



Autonomy in refusing life saving interventions: religious and cultural misconceptions

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ARTICLE INFO

Received : 28/10/2013
Accepted : 03/11/2013
Published : 09/03/2014

KEYWORD

Autonomy
Consent
Religion
Refusal of treatment
Culture

ABSTRACT

Autonomy is widely accepted to be the third pillar of medical ethics. However, if it comes to refusal of life saving treatments, some extra considerations are necessary, especially if decisions are made by surrogate decision makers. Four cases of problematic decision making are presented here, followed by a discussion about the cultural and religious misconceptions about the rights of surrogate decision makers.

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Introduction

Autonomy is one of the pillars of medical ethics. It is of extreme importance in research on human subjects. When this principle is applied to the delivery of medical services we often face dilemmas and challenges. In this paper 4 case scenarios are presented.

If a patient is standing on the balcony of the tenth floor and is ready to jump, no one in their right mind will explain in a cool way the dangers of jumping and then let the patient make his or her own decision. How is this different from a situation where a patient is refusing a lifesaving treatment? Do we, in the name of autonomy and non-paternalism just give the facts and let the

patient make his or her own choice? Do we have the duty to actively convince the patient of the right choice? When decisions about refusal of life saving treatments are made by surrogate decision makers because the patient is either not competent or perceived as being under control of the surrogate decision maker, major problems may occur.

The four case scenarios presented here illustrate the ethical dilemma faced when a surrogate decision maker intervened to refuse or delay lifesaving interventions, sometimes with detrimental outcomes for the patient. The cases are fictitious but based on a variety of real experiences by the contributing doctors.

Case summaries

Case 1

Mrs. A, a 40-year old Muslim lady, was admitted with 2 days history of generalised abdominal pain. Within 12 hours of admission, she developed an acute abdomen and deteriorated with low blood pressure. Surgical input was sought and it was felt that urgent exploratory surgery was indicated. The patient, who was fully conscious, consented to surgery and signed the consent form. However, her husband disagreed to this after discussion with his family. This caused considerable delay in surgery and when patient's husband finally consented the next day, she had deteriorated and arrested before surgery could be carried out.

Case 2

Mrs. B, a 33-year old Muslim lady, Gravida 3 Para 1, with one previous caesarean section, at 38 weeks period of amenorrhoea was planned for elective caesarean section. She agreed to the procedure during her last obstetric visit. Abdominal examination revealed twins in transverse lie. However, she did not turn up on the day of scheduled admission. Further investigations revealed that the husband disagreed to the Caesarean section and was not cooperative with the health care team. The local primary care team visited her at home during which the husband was not present, and advised her to proceed. She was very reluctant to disobey her husband. The case was referred to the local healthcare authority and a team was sent to the house to discuss with the whole family. After a long discussion with local health authorities, the husband finally agreed and a set of healthy twins was born.

Case 3

Boy C, a 15-year old Muslim patient, was diagnosed with acute myeloid leukaemia in advanced grade (M5). He was admitted to the hospital and received suppressive treatment and went into remission. His brother was a compatible donor with perfect HLA match for bone marrow transplant. The doctor in charge advised the patient's family to carry out the transplantation but the parents consulted a

“religious” figure who advised them to follow religious rituals to be cured. The parents decided to give up the medical treatment and follow the “religious” figure's advice. Boy C relapsed and died.

Case 4

Girl D, a 12-year Chinese old mentally challenged patient was hit by a car while crossing a road. She was brought to an accident and emergency department in a semiconscious state with unequal pupillary size. An urgent CT brain revealed a large extradural hematoma on the left side. A life-saving surgery to remove the intracranial clot was indicated and was communicated to her father. However, her father refused to give consent for the surgery. The girl expired within 2 hours.

Ethical issues

The following issues can be identified using the concept of MERCI:

- **Medical Issues:** Each case presented with conditions carrying a dismal prognosis unless a potential life saving therapy was administered, which was refused by the close relatives of the patients

- **Empathy:** The above scenarios must be extremely stressful with a significant impact on the patients and their families. As empathetic doctors we should realise and be able to express our awareness of the turmoil caused by acute or chronic life threatening events. They tend to fear the unknown medical treatments and their outcomes. Many interventions are surrounded by misguided beliefs and misconceptions about harm.

- **Rights:** All women and children have the rights to receive the best possible treatments. Women have the right to make their own decisions. Children should be able to participate in the decision about their care. Is this commonly practiced?

- **Communication:** The doctors should be aware about the feelings of all family members. We have to explore fears, ideas, concerns and expectations. Effective communication between doctors and the patient and the family members is crucial

- **Insight:** Proper patient education should be performed and the team should perhaps encourage the combinations of traditional therapies and allopathic therapy. At the same time the doctors have to be aware about the health beliefs of the patients.

Discussion

Both Mrs A and Mrs B were in a life threatening medical condition. They were aware of the situation and had both consented to treatment as guided by the doctors. Unfortunately, their husbands denied them their rights to make their own medical decision. In the case of Mrs A, this led to delay in treatment and ultimately resulted in her death. Her husband's decision to deny her treatment is a classic example of how one's autonomy has been taken away. Had the husband agreed and supported her, the outcome could have been different. On the other hand, although Mrs B's fate was more desirable, should her husband have continued to disagree with the caesarean section, she could have ended up with the same fate together with her unborn twins.

There are many legal systems to protect women's rights (1). The Convention on the Elimination of All Forms of Discrimination against Women in 1979 is often described as an International Bill of rights for women. We should ensure to women appropriate services in connection with pregnancy, confinement and post natal period. And we have to consider this statement to be implemented in these cases.

The Quran states that men and women are equal (2), but states in 4:34 that "Men are the protectors and maintainers of women, because Allah has made one of them to respect the other, and because they spend from their means. Therefore the righteous women are devoutly obedient and guard in the husband's absence what Allah orders them to guard." Although this is stated in the Quran, the relationship between man and wife is more complex with social and cultural influences. In most societies, the men resume the role as the head and protector of the family. However, in the case of Mrs A and Mrs B, the husbands took the role as dictators and

made decisions for their wife against their wishes and jeopardized their life and safety respectively.

According to Anisah Che Ngah "an adult person has the right and capacity to give or withdraw his consent to treatment. In order for consent to be valid, it must be made without compulsion. Hence, if consent were obtained by whatever means which is not considered free and voluntary, it would be rendered invalid under Islamic Law including undue influence from the physician, parents or near relatives" (3). Hence, in the cases of both Mrs A and B, their husbands should have honoured their wish from the outset. The cases of the child with head trauma and leukaemia both address the issue of parents making potentially dangerous decisions on behalf of their children.

In many countries there are laws protecting the children against such decisions. For example in Malaysia there is the child protection act (4) giving the right to the doctors to override potentially dangerous decisions from caretakers.

The problem arises when doctors are unaware of the legal possibilities and rights of the children. Even if they are aware it is often extremely difficult to address the issues properly and apply the right procedures to obtain legal protection for the child. Ideally every hospital should have a standard operating procedure regarding potentially dangerous decisions for children by caretakers.

In children with chronic conditions such as cancer or mental disability, parents may prefer no intervention to reduce the chronic suffering of the child and the family. Beliefs in traditional medicine need to be addressed by the empathetic doctor. It is quite often recommendable to encourage parents to continue with traditional therapies while not depriving the child of evidence based medical interventions. Beside this, if the child is capable of understanding the issues, the ideas and feelings of the child should be taken into consideration: they should be allowed to give an informed assent (5).

There are certain guidelines provided by Islam on decision making process. It is clearly stated in the Quran that women have similar rights to that of men on beneficence issues. The husband's role is to lead and protect the family and it doesn't mean that he has the dictatorial power during the decision making (6).

Collective discussion and decision are encouraged and is known as 'syura'. Those involved may not be only the husband and wife but can also include other persons. The possible solutions will be discussed and the best one will be decided as a consensus (6).

The decision making process is covered under the Islamic social system (*Muamalat*) which in turn a component of Islamic Syariah (7). Both share the same objectives that is to preserve ,in the order of priorities: religion, life, mind, progeny and property (8). Therefore, in any decision making process in Islam, the decision should abide to the above objectives. Protection and salvation of life come before everything except the religion.

When it comes to seeking the best clinical treatment to patients, it is obvious that it is the responsibility of the patients and their care givers to seek and comply with the clinical advice from experts (6). Therefore, refusal of treatment against clinical expert advice is not part of Islamic teachings. The autonomy of a mature adult to decide needs to be respected. "Syura" process, if it is to be practiced, should not delay any lifesaving medical intervention.

Conclusion

The case scenarios illustrate the need of adequate patient education about their rights in cultural and religious context. The doctor has to be aware about these rights and about the available legal protection that may be applied in these situations. Effective communication may help in the prevention of adverse outcomes.

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