

End-of-Life Care: Beneficence Undermines Patient's Autonomy

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ABSTRACT

End-of-life care is a decision-making process in which health care providers, patients, and their families play a crucial role in easing the suffering of the patients and their families. Usually, end-of-life decision-making takes place in a critical situation of the patient; therefore, health care providers, particularly, physicians and nurses play a major role in making a decision for the patient's life with regards to updated knowledge and practice. In this view, health care providers face many challenges in end-of-life decision-making due to controversy among equally unfavorable solutions; particularly between two ethical principles *i.e.*, patient autonomy and beneficence. Health care providers often overweigh beneficence over autonomy regarding less suffering for the patient and his/her family. This approach of health care providers raises a question for undermining patients' autonomy and violating the basic ethical right of a patient. To overcome these kinds of ethical challenges, it is imperative to equip health care providers with updated knowledge of advance directives for patients. In addition, patients and their families should be well informed from the beginning to the end stage of the patient stay in the hospital. Besides, each hospital should have an ethical expert committee including nurses to analyze the entire situation and to make the decision in the best interest of the patient and his/her family.

Keywords: *Autonomy, beneficence, ethics, end-of-life care, utilitarianism, ethical dilemma.*

CASE SCENARIO

Patient XYZ was a nineteen years old girl. She was admitted to the hospital after a month of being diagnosed with the metastatic stage of ovarian cancer. She was an enthusiastic teenager, had dreams to accomplish in her life. Doctors provided consultation to her regarding the metastatic stage of cancer; however, she decided to go with full code. Her health condition progressively worsened with time, and thereby a stage came when she became completely dependent. In addition, the cruel bug of cancer has affected the young lungs so badly that she became dependent on non-invasive ventilation support. She was still hopeful, but her parents did not make it to see their fairy in such pain, eventually, the family decided to go with Do Not Resuscitate (DNR). The patient was not given autonomy to decide for DNR status and ultimately passed away.

INTRODUCTION

End-of-life care is being considered a critical stage in one's life particularly when someone suffers from any terminal illness. This phase is not just filled with physical distress of the underlying pathophysiology but also has its psychological detrimental effects. These effects could be related to anxiety, permanent detachment from the family, incomplete tasks, unfulfilled desires, and so on. In addition, a patient's family is also sharing the equal burden of pain associated with their loved ones. However, ethical decision-making with futile treatment

at the end of life is one of the toughest challenges that Health Care Professionals (HCPs) face every day in their practice. These challenges occur as a result of the overriding nature of the four ethical principles namely autonomy, beneficence, nonmaleficence, and justice. Though all the principles are interrelated at the end of life, autonomy and beneficence are the ones that often remain in conflict. It is very problematic for the HCPs to decide between whether to respect a patient's autonomy to decide for his/her life or to give priority to patients' benefits and help them in ending their life peacefully. The above scenario gives a glance of what is faced by HCPs in deciding about futile treatments; such as considering withholding or withdrawing a cure. This paper presents a clinical case scenario of a patient from end-of-life care and analyzes the underlying dilemma between autonomy and beneficence. Further, a discussion is presented through ethical principles and theories followed by recommendations for HCPs and the role of a nurse in an end-of-life care situation.

Analysis of the Case Scenario

In the above-mentioned scenario, the family and the medical staff took the decisions on behalf of the patient. Almost 90% of the females diagnosed with ovarian cancer have advanced-stage disease, and the outcome is a relapse of disease or death [1]. Therefore, the decision of medical staff may justify the principle of beneficence for the patient by weighing the quality of life versus extending non-beneficial treatment. Contrarily, the autonomy of the patient for survival was violated. After the critical appraisal of the scenario, the question that pondered in our mind: "was it justified to unheard the voice of patient's autonomy for the sake of beneficence in end-of-life situations?" This dilemma between

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autonomy and beneficence at the end of life is of central importance to the medical profession. Moreover, health care professionals including Nurses are in a crucial position to assess patients' actual and potential quality of life with evidence-based knowledge.

Justification for the Decision Opt by HCPs

Beneficence is the act of providing benefits to others in the entire possible context [2]. Similarly, in this scenario, the family and the HCPs have given priority to the beneficence of the patient by alleviating the painful suffering. Additionally, as the outcome was demise due to the metastatic nature of third stage ovarian cancer, therefore despite prolonging the low-quality life; the decision was made for the best interest of the patient. Beneficence is not just the duty imposed on HCPs from their code of ethics but is an obligatory act in the light of The Holy Quran. "He who alleviates the suffering of a believer out of the sufferings of the world, Allah would alleviate his suffering from the sufferings of the Day of Resurrection" [3].

Furthermore, one of the two assumptions of non-maleficence is to remove harm and promote well [4]. Therefore, if the treatment options were not withdrawn, then the patient may have gone through all the possible treatment regimens; such as a ventilator support, chemotherapies, and other invasive procedures. This may put physical, financial, psychological, and emotional burdens on the patient and the family. One may argue about the ethical norm of veracity *i.e.*, truth-telling. Biegler [5] elaborated the idea that telling the truth that may give psychological misery to the patient; ultimately comes under the umbrella of maleficence. Therefore, here the principle of beneficence overrides the norm of veracity and helped the patient to leave this world with less distresses.

Compromised Ethical Principles in HCPs Decision

Mutual decision-making and informed consent from the patient are core components of the medical domain [6]. However, these two steps are impossible without fulfilling the autonomy of oneself. The concept of Mill's autonomy has been violated here; the autonomy of an individual is rooted in the conceptions of individual rights, confidentiality, and liberty to select from available alternatives without intrusions from anyone [2]. In the case scenario, the girl wanted to be full code and wanted to fight the battle of survival till the end. However, her autonomy was not respected at all, and the decision was taken on behalf of her family; even though she was above the age of 18 years and fully conscious.

Besides, the ethical norm of veracity was violated here. Deciding for the code status is the biggest decision of anyone's life. Moreover, when the patient is adult and conscious enough to take his/her own decisions, then taking decisions separately without informing the patient; challenges the physicians and nurses' code of ethics. It's a physician's responsibility to adhere to the principle of veracity, as it gives a way forward to respect the

patient's autonomy [7]. On the other hand, it's a nurse's responsibility to advocate on behalf of the patient for their rights [8]. However, in this scenario, HCPs did not raise their voices for not involving the patient in such a crucial decision of life.

DISCUSSION

After analyzing the clinical scenario, we extracted the concept of futility. Futility has two main constructs: (1) quantitative futility (treatment having physiologic changes with no prolongation of life); (2) qualitative futility (treatment does not affect the quality of life but has effects on prolonging it) [1]. In the above-mentioned context, the family and the physicians decided to go with quantitative futility (pharmacology support) because of the poor prognosis of the disease. Therefore, if the physician had decided to go for the patient's autonomy, then, on the other hand, he (doctor) has to violate the principles of beneficence and non-maleficence. Likewise, to prolong a patient's life; quality of life could have been suffered badly. Thus, not choosing a futile treatment was the best possible decision.

We justified our position in the light of Kant's autonomy and theory of act utilitarianism; thereby, adhering to the principle of beneficence and non-maleficence. Kantian autonomy does not deal with individualism rather it discusses the communal concept of autonomy *i.e.*, respect for autonomy [9]. In the scenario, the medical staff decided after analyzing the whole context in light of the risk-benefit ratio. Due to undergoing physical and psychological trauma, the patient may have exhibited the weakness of will and therefore was not able to judge her life from a broader perspective. Contrarily, the theory of utilitarianism could be applied here to forecast the potential effects of the decision. Utilitarianism deals with maximum happiness for a maximum number of people by analyzing each context separately [4]. In lieu of the scenario, the patient's and family's sufferings were relieved.

Recommendations and Role of a Nurse

First of all, it is the utmost duty of HCP to provide all the useful information pertinent to the disease process to the patient and their families. This is one of the prerequisites for informed consent and patients' bill of rights. Instead of just providing information to the patient, the deliberative model of decision-making should be used especially in end-of-life situations. In this model, there is a mutual collaboration of decisions between patients' preferences and physicians' proposed choices. Thereby, balancing evidence-based practice, patient education, and autonomy [10].

Secondly, autonomy should not be solely viewed as an individual perspective without any rationale. However, it should be rationale based, moreover, in end-of-life cases where families are under the double burden of stress; Paramedical staff should help them in analyzing the context in the light of the risk-benefit ratio.

Thirdly, truth-telling is an obligatory part of a physician's code of ethics and it should be in the best interest of the patient. Accordingly, in dilemma related to futile treatment; truth-telling should be initiated from the very beginning so that peaceful death could be achieved. However, in situations where the patient exhibits weakness of will and is unable to think rationally, then truth-telling can be violated as the outcome will be patients' beneficence.

Lastly, though the decision taken by the family and medical staff was right in our point of view, but could have been reversed if the nurse's advocacy for implementing the deliberative model has been used from the very beginning. In futile treatments, the role of a nurse as an advocator, counselor, and collaborator between the patient, family, and physicians could help in bringing win-win outcomes. The nurse's role as a true mediator in this process is of crucial importance. Furthermore, the inclusion of Nurses being the front liners in ethical and decision-making committees shall be given priority in health care settings.

CONCLUSION

In a nutshell, the advancements in the health care setting have gradually become a challenge for health care providers in the best interest of patients and their families. End-of-life care decision-making has not only gained ample attention from health care policymakers but has been debated for the best outcomes for ages. Health care providers usually suffer from ethical dilemmas in their practice. Among the others, autonomy and beneficence come into conflict in most situations. The edge of beneficence over autonomy has raised questions over the code of conduct for health care professionals. However, the decision of beneficence has always been taken for the sake of better outcomes for the patient and his/her family. A similar approach has been utilized in this paper to overcome further suffering

for the patient. In short, priority should be given to the patient's comfort rather than just prolonging the dummy breaths.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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