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Parental Report of Gender Differences in Sexual Functioning among Adolescents with Down Syndrome: A Jordanian Experience

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Abstract

Background: Recently, there has been an increased interest in sexuality among teenagers with Down syndrome (DS). Although DS has been well studied in the western continents, its research is relatively scarce in the Arab region.

Aims: This is a cross -sectional study to explore the demographic characteristics and the sexual profile among 23 adolescents with DS who attended the outpatient psychiatric clinic of a tertiary care hospital in Amman, Jordan.

Method: A semi-structured interview conducted with the parents of individuals with DS was used to record the socio-demographic profile, self-care skills, socio-sexual skills and sexual behavior.

Results: The mean age of the sample was 13.5 years, out of which 69% were males; 26% were sexually oriented and able to identify their gender identity. When questioned about masturbation and self-care skills, a significant statistical difference was observed where girls showed more self-care skills while boys showed more masturbation acts. The p- value was (p = 0.045) for masturbation, p = 0.02 for washing the genitals, p = 0.011 for changing the underwear, and p = 0.001 for hygiene after using the toilet.

Conclusion: The present study expands our knowledge about sexual issues in individuals with DS. We found that all adolescents reported adaptation to the physical changes of puberty. However, gender difference on some of the sexuality subscales was observed, mainly in the practice of some self- care, socio-sexual skills and sexual behavior.

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Introduction

Sexual development is a multi-dimensional concept. It is closely related to the basic human needs of being liked and accepted, displaying, and receiving love, feeling valued and attractive, and sharing feelings with a partner. It doesn't only involve anatomic and physiologic functioning, but it also relates to sexual knowledge, beliefs, attitudes, and values [1].

Normal sexuality

Sexuality is a crucial aspect of the adolescents' emotional, physical, and psychological development and well-being. It has a fundamental role in an individual's overall self-identity [2,3].

Normal sexuality means sexuality maturating into the proper adult roles at the proper age. It starts at puberty, where a neuro-behavioral cascade of developmental stages takes place. This results in adolescents reaching the adult levels of sexual and reproductive maturity. The World Health Organization (WHO) defines sexuality as a fundamental aspect of being human throughout life. It involves sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values behavior practices, roles and relationships. While sexuality can cover all of these scopes, not all of them are always practiced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, political, economic, cultural, legal, religious, and spiritual factors [4]. This developmental process might be affected negatively by a number of factors. Those factors, according to Schalet [5], are defining teenage sex as wrong or risky and assuming that they are unable to distinguish sexual acts that are safe from those that are high risk. Furthermore, viewing sexuality as an "either/or" activity rather than a continuum, leading to scanty attention to the skills necessary to express and communicate sexual wishes.

Also, not paying enough attention to the relationships with partners and adult caregivers that can support positive adolescent sexual experiences. Finally, failure to recognize the socioeconomic deprivations that are at the root of many negative sexual behaviors will shape the normal development of sexuality in teens. The development of a secure sexual identity is a difficult task even in the absence of a physical or mental disability [6].

In patriarchal societies, such as those from the Arab world, girls are subordinate. They possess an inferior position to men and lack access to resources and decision making processes [7]. Oppression of girls and women starts within the families. Parents usually show son preference, while discriminating against girls in the form of food distribution, the burdening of household work, lack of educational opportunities, lack of freedom and mobility, sexual harassment in the workplace, lack of inheritance or property rights, male control over women's bodies and sexuality, and no control over fertility or reproductive rights. Girls usually have no right to choose their husbands or express sexual interests in the other sex [8]. Thus, females are at a socio-cultural disadvantage in relation to males [9]. Males will be the only ones who benefit from this type of society, while all the disadvantages will be directed toward females. In many Arab communities, boys in the family are regarded as assets, investments to the social prestige of the family, while females are downgraded to burdensome and a potential source of shame [10]. Gender inequality is the end result of patriarchal societies which positively influence the sexual development in male members and negatively affects it in female counterparts. Boys will be encouraged to be involved in sexual relationships (or at least will not be punished if they do so), while females are oppressed and taught that their bodies are something to be shy and ashamed of. Furthermore, the patriarchal structure of the Arab society limits the possibilities for providing appropriate services to women





and their children that will satisfy their need for physical safety and emotional security, as well as for their sexuality and general well-being [11].

The cultural view characterizing patriarchal societies is far beyond the scope of this article. However, its role in sexuality will be summarized. First, promoting the authority of men to achieve a more advantaged social situation. Second, behaviors perceived as feminine will be discouraged in the male society. Thus, boys become aggressive and violent towards girls to avoid being labeled as non-masculine. Third, there is economic dependence of women on men. Men will earn more, and have a better chance to get educated and hired. Consequently, this unfair division of income and advantages will place the child bearing and upbringing of women alone. Mothers in the Arab society are usually the ones who will take care of their children in all aspects of life, particularly if these children are disabled. They will be forced to stay married to the neglectful fathers to avoid the stigma of divorce. Patriarchal societies are more tolerant toward men who neglect their roles as husbands than they are toward women who ignore their role as wives [12].

Sexuality in adolescents with disabilities:

Like all adolescents, teens with DS may express a desire and hope for marriage, children, and normal adult sex lives. Individuals with developmental disabilities feel similar needs for sexual development, desires, and sex drives like their peers without disability [13]. However, parents and health care professionals are often unenthusiastic regarding the potential of children with disabilities to enjoy intimacy and sexuality in their relationships [14]. Parents are also over protective, which leads to decrease in the opportunities for social interaction. Limited data is available about people with DS who get married. In 1988, Edwards published the results of a survey on marriage in this population[15]. Of 38 married subjects with DS, all but

three were women. None of their spouses had DS, although many had other developmental disabilities. It was found that most of the couples lived in highly supportive environments, including having family and other advocates nearby [16].

There are plenty of myths regarding children with disabilities, particularly those with DS. They are often mistakenly regarded as childlike, asexual, and in need of protection [16]. Conversely, they may be viewed as inappropriately hypersexual or as having uncontrollable sexual urges [17]. This negatively impacts their sexuality as parents think of their children as interminable kids. Parents are afraid of the extreme outcome of their children's sex life, such as unwanted pregnancy and risk of sexually transmitted disease. Health professionals revealed to be unprepared to provide sexual advice for individuals with DS or to educate parents about the proper attitude towards their children's sexual drive. Sexuality of individuals with DS develops similarly to that of normal individuals. However, individuals with DS experience restrictions depending on their social context [18].

The single study found by the authors examining the sexuality of DS in the Arab population was conducted by Attia [19], who carried out a case control study on 21 male patients with DS, aged 21-28 years, and an age-matched healthy control group. Full sexual history was obtained from all participants, including the age of puberty, desire of marriage and parenting children, practice of masturbation, and attraction to the other sex. Follicle-stimulating hormone, luteinizing hormone, prolactin, total testosterone, and estradiol levels were measured and the BMI (Body Mass Index ,which equals the weight in Kilograms / height in Meters²) was evaluated. It was found that patients included in the study reached puberty and became fully sexually mature, but later than their healthy peers. More than half (57.1%) of patients with DS were sexually active, masturbated, were attracted to the other





sex, and had the desire to marry. Patients with DS showed a higher BMI. Follicle-stimulating hormone, luteinizing hormone and prolactin levels were significantly higher in patients with DS compared with the controls. They showed a lower serum total testosterone. The serum estradiol was normal.

Sexuality in the Arab world

Youth sexuality is a taboo topic in the Arab world, particularly among the unmarried and specifically among younger generations. In a recent Lebanese study, the sexual behaviors, attitudes, and perceptions of private university students from Lebanon were investigated. The study was conducted over (n=1838) students, half of which (n=943) were sexually active and a third of them reported having had anal and/or oral sex particularly avoid hymen-breaking to (higher percentages among females). Penetrative sexual practices with an unfamiliar partner were 8 times more likely in males (p<0.0001). About 20% of female students reported non-consensual sex with sexual unveiling compared to 13% of males (p=0.013). Again, 20% of the females reported never having been sexually abused versus 7% of the males (p<0.0001). Common socio-cultural concerns included gaining a bad reputation about sexual initiation (60%), social rejection (69%), religion (75%), parental disapproval (76%), feeling guilty afterward (70%), and losing self-respect (69%). All were more commonly reported by females [20].

Gender differences in sexuality

Information about the differences between genders, physiological and psychological understanding about sexual development and orientation regarding inadequate social behavior is rare. According to [21], conversation concerning normal physical development and how to avoid sexual abuse should always be approached by children having DS and similar developmental disabilities. Blum [22] argued that when caring for youth with disabilities, it is of highest

importance that directives be provided about hygiene, menstruation, masturbation, sexually transmitted diseases (STDs), AIDS, contraception, and marriage.

In Middle Eastern settings, male children are more often supposed to be outgoing compared to female children. As a result, social deficits in females may be attributed to shyness or a lack of opportunity to interact with others. Also, compared with males, they are thought to show more warmth and emotionality [11]. Female activities outside the home are watched and restricted. Furthermore, they are expected to assume greater accountability in the household and prepare to be good housewives, while their male counterparts are able to escape much of this responsibility. Thus, females may be perceived as having a greater level of social deficits than males. Cultural differences are evident in the ways in which males and females are treated, extend to individuals with developmental disabilities, and may further influence the phenotypic expression of some developmental disabilities [23]. To the author's knowledge, there are no studies in the Arab world that examined gender differences in the sexuality of adolescents with DS. In this study, we investigated the sexuality and gender differences of 16 male and 7 female adolescents with DS in an Arab psychiatric facility.

Aim of the study:

The present study aimed to investigate gender differences in the application of self-care skills, socio-sexual skills and range of sexual behavior. It was applied over a group of adolescents with DS attending a psychiatric facility in Amman, Jordan.

III. Subjects and Methods:

This is a cross-sectional study conducted at the mental health center of Amman, Jordan. The study recruited the parents of 23 adolescents with DS through verbal invitation by the study team to the target parent





during their routine follow up visits to the mental health center for care of their children. Recruitment procedure ensured the voluntary participation of the parents. It was explained to them that their participation is completely voluntary. They were reassured that they will still receive the same quality of health services even if they decide not to participate. Furthermore, they were informed about intact confidentiality and that no identifying data will be revealed on publication of the results. The study team recruited the parent who accompanied the subjects with DS (the mother in 18 cases, the father in 3 cases and both parents in two cases). Information about the other parent was taken from the attending parent. An informed consent was taken from the participating parents and guardian. The study was approved by the local ethical committee of the Mental Health center

Instruments:

Information about patients with DS was obtained from the caregivers who accompanied them. For practical reasons, it was decided to interview parents instead of a direct interview of the individuals. Parents were overprotective and to some extent hesitant to approve a direct interview of their children. Moreover, communication of the research team with children with DS to obtain sexual data would have been a difficult target. It is a common practice to interview parents instead of children themselves in studies investigating similar topics. Listed here are just a few of these studies [24,25,26,27].

A semi-structured interview containing personal and demographic items was used to obtain the socio-demographic and sexual behavior profile -modified from [28]. The family income was classified into satisfactory and non-satisfactory, depending upon the subjective rating of the parent since no governmental guidelines are available for such classification. Occupations were listed and grouped according to the given information from the parents, where the father's job was rated as

professional or non-professional, and mothers were grouped as housewives or working mothers. The original questionnaire was designed to assess sexuality of children with autism versus children with mental retardation. It was formed of three parts. The first part was about sexual hygiene, self-care skills and a single question about the physical adaptation to puberty. The second part of the instrument assesses the sexual behavior itself, while the third part rates specific autistic symptoms in sexual behavior. Originally the self-care skills were rated over a five point Likert scale ranging from: 1. very poor, 2. poor, 3. moderate, 4. good, and 5.very good. The question about adaptation to physical changes in puberty was rated on a five point frequency scale starting: 1. never, 2. once, 3. sometimes, 4. often, and 5. always. The remaining questions of the sexual behavior were dichotomized into present and not present. After modification of the initial test to suit the needs of the current study, we omitted the part related to autistic features, and we made the rating of all questionnaire items dichotomized into present /not present for simplicity and feasibility of application. Furthermore, no comparison with other disorders was conducted so the Likert scale rating of the questionnaire was used as no sub-items were needed. The questions of the semi-structured interview after modification were translated into Arabic and translated back into English. Each interview was 30 minutes in duration. The testretest reliabilities for the individual items with two week intervals ranged from 0.81 to 0.93, which were similar to the original version. The questionnaire covered a number of sexual skills that are summarized in Table (1).)

Statistical methods

Demographic data were represented as numbers and frequency percentages, means and standard deviations of numerical variables. *T-tests* were used to compare both sexes on sexuality variables.





Semistructured interview items	Subscale			
Self-care skills	washing the genitals			
	changing underwear			
	proper use of toilet			
	hygiene after visiting the toilet			
Socio-sexual skills	knowing whom is allowed to touch or kiss			
	suitable clothing			
	talking about sex apropiately			
	toughing the genitals in public			
	knowing whom is allowed to kiss			
Sexual behaviour	masturbates			
	interested in opposite sex			
	talks about need for relationship			
	expressed frustrations about not being able to establish or maintain relationships			

Results

The age of the teenagers ranged from 12 to 18 years, with a mean of 13.5 years, out of which 69% were males, 60% were not enrolled in school, 52.2% of the fathers had education below secondary school, while 73.9% of the mothers were housewives. The demographic characteristics of the sample can be summarized in Table (2)

In analyzing the functionality of these teenagers, it was found that they were able to function independently as seen from the items of the self-care subscale, indicating that the adolescents were not totally dependent on their parents. Of all the interviewed participants, 26% affirmed knowing what sexual desire was and were sexually oriented. Additionally, 26.5% were able to identify their gender identity. Despite that, 14% of the original sample didn't receive proper sex education.

A strong trend toward a statistical difference was observed in the act of masturbation, between boys and girls practicing the habit (p = 0.045). Regarding kissing, there was no observed statistical difference between boys and girls. A total of 7 girls and 12 boys had no idea who is allowed to touch and kiss them. On

demonstrating self-care skills there was an obvious statistical difference between boys and girls. For instance, regarding washing the genitals (p = 0.02), changing the underwear (p = 0.011), and the hygiene after using the toilet (p = 0.001). This part of the questionnaire also revealed that the majority of the sample does touch their private parts in public (Table 3)

Discussion

Data from this study could be considered the first of its kind in the Arab world. We recruited subjects with DS. None of them had congenital anomalies severe enough to impede with their functioning, indicating that all sexual discrepancies noted were primary and due to the Trisomy itself. Moreover, sexual rights such as enjoying relationships, receiving reachable advice and support, feeling comfortable about oneself and his/her desires and sexuality, enable individuals to enjoy sex and gain personal satisfaction. This may include marrying or forming ongoing sexual relationships, receiving contraceptive advice and services in order to avoid pregnancy and the risk of sexually transmitted infections, and enjoying parenthood, if desired. With appropriate advising and teaching, young people should be assisted to develop essential parenting skills. They





Table (2): Socio-demographic characteristics *of the sample (N=23)*

Variable	N	%	
Gender			
Female	7	30.4	
Male	16	69.6	
Father education			
Above 2ndry education	12	52.2	
Below 2ndry education	11	47.8	
Mother education			
Above 2ndry education	15	65.2	
Below 2ndry education	8	34.8	
Father occupation			
Not professional	17	73.9	
Professional	6	26.1	
Mother occupation			
Housewife	7	30.5	
Working	16	69.5	
Income			
Satisfactory	11	47.8	
Unsatisfactory	12	52.2	
Residence			
Urban	5	21.7	
Rural	18	78.3	
School			
Child goes to school	9	39.1	
Child doesn't go to school	14	60.9	
Age			
Mean	13.5		
SD	1.4		
Min	12		
Max	18		





Table (3): difference between boys and girls on sexual functions obtained from Hellman's questionnaire

	Females		Males			
	Present	Absent	Present	Absent	x2 value	p
Self-care skills						
Washing the genitals	3	4	0	16	7.8	0.02
Changing underwear	5	2	14	2	7.9	0.011
Proper use of the toilet	7	0	12	4	2.1	0.2
Hygiene after visiting the toilet*	5	2	0	16	14.6	0.001
Socio-sexual skills						
Knowing whom is allowed to touch or kiss	0	7	4	12	2.1	0.2
Suitable clothing	7	0	15	1	0.45	0.69
Talking about sex appropriately	2	5	5	11	3.1	0.9
Touching the genitals in public	7	0	9	7	4.4	0.04
knowing whom is allowed to kiss	1	6	3	13	0.06	0.67
Sexual Behaviour						
Masturbates	3	4	14	2	5	0.045
Interested in opposite sex	2	5	11	5	3.1	0.9
Talks about need for relati Expressed frustration	1997	4	8	8	1	0.5
about not being able to establish or maintain relationship	0	7	2	14	0.95	0.47

can choose to avoid parenthood or seek an abortion. They have the right not to be sexually abused and to be protected from sexual abuse

Developed countries allow their residents to have their sexual rights even if they have a mental disability. On the other hand, in developing countries children with DS constitute a major stigma and burden to their families. This implies a further rejection and the public will usually look to individuals with DS as ugly and humiliating. Consequently, this will affect their development in general and their sexuality in specific. Sexuality is a developmental milestone that depends mainly on cultural context.

In a study by Attia et al [19] In adult subjects with DS, they found a marked delay in puberty of the recruited sample. None of the subjects in the study had

anatomical abnormalities in the development of the genitalia apart from cryptorchidism (14.3%). Moreover, half of the sample practiced masturbation (57.1%) and were interested in and attracted to the other sex, as reported by their parents. They also had the desire to marry and only 9.5% of patients with DS included were married, compared with 66.7% of the control group.

It was noted that girls had better sexual hygiene than boys. This might be due to founding routines and parental education about menses and self-care. Mothers give extra care to daughters, especially during their monthly periods, and education about hygiene is increased as they are being prepared to become a future wife and mother. These hygienic practices are also encouraged religiously by Islam. Further research is suggested to investigate the handling and coping of





females with DS during the physical and emotional changes of puberty, periods, and other possible interventions [29]. In a study by Mensch [30] on Egyptian youths, girls had much less free time than boys, were less mobile, were much less likely to participate in paid work, and had heavier domestic responsibilities regardless of whether or not they were in school. Girls favor a later age of marriage. Boys were significantly more likely than girls to favor educational inequality between spouses, although neither boys nor girls had particularly progressive gender role attitudes. In the late nineteenth century, masturbation was condemned in many countries as sinful and also harmful to health. Now it is widely accepted as normal in some cultures [31] although not in the middle-east or Arab region. Masturbation is prohibited by Islam. The Quran reads (23: 5-7): "And they who guard their private parts, except from their wives or those their right hands possess, for indeed, they will not be blamed; but whoever seeks beyond that [in sexual gratification], then those are the transgressors". It is clear that any sexual act outside the marriage framework provided in the Quranic verses is unlawful. Imam Ja'far as-Sadiq, one of the close followers of Prophet Mohammed, when once asked about the Quran viewpoint on masturbation declaimed the verse above and mentioned masturbation as one of its examples, labeling masturbation as a filthy act [32]. In this study, the percentage of masturbation had a higher trend in the participating boys than the girls. This is a different finding from previous studies reporting masturbation more common among females. That is, 40% in males and as 52% in females [23]. Rates of masturbation are not significantly higher in individuals with DS than those in the general population [33]. Our finding of sex differences with males performing masturbatory behavior more than females is particularly noteworthy. Parents were ashamed when mentioning this fact about their children because they do not want to show their lack of religiosity or their inability to properly discipline their DS children, which is

considered to be unaccepted in the society. Again, due to the cultural belief of male dominance and female subordination, parents were more accepting of their boy's masturbation more than the girls and were less ashamed about it, which might explain our findings. However, it is not clear whether the developmental process differs between males and females. Previous studies supported that females showed superior motor function compared to that of males which results in masturbating more frequently [34].

It was noticed that adolescents included in the study showed high levels of inappropriate sexual behaviors in addition to lack of hope in the ability to bond and maintain relationships with other sex. In the majority of cases, this is due to the effect of parenting. Development of sexually inappropriate behaviors in persons with DS has been discussed in several studies previously. Richards et al [35] listed the reasons behind such behavior: those who lack sexual education, lack social exposure, are deprived of peer group interaction, whose activities are restricted by family, their motor coordination, and negative feelings and attitudes toward sexuality. Parents of DS think that their children will give birth to offspring with disabilities, will be incapable of adequate parenting, will not understand the legal implications of marriage and parenting, and will be unable to bond. Individuals with DS are rarely provided with the choice to express sexuality. They are deprived of privacy and knowledge. These findings are similar to a study conducted in Poland by Barg [36] where 70% of girls with DS recruited in the study had menarche. Ninety one percent of their parents noticed changes in behavior - instability of mood. Thirty seven percent of parents talked with their child on sexual topics, most of them in response to the child's interest. Forty seven percent of boys with DS showed interest in the opposite sex. Half of the subjects with DS in the study had plans of having a family, in spite of most of parents not





approving of their children starting a family, a concern shared by parents in the Arab region.

Similarly in a survey conducted in the Egyptian village of Silwa, adolescents were timid, apprehensive, and withdrawn, which was the cumulative effect of social disciplining. The maturing of sex characteristics at that age were faced with embarrassment, shame, and guilt, together with secrecy. Sexual pleasure of any kind before marriage is condemned by religion [37].

School can potentially shift the orientation of a young person from adults to peers. Schooling places adolescents in a peer environment for most of the day, reducing the amount of time they spend with adults and increasing "the salience of their involvement with agemates" [38]. However, it is unclear what role peers play in the socialization of people with DS.

Teenagers with DS present an abundant variety manifestations in relation to sexuality reproductive health. Such variety is highly dependent on pubertal development, individual experiences, and familial and social situations. When evaluating the interests of teenagers with DS in the exercise of sexuality, over half of the adolescents demonstrated interest in the opposite sex. The results show 18% of the respondents know what masturbation is, with 42% masturbating frequently and 24% of those masturbate on a daily basis. It also highlights the need to satisfy sexual impulses. Possibly not the most suitable way to do so, but probably the only way available for these adolescents. Such findings agree with findings from Pueschel [23]. Another consequence of social isolation for these teenagers is that they receive less information regarding sexuality, reproduction, and conception.

The preponderance of boys in this study suggests a role of the cultural parenting, such as constraining disruptive behavior in Arab girls. In the Euro-American culture, children are usually raised in ways that encourage them to become self-reliant and

independent. In such a socialization pattern, impulsivity and risk taking behaviors may be instrumental for the individual [39]. In contrast, children in the Arab region are usually encouraged to think and act as a member of their families. They learn to suppress their individual wishes when their wishes are in conflict with the needs of the family. Sometimes this is called an allocentric cultural parenting [40]. This allocentricity is mainly practiced with the girls within the families and less practiced with the boys. Thus, in such societies, independence, and self-reliance of their female children are discouraged by the parents. This makes it more difficult for a girl to express her desire, compared to a boy. Such pursuits are viewed and judged as selfish. This evaluation is likely to be harsher for girls/ women and Arab females are expected to be tame and contented. This pattern of parenting might have affected the sexual behaviors of girls and boys in this study with the boys touching their genitals in public more than the girls without having a fear of being punished by the parents ,furthermore the girls in this study were more shy and restrictive in expressing their sexuality and sexual desires.

This study has some limitations. Firstly, the small sample of individuals with DS, which does not allow drawing of conclusions about the general population of this group of adolescents and limits generalization of findings. The stigma of mental disorders in the Arab world is very high - thus, despite the presence of a considerable number of people with DS, their parents choose to lock them up at home and avoid visiting mental health centers, which makes it difficult to recruit an appropriate number of study subjects. Secondly, the number of males was larger than females. Thirdly, the indirect approach of an interview with parents, not the adolescents themselves. The information obtained in the present study was received exclusively from parents who were willing to participate in gathering information about DS. As such,





the experiences of the present sample may not be representative of the experiences of the larger population of families having children with DS, especially with the small sample size. This could result in an underestimate of the frequency of sexual behavior. Furthermore, we did not collect any data regarding the mental age of the recruited children with DS. This would have helped in the further profiling of the sexual development of the sample.

The present study expands the knowledge about sexual issues in individuals with DS, particularly in the Arab world. It was found that all adolescents reported adaptation to the physical changes of puberty. However ,there was a gender difference in the practice of some self- care, socio-sexual skills and sexual behavior. Females showed more interest in hygiene after visiting the toilet and talking about sex appropriately than their counterpart males. On the contrary, males evidenced more practice of masturbation than females. Our study confirms the previous studies conducted in the Western countries. Future research should address these issues by directly interviewing larger samples of males and females with DS from multiple centers all over Jordan.

Recommendation:

Since, sexuality is an intrinsic aspect of human development, men with DS need to learn testicular self-examination as their cognitive level permits. Likewise, women with DS need to learn breast self-examination and the necessity for regular gynecological care. Sexuality is an important aspect of human development. Individuals with DS need tailored instruction and education to develop appropriate socio-sexual behaviors. While individuals with DS have unique and sometimes complex medical needs, they still require routine reproductive health services similar to those offered to the general population. Those general routine checks include urological care for men, gynecological care for women, and preventive medical services. Education and

counseling to prevent unplanned pregnancy, abuse, and sexually transmitted disease should be part of the routine medical care and education for individuals with DS.

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References

- Murphy, N. A., & Elias, E. R. (2006). Sexuality of children and adolescents with developmental disabilities. Pediatrics, 118(1), 398–403. doi:10.1542/peds.2006-1115.
- Ailey, S. H., Marks, B. A., Crisp, C., & Hahn, J. E. (2003). Promoting sexuality across the life span for individuals with intellectual and developmental disabilities. Nursing Clinics of North America, 38(2), 229-252. doi:10.1016/S0029-6465(02)00056-7.
- Duncan, P., Dixon, R. R., & Carlson, J. (2003). Childhood and adolescent sexuality. Pediatric Clinics of North America, 50(4), 765-780. doi: 10.1016/ S0031-3955(03)00068-3.
- WHO. (2006). Defining sexual health: Report of a technical consultation on sexual health, 28–31.
 Geneva, World Health Organization.
- Schalet, A. (2010). Sexual Subjectivity Revisited The Significance of Relationships in Dutch and American Girls' Experiences of Sexuality. Gender & Society, 24 (3), 304-329. doi: 10.1177/0891243210368400.
- 6. Grant, L. (1995). Sex and the adolescent. In S. Parker, B. Zwellerman (Eds), Behavioral and





- Developmental, Pediatrics, p 269-277, Boston: Little Brown & Co.
- 7. Lerner, G. (1989). The Creation of Patriarchy. Oxford University Press:New York
- 8. Sultana, A. (2012). Patriarchy and women's Subordination: A theoretical analysis. Arts Faculty Journal, 4 . doi:10.3329/afj.v4i0.12929.
- El-Islam, M. F. (1982). Arabic cultural psychiatry.
 Transcultural Psychiatry, 19(1), 5–24.
 doi:10.1177/136346158201900101.
- Eickelman, D. F. (1981). A search for the anthropology of Islam: Abdul Hamid el-Zein. International Journal of Middle East Studies, 13(03), 361-365. doi.org/10.1017/S0020743800053472.
- 11. Haj-Yahia, M. M. (2005). Can people's patriarchal ideology predict their beliefs about wife abuse? The case of Jordanian men. Journal of Community Psychology, 33(5), 545–567. doi:10.1002/jcop.20068.
- Haj-Yahia, M. M., Sousa, C., Alnabilsy, R., & Elias, H. (2015). The influence of Palestinian physicians' patriarchal ideology and exposure to family violence on their beliefs about wife beating. Journal of Family Violence, 30(3), 263–276. doi:10.1007/s10896-015-9671-4.
- Greydanus, D. E., & Omar, H. A. (2008). Sexuality issues and gynecologic care of adolescents with developmental disabilities. Pediatric Clinics of North America, 55(6), 1315-1335. doi:10.1016/j.pcl.2008.08.002.
- Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T., & Bukovy, G. (1999). Sexuality And The Adolescent With A Physical Disability: Understandings and misunderstandings. Issues in Comprehensive Pediatric Nursing, 22(4), 183–196.

- doi:10.1080/014608699265275.
- 15. Edwards, J. (1988). Sexuality, marriage, and parenting for persons with Down syndrome. Pueschel SM. The young person with Down Syndrome: transition from adolescence to adulthood. Baltimore: Brookes, 187-204.
- Oresi, S., Nota, L., & Ferrari, L. (2006). Family Setting in Down Syndrome. Down syndrome: Neurobehavioural specificity, 191.
- Neufeld, J. A., Klingbeil, F., Bryen, D. N., Silverman, B., & Thomas, A. (2002). Adolescent sexuality and disability. Physical Medicine and Rehabilitation Clinics of North America, 13(4), 857–873. doi:10.1016/s1047-9651(02)00045.
- 18. Castelao TB, Schiavo MR, Jurberg P. Sexuality in Down syndrome individuals. Rev. Saude Publica. 2003;37(1):32-9.
- Attia, A. M., Ghanayem, N. M., & El Naqeeb, H. H. (2015). Sexual and reproductive functions in men with Down's syndrome. Menoufia Medical Journal, 28(2), 471. doi: 10.4103/1110-2098.163904.
- 20. Yasmine, R., El Salibi, N., El Kak, F., & Ghandour, L. (2015). Postponing sexual debut among university youth: how do men and women differ in their perceptions, values and non-penetrative sexual practices?. Culture, health & sexuality, 17(5), 555-575. doi:10.1080/13691058.2014.972457.
- 21. Haefner, H. K., & Elkins, T. E. (1991). Contraceptive management for female adolescents with mental retardation and handicapping disabilities. Current Opinion in Obstetrics and Gynecology, 3(6), 820??? 824. doi:10.1097/00001703-199112000-00013.
- 22. Blum, D. (1997). Sex on the brain: The biological differences between men and women. Penguin
- 23. Abu-Habib, L. (1997). Gender and disability:





Women's experiences in the Middle East. Oxfam.

- 24. Pueschel, S. M., & Scola, P. S. (2008). Parent's perception of social and sexual functions in adolescents with down's syndrome. Journal of Intellectual Disability Research, 32(3), 215–220. doi:10.1111/j.1365-2788.1988.tb01407.x.
- 25. Marques Bononi, B., Carvalho Sant'Anna, M. J., Chao Vasconcellos de Oliveira, A., Silveira Renattini, T., Franchi Pinto, C., Passarelli, M. L., ... & Omar, H. A. (2009). Sexuality and persons with Down syndrome. A study from Brazil. International journal of adolescent medicine and health, 21(3), 319-326. doi: 10.1515/IJAMH.2009.21.3.319.
- 26. Burke, N. J., Hellman, J. L., Scott, B. G., Weems, C. F., & Carrion, V. G. (2011). The impact of adverse childhood experiences on an urban pediatric population. Child abuse & neglect, 35(6), 408-413. doi:10.1016/j.chiabu.2011.02.006.
- 27. Ginevra, M. C., Nota, L., & Stokes, M. A. (2015). The differential effects of autism and down's syndrome on sexual behavior. Autism Research, 9(1), 131–140. doi:10.1002/aur.1504.
- 28. Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., & Deboutte, D. (2006). Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder. Journal of Autism and Developmental Disorders, 37(2), 260–269. doi:10.1007/s10803-006-0159-1.
- Mason, C. A., Gaffney, M., Green, D. R., & Grosse,
 S. D. (2008). Measures of follow-up in early hearing detection and intervention programs: A need for Standardization. American Journal of Audiology, 17 (1), 60. doi:10.1044/1059-0889(2008/007).
- Mensch, B. S., Ibrahim, B. L., Lee, S. M., & El-Gibaly, O. (2003). Gender-role attitudes among Egyptian adolescents. Studies in Family Planning, 34

- (1), 8–18. doi:10.1111/j.1728-4465.2003.00008.x.
- 31. Murray, C. E., & Murray, T. L. (2004). Solution-Focused Premarital Counseling: Helping Couples Build A Vision For Their Marriage. Journal of Marital and Family Therapy, 30(3), 349–358. doi:10.1111/j.1752-0606.2004.tb01245.x.
- 32. Hoseini, S. S. (2013). Masturbation: Scientific evidence and Islam's view. Journal of Religion and Health. doi:10.1007/s10943-013-9720-3.
- 33. Myers, B. A., & Pueschel, S. M. (1991). Psychiatric disorders in persons with down syndrome. The Journal of Nervous and Mental Disease, 179(10), 609–613. doi:10.1097/00005053-199110000-00004.
- 34. Rihtman, T., Tekuzener, E., Parush, S., Tenenbaum, A., Bachrach, S. J., & Ornoy, A. (2010). Are the cognitive functions of children with down syndrome related to their participation? Developmental Medicine & Child Neurology, 52(1), 72–78. doi:10.1111/j.1469-8749.2009.03356.x.
- Richards, M. H., Crowe, P. A., Larson, R., & Swarr,
 A. (1998). Developmental patterns and gender differences in the experience of peer companionship during adolescence. Child development, 69(1), 154-163. doi: 10.1111/j.1467-8624.1998.tb06140.x.
- 36. Barg, E., Bury, M., Marczyk, T., Pałac, K., & Wirth, M. (2007). [Psychosexual problem in young people with Down syndrome in parents' opinions-personal experience]. Pediatric endocrinology, diabetes, and metabolism, 14(4), 225-230.
- 37. Ammar, H. (1998). Growing up in an Egyptian village: Silwa, province of Aswan (Vol. 4). Taylor & Francis.
- 38. Browning, D. L. (Ed.). (2013). Adolescent identities: A collection of readings. Routledge.
- 39. Al-Sharbati, M., Al Adawi, S., Al-Hussaini, A. A., Al





Lawati, S., & Martin, R. (2004). ADHD In Omani Schoolgirls. Journal of the American Academy of Child & Adolescent Psychiatry, 43(2), 132–133. doi:10.1097/00004583-200402000-00007.

40. Dwairy, M. (2006). Parenting styles, individuation, and mental health of Arab adolescents: A Third cross-regional research study. Journal of Cross-Cultural Psychology, 37(3), 262–272. doi:10.1177/0022022106286924.