

Is Health a Right or Family's Property?

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ABSTRACT

We are often geared by the notion that health is an individual right and every individual has equal rights and opportunities for healthcare. However, in Eastern society, the family conquers the right of the individual and decides the treatment modalities. Alongside, healthcare professionals have regulated themselves with the culture of society. Thus, the autonomy of the individual is being compromised. This has enforced us to think about whether "health is an individual's right or a family's property"?

Keywords: *Healthcare professionals, amputation, autonomy, theory of ethics of care, obligation.*

SCENARIO

A 70 years man was admitted to a tertiary care hospital for diabetic foot wound debridement. His co-morbid were hypertension, uncontrolled diabetes and malignant myeloma for which chemotherapy was being done. After examination, the surgeon decided that the only debridement will not be sufficient and amputation of the foot is necessary. His son signed the consent on behalf of the patient and requested that his father should not be told about the amputation; the surgical team agreed. On regaining consciousness, the patient became anxious, agitated, and started having angina. His Troponin-I leaked, ABGs worsened, required BIPAP and transfer to ICU. He told his family that if he was informed before he might not have chosen surgery as an option rather preferred to have died on his feet. The primary care team took the decision based on medical management to save the life and did not take into account the quality of life of the patient.

Healthcare professionals are gearing up the challenge of improving the survival rate in the world of challenging infections and progressive diseases along with safeguarding the dignity of people. The preference of people changes with a change in their health statuses and different stages of their lives. A secondary analysis was conducted in Canada on the role of patients in the decision-making of their treatment through a series of interviews and focus group discussions; they found out that no contributor preferred an autonomous decision [1]. Yet, most participants did not want to go for an inert role either. Instead, all study participants strongly preferred a mutual decision. This preference suggested that the more knowledge people have related to their health condition, the desire of patients to participate in their treatment increases.

This scenario grabs attention on multiple questions that are imperative from an ethical standpoint. Does being compassionate for a dear family member can overshadow the independence of the person? If in case of life and death conditions, should autonomy be given priority? Does screening the reality for the advantage of a person is the right approach? This paper will highlight different aspects of the above situation based on an ethical approach.

AUTONOMY VS. THEORY OF ETHICS OF CARE

It is a right of every conscious and competent adult individual to decide about his life, health and its consequences [2]. Routinely in a hospital setting, before undergoing a surgical procedure, a person is given knowledge regarding his disease process and what procedures need to be done; he is autonomous to make a decision about taking the aggressive treatment or not, and to bear its consequences [3]. Patients desire that they should be involved in their care decision [4]. Therefore, the patient's autonomy should be given priority as advised by different religions and societies. Moreover, there should be respect for the autonomy of patients who have the capacity to make decisions. Autonomy requires both liberty and the capacity to take autonomous decisions [5]. Therefore, if a patient is fully capable enough to make decisions, must be given liberty to opt for his decisions; this, in turn, will lead to satisfaction of the individual.

On the other hand in Eastern society, most of the decisions are being taken by family members by virtue of care. The family takes responsibility for the patient, care decisions and the consequences that might occur with the patient. They do not want to inform the patient regarding the deteriorating conditions as they might feel blue by hearing a complex health situation; this is evident in day-to-day practice too. The theory of ethics of care imposes family to justify their responsibility to a loved one. However, it brings some obligations too along with responsibility. Obligation-based ethics of care describes

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the actions based on rules rather than consequences [6, 7].

PEACEFUL DEATH VS. DUTY OF CARE AND RELATIONAL LOVE

Determining the pavement of treatment choices becomes challenging when the patient is having critical illness along with comorbidities; whether to direct the patient for futile treatment or not! The question arises whether the patient will benefit from an improved quality of life (QOL)? Will survival be promoted? Considering the risk-benefit ratio, will the treatment be cost-effective and does the patient need this aggressive treatment?

Quality of life (QOL) is as imperative as saving a life. In view of the critical medical condition along with other comorbidities, patients might select non-futile treatment rather aggressive one as people with growing age wish to die peacefully. They want to live their lives with comprehensive mental and physical functioning; they do not prefer to be burdened. While taking the decision regarding treatment options, they ponder four aspects: effect on QOL, the probability of success, emotions and finance and outcome on lifespan [8]. In this case, nobody acknowledged his preference of not adopting futile treatment rather tried to promote the patient's lifespan and minimize suffering. They tried to imply the moral obligatory rule of beneficence; explicitly benevolence.

However, physicians are bound to the Hippocratic Oath as a central obligation to their profession; thus they cannot give up when there is a single chance of survival. The physician's prime responsibility is beneficence to the patient, whereas in doing so they override the patient's autonomy, this shows paternalism by a physician. Similarly, the family is bound to the relational love towards the patient and despite having financial challenges they cannot let their loved one die without taking a single chance of interventional management. Also, the family's autonomy plays an integral role in deciding loved one's treatment modalities in Eastern society as they are the key people involved along with the patient.

DISTRIBUTIVE JUSTICE VS. HEALTH- A RIGHT

To provide fair, equitable and appropriate distribution of benefits and burdens is termed as distributive justice [5]; this suggests that healthcare resources be distributive according to the need. Spending health care resources on a severely ill patient with multiple diseases at the age of 70 years in a developing country like Pakistan is an argument to contemplate. In developing countries, resources are scarce with respect to health care and there is a dire need to allocate resources according to priority and benefit. The resources including surgical expenses, ICU admission, ventilator expense, and inotropic costs could have been expurgated if aggressive treatment would not have been done. Though there were no other patients waiting in this case, still these

resources could have been utilized for other patients in the state or country in need. Therefore, it has become necessary to set limits on the treatment of chronic and degenerative diseases thereby promoting equity [9]. The concept of distributive justice not only inspires equity but also focuses on communitarian theory wherein they emphasize community-related moral obligations. The right of the whole community must be enlightened when taking into account the idea of supply provision [5]. It clearly emphasizes the need for distributing resources to the community on the basis of equity rather than an individual.

On the contrary, the World Health Organization (WHO) promotes the notion of equal rights and opportunities for every individual [10]. Availability of health care to vulnerable and aged populations must be ensured according to this perception. It is the right of every individual, regardless of age, gender, and disease, to avail the best quality healthcare being a global citizen. The aspect of the equal right to health works on the principle on Egalitarian theory- which states that all humans should be treated equally because they are bent alike along with equal moral statuses [5]. According to this theory, if we ponder upon the disease, it was curable and does not take the lives of every individual. However, exceptions are rare in terms of comorbidities.

THE JUSTIFICATION

In the afore-stated scenario, I reflect that my position is ethically sound and defensible. The patient is an autonomous individual, therefore autonomy is his foremost right that needs to be safeguarded. He must be given the first hand in decision making when it comes to the discussion of his treatment and lifesaving modalities. If a patient is brutally ill, his option of not prolonging death must be respected by health care providers [11]. This consecutively will lead to justified resource distribution to those who need the utmost. In all, it will lead to a victorious situation where the person's autonomy would be safeguarded, the family will be contented spending time with the loved one and the deprived one will receive institutions' resources.

CONSEQUENCES OF MY POSITION

The consequences that will ensue according to my stance would provide beneficence to the patient and institution but will make the family go through the emotional trauma by being helpless in decision making. Since the patient will be the autonomous entity and this can lead him to take any action that can bring detrimental effects in his life thus letting the family seeing their loved one suffer and die due to reversible causes. Moreover considering the quality of life and dignity of patient's body, if aggressive treatment has been prohibited at all times, medicine would not have flourished and there would not have been different treatment modalities originated that now are a blessing for many people in improving the survival rates and enhancing their lifespan. Also, glancing from

the lens of distributive justice, it would be unjust for the people who actively need the resource and might not make the paramount use of that reserve.

CONCLUSION AND RECOMMENDATIONS

Every individual is born independent and respecting autonomy is a cornerstone in medical practice. Nevertheless, the family has a significant role in decision-making in Eastern society, but the patient's rights should be kept foremost. Nonetheless, nurses and doctors also work as patients' advocates. They make a sound decision related to the patient's condition and decide whether the patient requires futile treatment or will the QOL be compromised. Viewing the case, the following are the recommendations that can enhance proper decision making and can bring improve outcomes for patients, families, and organizations.

Collaborative Decision Making: The patient, family and health care team should collaboratively discuss the patient's condition in detail, the treatment modalities and the consequences of modalities. This would create respect for each other's views and advice and will bring a positive outcome.

Use of Multimedia as a Guide: Healthcare providers can use videos and images to make patients and family understand regarding the surgical process since wound debridement and amputation is a painful process and brings about major disability and psychological symptoms. This would prepare the patient and family for sound decision-making.

Support Groups: The patient should be introduced to other patients who are suffered or have suffered from the same problem; in order to share the feelings and identify positive coping skills. This will also help them in making proper decision making for them based on their consequences.

Care Counselling Sessions: Counselling sessions are done at different levels but this should be implemented in hospital policy to plan a care counselling session for patients having poor prognosis and decisions should be done on mutual understanding.

Family and Patient Alone Meeting: Healthcare providers must give a room to family and patients to spend some time together, share feelings for each other and ventilate out their stressors. This would even become a beautiful memory for the family when the patient leaves the world.

Curriculum of Undergraduate Medical and Nursing Students: The undergraduate medical and nursing students must be taught ethical principles in their study curriculum. The students must be taught during their theoretical classes about the different ethical principles that are followed in healthcare practice *via* scenarios and role-plays. Also, they should be involved in ethical scenarios during their clinical practicums in order to have first-hand training.

CONFLICT OF INTEREST

The authors certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

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