Original Article

Parental Experiences about the Sexual and Reproductive Health of Adolescent Girls with Intellectual Disability: A Qualitative Study

Shadi Goli[1,2], Mahnaz Noroozi[3], Mehrdad Salehi[4]

[1]Student Research Committee, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran, [2]Nursing and Midwifery Sciences Development Research Center, Najafabad Branch, Islamic Azad University, Najafabad, Iran, [3]Department of Midwifery and Reproductive Health, Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran, [4]Medical School, Isfahan University of Medical Sciences, Isfahan, Iran

Abstract

Background: Intellectually disabled persons, as compared with normal people, experience different changes during the adolescence period including the appearance of secondary sexual characteristics. However, owing to their low intelligence quotient, these changes are usually accompanied by more problems and challenges. The present study was conducted to determine the experiences of parents regarding the sexual and reproductive health of educable intellectually disabled adolescent girls. **Materials and Methods:** This qualitative study was carried out on 52 participants (adolescent girls, parents, teachers, healthcare providers, and managers) who were selected via purposeful sampling in Isfahan between July 2016 and April 2017. Data were collected through semi-structured interviews, focus group discussions and field notes, and analyzed using conventional content analysis. **Results:** Five sub-categories were extracted: "unawareness about sexual needs of the adolescent girl and her potential vulnerability," "inappropriate actions in directing the sexual behaviors of the adolescent," "insufficient supervision and care over the adolescent's sexual health," "inappropriate actions toward marrying off the adolescent," and "inappropriate actions regarding the menstrual and genital health" which formed the main category of "parents' inefficiency in maintaining adolescent girls' sexual and reproductive health." **Conclusions:** Based on the results, parents face different challenges about the sexual and reproductive health of intellectually disabled adolescent girls. Hence, empowering the parents especially mothers through teachers and healthcare providers with the knowledge and skills to maintain the sexual and reproductive health of intellectually disabled adolescent girls would make them emboldened to find the ability to protect themselves in different situations.

Keywords: *Intellectual disability, Iran, parents, sexual health*

Introduction

Intellectual disability is characterized by Intelligence Quotient (IQ) of less than 70 and limitations in adaptive functioning manifested during the developmental years.[1] Intellectually Disabled (ID) people are classified into four groups: mild or educable, moderate or trainable, severe or maintainable, and profound.[2] The prevalence of intellectual disability is about 1 to 3% in the world. According to the census results of 2011, the prevalence of intellectual disability in Iran is about 1.3%.[3]

Sexual health is an individual's ability to express issues related to sexual life, within the framework of the society's value system, laws, beliefs, and the dominant culture, without being afraid of Sexually Transmitted Infections (STIs), unwanted pregnancies, and implementation of force, violence, or discrimination.[4] Sexuality, which is considered as a kind of pleasure for every individual, is still being ignored and not acknowledged as part of the rights of ID people.[5] Studies suggest that in ID people, changes during the adolescence period are usually associated with enormous problems and challenges.[4-7] ID adolescents are vulnerable to sexual abuse by family members, caregivers, and close friends, twice more than normal people.[8] Sexual abuse could have long-term effects such as incompatibility, involvement in risky sexual behaviors, and serious consequences such as unwanted pregnancy, STIs, and HIV/AIDS, as well as the occurrence of anxiety and depression.[9]

The family, as the first social unit, has the most imperative role in educating and

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Address for correspondence:
Dr. Mahnaz Noroozi, Department of Midwifery and Reproductive Health, Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran. E-mail: noroozi@nm.mui.ac.ir

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inculcating healthy behaviors to the adolescent. However, parents often feel ashamed of discussing sexual issues with their children and lack the required skills for this matter.[10] The results of a study showed that although parents play an important role in protecting their adolescent's sexual health, they may be inexperienced in this task.[11] Identifying parental, experiences in issues related to ID adolescent girls, sexual health can be helpful in solving their problems. Qualitative research is an approach towards discovering and describing the experiences of participants and conceptualizing them, it could increase insight and awareness about human experiences.[12] Considering the differences in the social, cultural, and religious context of Iran with other countries and the importance of sexual and reproductive health of ID adolescent girls, the present study was conducted to determine the experiences of parents regarding the sexual and reproductive health of ID adolescent girls.

Materials and Methods

This qualitative research is part of expanded qualitative research conducted between July 2016 and April 2017 via a content analysis approach. Participants in the present study were 4 educable ID adolescent girls, 23 parents, 7 teachers (educators), 16 healthcare providers (psychologists, psychiatrists, counselors, midwives, gynecologists, and forensic medicine specialists) as well as 2 managers who were living in Isfahan, Iran. The educable ID adolescent girls, parents, teachers (educators), school counselors, and managers were accessed through visitation to the Behzisti centers and schools for children with special educational needs. Other participants (psychologists, psychiatrists, gynecologists, midwives, and forensic medicine specialists) were accessed through counseling centers, hospitals, and private offices.

The participants were selected using a purposeful sampling method with maximum variation based on their age, occupation, educational level, and socioeconomic status. The inclusion criteria were parents who had an ID adolescent girl within the age range of 11 to 20 years, lack of any diagnosed psychological disorders, willingness to participate in the study, and giving informed consent (in cases of ages below 18 years, consent was obtained from their parents). The inclusion criteria were having at least 5 years of working experience with healthcare providers and teachers. Data were gathered through face-to-face in-depth semi-structured interviews, Focus Group Discussions (FGDs), and field notes. In the present study, 41 face-to-face interviews and 1 FGD (for 11 mothers) were conducted.Moreover, the participants were required to have first-hand experiences and information about the research topic in qualitative research,[12] face-to-face interviews and FGDs were carried out. The places for the interviews were selected based on the participants' preferences. The interviews lasted between 40 to 90 min and continued until there was data saturation. The interviews and FGD were started with open questions such as "what problems have you encountered with your adolescent about sexual issues?" (for parents) or "based on your experiences, what are the problems of ID adolescent girls regarding their sexual health?" (for other participants) and continued with probing questions. The first author documented her observations of the non-verbal behaviors of participants during the interviews (field notes).

Data analysis was performed simultaneously along with data collection. The interviews were transcribed verbatim. The data obtained were analyzed employing conventional qualitative content analysis. This technique is appropriate for subjective interpretation of the data text content through the regular process of coding to determine the categories.[13] In this regard, interviews and FGDs were repeatedly reviewed to achieve a comprehensive approach for the data. The transcriptions of the interviews were divided into meaningful units, and after compression, they were labeled with abstract codes. Codes were compared with each other depending upon their similarities, wherein those with the same concept were placed in the same category (in an inductive manner) and were then classified into sub-categories and eventually the main category. To ensure the credibility of the data, a 10-month period was spent on data collection. In-depth interviews were carried out at different times and places with a combination of data gathering methods being used when selecting participants. In addition, sampling with the maximum variation enhanced the validity of the data. Once the primary codes were formed, the opinions of five participants (three mothers and two fathers) were sought to approve the accuracy of the codes and interpretations (member checking). In the present study, to ensure the transferability of the data, the study results were given to five individuals (three mothers and two fathers) with similar characteristics to the participants who did not participate in the study to judge the similarity of the results to their own experiences. Dependability of the data was approved following a review made by the research team members. In addition, the data were reviewed by experts in this field who were not involved in this study. In this way, the accuracy of the coding process was evaluated.

Ethical considerations

The present study was approved by the Institutional Ethics Committee of the Isfahan University of Medical Sciences (ethics code: IR.MUI.REC.1395.3.281). Informed consent, anonymity, confidentiality, and the right of participants to leave the study at any time were assured.

Results

Tables 1 and 2 present the demographic characteristics of the participants. During data analysis, 37 codes and five sub-categories were developed. Five sub-categories

Table 1: Demographic characteristics of the ID* adolescent girls

Characteristic		Number
Age (years)	14-18	4
Educational level	High school, first round	2
	High school, second round	2
Education at schools for children with special educational needs	Full time	-
	Part-time	4
Job	Student	4

*Intellectually Disabled

Table 2: Demographic characteristics of other participants (parents, teachers, healthcare providers, and managers)

Age	26-61 years
Gender	Male (6), Female (42)
Marital status	Married (46), Single (2)
Educational level	Elementary school (9), Diploma (11), Bachelor's degree (18), PhD (10)
Job	Housewife (16), Employee (5), Freelancer (1)
	Laborer (1), Psychiatrist (5) Psychologist (3)
	Gynecologist (1), Forensic medicine expert (1)
	Midwife (1), Teacher or educator (7)
	School vice-principal (1), School counselor (5)
	Behzisti center authority (1)
Working experience	3-28 years

under the headings: "unawareness about sexual needs of the adolescent girl and her potential vulnerability," "inappropriate actions in directing the sexual behaviors of the adolescent," "insufficient supervision and care over the adolescent's sexual health," "inappropriate actions toward marrying off the adolescent," and "inappropriate actions regarding the menstrual and genital health" were extracted which formed the main category under the heading: "parents' inefficiency in maintaining adolescent girls' sexual and reproductive health" [Table 3].

Parents' inefficiency in maintaining adolescent girls' sexual and reproductive health

The results revealed that parents are not sufficiently aware of the natural course of sexual development in their adolescent girl. They are not able to establish an appropriate interaction with the adolescent girl to keep her menstrual and sexual health. Similarly, they do not have enough skills to manage their sexual behaviors. Parents have inappropriate functions such as corporal punishment as well as serious control and limitation on the adolescent girl while in some other cases, they may have no supervision and control over their behaviors. A number of parents are trying to finance the family through repeated adolescent marriages, pursuing divorce, and receiving the marriage proportion.

Unawareness about sexual needs of the adolescent girl and her potential vulnerability

The results indicated that parents consider these adolescents different from other adolescents. They believe that they would not understand sexual matters since they do not have any sexual desires. Most parents deny or conceal the inappropriate sexual behaviors and sexual problems of their adolescent girls. *"The family thinks that this adolescent has no sexual desire and cannot understand sexual relationships."*(Educator)

According to the participants, parents; especially fathers, despite their insufficient knowledge regarding sexual behaviors and problems of adolescents, do not have any interest in receiving education about the appropriate way of confronting adolescents' sexual behaviors. They do not make any concerted efforts either to get an education on adolescents' sexual behaviors by the school authorities. *"When we want to conduct educational classes for the parents in this regard, they show no interest; especially fathers who participate less in the meetings."* (Counselor)

Inappropriate actions in directing the sexual behaviors of the adolescent

According to the participants, parents would feel concerned and anxious in the face of the sexual behaviors of their adolescent. When parents witness their adolescent's masturbation, nudity, or lack of respect for privacy, they would reprimand her or use physical punishment. Some parents, due to their inability to confront the sexual behaviors of their adolescent, would restrict their communication outside the house and would even forbid them to go to school. *"My daughter always says that she wants to find a boyfriend so that she can marry him. I think her friend at school says these things to her. If she continues like this and always talks about having a boyfriend and getting married, I will not allow her to go to school anymore."*(Mother)

Insufficient supervision and care over the adolescent's sexual health

According to the participants, parents do not have adequate supervision and care over their adolescent girls against sexual scenes and issues in outdoor environments for different reasons such as the busy nature of their lives, having several disabled children, poverty, low literacy level, and lack of appropriate interactions between the parents and the adolescent. *"Some families have no knowledge about the present sexual threats their adolescents are exposed to in the society and as such leave them alone."*(Teacher)

In addition, parents would take no action or are unable to take any action to control access to available media including the internet and satellite channels on their adolescents' sexual behaviors. *"My daughter knows how to use telegram and internet… many times she would look at the sexual photos and watch pornographic movies*

Table 3: Results of data analysis

Codes	Sub-category	Main category
Limiting the adolescent to the home	Inappropriate actions in directing the sexual behaviors of the adolescent	Parents' inefficiency in maintaining adolescent girls' sexual and reproductive health
Punishing the adolescent due to violating the privacy		
Punishing the adolescent due to masturbation		
Lack of training the adolescent on health and issues related to the sexual health		
Lack of supervision on adolescent in out of home	Insufficient supervision and care over the adolescent's sexual health	
Lack of supervision on the use of the mobile phone by the adolescent		
Lack of supervision on the use of accessible media like the internet and satellite channel by the adolescent		
Regarding the adolescent's knowledge of sexual issues as an unimportant subject	unawareness about the sexual needs of the adolescent girl and her potential vulnerability	
Denying the adolescent's sexual problems		
Lack of cooperation for receiving the training on adolescent's sexual health		
Making an attempt for the marriage of a girl	Inappropriate actions toward marrying off the adolescent	
Hiding the intellectual disability in a girl at the time of marriage		
Misusing the adolescent to get married and receiving the wedding proportion		
Fear of adolescent's sexual stimulation by training the menstruation health	Inappropriate actions regarding the menstrual and genital health of the adolescent	
Avoidance of helping the adolescent in meeting the genital health to prevent the sexual stimulation		

her friends have sent her. Unfortunately, I cannot control her."(Mother)

Inappropriate actions toward marrying off the adolescent

According to the participants, some parents are very keen on getting their daughter married and usually conceal the ID of their daughter at the time of marriage. In this regard, due to economic problems, these parents would try to marry off their adolescent girl to benefit from the resultant financial resources. *"We have a family that takes advantage of their daughter's intellectual disability. As their daughter has a healthy and beautiful appearance, suitors always come for her; they would accept and then get the girl married. After a while, they would have her get a divorce and take the dowry."*(Teacher)

Inappropriate actions regarding the menstrual and genital health of the adolescent

According to the participants, ID adolescents usually face various challenges during menstruation. In this regard, many of the mothers do not have sufficient information and skills for handling the issues related to the adolescent's menstruation and genital health. Some of the mothers believe that educating the adolescent girl on her genital health would increase the adolescent's sexual motivation. *"I do not educate my daughter about menstruation and its related issues. It is better if we do not provide information to them because it might stimulate their sexual desire."*(Mother)

Discussion

The present study was conducted to determine the experiences of parents regarding the sexual and reproductive health of educable ID adolescent girls. According to the results, parents face various challenges about the sexual and reproductive health of ID adolescent girls. Based on the results, when parents witness their adolescent's masturbation or nudity, they would reprimand them or use physical punishment. In a study conducted in Iran, more than half of the parents of the ID adolescents disapproved of their masturbation.[14] Thus, healthcare providers and teachers (educators) have an important role in educating parents (especially mothers) about physical, psychological, and sexual changes during puberty. They should teach parents to properly direct their adolescent's sexual behaviors. Based on the results, parents of ID girls believe that their children do not have sexual desire and cannot comprehend sexual matters. According to Pownall *et al*. mothers believed that their adolescent girls would lack sexual motivation owing to their ID.[15] It seems that healthcare providers and teachers (educators) should educate parents and eliminate misconceptions about ID adolescent girls' sexual desire and behaviors.

In the present study, parents believed that education of their girls on sexual matters would arouse the adolescent's sexual desire and would stimulate them to have sexual relationships. Thus, they did not teach their ID adolescent girl about sexual matters. In this regard, the results of

a study in Turkey revealed that most of the parents were concerned that education of their children on sexual matters would make them curious about these issues and stimulate them to indulge in inappropriate experiences.[16] Researchers in another study mentioned that although the mothers of ID adolescents were worried about their sexual health and the possibility of being sexually abused, they had no interest in educating their adolescents on sexual matters.[17] Based on the results of the present study, although most of the parents were confused about confronting the sexual behaviors of their adolescent girl, they had no interest in participating in educational classes and obtaining information on sexual matters. In contrast, in a study performed in Boston, parents considered educational classes conducted on sexuality by the school authorities as one of their essential needs.[18] It seems that in our country, due to the taboo associated with sexuality, parents do not have sufficient knowledge and skills required to manage the sexual behaviors of the adolescents, and they have no interest in receiving education in this regard. Thus, the elimination of sexual taboos and alteration of parents' attitude toward adolescents' sexuality seem necessary. Here, parents did not have adequate supervision and care over the sexual health of the ID adolescent girls. However, negligence in these matters might lead to terrible consequences including sexual abuse and harassment as well as its complications.[9] Sharabi and Margalit found that adolescents' access to the cyberspace has facilitated their access to pornographic materials which is followed by risky sexual behaviors.[19] Thus, improvement in interactions between the family and the school as well as parents' participation in schools' educational programs seems necessary.

Based on the results of the present study, parents would try to marry off their ID adolescent girls. A study showed that 68% of the teachers and 78% of the parents believed that ID people have the right to get married and should not be deprived of their right.[17] Although based on article 23 of the Convention on the Rights of Persons with Disabilities (CRPD), these people have the right to establish a family and have children[20]; a successful and lasting marriage requires special knowledge and skills, which ID adolescents usually lack.[21] Based on the results of the present study, many of the mothers do not have sufficient information and skills for handling the issues related to the adolescent's menstruation and genital health. It is believed that the use of methods such as behavioral therapy, education on menstrual and genital health, and caring skills could be efficacious.[22] Hence, healthcare providers should teach mothers about how to deal with their adolescent girl's menstrual and genital health issues. Generalization of the findings in the present study; considering its qualitative approach, should be done cautiously. Although qualitative studies are not designed to generalize the results, they are useful for those who are willing to use the findings while considering the limitations.

Conclusion

According to the results, parents face different challenges about the sexual and reproductive health of ID adolescent girls. Thus, empowering the parents, especially mothers by teachers and healthcare providers with the knowledge and skills to maintain the sexual and reproductive health of intellectually disabled adolescent girls, could be beneficial in preparing them for a healthy and safe, sexual and reproductive life.

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Conflicts of interest

Nothing to declare.

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