Autonomy and Its Limits: A Discussion of the Shortcomings of Informed Consent

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INTRODUCTION

Medicine is intertwined with promotion of positive health while prioritizing a patient's diagnosis, prognosis, and treatment. The prioritization of a patient's needs stems from a branch of morality called biomedical ethics, which focuses on moral principles that arise in healthcare, medical research.[1] Biomedical ethics serves to provide a framework for addressing complex medical questions while safeguarding the rights, dignity, and well-being of individuals.[1] Often times in healthcare, decisions made by physicians and patients result in beneficence and/or maleficence. Beneficence implies that healthcare professionals and institutions have a moral duty to act in a patient's best interest by providing positive health outcomes while minimizing harm (maleficence).[1] As a result of biomedical ethics' emphasis on beneficence and maleficence, healthcare is designed to respect a patient's needs, beliefs, and decisions. The practice of allowing patients to make their own medical decisions is called autonomy, and it is vital to biomedical ethics because it emphasizes the concerns of the patient.[2] However, it is difficult to ensure that a person has autonomy over their medical decision-making if they are not fully informed about the circumstances of their health or treatment options.

ANALYSIS

Thus, an important aspect of biomedical ethics is informed consent. Informed consent is a practice in healthcare and research where individuals must voluntarily agree to or decline medical care after being educated about their medical condition.[3] Informed consent protects an individual's right to express their beliefs and make educated decisions about their health. Furthermore, there is an important distinction to be made between voluntary consent and informed consent. While informed consent emphasizes that individuals are fully educated and comprehend information about a procedure, voluntary consent maintains that a person must freely and willingly make decisions without any form of pressure or coercion.[3] While a patient might be educated or informed about their health, they might not have the power to voluntarily make medical choices. Thus, consent must be both informed and voluntary to ensure that a patient is fully educated while preserving the right to make medical decisions. Without autonomy and (voluntary) informed consent, individuals would be deprived of their freedom to make educated medical choices, leading to interventions that do not align with their wishes or desires. However, autonomy and

informed consent also have severe limitations and barriers, specifically when it comes to the informedness gap, cognitive capacity, and underestimation or overestimation of treatment risks.

According to author Onora O'Neill, the informedness gap occurs when patients may not fully understand the complex medical information provided to them by their physician.[4] The informedness gap is especially prevalent when medical professionals discuss complex procedures or treatments, as the patients may feel overwhelmed by the information and not make truly informed decisions. In addition to the informedness gap, limited cognitive capacity and mental health can hinder effective communication and informed consent.[5] When patients are unable to provide informed consent due to factors like dementia, mental illness, or unconsciousness, ensuring thorough communication and education becomes extremely challenging.[4]

Additionally, it is important to consider how informed consent is limited by underestimation or overestimation of treatment risks. Patients may be overly optimistic about the success of a treatment or procedure, thereby underestimating the likelihood of complications or adverse outcomes. On the other hand, patients may possess fear and anxiety, causing them to overestimate the effects of treatment. Anxiety can cause a heightened perception of risk, which can lead to refusal of beneficial treatments, despite the presence of objective medical evidence.[6] Overall, these limitations of informed consent demonstrate that even when a patient is educated about their health, they still might not be fully knowledgeable when making medical decisions. In fact, while patients have the power of autonomy to make medical choices, the limitations of informed consent can have fatal effects. This becomes abundantly clear when looking at the case study of the world-famous musician, Michael Jackson.

Michael Jackson's death was the result of acute propofol and benzodiazepine intoxication. Propofol and benzodiazepine are extremely powerful medications commonly used for ICU sedation.[7] Dr. Conrad Murray, Michael Jackson's personal physician, was involved in Jackson's care leading up to his death and played a central role in the events surrounding it. To briefly summarize the case, Michael Jackson was experiencing chronic insomnia and sought medical treatment after struggling to sleep for months.[8] Initially, Dr. Murray prescribed conventional anti-anxiety medications to help the artist sleep, but he was unsuccessful in resolving Jackson's symptoms.[7] Without coercing the artist, Dr. Murray offered to administer the powerful anesthetics, propofol and benzodiazepine. After Dr. Murray's brief description of the effects of propofol and benzodiazepine, Jackson voluntarily agreed to this treatment.[7] Initially, the treatment was a success, but Jackson was unaware of the significant toll these sedatives had on his health. On June 25th, 2009, after 2 and a half months of treatment, Jackson experienced severe propofol intoxication, causing him to die from cardiac arrest.[9]

Clearly, this case highlights how limitations of informed consent, specifically the informedness gap and underestimation of treatment risks, can have fatal consequences. Michael Jackson was granted the autonomy to make medical decisions about treatments for his insomnia, and he was briefly informed that propofol and benzodiazepine are potent sedatives.[7] However, according to the artist's family, Jackson wasn't fully educated about the level of addictivity and long-term ramifications of the drugs he was administered.[8] The Jackson family cited that while the artist voluntarily agreed to treatment, his chronic sleep deprivation caused him to underestimate the effects of his medication. The family explained that Jackson lacked the mental capacity to make informed decisions about his health.[8] Perhaps the outcome of this case may have been different if Dr. Murray had fully explored alternatives for treatment or made a thorough effort to fully educate Jackson about the effects of propofol. Additionally, it is difficult to discredit how sleep deprivation hindered Jackson's ability to make rational decisions about his health.[8] While it is

true that Dr. Murray informed Michael Jackson about the strength of the sedatives he was administered, that doesn't mean Jackson fully understood the treatment's consequences or the weight of his decision.

Furthermore, Michael Jackson didn't suffer from the limitations of informed consent because of his unique status as a celebrity; Jackson is not an exception from the norm. Research suggests that factors such as limited interaction time between patients and physicians causes an informedness gap in about 1 out of every 3 people.[10] Michael Jackson had the wealth and resources to be informed about his health; he could have employed any doctor to provide his treatment. Yet, the average person does not have the resources to employ their own doctor or be thoroughly educated about their health.[10] If Michael Jackson wasn't fully informed about his medical condition or treatment, it is likely that the average person is uninformed as well.

CONCLUSION

To put it simply, autonomy and informed consent ensure that individuals can express their personal beliefs while making educated decisions about their health. However, it is crucial to consider the limitations of informed consent such as the informedness gap, cognitive capacity, and misjudgment of treatment risks. How useful is autonomy and informed consent if patients lack the ability to think clearly, logically, and holistically about their health?[11] The tragic case of Michael Jackson exemplifies how limitations of informed consent have profound consequences. Although Jackson was informed about the risks associated with propofol and voluntarily agreed to his treatment, he was not fully aware of the drug's long-term ramifications. If healthcare seeks to achieve positive health outcomes, there is an ongoing need for effective communication and patient education to address the limitations of autonomy and informed consent.

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[1]Tom L. Beaucham, *Standing on Principles: Collected Essay* p, *European Journal of Health Law* 19, no. 5 (2012): 544–51.

[2] Daniel Callahan, "Autonomy: A Moral Good, Not a Moral Obsession," *The Hastings Center Report* 14, no. 5 (1984): 40–42, https://doi.org/10.2307/3561098.

[3] Onora O'Neill, "Between Consenting Adults," *Philosophy & Public Affairs* 14, no. 3 (1985): 252–77.

[4] Onora O'Neill, "Some Limits of Informed Consent," *Journal of Medical Ethics* 29, no. 1 (February 1, 2003): 4–7, https://doi.org/10.1136/jme.29.1.4.

[5] Antoine Aoun, Sibelle Al Hayek, and Flora El Jabbour, "The Need for a New Model of the Physician–Patient Relationship: A Challenge for Modern Medical Practice," *Family Medicine & Primary Care Review* 20, no. 4 (2018): 379–84, https://doi.org/10.5114/fmpcr.2018.79351.

[6] Rebecca Dresser. "Sunday Dialogue: Conversations Between Doctor and Patient," *The New York Times*, August 25, 2012, sec. Opinion, https://www.nytimes.com/2012/08/26/opinion/sunday/sunday-dialogue-conversations-between-doctor-and-patient.html.

[7] Katherine Harmon, "What Is Propofol--and How Could It Have Killed Michael Jackson?" Scientific American, accessed October 15, 2023, https://www.scientificamerican.com/article/propofol-michael-jackson-doctor/.

[8] "Doctor Is Guilty in Michael Jackson's Death - The New York Times," accessed October 15, 2023, https://www.nytimes.com/2011/11/08/us/doctor-found-guilty-in-michael-jacksons-death.html.

[9] B. Lyons, "Medical Manslaughter," *Irish Medical Journal* 106, no. 1 (January 2013): 26–27.

[10] D. R. Hansberry et al., "Are We Effectively Informing Patients? A Quantitative Analysis of On-Line Patient Education Resources from the American Society of Neuroradiology," *American Journal of Neuroradiology* 35, no. 7 (July 1, 2014): 1270–75, https://doi.org/10.3174/ajnr.A3854.

[11] Rebecca Kukla, "How Do Patients Know?," *Hastings Center Report* 37, no. 5 (2007): 27–35.