. Addressing these conditions, especially those with a significant psychological and family burden, with an interdisciplinary team and a bioethical approach, makes a difference and makes it possible to truly recognize what is best for the child. This goes beyond physical well-being, which is not even respected in this case by the medical team.

In pediatric cases, autonomy and non-maleficence take on special relevance. Parents are responsible for making medical decisions for their children, relying on the information provided and considering all the implications with the emotional burden of seeing a loved one suffer. Although a minor may oppose an intervention, physicians must analyze each case individually, considering the cognitive capacity of each minor to make decisions for the benefit of the patient, respecting his or her autonomy or, in any case, that of the parents (10). This is established in the informed consent that will be mentioned below. When speaking of non-maleficence, it is crucial to remember the psychosocial-spiritual aspect of each person that we mentioned previously. Absolute well-being is not only limited to the physical sphere; having a support network nearby, being listened to, accompanied, and believed in are fundamental to avoid causing harm to the patient, especially when the patient is a minor who is highly dependent on his or her caregivers.

7. Informed consent

Informed consent is an ethical and legal process and document by which patients receive complete and understandable information

about their medical treatment before giving their authorization. This process involves communicating relevant details about the nature of the intervention, its risks and benefits, available alternatives and any pertinent information that will enable the patient to make an informed and voluntary decision. The relevance of informed consent lies in its respect for the patient's autonomy and dignity, recognizing the patient as an active agent in his or her medical care. By providing transparent information, the patient is empowered to actively participate in decisions about his or her own care, promoting trust in the patient-physician relationship. This process not only meets fundamental ethical standards, but also establishes a sound legal basis, protecting health professionals and ensuring respect for patient rights (11).

8. Principlism bioethics and patient autonomy

Principlism, the bioethical theory, developed by Beauchamp and Childress, is based on four fundamental principles that guide ethical decision-making in health care. These principles are autonomy, beneficence, non-maleficence, and justice. Autonomy emphasizes the importance of respecting the patient's decision-making capacity, encouraging informed decision making and respect for individual preferences. Beneficence requires acting in the patient's best interest, seeking his or her well-being and promoting actions that improve his or her health. Non-maleficence establishes the obligation not to cause unnecessary harm and to minimize risks in medical care. Finally, justice stresses the need to distribute resources and benefits equitably, avoiding unfair discrimination. These principles provide a sound ethical framework for addressing complex medical issues, ensuring patient-centered care oriented toward the common good (10).

Patient autonomy is a fundamental principle in bioethics that upholds the individual's right to make informed decisions about his or her own medical care (10). In the case of Maya Kowalski, autonomy was severely compromised when physicians disregarded her prefer-

ences and decisions about her treatment. The need for informed consent, with all the characteristics it should have (11), reflecting the 10-year-old patient's understanding of the situation, the disease and her treatment, was completely ignored. The imposition of keeping her hospitalized and on certain medications without her consent and the subsequent separation from her parents reveal a lack of respect for her ability to actively participate in decisions affecting her health.

This case highlights the need to strengthen mechanisms to guarantee the active participation of patients and their families in medical decisions, understanding that many times the patient knows about her illness and what makes her feel better (11). Open and transparent communication between health professionals and patients is required, fostering a collaborative approach in which the person's preferences and wishes are valued.

9. Non-maleficence

The principle of non-maleficence establishes the obligation of health professionals not to cause unnecessary harm to patients (12). In Maya's case, the separation from her parents and the lack of adequate treatment constituted a clear breach of this principle. The medical negligence and lack of understanding of Maya's condition resulted in additional suffering and contributed to the loss of a life.

This aspect of the case highlights the importance of ongoing training and supervision in the medical setting to ensure that health professionals are fully aware of their responsibility to do no harm (13). It also highlights the need to review hospital protocols to avoid repetition of similar situations.

10. Beneficence

Beneficence implies acting in the patient's best interest, ensuring his or her well-being and promoting his or her health (14). In Maya's

case, the lack of timely and continuous care, as well as the denial of treatment that had previously been shown to be effective, contradicted the principle of beneficence. The delay and negligence resulted in significant harm to the patient and her family.

It is essential to reevaluate medical decision-making processes to ensure that the actions taken are truly in the best interest of the patient (15). Beneficence should be at the core of medical care, and any obstacles to its application should be identified and addressed.

11. Justice

Justice in bioethics involves the equitable distribution of resources and access to medical care (16). The lack of recognition and adequate treatment of Maya's status highlights disparities in medical care and highlights the need to address systemic inequities. Female patients, as well as infants, are particularly susceptible to incorrect treatment or under-diagnosis, even for conditions that are appropriate for their age group or gender. The prejudices associated with these groups, considering them to be more "liars" or "emotional", fuel the injustice to which they may be subjected (17).

The case highlights how deficiencies in the health system can disproportionately affect certain individuals, generating tragic consequences. In this case, both Beata and Maya are prosecuted by both medical group opinion and legislation, appealing to an emotional instability that was not justified by the evidence. Even having to defend their own condition and their right to treatment, as well as Beata's right to protect and accompany her daughter, affirms the injustice they faced.

12. Principlism bioethics as the foundation of the person

From the principlism perspective in bioethics, we must return to the concept of the person, who is seen as a unique, unrepeatable being

endowed with intrinsic dignity. Personalist bioethics is based on principles that recognize the inherent dignity of everyone, highlighting its relevance in the case of Maya Kowalski. Person-centeredness, one of the key principles, emphasizes that patients should not be reduced to mere objects of treatment, but treated with respect and consideration for their uniqueness. In this case, the lack of medical empathy and disbelief towards Maya's symptoms evidences a direct infringement of this principle, underlining the importance of an approach that values the patient's experience and autonomy (16).

Likewise, responsibility and solidarity are fundamental tenets of personalist bioethics. Maya's story highlights how the lack of responses and support from the healthcare system contributed to devastating consequences for the family. Medical responsibility implies an ethical commitment to provide adequate care and respect the patient's rights. Solidarity, on the other hand, advocates collaboration between healthcare professionals and patients to address medical challenges together. In the case of Maya, a lack of solidarity resulted in a tragedy, highlighting the need to strengthen these principles in daily medical practice (16).

13. Truthfulness and effective communication

Truthfulness implies providing accurate and complete information to patients (18). In Maya's case, the lack of clear and accurate communication between physicians and the Kowalski family led to confusion and mistrust. Incorrect information about Maya's treatment and condition contributed to a scenario where the family was unable to make informed decisions, fueling widespread anxiety and conflict within the family and between the legal system, physician, and the individuals involved.

Significant improvement in communication between health professionals and individuals is required (19) to achieve an ideal patient-physician relationship, as previously mentioned. Physicians should be transparent in their interactions, providing accurate and

understandable information to facilitate informed decision making by patients and their families. Thus, it is necessary to ask enough questions, with empathy and respect, to obtain the necessary information for decision making. The relationship between the health personnel, the patient and the relatives depend mainly on the medical professional, since he/she is the one who represents the authority and who must have the temperance to approach the conflict with attitudes and techniques that promote the benefit of those involved.

14. Family context

The family context plays a vital role in pediatric medical care (20). Children's illnesses affect the entire family, and parents develop adaptive mechanisms that can influence the patient's well-being. In Maya's case, the lack of attention to the family context contributed to the deterioration of the Kowalski family's mental health. Comprehensive care must consider not only the patient but also his or her family environment (21). The implementation of an interdisciplinary approach, including mental health and social services professionals, can provide the necessary support to mitigate the negative impacts on the family.

15. Ethical training

Ongoing ethics training is crucial to ensure that health professionals understand and effectively apply bioethical principles in their daily practice (22). Maya's case evidences the lack of understanding of the patient's condition and the misapplication of treatments, underscoring the imperative need for more robust ethical and medical training. At no point in the hospital process is a bioethical analysis conducted, underscoring the importance of bioethics committees or more comprehensive bioethics education in complex clinical situations such as

this one. Upon reflection, don't all cases have unique nuances? Patients are always biopsychosocio spiritual beings, and unless each of these dimensions is addressed with a bioethical approach, neither the patient, nor his or her family, nor the health care provider will be able to achieve success. This highlights the crucial relevance of bioethics training, the presence of hospital bioethics committees and the application of bioethical methodologies in clinical practice.

16. Institutional responsibility

Institutional accountability is crucial to ensure quality and ethics in health care (23). The Maya case highlights the importance of institutions reviewing and improving their protocols to avoid repeating similar errors. Lack of timely response and lack of accountability contributed to the tragic consequences in this case.

Medical and social work staff should act expeditiously in analyzing the situation and strive to reduce the trauma associated with illness and hospitalization. In Maya's case, far greater harm was inflicted on her than she could have experienced with the disease or the experimental treatment because of the idea that what was being done was "what was best for her." However, this stemmed from the unethical belief that nothing she was saying or feeling was real, leading to devastating consequences for the family. Leaving a vital bioethics lesson: believe patients and analyze the situation beyond medical practice and our own knowledge whenever we are faced with a medical crossroads in a pediatric patient (24).

17. Conclusion

In summary, the case of Maya Kowalski highlights the urgency of addressing ethical and systemic deficiencies in medical care. Rigorous application of bioethical principles, improved communication

between health care professionals and patients, and ongoing review of institutional processes are critical steps toward more ethical, person-centered, and just health care. Maya's tragic story underscores the need for a continued commitment to ethics in health care to prevent future similar cases.

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