

## STERILIZATION AMONG MENTALLY RETARDED WOMEN

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### Introduction

A twenty year old female, with the mind of a three-year-old child (Mentally retarded) and who was so ugly that it was supposed that she would never be molested, so her parents used to leave her alone in the house sometimes un supervised. On one such occasion she was raped by her teenager neighbor. Following this her parents sent her to a hospital to be sterilized by hysterectomy.

While reading this case many questions came to mind,

- 1) Is there any excuse for the permanent sterilization of a mentally retarded woman?
- 2) Is it ever appropriate to assume the mentally retarded incapable of consenting to the procedure of sterilization?
- 3) Does sterilization to those women protect them from sexual exploitation?

Usually these decisions have a very strong social undertone. The women are the ones who are having the children, so they are the ones who are the victims of the sterilizations. Parents usually fear that females with mental retardation may face risks associated with sexual abuse and/or pregnancy and hence consider sterilization. Moreover, some parents elect for hysterectomy for female children as a means of eliminating menstruation and related problems (Stansfield et al. 2007).

According to the American College of Obstetrics and Gynecology, 65% of parents of severely retarded women had thought of sterilization as had 63% of parents of moderately retarded women? Two thirds of these parents had difficulty dealing with menstrual hygiene. Parents of mildly retarded women were three times more likely to consider tubal ligation than hysterectomy. Parents of the severely retarded were three times more likely to choose hysterectomy. The most common primary reason given by sterilization seekers was protection from pregnancy, but 60% of parents seeking hysterectomy gave elimination of menses and related problems as the primary reason (McCarthy, 2009).

Sterilization of mentally retarded women is an ethical dilemma in health care that need to be addressed. Sterilization has made a huge debate in many levels legally, morally and religiously.

Current author position of this dilemma "Surgical sterilization is an act of violence against mentally retarded women and a violation of the human rights, inhuman unnecessary procedure; mental retarded female need parent support to protect them from sexual harassment."

The purpose of this essay is to represent a comprehensive overview of this debate, the essay will generally define the issue properly then proceed to explore the controversial opinions, firstly with a summary of the opinions

against sterilization of mentally retarded women (Opponents), Secondly, Summary of the opinions for sterilization of mentally retarded women (Proponent), and finally supports for the author's position, then conclusion and recommendations.

### Discussion

#### Definitions

Mental retardation, as defined by the DSM-IV is characterized by significantly sub average intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning in at least two of the following skill areas: communication, self-care home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety (American Psychiatric Association, 2000).

Sterilization refers to the surgical methods of contraception such as tubal ligation, hysterectomy or vasectomy. There are also distinctions between compulsory, voluntary, and involuntary sterilization. Sterilization is considered compulsory (forced) when it is required by law (Begun, 2008).

If a competent individual freely chooses to be sterilized to limit his or her ability to have children in the future, this is considered voluntary sterilization. Involuntary sterilization is the sterilization of an individual incapable of providing consent to the procedure. However, Coerced sterilization occurs when financial or other incentives, misinformation, or pressure plans are used to induce an individual to undergo the procedure (Begun, 2008).

According to Mosby's Medical Dictionary (2009) voluntary sterilization refers to the process or act being undertaken with the individual's free and informed consent. Conversely, involuntary sterilization refers to the process or act being undertaken without the free and informed consent of the individual, such as when a person is forced or coerced into submitting to a sterilization procedure.

### Background Information

Forced sterilizations have occurred all over the world and in huge masses. For example, in Nazi Germany 400,000 men and women were forcibly sterilized. In Sweden 63,000 people, mostly women, were sterilized. Over 800,000 men and women in Japan as well as 11,000 women from Finland were also sterilized without consent. These have all happened in the recent past. However, Australia's figures are astonishing because there have been over one thousand cases since 1992 (Chou & Lu, 2011).

In the early 1900's, the United States had a eugenics program; with that program the U.S. was attempting to perfect the gene pool. The hopeful outcomes were that of a society without crime, mental illness, and homelessness. The idea was that if the degenerates of society were kept from having children then society's problems would disappear (Begun, 2008).

It was in 1907 that Indiana put the first law on the books on the subject of forced sterilization. Indiana was the first state to do so. Overall, thirty-five states had at one point had laws allowing forced sterilization (Hodges, 2001).

Public attitudes toward forced sterilization in the mentally retarded began to change just before the end of the Second World War, somewhat in response to the way eugenic principles had been applied by Nazi Germany. Although forced sterilizations significantly decreased in number, it wasn't until

the 1960s that states began to repeal involuntary sterilization laws. Some states passed legislation requiring that judicial review and other conditions should be set before mentally retarded could be sterilized (Diekema, 2003).

In Jordan, according to the Jordan Now news (2013), sixty five operations of hysterectomy on mentally retarded female are done annually. The Director of Albsher Hospital Dr. Essam Shrideh stated that they did this operation on 10 girls aged between ten to twenty years old as the parents requested, because the mentally retarded females can't take care of themselves and these operations are done without a court order.

### Opposing opinions

Eugenics programs had much opposition in the early 1900's with the rationale falling out of favor and access to sterilization procedures was restricted by various laws. Many scientists refused the principle of sterilization of mentally retarded. Moreover, the critics slippery-slope argument was that once we start sterilizing the retarded, then we open the floodgates for minorities and political prisoners (Paransky & Zurawin, 2003).

On the other hand, some demonstrated that sterilization in the short term would not greatly alter the gene frequency of heritable traits. In the 1960's medical research proved that much of the defects doctors thought were genetic turned out to be linked to ground and water toxins (Hodges, 2001).

According to the UN Human Rights (2008) The Convention on the Rights of Persons with Disabilities provides a basis for upholding the rights of persons with disabilities and contains specific articles of relevance to the issue of involuntary sterilization. Article 23 reinforces the right of people with disabilities to found and maintain a family and to retain their fertility on an equal basis with others. Article 12 affirms the

right of persons with disabilities to recognition everywhere as persons before the law and to enjoy legal capacity on an equal basis with others, including access to the support they may require to exercise their legal capacity. Article 25 clearly articulates that free and informed consent should be the basis for providing health care to persons with disabilities. Moreover, the United Nations Special Rapporteur on Violence against forced sterilization is a method of medical control of a woman's fertility without the consent of a woman. Essentially involving the battery of a woman, -violating her physical integrity and security, forced sterilization constitutes violence against women.

Many people who support the sterilization defend themselves that women or girls with mental disability can't take care of themselves during the menstrual period, and another decline about parents concern regarding the mentally retarded getting pregnant as a result of rape, the answer is what was said by Brady (1994) who counters the arguments that sterilization would make menstruation more manageable and provide protection against the dangers of pregnancy. It is true that hysterectomy will solve the problem of menstrual management for care givers. The child will no longer bleed for five days a month. However, she will continue to urinate and defecate each day for the rest of her life. This is a greater nursing management problem. And the response regarding parents concern about mentally retarded women getting pregnant Brady addresses that there is no data to suggest that pregnancy is a significant risk in this population; the numbers of unwanted pregnancies (or pregnancies) in this population seem statistically insignificant.

Diekema (2003) in his ethical analysis of involuntary sterilization of persons with mental retardation presented that Involuntary sterilization clearly represents a violation of the principle of respect for autonomy if performed against

the wishes of mentally retarded persons who maintain the capacity to make their own decision about sterilization. On the other hand, the rigid application of the principle of respect for autonomy does not make sense for individuals who are not capable of experiencing competence. Thus, the determination of competence is crucial to the discussion about the sterilization of persons with mental retardation.

However, IQ by itself does not provide an assessment of an individual's ability to function in or adapt to a given situation. Because intelligence is a simple measure, the functional capacities of persons with similar IQ may vary considerably. While some mentally retarded persons may have difficulty with communication of instructions or facts, they may be capable of problem solving and coping by using effective strategies that differ from those of "normal" people. Incompetence and incapacity should never be assumed.

The United Nations Convention on the Rights of People with Disabilities (CRPD), adopted in 2006 and ratified so far by 119 countries, recognizes that disabled individuals have the right to make decisions freely and responsibly regarding their reproductive lives. Strongly advocating the rights of women with disabilities at the conference was Prince Zeid Ra'ad Zeid Al-Husseini, Jordan's ambassador and permanent representative to the United Nations. Hussein outlined the role Jordan's Higher Council for Affairs of Persons with Disabilities (HCD) has played in raising awareness of and advocating for the rights of Jordanian women with disabilities who are subject to sterilization, which he called a "misconceived and shameful practice". Hussein explained "The committee targeted parents, doctors and gynecologists, legal experts and judges as well as religious leaders to address this issue" (Stawecka, 2012).

In our Islamic religion it is prohibited to do hysterectomy of mentally retarded females if there is no medical necessity because this can expose them to danger, as stated by Secretary-General of the Department of Fatwa Mohamed AlKhalileh. He also stated that Islamic religion forces the parents to take care of their mentally retarded girls and give them all their rights as any other normal child, and protect them from danger and harm (Jordan Now, 2013).

### Proponents

At the beginning of the 20th century, involuntary sterilization of the institutionalized retarded was frequently performed using the rationale that society should not be burdened by future generations of handicapped citizens. The Race Betterment Foundation was established, founded by Dr. John Harvey Kellogg, and their goal in this foundation was to bring together a group of leading scientists, educators and others for the purpose of discussing ways and means of applying science to human living in the same thorough going way in which it is applied to industry-in the promotion of longer life, greater efficacy and well-being and of race improvement". However, this Foundation faced huge contrapositions after World War II from human rights defenders (Begun, 2008).

Patel, Greydanus and Calles (2010) recommends an instruction to proper hygiene management for patients with cognitive impairment; they stated that the proper method to control problematic menstruation and related hygiene issues is gynecologic surgery (endometrial ablation or hysterectomy).

Legally, laws in many countries allow for the sterilization of minors who are found to have severe intellectual disabilities. The Egyptian Parliament failed to include a provision of preventing the use of sterilization as a "treatment" for mental illness in its patient protection law (Mental Health Law, 2009).

In the United States, 15 states have laws that do not protect women with disabilities from involuntary sterilization. Across the world, adults with disabilities are violated in their right to refuse sterilization. Through a process known as guardianship, if a court declares a person "incompetent," all of their decision-making rights are transferred to a guardian. The threshold for declaring a person incompetent is often very low and lacks legitimacy. People under guardianship are highly vulnerable to forced sterilization because they don't have the right to refuse medical procedures such as hysterectomy (Mental Disability Advocacy Center, 2007).

In many countries, the practice of forced sterilization continues to be debated and justified by governments, legal, medical, and other professionals, and family members and carers as being in the "best interests" of women and girls with disabilities (Chou & Lu, 2011).

### The Current Author Opinion: Against Sterilization

Firstly, sterilization of mentally retarded women is inhuman and against human rights; it's considered violence against women and violation of her psychological integrity, and humiliates her dignity (UN Human Rights, 2008).

Secondly, regarding parents' concern for the women becoming pregnant as a result of rape, literature states that pregnancies to mentally retarded women are in significant, on other hand hysterectomy will not stop sexual harassment, or is it okay to be raped but the problem is getting pregnant? And according to menstrual hygiene as Bradley (1994) stated that those females also urinate and defecate what we will do next?

Thirdly, our Islamic Religion protects the rights of women and even if they chose to sterilize themselves it is prohibited for normal or disabled women unless there is medical necessity. Islam gives direct

instructions to carer to take care of their daughters and never expose them to un-necessary harm.

Finally, the most important issue is that the primary goal is to identify the right and good action for the retarded person. It is not to seek what is best for society or for the family of the mentally retarded person, but rather what is best for the person for whom sterilization is being considered. That is not to say that the interests of others should not be considered. Rather, the interests of others become most important when they correspond to the interests of the retarded person or, failing that, at least do not interfere with the legitimate interests of the retarded person. When interests conflict, the interests of the mentally retarded person should be overcome before any other interest (Diekema, 2003).

## Recommendations

The previous discussion about the ethical dilemma of sterilization among mentally retarded females gives directions to recommendations that are important to set limits and deal with this dilemma. Firstly, it's important to institute laws to protect mentally retarded females from sterilization, and not to justify the sterilization by any excuse except medical necessity.

Secondly, the free and informed consent of the woman herself is a requirement for sterilization. Only women with disabilities themselves can give legally and ethically valid consent to their own sterilization, not family members or legal guardians and only if there is a medical necessity. If the women are incompetent the decision will be left to the court after counseling of medical professionals. Perceived mental incapacity, including medically or judicially determined mental incapacity, does not invalidate the requirement of free and informed consent of the woman herself as the sole justification for the sterilization.

Thirdly, cognitive learning for mentally retarded women must

be adopted in the centers where they are learning to increase their ability to take care of themselves and it is necessary to help them understand their rights surrounding sterilization. The family needs to be educated about taking care of those who are mentally retarded; national campaigns to increase public awareness toward dealing with mentally retarded females must be adopted by the government.

Finally, a more comprehensive picture of the sexual health of mentally retarded females is required, as well as severity level, living environment, family, and health and social care workers. Research should also be undertaken on the development and effectiveness of social services offering sterilization and menstrual management information and developing approaches for providing practical support to individuals and families.

The purpose of this essay was to address the dilemma of sterilization among mentally retarded women in different types of views and summarize the opponent and proponent opinions and finally discuss the current author position which was supported by the opponent opinions.

At the beginning of this essay we asked important questions, such as is there an excuse for the permanent sterilization of mentally retarded women? Can we assume incompetence? Does it protect women from sexual exploitation? After reviewing the facts and the causes we can simply answer that there is no justification for sterilization of mentally retarded women; it's never acceptable to assume incompetence in mentally retarded women. Moreover, sterilization in no way will protect those women from sexual exploitation.

## Summary & Conclusions

Sterilization of mentally retarded women refers to the surgical methods of contraception "hysterectomy". Many people use

sterilization to protect those women from becoming pregnant as a result of rape and to control menstrual periods. This act had its proponents and opponents. This essay highlights and summarises each opinion, and finally addresses the current author's opinion which is for whatever the reason that sterilization of the mentally retarded is done, it's an inhuman act, unethical and finally prohibited in the Islamic religion.

So we conclude that this debate must be taken according to our consideration and mentally retarded women must be protected from involuntary sterilization and their humanity must be respected, we should never assume their incompetence and we must take care of them and protect them from harm. Legal actions must be taken in Jordan to stop sterilization, and to control these phenomena.

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