

Hysterectomy of Girls with Intellectual Disabilities in Jordan: A Family Perspective

Murad A. Al-Bustanji, Ph.D. (Corresponding author)

Assistant Professor of Special Education

Al-Hussein Bin Talal University, Jordan

E-mail: mualbustanji@yahoo.com

Noor T. Al. Bdour, Ph.D.

Assistant Professor of Special Education

Al-Hussein Bin Talal University

Mohammad A. Beirat, Ph.D.

Assistant Professor of Special Education

Al-Hussein Bin Talal University

Received: December 20, 2017 Accepted: January 7, 2018 Published: January 29, 2018

doi:10.5296/ijld.v8i1.12342

URL: <https://doi.org/10.5296/ijld.v8i1.12342>

Abstract

The current study aimed at determining the Jordanian families' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities (ID). It also aimed to study the differences based on the age of the girl with intellectual Disability, the type of the Intellectual disability of the girl, the severity level of disability, the gender of surveyed parent, the level of education of surveyed parent, and the level of monthly income of the family. The participants of the study were (329) parents of girls with intellectual disabilities. Each one of the participant completed a questionnaire consisted of (21) items. The study concluded that the overall participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities was low. The findings indicated that the families who had disabled daughters between the ages of 11-20 years had higher degree of acceptance of having their daughters undergo hysterectomy than the families who had disabled daughters

between the ages of 5 - 10 years or even the ages of 21-30 years. The results showed that the families did not differ in their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' type of disability. The results showed that the families who had daughters with severe or profound disability had higher degree of acceptance of having their daughters undergo hysterectomy than participants who had daughters with mild or moderate disability. The results showed that the degree of acceptance of the mothers of girls with intellectual disabilities to perform hysterectomy on them was higher than the degree of acceptance of the fathers of girls with intellectual disabilities. The results showed that the participant parents (either mother or father in each family) who had no education had higher degree of acceptance of having their daughters undergo hysterectomy than the participant parents who had different levels of education. The results also showed that the families who had higher income had a higher degree of acceptance of having their daughters undergo hysterectomy than the families who had less income.

Keywords: Hysterectomy, women with intellectual disabilities, families of girls with intellectual disabilities

1. Introduction

Several medical, religious, legal and educational researchers are concerned with an important contemporary issue which is: do the families of girls with intellectual disabilities have a hysterectomy performed on their daughters? During the operation, the entire uterus, part of the uterus or other surrounding structures, such as ovaries or tubes, are removed through surgery or using laparoscopy.

Some families of girls with intellectual disabilities usually have a hysterectomy performed on their daughter with no medical necessity. These families believe that hysterectomy can help avoid hygiene issues during menstruation. In addition, these families use hysterectomy to protect their daughters from rape in order to protect the honor and reputation of the family.

In general, many families of persons with intellectual disabilities suffer from problems related to providing care and effort to them, feelings of embarrassment and negative social attitudes, and feeling of constant anxiety and fear regarding the future of their adult and children with intellectual disabilities. The negative feelings toward people with intellectual disabilities are particularly to girls more than of boys with intellectual disabilities. (Masoud, 1988)

Many families of girls with intellectual disabilities use hysterectomy to protect their daughters from rape and to prevent them engaging in sexual activities. They try to have a hysterectomy performed on their daughters at young ages. Isler, Beytut, Tas, and Conk (2009) reported that some families have fear regarding sexuality in their children with intellectual disabilities in terms of their children's perception and attitudes toward sex. In addition, families have fears of their children with intellectual disabilities being at risk for sexual exploitation and abuse. Talbot and Langdon (2006) pointed to the importance of assessing the sensory perception of people with intellectual disabilities to protect them from risk of sexual exploitation and abuse.

Imran (2008) found that personal communication had positive impact on developing the awareness of self protection concepts against sexual abuse for children with mild mental

retardation. Aql (2015) stressed on the importance of developing parents and teachers' skills that are required to reduce adolescents' sexual problems related to excessive hugging and embracing of others and the difficulties of adapting to physical changes during adolescence.

In the conservative Eastern societies, the families of girls with intellectual disabilities have a hysterectomy performed on their daughters as a proactive and precautionary method in order to preserve the reputation and honor of these girls. Because very little people would consider marrying off a girl with intellectual disability, performing a hysterectomy would avoid the risk of sexual assault and rape. Also, hysterectomy would prevent pregnancy that might occur outside of marriage.

A few decades ago, Bambric and Roberts (1991) had found that 53% of the parents who participated in their study, pointed out that they had or would consider sterilization for their child with a mental handicap. The great majority of the participants believed that they alone, or with help of a doctor, should be able to approve on sterilization as an acceptable method for people with mental handicaps.

In more recent study, Chou and Lu (2011) examined decision-making process concerning sterilization for women with intellectual disabilities who live with their family in Taiwan. The results showed the sterilization process took two forms: tubal ligation and hysterectomy. The majority of women with mild intellectual disabilities, who underwent tubal ligation, were married. The ones who took the decision of sterilization were whether the husband or parents-in-law, where they took decisions following the women had given birth. These families reported that the key factors to take such a decision were: "the woman was unable to care for the children, the family could not afford to raise many children, the concern that the cause of ID in children might refer to hereditary, or a perceived risk of pregnancy from rape" (p.63). The women whose their families had them undergone hysterectomy, were single and had severe intellectual disabilities. The ones who took the decision of hysterectomy were their mothers. These mothers reported that the key factor to take such a decision was related to managing the menstruation of women with intellectual disabilities. Furthermore, Chou and Lu (2011) found that decisions of sterilization and hysterectomy for women with intellectual disabilities were taken by the families of women with intellectual disabilities, or in a conjunction with doctors and service personnel. In some cases, the women were not informed about the nature of the surgical treatment. The families of these of women and their treatment professionals had not consider that sterilization or hysterectomy would violate fundamental human rights of the women concerned.

Goktas, Gun, Yildiz, Sakar, and Caglayan (2015) pointed to the effects of hysterectomy and bilateral Salpingo-Oophorectomy on women. They found that hysterectomy and bilateral Salpingo-Oophorectomy may lead to short-term enhancement in urinary troubles after the surgical procedure mainly for sexually active women. Furthermore, these operations cause sexual malfunctioning and increase in depression. In addition, other factors might play important role on the consequences of these surgical procedures on women; these factors include age, educational level, working conditions, and family structure. Al-Habarnah (2015) found that the families of girls with intellectual disabilities had accepted their daughters'

disabilities and they believed in her right of education. These families knew that hysterectomy is against religion rules. However, some of these families had a hysterectomy performed on their daughters since they had extreme difficulties in teaching their girls menstrual hygiene.

According to the official statistics issued in 2012, the total percentage of disabled women in Jordan is 39% of the people with disabilities (Report of the Hashemite Kingdom of Jordan on the status of the rights of persons with disabilities in the Kingdom, 2012). About 64 hysterectomies are performed annually in Jordan for girls with mental disabilities according to higher council for affairs of persons with disabilities. However, there are no accurate figures available until now (The Convention on the Rights of Persons with Disabilities in Jordan / Mirror of Reality and Tool for Change, 2012).

The Article 6 of Convention on the Rights of Persons with Disabilities for the year of 2012, which was signed by a number of countries including Jordan, states that “States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms”. In addition, the legal opinion of hysterectomy is that there is no provision in the law permitting or authorizing such operation. According to the **Penal Code** of Law, It is not permissible to cause any harm to a person for no reason or medical justification.

The Jordanian Constitution guaranteed all the rights of persons with disabilities. In accordance with the law of number 31 (Rights of Persons with Disabilities Act No. 31, 2007), the article 2 stressed on “The right to equal opportunities; and non-discrimination among persons on the basis of disability”. However, till now there is no specific law that prevents hysterectomy for women with intellectual disabilities (Al-Remawi, 2014)

Because most people in Jordan are Muslims, Islam has high effect on the culture of people in Jordan. A recent fatwa (Fatwa means Islamic perspective regarding a certain issue) was issued on January 9, 2014 by the Council of Fatwa and Research and Studies. The Fatwa states that it is forbidden in Islam to have girls with intellectual disabilities to undergo hysterectomies, due to the negative effects of these operations (The Convention on the Rights of Persons with Disabilities in Jordan / Mirror of Reality and Tool for Change, 2012).

The current study aimed at determining the Jordanian families’ degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities. It also aimed to study the differences based on the following variables:

- The age of the girl with intellectual disability
- The type of Intellectual disability of the girl
- The severity level of intellectual disability of the girl.
- The gender of surveyed parent
- The level of education of surveyed parent
- The income level of the family

2. Methodology

2.1 Study Sample

The study sample consisted from 329 families; a father or a mother was a representative of the family. The surveyed people had different levels of education. The participating families had different levels of income. The study was conducted in the summer semester in the academic year of 2016-2017 in the three regions of Jordan (north, center and south). The participating families had daughters with intellectual disabilities with the ages ranged from 5 to above 31 years. These girls suffered from different types of intellectual disabilities i.e., Down syndrome, cretinism, small head, and enlarged head. These girls suffered from different levels of severity of intellectual disability i.e., mild, moderate, severe and profound. (See Table 1)

Table 1. Summary of participating families of daughters with intellectual disabilities characteristics

	Categories	Frequency	Percentage
Age of the girl with intellectual	5-10 years	49	14.9
	11-20 years	121	36.8
	21-30 years	86	26.1
	31 years or more	73	22.2
Type of disability of the girl with intellectual disabilities	Down's syndrome	142	43.2
	Cretinism	48	14.6
	Small head (Microcephaly)	92	28.0
	Enlarged head (Hydrocephaly)	47	14.3
Level of disability of the girl with intellectual disabilities	Mild	66	20.1
	Moderate	59	17.9
	Severe	97	29.5
	Profound	107	32.5
Gender of surveyed parent	Father	112	34.0
	Mother	217	66.0
Level of education of surveyed parent	Illiterate/ no education	59	17.9
	Primary education	48	14.6
	Secondary education	58	17.6
	Community college education	71	21.6
	University education	93	28.3
Family level of monthly income (In JD)	Less than 500	89	27.1
	500-1000	97	29.5
	More than 1000	143	43.5
Total		329	100.0

2.2 Instrumentation

The study used a descriptive research approach to examine the Jordanian families' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities. The used data collection instrument was a questionnaire. The researchers designed the questionnaire instrument to achieve the purpose of the current study. The first draft of questionnaire consisted from 23 items. A panel of experts was asked to review this draft, they suggested deleting two items. The panel of experts consisted from 8 members. The final draft questionnaire consisted from 21 items. The questionnaire items were designed to measure the families' level of support for or opposition to hysterectomy. To ensure face validity, all the items of the questionnaire were reviewed by a panel of experts who were familiar with the subject of the current study. Each item in the questionnaire was rated as valid by at least 85% of reviewers. To ensure reliability of the questionnaire, the questionnaire was pilot-tested twice with a 30 families who were not part of the study. Pearson correlation coefficient was computed between the test-retest scores in order to verify the internal consistency of the data collection instrument. The value of Pearson correlation coefficient was 0.91. Cronbach's alpha coefficient was computed for data from the pilot study on order to verify the reliability of the data collection instrument. The value of Cronbach's alpha coefficient was 0.84. The values of Pearson correlation coefficient and Cronbach's alpha were accepted for the purpose of the current research study. The questionnaire instrument used a four-point Likert-type scale: strongly agree, agree, disagree, and strongly disagree. Families, who have daughters with intellectual disabilities, were randomly selected to participate in the current study. These families were from three regions of Jordan (north, center and south). The participants were told at the beginning of the questionnaire the purpose of the paper. They were asked to reply honestly and they were told that if their response is negative this was just as useful as a more positive opinion.

2.3 Research Questions

- 1) What is the Jordanian families' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities?
- 2) Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the age of their disabled daughter?
- 3) Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their gender?
- 4) Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the type of disability (Down's syndrome, Cretinism, Small head (Microcephaly), Enlarged head (Hydrocephaly)?
- 5) Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the

level of disability?

- 6) Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education?
- 7) Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on family's level of income?

3. Results

Research question 1: What is the Jordanian families' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities?

To answer this question, descriptive statistics i.e., means and standard deviations were used. (See Table 2)

Table 2. Means and standard deviations of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities

Items	Mean	SD	Level
Total degree	1.91	.444	Low

Table 2 showed that the overall participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities was low ($M = 1.91$, $SD = .444$).

Research question 2: Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the age of their disabled daughter?

To answer this question, descriptive statistics i.e., means and standard deviations were computed for participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the age of their disabled daughter. (See Table 3)

Table 3. Means and standard deviations of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the age of their disabled daughter.

Category	N	Mean	SD
5-10 years	49	1.77	.335
11-20 years	121	2.01	.476
21-30 years	86	1.85	.383
31 years or more	73	1.89	.486
Overall	329	1.91	.444

Table 3 showed that there were differences in the means of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the age of their disabled daughter. One-Way ANOVA was conducted to examine whether these differences were statistically significant at ($\alpha < 0.05$) (See Table 4).

Table 4. One-Way ANOVA- participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the age of their disabled daughter

Groups	Sum of Squares	Degree of Freedom	Mean Square	F	Sig.
Between Groups	2.524	3	.841		
Within Groups	62.018	325	.191	4.410	.005
Total	64.542	328			

Table 4 showed that there were significant differences at ($\alpha < 0.05$) in the participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based the age of their disabled daughter. A post hoc LCD test was conducted to check for significant differences between groups in the sample. (See Table 5)

Table 5. A post hoc LCD results

	Mean	5-10 years	11-20 years	21-30 years	31 years or more
5-10 years	1.77				
11-20 years	2.01	.24*			
21-30 years	1.85	.08	.16*		
31 years or more	1.89	.11	.13	.04	

*Statistically significant at ($\alpha < 0.05$).

Table 5 showed that there were significant variations between families who had disabled daughters between the ages 11-20 years and families who had disabled daughters between the ages 5-10 years old on their degree of acceptance of having their daughters undergone hysterectomy. There were also significant variations between families who had disabled daughters between the ages 11-20 years and families who had disabled daughters between the ages 21 - 30 years old on their degree of acceptance of having their daughters undergone hysterectomy. Participants who had disabled daughters between the age of 11-20 years had higher degree of acceptance of having their daughters undergone hysterectomy than participants who had disabled daughters between the ages 5- 10 years and participants who had disabled daughters between the ages 21-30 years.

Research question 3: Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their gender?

To answer this question, descriptive statistics i.e., means and standard deviations were computed for participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their gender. In addition, independent sample t-test was conducted to examine the differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their gender. (See Table 6)

Table 6. Results of t-tests and descriptive statistics for of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their gender

Gender	N	Mean	SD	t	Degree of freedom	Sig.
Father	112	1.82	.356	-2.578	327	.010
Mother	217	1.95	.477			

Table 6 showed that there was significant difference at ($\alpha < 0.05$) in the participants' degree of

acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their gender. The mothers scored higher than the father in their responses to degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities.

Research question 4: Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the type of disability (Down's syndrome, Cretinism, Small head (Microcephaly), Enlarged head (Hydrocephaly))?

To answer this question, descriptive statistics i.e., means and standard deviations were computed for participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' type of disability. (See Table 7)

Table 7. Means and standard deviations of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the type of disability

Categories	N	Mean	SD
Down's syndrome	142	1.90	.475
Cretinism	48	1.84	.453
Small head (Microcephaly)	92	1.93	.393
Enlarged head (Hydrocephaly)	47	1.93	.434
Overall	329	1.91	.444

Table 7 showed that there were differences in the means of of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on based on their daughters' type of disability, One-Way ANOVA was conducted to examine whether these differences were statistically significant at ($\alpha < 0.05$) (See Table 8).

Table 8. One-Way ANOVA- participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the type of disability.

Groups	Sum of Squares	Degree of Freedom	Mean Square	F	Sig.
Between Groups	.335	3	.112		
Within Groups	64.207	325	.198	.565	.638
Total	64.542	328			

Table 8 showed that there were no significant differences at ($\alpha < 0.05$) in the participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' type of disability.

Research question 5: Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on the level of disability?

To answer this question, descriptive statistics i.e., means and standard deviations were computed for participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' level of disability. (See Table 9)

Table 9. Means and standard deviations of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' level of disability

Category	N	Mean	SD
Mild	66	1.81	.395
Moderate	59	1.80	.408
Severe	97	1.94	.452
Profound	107	1.99	.465
Mild	329	1.91	.444

Table 9 showed that there were differences in the means of of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' level of disability, One-Way ANOVA was conducted to examine whether these differences were statistically significant at ($\alpha < 0.05$) (See Table 10).

Table 10. One-Way ANOVA- participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' level of disability

Groups	Sum of Squares	Degree of Freedom	Mean Square	F	Sig.
Between Groups	2.226	3	.742		
Within Groups	62.317	325	.192	3.869	.010
Total	64.542	328			

Table 10 showed that there were significant differences at ($\alpha < 0.05$) in the participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' level of disability. A post hoc LCD test was conducted to check for significant differences between groups. (See Table 11)

Table 11. A post hoc LCD results

	Mean	Mild	Moderate	Severe	Profound
Mild	1.81				
Moderate	1.80	.01			
Severe	1.94	.13	.15*		
Profound	1.99	.18*	.20*	.05	

*Statistically significant at ($\alpha < 0.05$).

Table 11 showed that there were significant variations between families who had disabled daughters with mild disability and families who had disabled daughters with profound disability on their degree of acceptance of having their daughters undergone hysterectomy. In addition, there were significant variations between families who had disabled daughters with moderate disability and families who had disabled daughters with severe disability and profound disability on their degree of acceptance of having their daughters undergone hysterectomy.

Participants who had disabled daughters with profound disability had higher degree of acceptance of having their daughters undergone hysterectomy than participants who had disabled daughters with mild disability or mild disability. Participants who had disabled daughters with moderate disability had lower degree of acceptance of having their daughters undergone hysterectomy than participants who had disabled daughters with severe disability.

Research question 6: Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education?

To answer this question, descriptive statistics i.e., means and standard deviations were computed for participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education. (See Table 12)

Table 12. Means and standard deviations of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education

Category	N	Mean	SD
Illiterate/ no education	59	2.07	.535
Primary education	48	1.91	.404
Secondary education	58	1.88	.311
Community college education	71	1.84	.414
University education	93	1.87	.475
Overall	329	1.91	.444

Table 12 showed that there were differences in the means of of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education, One-Way ANOVA was conducted to examine whether these differences were statistically significant at ($\alpha < 0.05$) (See Table 13).

Table 13. One-Way ANOVA- participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education

Groups	Sum of Squares	Degree of Freedom	Mean Square	F	Sig.
Between Groups	1.941	4	.485		
Within Groups	62.601	324	.193	2.512	.042
Total	64.542	328			

Table 13 showed that there were significant differences at ($\alpha < 0.05$) in the participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education. A post hoc LCD test was conducted to check for significant differences between groups. (See Table 14)

Table 14. A post hoc LCD results

Level of education	Mean	Illiterate/no education	Primary education	Secondary education	Community college education	University education
Illiterate/ no education	2.07					
Primary education	1.91	.16				
Secondary education	1.88	.19*	.03			
Community college education	1.84	.22*	.07	.03		
University education	1.87	.19*	.04	.00	.03	

*Statistically significant at ($\alpha < 0.05$).

Table 14 showed that there were significant variations between participants who were uneducated and the participants who had different levels of education on their degree of acceptance of having their daughters undergone hysterectomy. Participants who had no education had higher degree of acceptance of having their daughters undergone hysterectomy than participants who had different level of education (primary education, secondary education, community college education, university education)

Research question 7: Are there any differences in participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on family's level of income?

To answer this question, descriptive statistics i.e., means and standard deviations were computed for participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of income. (See Table 15)

Table 15. Means and standard deviations of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of income

Category	Number	Mean	SD
Less than 500 JD	89	1.81	.439
500 – 1000 JD	97	1.88	.413
More than 1000 JD	143	1.99	.455
Overall	329	1.91	.444

Table 15 showed that there were differences in the means of of participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of income, One-Way ANOVA was conducted to examine whether these differences were statistically significant at ($\alpha < 0.05$) (See Table 16).

Table 16. One-Way ANOVA- participants' responses to their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of income

Groups	Sum of Squares	Degree of Freedom	Mean Square	F	Sig.
Between Groups	1.789	2	.895	4.648	.010
Within Groups	62.753	326	.192		
Total	64.542	328			

Table 16 showed that there were significant differences at ($\alpha < 0.05$) in the participants' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of income. A post hoc LCD test was conducted to check for significant differences between groups. (See Table 17)

Table 17. A post hoc LCD results

	Mean	Less than 500 JD	500 – 1000 JD	More than 1000 JD
Less than 500 JD	1.81			
500 – 1000 JD	1.88	.07		
More than 1000 JD	1.99	.18*	.11	

*Statistically significant at ($\alpha < 0.05$).

Table 17 showed that there were significant variations between participants who had less than 500 dinar income and the participants who had more than 1000 dinar incomes on their degree of acceptance of having their daughters undergone hysterectomy. Participants who had higher income had a higher degree of acceptance of having their daughters undergo hysterectomy than participants who had less income.

4. Discussion

The findings indicated that families had low degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities. The result might be attributed to several factors. One of the main factors includes the families' awareness of the fatwa (the Islamic rule regarding a certain issue) that prohibits hysterectomies for girls with intellectual disabilities, according to Islam religion. Also, the negative effects on body health are included of these types of surgeries. Furthermore, the families' awareness of the legal judgment of hysterectomy is that there is no provision in the law permitting or authorizing such operations, therefore, families' perceptions of hysterectomy are as violations of human dignity. Finally, the costs of hysterectomy surgery are high. Goktas et al., (2015) pointed to the medical risks of total hysterectomy that include depression and low sexual activity. Al-Asha (2009) identified the most important factors that might make families reluctance to have their daughters with intellectual disabilities undergo hysterectomy. Some of these factors were related to the medical risks associated with hysterectomy, where hysterectomy is a risky surgery that require comprehensive anesthesia and may result in bleeding problems. In addition, hysterectomy may lead to urinary tract infection and it has negative side effects on the skin and heart. Furthermore, hysterectomy would not prevent the girls with intellectual disabilities from being raped or sexually abused. Hysterectomy may increase the risk that girls' with intellectual disabilities are being raped. In addition, hysterectomy might make the sexual offenders of girls with intellectual disabilities avoid punishment. Furthermore, many families of girls with intellectual disabilities had fears from performing a hysterectomy on their daughters in the light of the presence of some cases of deaths during the course of surgery. Pollack (2005) reported that some families of girls with intellectual disabilities preferred using alternatives and different means of hysterectomy. For example, training community on how to protect people with intellectual disabilities from sexual abuse, teaching people with intellectual disabilities how to avoid abuse and sexual harassment, providing a family counseling for the people who have persons with intellectual disabilities, and teaching people with intellectual disabilities how to maintain a personal hygiene are all alternative means of hysterectomy.

The findings showed that there were variations in the Jordanian families' degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on different variables. For instance, the families who had disabled daughters between the ages of 11-20 years had higher degree of acceptance of having their daughters undergo hysterectomy than the families who had disabled daughters between the ages 5-10 years or even the ages of 21-30 years. Such findings can be attributed to the fact that within the age range of 11-20 years, girls reach puberty (menstruation every month). Therefore, some families of disabled girls during these ages have concerns related to the hygiene issues, responsibilities of extra care, fear and sensitivity in dealing with these girls during menstruation. Such finding aligned with the

findings of Chou and Lu (2011). On the other side, Aql (2015) reported that adolescent males with intellectual disabilities faced several social–emotional problems related to adapting to body changes during puberty. When disabled girls reach the age of puberty, the issues of poor hygiene during menstruation start to appear and the possibilities of sexual assault and harassment of these girls might increase. Isler et al., (2009) found that the families of people with mild to moderate intellectual disabilities who aged between 15 and 21 years had low knowledge of the sexual needs of their children. He found that %75 of these families had not received any sex education, 32 % of them did not talk about sex and a large percentage of these families had concerns about the future of their children with intellectual disabilities, where the right to receive special education services ends during these ages.

The results indicated that Jordanian families did not differ in their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' type of disability. This is due to the fact that their girls with intellectual disabilities, even with different types of intellectual disabilities have common main characteristics that include having low cognitive performance, having adaptive behavior problems, and having problems dealing with people. Girls with intellectual disabilities had inability to protect themselves, where they cannot take decision regarding hysterectomy. Pollack (2005) reported that the decision regarding hysterectomy must be made by the appropriate legal guardian.

The results showed that Jordanian families differed in their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their daughters' level of disability. Families who had daughters with severe or profound disability had higher degree of acceptance of having their daughters undergo hysterectomy than participants who had daughters with mild or moderate disability. This can be attributed to the families 'negative attitudes toward and low degree of acceptance of the daughters with severe and profound disabilities. Masoud (1988) reported that the families of children with intellectual disabilities may feel embarrassed or ashamed and they may feel that the society have negative views toward them because they have children with mentally disabled. Therefore, families of children with intellectual disabilities would avoid contact with their relatives. Girls with severe or profound intellectual disabilities are characterized by inability to function independently and to have significant difficulties in learning. Al-Habarnah (2015) reported that the families of these girls would face difficulties to teach them personal hygiene. In addition, no one would consider marrying off a girl with severe or profound intellectual disabilities.

With regard to the families of girls with intellectual disabilities, the degrees of acceptance of the mothers that their girls with intellectual disabilities perform hysterectomy was higher than the degrees of acceptance of the fathers of the girls with intellectual disabilities. This can be attributed to the fact that the mother is the main person involved in taking care of her daughter with intellectual disabilities. In addition, the feminine nature of the mother makes her understand her daughter's needs and suffering, mainly in eastern communities. The mothers of girls with intellectual disabilities take more responsibilities of their girls with intellectual disabilities than the fathers. Chou and Lu(2011) reported that mothers of girls with intellectual disabilities are often take the decision of having a hysterectomy performed on their daughters as a result from the fear of personal hygiene for their daughters during menstruation. Bambric

and Robert (1991) reported that the majority of fathers feel that they are not the ones who should take decisions regarding performing hysterectomy to their daughters with intellectual disabilities, and they believed that the mothers of girls with intellectual disabilities should be responsible to take such decisions.

The findings indicated that Jordanian families differed in their degree of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of education. The families' representatives (either mother or father) who had no education had higher degree of acceptance of having their daughters undergo hysterectomy than families' representatives who had different level of education (primary education, secondary education, community college education, university education). This might be explained by the fact that illiterate or uneducated parents face difficulties following up research and studies that denounce the risks of hysterectomy and show that hysterectomy is prohibited from the point views of religion and law. Frost et al., (1990) pointed to that the families of girls with intellectual disabilities need to know about the law and legislation related to hysterectomy.

Finally, the findings showed that Jordanian families differed in their degrees of acceptance of having a hysterectomy performed on their daughters with intellectual disabilities based on their level of income. The families who had higher income had a higher degree of acceptance of having their daughters undergo hysterectomy than families who had less income. Hysterectomy surgery is expensive; many families cannot afford to pay for costs of hysterectomy surgery. The families that had high degree of acceptance of having hysterectomy performed on their daughters with intellectual disabilities are related to the upper-class and the middle-class families that can afford hysterectomy. These families have concerns regarding maintaining their social status, reputation and honor; which they think it may be at risk in the presence of a girl with intellectual disabilities. These families believed that girls with intellectual disabilities might be at higher risk being sexually abused than normal girls. Chou and Lu (2011) found that the key factors to perform sterilization or hysterectomy on girls with intellectual disabilities were related to the concerns of personal hygiene, the concerns that the intellectual disability might be inherited, and the concerns were related to the risks of pregnancy because of rape.

5. Conclusion

The results of the study indicated that there is an urgent need to raise awareness of the society, specifically for the families of girls with intellectual disabilities, regarding the risks of hysterectomy and encouraging them to take safer alternative solutions. There is a need to examine the legal perspective of hysterectomy in Jordan and to activate the laws regarding hysterectomy for girls with intellectual disabilities. There is a need to establish a center for psychological and moral support to guide the families of girls with intellectual disabilities to overcome the psychological problems of their children. Finally, in case of urgent need to hysterectomy operations for girls with intellectual disabilities, it must be performed in proper ways to achieve its desired goals.

References

- Al-Asha, A. (2009). *Hysterectomy for Womens with Intellectual Disabilities. Working Paper Presented to The Supreme Council for Persons with Disabilities. National Campaign to Prevent Hysterectomy of Intellectual Disabled Girls in Cooperation with The International Institute for Women's Solidarity, Amman, Jordan.*
- Al-Habarnah, I. (2015). *Attitudes of Families of Girls with Intellectual Disabilities Towards Hysterectomy.* Unpublished Master Thesis, University of Jordan, Jordan.
- Al-Remawi, S. (2014). Problems Facing Disabled Women in The Hashemite Kingdom of Jordan and Their Relation to Some Variables. *Journal of Educational Sciences, 22, 4(1), 215-240.*
- Aql, M. (2015). *Effect of A Training Program for Teachers and Parents in Reducing Sexual Problems Among Adolescents with Intellectual Disabilities.* Unpublished PhD Dissertation. University of Jordan, Jordan.
- Bambrick, M., & Roberts, G. (1991). The Sterilization of people with a mental handicap: the views of parents. *Journal of mental deficiency research, 35. 353-363.* <https://doi.org/10.1111/j.1365-2788.1991.tb00407.x>
- Chou, Y. C., & Lu, Z. Y. (2011). Deciding about sterilisation: perspectives from women with an intellectual disability and their families in Taiwan. *Journal of Intellectual Disability Research, 55(1), 63-74.* <https://doi.org/10.1111/j.1365-2788.2010.01347.x>
- Frost, N., Clayton, E., Grodin, M., Kohrman, A., et al., (Committee of bioethics). (1990). Sterilization of women who are mentally handicapped. *Pediatrics, 85, 5.*
- Goktas, S. B., Gun, I., Yildiz, T., Sakar, M. N., & Caglayan, S. (2015). The effect of total hysterectomy on sexual function and depression. *Pakistan journal of medical sciences, 31(3), 700 .*
- Imran, M. (2008). The Impact of Personal Communication on The development of Awareness of The Concepts of Protection from Sexual Abuse of Children with mild Intellectual Disabilities. *Journal of Childhood Studies, 81,* Institute of Childhood Studies, Ain Shams University, Cairo.
- Isler, A., Beytut, D., Tas, F., & Conk, Z. (2009). A study on sexuality with the parents of adolescents with intellectual disability. *Sexuality and Disability, 27(4), 229.* <https://doi.org/10.1007/s11195-009-9130-3>
- Masoud, W. (1988). *The Impact of Disability on Family Adaptation.* A paper presented to the Center for Educational Research and Development, Yarmouk University, Jordan.
- Pollack, D. (2005). The Capacity of mentally challenged person to consent to abortion and sterilization. *Health and Social works, 30(3).* <https://doi.org/10.1093/hsw/30.3.253>

Report of the Hashemite Kingdom of Jordan on the status of the rights of persons with disabilities in the Kingdom, (2012). Department of Statistics. Retrieved from hcd.gov.jo/sites/default/files/ltqrry_rlsnwy_2012.docx

Rights of Persons with Disabilities Act No. 31 of the year. (2007). The publications of the Supreme Council for persons with disabilities, Jordan. Retrieved from, <http://hcd.gov.jo/ar/node/275>

Talbot, T., & Langdon, P. (2006). A Revised sexual knowledge assessment too for people with intellectual disabilities : Is sexual knowledge related to sexual offending behavior?. *Journal of intellectual disabilities research*. 50(7), 523-531. <https://doi.org/10.1111/j.1365-2788.2006.00801.x>

Copyright Disclaimer

Copyright for this article is retained by the author(s), with first publication rights granted to the journal.

This is an open-access article distributed under the terms and conditions of the Creative Commons Attribution license (<http://creativecommons.org/licenses/by/4.0/>).