

Sexual Health Challenges of the Iranian Intellectually Disabled Adolescent Girls: a Qualitative Study

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Abstract

Background: Sexual health is individuals' ability to express their sexual needs within the framework of their society's values without being afraid of sexually transmitted infections, unwanted pregnancies, violence and discrimination. Given the importance of sexual health in intellectually disabled adolescents, the present study was conducted to explore the sexual health challenges among the intellectually disabled adolescent girls.

Methods: The present qualitative study was conducted on 48 participants including the parents, teachers, healthcare providers and managers who were selected through purposeful sampling, in Isfahan, Iran. Data was gathered using semi-structured in-depth interviews, focus group discussions and field notes. The collected data was analyzed using conventional content analysis.

Results: After data analysis, four sub-categories of "adolescent's disability in understanding sexual matters and respecting social rules", "the Comorbidity of psychiatric disorders and intellectual disability", cultural taboos on sexual issues" and "teachers' inability to deal with issues related to adolescent's sexual health" were extracted. These sub-categories together formed the main category of "sexual health challenges".

Conclusion: Based on the results, designing comprehensive programs of sex education for intellectually disabled adolescent girls seems necessary. Also, empowering teachers to teach sexual health to these girls and their parents is of particular importance. Furthermore, the interaction between the school and parents to maintain the sexual health of intellectually disabled adolescent girls could have an effective role in decreasing the rate of sexual abuse/harassment and their involvement in sexual relationships.

Key Words: Intellectual disability, Iran, Qualitative study, Sexual abuse, Sexual health.

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1-INTRODUCTION

Sexuality is an inseparable part of human's life and its complete development depends on the individual's satisfaction from fulfillment of their primary needs such as communicating with others, intimacy, expressing the emotions, kindness and love (1). Sexual health, defined as coordination and compatibility between physical, emotional, and social aspects of the individual's sexual matters, has been confirmed as a right for everyone by the world health organization (WHO). Sexual health is the individuals' ability to express their sexual matters within the framework of their society's values without being afraid of sexually transmitted infections (STIs), unwanted pregnancies, violence, and discrimination. Sexual health could only be achieved in a society where sexual rights are formally recognized, respected and applied (1, 2).

The Convention on the Rights of the Persons with Disabilities (CRPD) has clearly emphasized on protecting the rights of persons with disabilities against sexual abuse, sexual violence and access to correct sexual information (3). Intellectually disabled (ID) people are classified into four groups: mild or educable, moderate or trainable, severe or maintainable, and profound (4). In ID people, sexual abuse and violence can have long term complications such as repeated sexual abuse and violence, anxiety, depression, poor sexual performance in future, and engagement in risky sexual behaviors. Also, risky sexual behaviors are associated with the occurrence of outcomes such as unwanted pregnancies, STIs and HIV/AIDS (5).

The belief that considers ID adolescents similar to children without any sexual desire has deprived their opportunities for learning skills to make informed choices about sexual matters and has consequently increased the risk of sexual abuse and violence (3, 6, 7). Despite the importance

of sexual health in ID adolescents, a few studies have examined sexuality-related issues in this group (especially ID adolescent girls) in recent years in Iran (8-11) and our knowledge about sexual health challenges of these people is very limited. Considering various aspects of sexuality, exploring the sexual health challenges in ID adolescent girls could provide an appropriate context for comprehensive and cultural-based interventions in the society. Since qualitative research is an approach for describing and conceptualizing the experiences of the participants, it could improve the knowledge and attitude toward human experiences. This type of approach is usually used when there is a need for describing the concepts and their relation to each other (12). Therefore, the present study was conducted to explore the sexual health challenges in educable ID adolescent girls.

2-MATERIALS AND METHODS

2-1. Study design

The present study is a part of a mixed-method study (13, with the content analysis approach which was conducted from July 2016 to April 2017, in Isfahan city, Iran.

2-2. Participants

Participants in the present study were 23 parents, seven teachers (educators), 16 healthcare providers (psychologists, psychiatrists, counselors, midwives, gynecologists and forensic medicine specialists) as well as two managers. In this study, eligible parents, teachers (educators), school counselors, and managers were accessed through 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. They were recruited directly or their telephone

numbers were obtained and they were subsequently telephoned.

The inclusion criteria included the parents who had an educable 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. Having at least 5 years of working experience was the

inclusion criteria for the healthcare providers and teachers. The participants were selected by the purposive sampling method with maximum variation based on their age, occupation, educational level, and working experience. Demographic characteristics of the 48 participants are shown in **Table 1**.

Table-1: Demographic characteristics of the participants

variable	value
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), Ph.D. (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) Behsizzi authority (1)
Working experience	3-28 years

2-3. Data collection

Data was collected using personal in-depth semi-structured interviews, focus group discussions (FGDs) and field notes. After reaching the eligible participants, none of them refused to participate in the study. The first author (Sh. G.), who had 12 years working experience in midwifery and was a Ph.D. candidate in reproductive health, conducted the interviews. The other authors had previous interviewing experience and qualitative paper/report writing. Prior to data collection, the first author wrote down some initial preconceptions and beliefs about the research topic based on her previous working experience and from a review of the literature. Interviews started with open questions such as "What problems did you have with your daughter's sexuality? Please explain." (for the parents); and

"Based on your experiences, what are the sexual health problems of ID adolescent girls? Please explain." (For the other participants) and then continued with exploratory questions. Also, the first author (Sh. G.) documented her observations of the non-verbal behaviors of the participants during the interviews (field notes). The places of the interviews were selected based on the participants' preferences. The Interviews lasted from 40 to 90 minutes, being continued until data saturation occurred. In the present study, 37 personal interviews and one FGD (for 11 mothers) were conducted.

2-4. Ethical considerations

This study was approved by the Ethics Committee of the Isfahan University of Medical Sciences (ethics code: IR.MUI.REC.1395.3.281). In the present study, obtaining informed consent, the

right of anonymity, confidentiality of the information and the right of withdrawal from the study at any desired time were respected.

2-5. Data analysis

Data analysis was performed simultaneously with data gathering. All interviews were digitally recorded. Interviews were transcribed verbatim by the first author (Sh. G.). Achieved data were analyzed using the conventional qualitative content analysis. This method is appropriate for subjective interpretation of the content of text data through the regular coding process for determining categories (14). In this regard, interviews were reviewed repeatedly to achieve a comprehensive overview of the subject. The texts of the interviews and one FGD were divided into meaning units that were compressed and labeled with abstract codes. Then codes with similar concepts were placed in one category and formed the sub-categories (in an inductive manner). Afterwards, by comparing the sub-categories with each other, categories that had similar concepts were placed in the same main category.

2-6. Data trustworthiness and rigor

To assure the correctness and accuracy of the data, the suggested criteria by Lincoln and Guba including credibility, dependability, confirmability, and transferability were used (15). To assure the credibility of the data, 10 months were spent gathering the data and establishing a close relationship with the participants and gaining their trust, which helped improve the credibility of the information. Sampling with maximum variation also improved the credibility of the data. After forming the preliminary codes, opinions of 5 participants (three mothers and two fathers) were obtained to confirm the correctness of the codes and interpretations (member checking). Dependability of the data was assured through reviewing by the

research team members. The opinions of experts who were not involved in this study was also obtained to assure the consistency of the results (external checking). Therefore, the correctness of the coding process was evaluated. To assure transferability of the data, the viewpoints of three mothers and two fathers who had similar characteristics to the participants, but were not involved in the study, were asked to judge the similarity of the results to their own experiences.

3- RESULTS

After data analysis, 49 codes, four sub-categories and one main category developed. Four sub- categories including: “adolescent’s disability in understanding sexual matters and respecting social rules”, “the Comorbidity of psychiatric disorders and intellectual disability”, “cultural taboos on sexual issues” and “teachers’ inability to deal with issues related to adolescent’s sexual health” These sub-categories together formed the main category of “sexual health challenges” (Table 2).

3-1. Adolescent’s disability in understanding sexual matters and respecting social rules

According to the participants, ID adolescent girls are weak in understanding sexual matters, respecting social rules, and respecting privacy. They mentioned examples such as the lack of understanding the difference between the private and public places, replacing the sanitary napkin in the presence of others and performing behaviors such as showing off themselves, nudity and masturbation in public. Also, they pointed out that these girls do not observe boundaries and restrictions in their behaviors and interactions with the opposite sex in the society.

"... For example, if these girls like the opposite sex, they show it quite clearly"!!!
(A teacher).

Table-2: Results of data analysis

Code	Sub-category	Main category
<ul style="list-style-type: none"> *Lack of compliance with appropriate clothing and privacy *Disability in understanding the nature of sexual abuse and rape *Performing sexual behaviors such as showing off themselves, nudity and masturbation in public *Disability in understanding risky sexual behaviors 	Adolescent's disability in understanding sexual matters and respecting social rules	Sexual health challenges
<ul style="list-style-type: none"> *Parents' secrecy of their adolescent's sexual health problems to preserve the honor *Adolescent's secrecy of sexual harassment/abuse due to fear of being punished by the parents 	Cultural taboos on sexual issues	
<ul style="list-style-type: none"> * Teachers' lack of skills in adolescent's sexual health care * Teachers' lack of knowledge and skills in in teaching sexual issues to ID adolescent girls *Lack of retraining courses for teachers about ID adolescent girls' sexual health * Lack of education for the mothers about caring for their daughter's sexual health due to the shame on the part of the teachers *Lack of education for the mothers about ID adolescent girls' sexual health due to the teachers' negative attitudes 	Teachers' inability to deal with issues related to adolescent's sexual health	
<ul style="list-style-type: none"> *The Comorbidity of bipolar disorders and intellectual disability *The Comorbidity of ADHD and intellectual disability 	The Comorbidity of psychiatric disorders and intellectual disability	

The participants believed that since these girls do not realize the sexual issues, doing these behaviors can facilitate the occurrence of sexual abuse and sexual harassment (such as rape) on them.

“... Sometimes these girls perform nudity in the school or in public, because they do not know about its indecency. So, they are more likely to be sexually abused” (A psychiatrist).

Also, the participants narrated that weak verbal communication and inability to express emotions lead the ID adolescent girls to express their emotions through

their sexual behaviors. Therefore, these girls show more uncontrolled sexual behaviors and get involved in more sexual relationships.

“... ID adolescent girls may exhibit more uncontrolled sexual behaviors and be more exposed to sexual harm” (A psychiatrist).

3-2. The Comorbidity of psychiatric disorders and intellectual disability

The participants narrated that compared with the general population; people with intellectual disability have a higher prevalence of psychiatric disorders such as bipolar disorders or Attention Deficit

Hyperactivity Disorder (ADHD). They believed that the Comorbidity of psychiatric disorders and intellectual disability in adolescent girls could be effective in increasing sexual desire and impulsive behaviors (behaviors with immediate motivation and without prior thinking).

“... ID adolescent girls with bipolar disorders have higher sexual desires, and those with ADHD are also more impulsive!!!” (A psychiatrist).

The participants believed that during puberty, ID adolescent girls cannot control their sexual desire and engage in sexual relationships. Also, they are at risk of sexual abuse/harassment. Engagements of ID adolescent girls in sexual relationships have consequences such as unwanted pregnancies, STIs and HIV/AIDS.

“... When they (ID adolescent girls) reach puberty, they could not control their sexual desire and therefore, they are engaged in sexual relationships” (A psychiatrist).

3-3. Cultural taboos on sexual issues

The participating teachers and healthcare providers considered the presence of cultural taboos on sexual issues as an obstacle in maintaining the sexual health of ID adolescent girls. The participating teachers narrated that because expressing sexual matters in the family is a taboo, the ID adolescent girls usually hide the cases of sexual abuse and rape; and these all could lead to repetitive events.

“... One of the ID adolescent girls told me that she had a boyfriend and he took her to his friend's shop and had sex with her in WC. She said she wanted to tell her mother, but was afraid her mother would punish her.” (A teacher)

Also, the participating healthcare providers narrated that cultural taboos on sexual issues cause the parents usually keep their adolescent's sexual problems (especially in cases of rape) as a secret or even deny

them to preserve the honor of their family. They believed that hiding these incidents would cause them to be repeated among ID adolescent girls. Also, based on the participants' narrations, the occurrence of unwanted pregnancies in ID adolescent girls (following rape) and illegal abortions are not reported by the parents and are kept secret. They narrated that hiding these cases would cause complications of illegal abortions in ID adolescent girl.

“... I had a case where an ID adolescent girl was raped and she has become pregnant. When her parents realized that their daughter is pregnant, they performed an illegal abortion and made all of their efforts to hide this problem” (A gynecologist).

3-4. Teachers' inability to deal with issues related to adolescent's sexual health

The participating teachers narrated that they have obtained information about sexual health in ID adolescent girls through experience and have not received any formal and comprehensive education in this area. They believed that did not have enough information to teach ID adolescent girls about how to maintain their sexual health and deal properly with their sexual behaviors.

“...These girls do a lot of masturbation. ... We don't really know how to deal with these adolescent behaviors?” (A teacher).

Also, a participating mother narrated that school teachers/counselors did not provide comprehensive education and useful guidance on how to deal with their adolescents' sexual behaviors (such as masturbation), due to their low level of knowledge.

“... Every time I talk to the school counselor concerning the fact that I don't understand how I should solve my girl's sexual behaviors ... I think she (the school

counselor) doesn't know about it" (A mother).

A number of teachers did not agree with sexual education for ID adolescent girls and believed that these girls had more sexual desire than adolescents with normal intelligence quotient (IQ) and discussing about sex would stimulate their sexual desire, encourage sexual behaviors or increase inappropriate behaviors.

"... I think sex education further stimulates their sexual desire. If we explain to them, their situation will get worse" (A teacher).

4- DISCUSSION

The present study was conducted to explore the sexual health challenges in educable ID adolescent girls. According to the results of the present study, since ID adolescent girls are unable to understand sexual matters and respect social rules, they would express inappropriate sexual behaviors which could expose them to sexual abuse/harassment or make them engaged in sexual relationships. Martinello believed that in healthy adolescents, respecting social norms has been normally internalized from childhood; however, ID adolescents are weak in learning this skill (16). Shukohi Yekta et al. believed that sexual education is a part of therapeutic programs for ID individuals who have inappropriate sexual behaviors (8). Regarding the importance of sexual education for ID people (7), it seems that special sexual health education for ID adolescents about expressing sexual behaviors in appropriate time, place, and privacy is essential for protecting them against sexual abuse/harassment, and its consequences such as unwanted pregnancies, STIs and HIV/AIDS.

Based on the results of the present study, due to the Comorbidity of psychiatric disorders and intellectual disability, ID adolescent girls are at risk of sexual abuse/harassment and engagement in sexual relationships. Soyulu et al. also

believed that the presence of psychiatric disorders such as bipolar disorders and ADHD in ID adolescent girls would increase the risk of sexual abuse (17). In this regard, it is very important that the ID adolescent girls be monitored by the school authorities, counselors, psychiatrists or psychologists to properly diagnose any coexisting psychiatric disorders, so that the appropriate services can be provided.

According to the results of the present study, cultural taboos on sexual issues in the family and the society could expose ID adolescent girls to sexual abuse/harassment. In this regard, the ID adolescent girls usually hide the cases of sexual harassments and the parents usually keep their adolescent's sexual problems as a secret or even deny them to preserve the honor of their family. In most Muslim societies, like Iran, due to the cultural taboos on sexual issues, discussions on sexuality and providing sexual education for non-married adolescents is culturally unacceptable. Medina-rico et al. showed that due to the taboo nature of sexual issues, the parents deny their adolescent sexual problems and are reluctant to receive school-provided training (18). Other studies have shown that socio-cultural beliefs make strong barriers to sexual desires of the ID adolescents, which by itself cause a further incapacitation rather than their own disability (19, 20). Latifnejad Roudsari et al. showed that cultural resistance is more important than religious prohibitions for sexual health education among female adolescents (21). Moreover, based on the results of the present study, a number of teachers do not have positive attitude toward sexual education for ID adolescent girls and they consider it a stimulus for the adolescents' sexual arousal. A study showed that the teachers, according to their personal experience, usually avoid providing sexual education for ID adolescent girls because they think that these girls may behave

inappropriately after education (16). Therefore, it is necessary to design programs for educating teachers/educators for changing their attitude toward sexual education, in a way that the ID adolescent girls could be protected against sexual abuse/ harassment, and engagement in sexual relationships.

Based on the results of the present study, the teachers are unfamiliar with how to educate and care for ID adolescent girls' sexual health. In this regard, Barnard-brak et al. showed that many teachers are not prepared to deal with the sexual issues of ID adolescents (22). In order to be capable of identifying the ID adolescent girls' sexual issues, the teachers must have certain characteristics and skills (23). Therefore, empowering them to teach sexual health to these girls is of particular importance.

In the present study, the narrations of the participants showed that the teachers' performance in guiding parents in solving their adolescent's sexual problems was poor. In this regard, the United Nations Educational, Scientific and Cultural Organization (UNESCO) emphasizes the key role of teachers in sex education (24). It seems that if schools work well and provide high quality sexual health education programs for the parents, by motivating them, they will be able to guide their ID adolescent girls' sexual behaviors. Therefore, the interaction between the school and parents is very important in maintaining the sexual health of ID adolescent girls. The main strength of this study was to adopt a qualitative methodology, which gave the opportunity to the teachers/educators, parents and healthcare providers whose voices need to be heard and in this way, the sexual health challenges of ID adolescent girls can be understood. Therefore, steps can be taken to address these challenges and improve sexual health of ID adolescent girls.

4-1. Study limitations

Since sexuality-related topics are personal and influenced by different social, religious, ethical and legal norms, it could have affected the results of the present study; which is considered as one of the limitations.

5- CONCLUSION

Based on the results, ID adolescent girls face various challenges related to their sexual health. Adolescent's disability in understanding sexual matters and respecting social rules, the Comorbidity of psychiatric disorders and their intellectual disability, cultural taboos on sexual issues in the family and society, and the teachers' inability to deal with issues related to adolescent's sexual health are some of the sexual health challenges in ID adolescent girls. Therefore, designing and developing comprehensive programs of sex education for ID adolescent girls seems necessary. Also, empowering the teachers to teach sexual health to these girls and their parents is of particular importance. Furthermore, the interaction between the parents and school could have an effective role in maintain the sexual health of ID adolescent girls, in decreasing the rate of sexual abuse/harassment, and their involvement in sexual relationships.

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7- CONFLICT OF INTEREST

None.

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