

Hysterectomy of Mentally Disabled Female: An Ethical Dilemma

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ABSTRACT

Menstrual hygiene of mentally disabled female is one of the important concerns for their care providers that need to be addressed. Performing hysterectomy of such individuals' is becoming a trend of society that arises many ethical questions. This commentary paper is based on a case of an adult female, who is unable to perform her menstrual hygiene. Therefore, this paper aims to address this scenario from an ethical, global, and Islamic perspective and attempts to provide a reasonable justified and systematic framework to make sound decisions in similar cases.

Keywords: Hysterectomy; Mentally disabled; Non-maleficence; Consequentialism; Right based ethics; Paternalism; Duty based ethics

INTRODUCTION

Intellectual Disability (ID) has been defined by the World Health Organization as "a state of arrested or incomplete development of mind, which means that the person can have difficulties in understanding, learning, and remembering new things, and in applying that learning to new situations". Approximately 300 million women and girls around the world have an intellectual, mental, sensory, and physical disability. Globally, women make up three-fourths of the disabled people in low and middle-income countries [1]. Menstruation is a normal physiological process for every female that needs to be managed properly with hygienic measures. Individuals with Intellectual Disability (ID) cannot take care of her menstrual hygiene therefore; their caregivers are the ones who manage their menstruation. And it could be very challenging for them to take care of such an individual. Therefore, their caretakers might suffer from emotional and physical fatigue.

CASE SCENARIO

Author experience this kind of situation in which a 19-year-old female brought to a gynecologist by her mother for hysterectomy. The doctor inquired about the reasons for this decision. Then the mother told her that she is mentally disabled and cannot perform her menstrual hygiene. I am the one who takes care of her during menstruation days and now I am also getting old and suffering from arthritis. Thus it is strenuous for me to face this situation every month.

This situation provoked some questions under the umbrella of ethics. Does this option benefit for the patient and family? Can it violate the individual right? Why mother is taking this decision?

How she will be accepted by society without her reproductive organ?

POSSIBLE REASONS FOR DECISION

Possible reasons for the mother's decision could be that the mother cannot take care of her mentally disabled daughter because she is getting old. She might be afraid of her potential care provider because, in our context, societal values do not allow a father or brother to give personal care to the daughter or sister. The mother might be afraid of pregnancy and sexual abuse of her daughter. This situation might be embarrassing for her and other family members. Societal values and pressure could be another reason.

In the Pakistani context, societal trends and values play an important role in making such painstaking decision. Our society takes this situation as a taboo or stigmatizes the disability and its consequences. So caregivers and families of sufferers feel overburdened and low self-esteem due to lack of social and emotional support. Therefore, parents of intellectually disable females take such decisions without considering any other alternative solution due to societal pressure. Moreover, this condition of sufferers restricts their families' movement in society because they cannot leave their daughter alone. Hence, the mother is seeking for hysterectomy of her daughter [2,3].

CASE ANALYSIS

According to Edward De Bono, "An expert is someone who has succeeded in making decisions and judgments simpler through knowing what to pay attention to and what to ignore" [4]. While the interpretation of this scenario I came to know that it is very difficult to deal with such meticulous cases. Such cases are indebted and less talked in our society. Therefore, a critical point in such

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cases is to make a justified and reasonable decision by analyzing it under the light of ethical principles.

NON-MALEFICENCE VERSUS CONSEQUENTIALISM

Non-maleficence “do no harm” is prima facial [5]. Thus sufferers’ do not be harmed. Surgery is the undue harm to the individual and may develop complications. Instead of giving harm other alternative options include training and guidance of sufferers’ and their primary care providers about menstrual hygiene should be considered. However, Intellectually Disabled (ID) individuals have learning disabilities so, they cannot learn menstrual hygiene and prone to reproductive tract infections. Ultimately their mothers or primary caretakers are the ones who suffer. Moreover, siblings of sufferers could be affected negatively and feel embarrassing to see this strenuous circumstance every month. As they might be in pubertal age and they can adopt such behavior. If it does so then how family burden to take care of such a child will be justified?

Contrary to this if we look upon consequentialism theory which considers the consequences of actions. Performing hysterectomy for intellectually disabled (ID) individuals promotes good for themselves, mother and other family members. Individuals’ discomfort, irritation, restlessness, disturbed sleep and aggressiveness associated with menstruation will subside. Mother's exertion related to her daughter's menstruation that she is the one who changes her pads and clothes will also subside. Other families members who effected by the aggressive behavior of their child and feel embarrassed in front of each other related to menstruation will be abate. Furthermore, it reduced the family stress and financial burden as they monthly purchased the menstrual product for their daughter.

RIGHT BASED AND DUTY BASED ETHICS VERSUS PATERNALISM

According to right-based ethics, every person has its rights. Individuals having an intellectual disability doesn't mean that they don't have human rights. Being a female it's her right and dignity to preserve her reproductive organ and it should be respected by others. The right of the sufferer cannot be suppressed for mother/caregiver interest. In the present case performing surgical procedure lead to violation of human right. Although parents' right over their child having ID can extend to hysterectomy for menstrual hygiene. But the right of a female with Intellectual Disability (ID) cannot be violated for mother interest that she cannot take care of her daughter during mensuration days. Moreover, according to duty-based ethics theory, a mother has to take care of her daughter even in her mensuration days [5-7].

Contrary to this, according to the paternalistic approach interruption in a person's right to do good without his/her will can be overridden. In this case, the mother is taking a paternalistic approach to promote good for her daughter. The mother's concern is not to violate her rights but to give her respect and dignity [8,9]. As she is not eligible for marriage due to ID that supports mother decision. If the reproductive rights of sufferer ignored because of not eligible for marriage then how this decision will justify her right? It's right of a female to retain her reproductive organ regardless of intellectual disability.

GLOBAL PERSPECTIVE

International ethical guidelines suggest that hysterectomy is not an appropriate decision to cope with menstrual hygiene issues for intellectually disable females [10]. Globally, nontherapeutic hysterectomy for the purpose to cope with menstrual hygiene is a common issue. In developing countries hysterectomy for menstrual hygiene performed with the court authorization. In which doctors' opinions and levels of intellectual disability taken into account. But in developing and low middle-income countries, the court is not involved in such decisions.

ISLAMIC PERSPECTIVE

In Jordan 64 to 70 nontherapeutic hysterectomies performed annually to cope with menstrual hygiene. So, Islamic countries scholars joined and signed the Article “convention on rights of persons with disabilities” in 2012. It states “there is no provision in the law that permitting or authorizing such operations. And it is not permissible to cause any harm to a person without any medical justification [11].

Moreover, Fatwa (Fatwa means the Islamic perspective regarding a certain issue) was issued by the Council of Fatwa and Research and Studies that states “It is forbidden in Islam that girls with intellectual disabilities undergo hysterectomies without any medical indication due to risks and negative effects of operation”. Moreover, in the Islamic context “Women should treat in the same way when she is on her period as when she is not. We need to understand that menstruation is a natural phenomenon. If periods were a thing to be ashamed of, why would God give women periods?” [12].

MY POSITION AND ITS JUSTIFICATION

After interpreting this case in light of ethical principles, global and Islamic aspects, I realize it is very difficult to make reasonable decisions in such cases. In my opinion, surgery should not be performed for the sake of mother interest. It is undue harm to the sufferer that could develop a complication. Alternative options should opt rather than surgery. Medication that stops mensuration could be used after taking an opinion from the doctor. Training and counseling sessions for such individuals and their families could be arranged.

I consider my position for this case is morally and ethically appropriate that is in favor of affected females. In addition to this Islamic and global aspect supports my position. There is no doubt that it is a very challenging situation for the caregivers and other family members but individual rights cannot be suppressed. However, any decision that violates or could violate a human fundamental right should be avoided or viewed carefully.

POSSIBLE CONSEQUENCES

Every action has its consequences. If I looked upon the option of performing surgery, it has many consequences. Firstly it is undue harm to the individual; secondly leads to violation of the female right and thirdly surgical complications may occur. Surgery expense and treatment costs increase the financial burden on the family. Contrary to this, if surgery is not performed then the affected individual prone to infection because she cannot perform her menstrual hygiene. Mother and other family members are stressed and the affected female is at risk of sexual abuse and pregnancy.

RECOMMENDATION

Based on the interpretation of this case from every possible aspect and its consequences, it is recommended to provide awareness to society and families of sufferers about menstrual hygiene and possible alternative options to cope with this situation. Additionally, emphasize on coping strategies and awareness on surgery risks and complications. And legal aspects for such cases should be explored and established to stop human rights violations. Furthermore, moral and psychological support programs should be started for the families of such individuals that help them to overcome their problems related to their daughter's condition. In addition to this training sessions and counseling sessions for such individuals and their families should be arranged.

Health care policies should be established in all health care settings. That guide health care professionals to decide in such cases based on medical situations and patient condition. Additionally, health care professionals should be trained to deal with such meticulous cases. Every health care setting should have a record-keeping system to identify the number of cases and utilize the recorded data in policy development.

CONCLUSION

As a health care professional, it is very difficult to deal with such painstaking cases. In light of ethics, every aspect has its significance related to particular situations. There are no clearly defined criteria to decide in such a critical situation. However, by analyzing risk-benefit ratio and situation analysis decisions can be made for the good of humanity.

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CONFLICT OF INTEREST

None to declare.

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