



Autonomy to refuse: Please doctor, I want to fast, I don't want my medications

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ABSTRACT

This paper discusses the ethical issues of patient autonomy based on a case of a patient who refused medication during Ramadhan fasting period. Issues on patient autonomy include the right of a patient to refuse medication, informed decision making, the importance of effective communication and the physician roles and responsibilities are discussed. In conclusion, patient autonomy must be respected and valued. However, the need of effective communication in facilitating informed decision making to improve doctor-patient relationship, should not be overlooked and compromised.

KEYWORD

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Introduction

In a clinical setting, practitioners often encounter ethical issues which put them in a difficult situation. One of the most common ethical issues that arise is patient's autonomy which refers to the right of the patients to make their own decision (1). However, the right to autonomy has to correspond to their level of understanding and the impact of their decision they are making to themselves and the people around them. Among the elements that may influence decision making are their past experiences, religious practices, cultural values as well as their trust in their health practitioner to manage them. Patient-doctor relationship plays a major role in the practice of autonomy in the healthcare setting. The following case summary illustrates a common scenario which practitioners often

encounter especially in treating someone with chronic illnesses.

Case summary

A 45-year old Muslim married lady with three young children, who is a known case of rheumatic fever with mitral regurgitation, presented with severe heart failure. She was treated conservatively on oral and intravenous medication on admission. She was showing gradual signs of recovery. However just before the fasting month of Ramadhan, she informed the medical officer that she would not take any oral and intravenous medications during the day in Ramadhan. She requested to be given treatment after breaking her fast. The attending medical officer (MO) was upset and insisted the patient to continue her medication for her own benefit. However, the patient was adamant and

stood by her decision. The MO informed his consultant. The consultant failed to convince her as well and requested the patient's husband to be called. The husband later informed the medical team that his wife was a very pious woman and has never missed a single day of fasting for the last 20 years. "I told her she might even die", but she said "If that is the wish of Allah SWT, be it so". A religious scholar was invited to discuss with the patient and explained to her on the issues of treatment during the month of Ramadhan. However, the patient still refused the treatment and continued her fasting. Her condition deteriorated and she died two days later.

Ethical Issue Discussion

This case demonstrates a clinical ethical dilemma faced by the medical team. We will discuss several ethical issues and discussion points are as follows:

1. What are the ethical issues in this case?
2. Does the patient have the right to refuse treatment?
3. Can the medical team override the patient's decision?
4. What the medical team can offer?

Ethical issues in the case

The issues identified in this case are in respect for autonomy beneficence and maleficence. However in this case the respect of autonomy is in conflict with maleficence and beneficence. The patient has the right to make an informed decision. However respect for autonomy and autonomous decision making may give rise to some neglected negative implications. Physician has the inclination to offer treatment options and requesting the patient to choose but a competent patient may not have the confidence to choose or is worried about making the wrong choice and thus insisting the patient to decide may cause the patient to feel abandoned and later lose hope.

This patient's medical condition is a treatable one the patient had shown a positive response towards the given treatment. However, the situation is complicated by patient's refusal to

continue her treatment, during the fasting period. Her refusal to be treated may have originated from the patient's religious beliefs and her personality. The issues of patient's right to refuse medication, i.e. patient's autonomy, may defer the treatment benefit and might result in an adverse outcome for the patient. The managing team's disinclination to follow the patient's wishes is understandable as failure to treat will result in an adverse outcome to the patient going against the ethical principle of maleficence (do no harm) and beneficence.

The importance of effective communication in this case is very crucial. The patient as well as the family members has to understand the grave prognosis of the patient's medical condition if she is not treated adequately. Discussion on her condition revolving on her autonomy and confidentiality of her medical information (revealing her condition to the religious scholar before religious counselling), privacy (discussion to involve other family members), the need for truth telling (1) and dealing with conflict of interest between the management team and patient's request. Clear evidence based explanation of the treatment regime offered and the expected outcomes to the patient, with the treatment and without the treatment must be given.

As this problem evolved from the patient's religious beliefs, the differences between the religious understanding of the medical team members and the patient's beliefs need to be addressed. The medical team must show their empathy to be able to listen to her concerns and convey appropriate advice which could enable her to decide in a manner that fulfils her religious beliefs and practice and at the same time alleviate her medical symptoms. Discussion should also focus on alternatives methods of treatment, for example to replace oral medication or using longer acting drugs if available and must be reinforced with the religious scholar's help to explain the concept of *rukhsah* which allows an ill-person to be exempted from fasting.

The patient's refusal of treatment in spite of a possible death outcome of non-treatment may

indicate that the information conveyed to the patient may not have been adequate or have been given in a threatening manner rather than empathetic in nature. This illustrates the role of having empathy in counselling. Her pious personality should not deter the medical team from trying to counsel her to make the right choice.

Patient's right to refuse treatment

In general, we understand that adult patients always have the right to accept or refuse treatment. In this case, the patient appears to have mental capacity, maturity and independence to formulate her own decision. Her faith may be the main contributing factor in the decision-making process. This is supported by the information derived from her husband on her pious personality. Despite that, she does seem to have a different understanding of her own medical condition and choice of treatment.

Respecting patient autonomy usually means enabling or allowing patients to make their own decisions, whether to accept or refuse any medical interventions such as medication. Entwistle et al, 2010 quoted Beauchamp and Childress' definition of autonomous decisions as those made intentionally and with substantial understanding and freedom from controlling influences. Thus, it is the attending physician's responsibility to ensure that the patient has the capability to make a decision with adequate information within the time given. The doctrine of informed consent necessitates the information on the details about the illness, intended benefits of the treatment, alternatives and possible risks and complications of treatment before seeking consent from the patient (2). This discussion must be done thoroughly and gently. The patient must be aware that the result of her refusal to treatment may lead to ill health and she has to be responsible for the outcome. Careful and detailed documentation of all the steps taken and her final voluntary refusal are important to avoid medico-legal issues, and must not be overlooked by the managing team.

Can the medical team override patient's decision?

In short, the simple answer is no. However, some bioethicists argue that if a person's beliefs concerning some matters are false, inconsistent with each other or he or she is not well informed, then the person is not autonomous with respect to the matter (3). In this case, the patient did not consent to treatment during the day but the medical team still has the responsibility to continue observation and treatment that has been agreed by both parties during the non-fasting period. However, if the person lacks mental capacity, legal competency and independency to make decisions, then the medical team or legal guardians who are responsible by law can make a decision on their behalf. However, in this particular case, the patient was mentally and legally competent and made the decision voluntarily.

Before accepting the patient's decision, it is important for the medical team to look into the possibility of the patient's desires and expectations of her faith which may affect her feeling as a person. Commonly, the relevant issue may not have been understood or explored by the family and the physician. The team also must ensure that all the advice given is consistent with the best interest of the patient and not others. Once the decision of refusal was made, it must not affect the on-going patient-doctor relationship.

What the medical team can offer

The role of the physician is to determine the best treatment for the patient's medical problems based on the physician's knowledge, judgment and experience and present the recommendations to the patient. (2). In a situation where the patient refuses treatment at the expense of her life, medical practitioners are still bound by the principle of beneficence in treating the patient (4). The most important aspect is for the practitioner to improve the doctor-patient relationship and preserve the trust and respect between the doctor and the patient during the ongoing consultation. Trust is a very important criterion to ensure that the patient will perceive the

doctor's empathy and decision are made based on patient's best interest in making their decision. This process of mutual agreement and coming to a common ground will also aid in improving the patient centered or holistic care.

Since the patient is a pious person, the assistance of a religious person is helpful and beneficial since this involves her personal belief. In the above case, the help of a religious scholar has been sought. This is to assure her that, Islam has given exceptions from performing the otherwise obligated practice. The involvement of her husband and other family members in decision making is also an important supportive process.

In certain circumstances, modification of the treatment may be possible to suit the need of the patient. In this case the oral medication may be adjusted may be during before the start of fasting and following the break of the fast. The intravenous medication can be an alternative route as it won't nullify her fasting.

It is very important for the medical practitioners to understand the variety and influence of local culture and religious practice as part of holistic care. Physicians should explore the reasons behind patient's decision and the legal implications of voluntary decision making.

Conclusion

This case may not be the excuse for not valuing patient personal autonomy. When discussing an ethical case, it is very important to determine what are the fundamental issues involved before deciding on the mode of intervention. In this case, her disease was a treatable illness thus it favored lifesaving treatment as the best available option.

In seeking consent, patient should be given sufficient information to make an informed decision. In the aid of obtaining the consent, medical practitioners may enlist help from any parties including the family members, community leaders as well as religious scholars depending on the need of the situation. The value of family conference cannot be overemphasized

in this matter because they are the people who are closely related to the patient and will be affected directly as a result of the decision made. In the case of refusal, medical practitioners would need to adhere to the principle of beneficence, and not to let the patient suffers without any back up plan and follow up. Good doctor-patient relationship may results in better outcome of the discussion and has great influence on the decision by the patient and their family (1).

Ethical dilemmas often involve conflicting ethical principles and are frequently encountered by medical practitioners such as saving life versus allowing peaceful death, the interest of the professional and the health care system versus the patient interest, as well as curative versus only focusing on the quality of life for the patient. Faith and beliefs are fundamentals in ethical consideration since personal decisions are often influenced by these factors in many cultures throughout the globe. Thus the practice of clinical ethics needs to take into account the patient's faith, cultural beliefs and personal practices.

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