Why Bioethics should become part of our curriculum?

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Case Summary

It was a routine out patient day of a government hospital. Few of the women were waiting in a queue, whereas others were fighting with the door attendant to get inside the consulting chamber. I was called to give opinion for a 20 year old girl, who was brought by her sister in law. She was a short height girl, with facial expressions typical of Down's syndrome, who was reluctant to have an eye contact with me. In the chamber, it was the sister in law who carried out the entire conversation. She told me the ordeal which the family had to pass through each month when the girl had her periods. She will not wear sanitary napkins and will spoil her clothes, which was a cause of embarrassment for the ladies of the family. She was of the opinion, that as she is not able to take care of herself, her uterus should be removed. I tried to make some conversation with the girl, but was unable to do so. The sister in law informed that she has 4 sisters and 2 brothers and all of them are married and the girl's mother is a heart patient and cannot look after her last child. A closer look at the child did show that she was not able to understand what was being asked, but was able to make us understand what she wanted. As she refused to undergo a physical examination and jumped out of the examination couch, sirens from ambulances which were blaring in the background made her comment that its hurting her ears. Apart from these two observations, I was not able to gather any positive attitude from the girl, but must admit that my interaction was also limited for not more than 10 minutes, that too in the presence of residents. In my mind I have decided that yes, she needs a hysterectomy.

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Discussion

Ethical issues: The ethical issues which arise in the above case are autonomy, beneficence and Justice.

Autonomy or respect: Tfor individual rights requires judgment on part of the individual. This question arises in cases of persons with mental disabilities, who are not able to decide for themselves. It is important to evaluate the mental capacity of the girl in the above case. A brief 10 minute encounter may not be sufficient, and that too in the presence of family members and resident staff. It is recommended that more than one such encounter is necessary between the physician and the patient, both in the presence as well as in the absence of family members and strangers. Though most of the Clinicians may not be aware of the Mental act of their own country, the bottom line of the act states that if the person does not have the capacity for decision making, others can decide what is in the best interest of that person. The Provincial assembly of the country also recently passed a bill, Sindh Mental Health Bill 2012 when a listed clinician can justify treatment when a person lacks the capability to decide for himself/herself.[1] Same decision can also be taken by the family member or relatives in the best interests of the person. ACOG guidelines for women with chronic or permanent disability suggest that in the event when women are not able to decide for themselves, decisions regarding medical treatment should be beneficence based.[2] In case of the above girl, it was obvious that she did not have the capacity for deciding for herself, and surrogate consent was applicable for her.

Is the decision beneficial?

Considering social circumstances of our society, where joint family system is the norm in most of the communities, monthly menstrual period are a source of embarrassment for other family members. As discussed by the sister in law of the girl, during menstrual period, it was difficult to confine her to the home, or prevent her from going out. Reproduction and reproductive rights were not a question in the above case. In fact, chances of getting sexually abused for such individuals have been reported high. In societies where social services are non-existent, Such individuals are soft targets for sexual abuse. There is a place for a shared decision making with other care givers, also few more encounters with the above girl would have been more appropriate. Why I decided on a single visit? Was it a paternalistic or authoritarian attitude on my part? In the place where I work, people travel in public transports, and at times have to change them in middle as well. Perhaps it was a paternalistic attitude on my part, to avoid in convenience to family of bringing her to a public sector hospital repeatedly.

This ten minute consult was an eye opener for a routine clinician. The introduction of bioethics last year, exposed me to new horizons , new concepts, and I aimed to introduce this to my postgraduate students. The diploma course also introduced me to the ethical debates

focussed around reproductive rights of such mentally challenged individual. I came back home to see if I could find the relevant literature. There were guidelines from ACOG (American College of Obstetrician & Gynecologist), with the emphasis on having repeat visits and also to see the individual in absence of family members. ACOG also recommends against hysterectomy for the sole purpose of sterilization and menstrual cessation.[2] Human Rights Watch also strictly advises against sterilization in mentally disabled girls.[3] The same is the opinion from FIGO.[4] Majority of the gynaecologists working in developing part of world are unaware of such opinion papers or recommendations from governing bodies. My own opinion about the whole issue was also the same, had never teased apart the basics of decision, until I was introduced to the concept of informed consent and beneficence. All that matters is the surrogate decision maker's plea and the fear of sexual abuse in the minds of caregivers as well as surrogate decision maker. Majority of the doctors will forget that chances of pregnancy may be reduced either by sterilization or by more radical hysterectomy, but chances of sexual abuse remain the same.

Next week when the girl was brought for admission, I decided to have few more minutes to have an idea about her mental status. To my surprise, she gestured prayers for me as I was going to operate upon her, she fondly held hands of her mother, who was asked to accompany her next time. The thoughts from literature which I read was operations should not be performed for the convenience of care takers or for social issues. After having a second look, I decided to talk to the family members, and suggested other options. One was putting her on oral contraceptive pills, arranging consults with special schools looking after such children. The other was putting up an intrauterine device (IUD) to decrease the amount of blood loss at menstrual bleed as well as to protect against unwanted pregnancy. This approach is less favourable for countries like Pakistan. There are also international opinions against this approach, with arguments like how many times the IUD will be replaced? Will the replacement take place under sedation or general anaesthesia and each time how much the consent will be informed?[5] I was able to convince the family members for this less radical approach. In the meantime, I asked my resident to look for such a centre, their address and the social issue, which was faced by the family. Fortunately, we came across a centre, with a trained doctor who told us that they do teach such girls how to take care of themselves in those special days.

This whole episode was an eye opener for me. I had been doing hysterectomies for mentally challenged people since the days I have been taught surgery. Never before, I realized these aspects need to be considered. Beneficence for the individual was not there in the above case. As hysterectomy would have resulted in the loss of ovarian function soon, resulting in early onset of menopause, with its own complications. An introduction to bioethics made me weigh the decision with focus on autonomy, beneficence and justice. A little thinking also made me change my decision for the girl as well.

References

1. Hussain M. Law making: Mental Health Legislation in Pakistan. Dawn. September 23,2012, 2012.
2. ACOG Committee Opinion. Number 371. July 2007. Sterilization of women, including those with mental disabilities. Obstet Gynecol. 2007;110:217-220.
3. Sterilization of Women and Girls with Disabilities. 2011. https://www.opensocietyfoundations.org/publications/sterilization-women-and-girls-disabilities-0.Cited on 30. September, 2022
4. Arkin E. Global: health federation issues ethics guidelines on forced female sterilization. HIV AIDS Policy Law Rev. 2011;15:36-37.
5. Insogna I, Fiester A. Sterilization as last resort in women with intellectual disabilities: protection or disservice? Am. J. Obstet. Gynecol.. 2015;212:34-36 e31.