

Case Report

## Contraceptive Choices for Women with Intellectual Disability

### *Pemilihan Kontrasepsi untuk Perempuan dengan Disabilitas Intelektual*

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#### Abstract

**Objective:** To describe the case of contraceptive choices for women with intellectual disability.

**Methods:** A case report.

**Results:** In the case of intellectual disability, we need to perform a holistic approach to the patient.

**Conclusions:** Contraceptive method selection needs much consideration such as medical, ethical, law, and social aspect, therefore it's recommended to start giving an informed choice since antenatal care. The downside of this case is that medical practitioners often overlook the patient's degree of intellectual disability, hence, the patients' judgement, compliance, and self-treatment of complications. The result of counselling with the patient's family, they have chosen LARC method for this patient. Sterilization for eugenic reasons cannot be done because it violates law and ethics of medical practice in Indonesia.

**Keywords:** contraceptive, eugenics, intellectual disability, sterilization.

#### Abstrak

**Tujuan:** Untuk menjelaskan tentang kasus pemilihan alat kontrasepsi untuk perempuan dengan disabilitas intelektual.

**Metode:** Laporan kasus.

**Hasil :** Dalam kasus disabilitas intelektual, kita perlu melakukan pendekatan holistik kepada pasien.

**Kesimpulan:** Pemilihan alat kontrasepsi memerlukan pertimbangan berberapa aspek seperti faktor medis, etika, hukum, dan sosial. Maka itu, edukasi tentang informed choice alat kontrasepsi perlu diberikan sejak mulai antenatal care. Kekurangan pada kasus ini yaitu tenaga medis tidak menilai derajat keparahan disabilitas intelektual pasien. Oleh karena itu, tenaga medis tidak dapat menilai tingkat kemampuan dalam pertimbangan, kepatuhan, dan perawatan diri sendiri terhadap komplikasi penyakit. Hasil dari konseling dengan keluarga pasien, mereka memilih metode LARC untuk pasien. Tindakan sterilisasi untuk alasan eugenik tidak dapat dilakukan, karena tindakan tersebut melanggar etika dan hokum praktik medis yang berlaku di Indonesia.

**Kata kunci:** disabilitas intelektual, eugenik, kontrasepsi, sterilisasi.

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#### INTRODUCTION

At this moment, there is a change of terminology from Mental Retardation into Intellectual Disability. Based on World Health Organization (WHO) International Classification of Disease (ICD) advance, the change of terminology is to help the patient obtain health care that they deserve. Intellectual Disability (ID) is characterized by a marked impairment of core cognitive functions necessary for the development of knowledge, reasoning, and symbolic representation of the level expected of one's age peers, cultural, and community environment. The severity of this condition can be classified by mild (IQ 50 – 70), moderate (IQ 30 – 50), severe (IQ 20 – 30), and profound (IQ <

20).<sup>1,2</sup>Intellectual disability can be found in every community, and geographical area, the prevalence as well as incidence roughly can be found in all over the world. Women with intellectual disability can experience many problems in their daily life, especially in reproductive health. They have the risk to experience bad menstrual hygiene, sexual harassment or abuse, early age pregnancy, premature birth, and increase the incidence of caesarean section. Besides that, they have the risk to experience many complications during pregnancy. Women with intellectual disability do not have a good mind set about birth or take care of a baby. Therefore, contraceptive has a huge role in protecting women with intellectual disability reproductive health. Contraceptive methods that available for women with intellectual disability are

similar with women without intellectual disability. Although, many health care provider have some trouble in choosing appropriate contraceptive for women with intellectual disability because of their capability in considering the pros and cons of each contraceptive method, compliance level, ability in reporting sexual abuse and overcome problems come from using contraceptive.<sup>3-7</sup>

There are few cases of women with intellectual disability are advised to do sterilization that was one-sided decision for the purpose eugenic. However, the action is no longer advised because it violates the medical ethics and informed consent law that applied in Indonesia.<sup>8</sup> If sterilization is not the method of choice; it is necessary to give cognitive behavioural therapy as an adjunctive treatment to prevent contraceptive complications. If the women with intellectual disability do not have any capacity in choosing an appropriate contraceptive, so the medical team need to do a holistic approach which is appropriate for the patient.<sup>3,8-10</sup>

### CASE

A twenty-year-old woman with intellectual disability (gravida 1, parity 0, abortus 0). The patient was a victim of rape. The patient has undergone antenatal care since 18 weeks of pregnancy and has made informed choice for choosing appropriate contraceptive after birth at Siloam General Hospital. The patient was hospitalized because of premature contraction at 36 weeks of pregnancy and consulted to a psychiatrist to assess her disability and to discuss some option for baby delivery and contraceptive method. The psychiatrist advised to do a cesarean section, and for contraceptive methods such as tubectomy or hysterectomy need to be considered the patient and family wishes of getting married and have children again. The patient was conducted cesarean section at 36 – 37 weeks of pregnancy at Siloam General.

Hospital, and a healthy baby was delivered. The patient is living with her parents and sister. Patient daily activities are taken care of by her mother. The rape incident was occurred near the patient's home. Other patient history was unremarkable. After discharge from hospital, the patient doesn't return for follow-up after delivery.

### DISCUSSION

Women with intellectual disability have low intellectual level and marked impairment of core cognitive functions necessary for the development of knowledge, reasoning, and symbolic representation of the level expected of one's age peers, cultural and community environment. Majority women with an intellectual disability need a caretaker to help his/her daily activities and maintaining their health. Besides that, every caretaker have the same concerns about menstrual hygiene, sexual abuse, pregnancy, and their offspring.<sup>1-5</sup> These problems occurred because women with an intellectual disability need more time to adapt the changes that occurred when puberty such as the development of secondary sex organs, hair growth, menstruation, and reproductive health than women without intellectual disability.<sup>5</sup> Incidence of sexual abuse can happen on every woman with or without intellectual disability. However, the incidence rate of sexual abuse found higher in women with intellectual disability population than women without intellectual disability because they have difficulty in recognizing any sexual activities, and reporting it. Besides that, women with intellectual disability experience difficulty in forming intimate relationships and are highly vulnerable to abuse in their relationships.<sup>6</sup> Women with intellectual disabilities have the tendency to be pregnant in young age, so it increases the risk of complication during pregnancy. Complication such as preterm birth and preeclampsia. This complication occurred because women intellectual disability can't recognize the signs. The incidence of cesarean section found higher in women with intellectual disabilities population than without intellectual disabilities because they can't recognize the early sign of giving birth.<sup>5,6</sup>

Clinicians offer family planning can be beneficial to women with intellectual disability. Contraceptive methods that available for women with intellectual disability aren't different than women without intellectual disability, such as abstinence, natural methods, barrier methods, vasectomy, combination oral contraceptive, contraceptive progesterone only, intrauterine device, and operation methods. However, in choosing appropriate contraception methods for women with intellectual disabilities need to consider many aspect such as medical, ethical,

law, and social aspect.<sup>3-7</sup> Many considerations need to be assessed in choosing an appropriate contraceptive.

### Medical Aspect

There are a few medical aspects that need to be reviewed, including the severity of an intellectual disability, ability in maintaining reproductive health, ability in considering the pros and cons of each contraceptive method, compliance level, and side effects of contraceptive, awareness of sexual activities, and ability in reporting sexual abuse incident. If women with intellectual disability don't have any abilities that mention above, so medical team whose response to the patient needs to discuss holistic management that appropriates for the patient.<sup>1-5</sup>

In this case, the medical team do poorly in assessing the severity of intellectual disabilities. As a result, patient ability in maintaining reproductive health, ability in considering the pros and cons of each contraceptive method, compliance level, cope with contraceptive side effects, identify and reporting sexual activities can't be assessed.

### Ethical Aspect

The medical team have an obligation to do good, beneficial, and do not cause harm to the patient. Besides that, the medical team needs to respect human dignity, where each need to be treated as they have the right to choose their faith. Therefore, sterilization decided unilaterally is a violation of medical ethics. If the medical team or family worried about patient menstrual hygiene, the foremost action to take first is less invasive contraceptive methods such as combination oral contraceptive, medroxyprogesterone injection, intrauterine device, and endometrial ablation<sup>3,6,8,9</sup>

The medical team responsible for the patient wellbeing have different opinions in managing this case. Obstetricians-gynecologist (ob-gyn) suggested doing sterilization as a form of precaution to prevent this incident reoccurs. However, the psychiatrist doesn't agree with ob-gyn and appreciate patient and family choice, which they chose a patient to get married and form a family. Medical team whose handle this case are doing a great job in discussing with

patient and family in choosing appropriate contraceptive method for the patient. In the end, they have reached an agreement to use long term contraceptive.

### Law Aspect

To perform a medical treatment is a need for medical approval or informed consent. Informed consent that can be done by patient him/herself or their representation. This is supported by PERMENKES no 290/MENKES/PER/III/2018 about medical approval. Clause 1, subsection (1) medical approval is approval given by the patient or closest family after getting a full explanation about medical or dentists procedure that will be done to the patient. Subsection (2) closest families are husband or wife, biological father or mother, biological children, biological relative. Subsection (3) medical or dentistry hereinafter referred to as medical procedure for preventive, diagnostic, therapeutic or rehabilitation that performed by doctors or dentists on patients. Subsection (7) competent patient who is an adult or not child based on legislation or already/ever married, no impairment of physical awareness, able to communicate naturally, not experiencing mental retardation and not experiencing other mental health so capable make decisions freely. Clause (2), subsection (1) every medical procedure requires medical approval. Subsection (2), approval as referred to in subsection (1) can be given in writing or verbally. If an adult suffers from a mental health disorder, the approval can be given by parents/guardian/curator. Civil code article clause 434, each blood member needs to be family curator because of mental health disorder.<sup>10-12</sup>

In this case, the medical team had educated patient and family in choosing an appropriate contraceptive method since the first visit of antenatal care at Siloam General Hospital, which the patient's pregnancy age is 18 weeks. Ob-gyn suggested patient do sterilization after giving birth. Based on the law issued by the ministry of health Indonesian republic number 290/MENKES/PER/III/2008, the patient is not competent in giving medical approval. Therefore, the patient family have the right to give medical approval for the patient. On the day of birth of the patient's child, the patient family did not give informed consent to do sterilization. Therefore, the medical

team didn't do sterilization. Legally, the medical team whose responsible for the patient did not break the law about the patient's informed consent.

### Social Aspect

The medical team need to assess caretaker ability in protecting the patient, neighbourhood. Caretaker for women with intellectual disability must be able to protect the patient, which they don't get sexual abuse and prevent for unwanted pregnancy. Patient's neighbourhood needs to be safe from sexual abuse incident. The patient's partner must be able to take care of and protect her.<sup>6</sup> In this case, the patient's social condition is considered to be unideal as the caretaker and the neighbourhood can't ensure patient safety and health. Patient needs full support from both of her parent to live. Patient's family come from a low social-economic background, with only her mother takes care of her.

Based on much clinical consideration, contraceptive methods that appropriate for the patient is LARC method. This contraceptive has effectiveness in pregnancy prevention up to 99%, with a long period, affordable, no change in sexual function and the patient can plan for the next pregnancy. Sterilization for eugenic purpose can't be done because of the law and medical ethics that applied in Indonesia.

### CONCLUSION

Contraceptive method selection needs much consideration such as medical, ethical, law, and social aspect, therefore it's recommended to start giving an informed choice since antenatal care. The downside of this case is that medical practitioners often overlook the patient's degree of intellectual disability; hence, the patients' judgement, compliance, and self-treatment of complications. The result of counselling with the patient's family, they have chosen the LARC method for this patient. Sterilization for eugenic reasons cannot be done because it violates law and ethics of medical practice in Indonesia.

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