Sexuality Among Adolescents and Young Adults With Intellectual Disability: Knowledge, Attitude, and Practices

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Abstract

Context: It is generally believed that persons with intellectual disability (PWID) do not have sufficient knowledge about sex and sexuality. As there is not much published work from India, such an attitude of clinicians and caregivers appears more to be an assumption. The scant information from other countries on sex and sexuality of the PWID cannot be generalized to India because of cultural differences.

Aims and Objectives: The study was conducted to find out knowledge, attitude, and sexual practices among persons with mild intellectual disability (ID).

Settings and Design: Thirteen participants with DSM-5 diagnosis of mild ID (intellect quotient [IQ] between 50 and 69) in the age ranging from 16 to 27 years (mean IQ and age was 56.69 and 21.0, respectively) were selected from the Government Rehabilitation Institute for Intellectual Disabilities, Chandigarh. For this study, exploratory method using focus group discussion (FGD) was used. Data was collected using qualitative method of FGD.

Results: The results showed that persons with mild ID have knowledge about sex and sexual practices and they are sexually active and are indulging in sexual acts.

Conclusion: Based on the findings derived from this research, it is concluded that PWID have knowledge and skills to experience sexual activities. However, findings of this study are limited to only persons with mild ID (IQ: 50-69). Need to sensitize and provide appropriate sexual health care for persons with ID are discussed.

Keywords: Sexuality, persons with intellectual disability, knowledge, attitude, practices

Introduction

Intellectual disability (ID) is characterized by significant limitations both in intellectual functioning and day-to-day adaptive behavior skills. In view of these limitations, persons with intellectual disability (PWID) experience a wide range of adjustment problems in the society.1 In fact, adolescents with ID experience more adjustment issues than normal adolescents. However, these problems go unrecognized and hence unmanaged.

Although, sexuality is an essential aspect of one’s life and offers a gateway to intimacy, love, and affection,2 there is very little literature on knowledge, attitude, and sexual practices among adolescents with ID. Despite the fact that PWID have the same sexual needs as those of normal persons,3 they are often perceived as asexual and are required to be protected from society. Adding to this, society also believes that persons with disabilities have uncontrollable sexual urges.4 It is a widely held misconception that marriage cures ID.

In India, sex education of even normal adolescents is very challenging due to stigma and taboo leading to
serious health hazards including teenage pregnancy, unsafe abortions, sexually transmitted infection, HIV/AIDS, and sexual violence; sex education of PWID has never been a priority agenda in the country. Very little is known about the source of sex education of PWID and their knowledge and attitude might be shaped by inaccurate information and unpleasant experiences such as unwanted pregnancy, sexually transmitted diseases, and HIV infections. Several researchers have reported a lack of knowledge about sexuality among adolescents with disabilities as compared to general population. Because of limited opportunities to engage with normal adolescents and navigate the scant sex-related literature, they may lack opportunities to learn about their sexuality or to engage in socially acceptable sexual experimentation. Research showed that mothers of young people with ID held more cautious attitudes about contraception, readiness to learn about sex, and decisions about intimate relationships. These mothers also stated that as compared to typically developing children, they had discussed sex topics less often and at a later age with PWID.

Whatever information is available in the literature about the sex and sexuality among PWID, it has been gathered from the teachers and their caregivers using quantitative research tools. The quantitative data collection has its own limitations and it is very difficult to explore the perspective of people with ID about their daily lives. The personal views of PWID are almost non-existent in the literature. Heshusius suggested that this lack of attention to the viewpoint of people with ID is indicative of the general stereotype that the PWID are less competent and are unable to say who they are and what do they want.

Aims and Objectives

This study was conducted to explore knowledge, attitude, and sexual practices among adolescents and young adults with ID using focus group discussions (FGDs).

Methods

Participants

Thirteen participants with ICD-10 diagnosis of mild ID (intellect quotient [IQ] between 50 and 69) in the age ranging from 16 to 27 years were selected from the Government Rehabilitation Institute for Intellectual Disabilities (GRIID) through purposive sampling. Mean IQ and age of the participants was 56.69 and 21.0 years, respectively. The group had 6 male and 7 female participants. Four participants were from rural background and rest were from urban locality. Since all the participants were from GRIID, their IQ was assessed as part of enrolment procedure. The inclusion criteria were: (a) willingness to participate in the study (written assent/consent), (b) IQ 50-69, done and certified by the trained and licensed clinical psychologist not beyond 3 years (for <18 years), (c) any gender, and (d) verbal ability to communicate. All those who were on medication for comorbid psychiatric illness and having any comorbidity except cerebral palsy were not included in the study.

Design

For this study, descriptive exploratory method has been used.

Tool/Technique

Data was collected using FGDs.

Procedure

The objective of this study was explained by investigators to the subjects and their legal representative and consents were taken from them. The study was approved by Research and Ethics Committee of the institution. For the purpose of data collection in this study, qualitative methods were employed by use of FGDs. The questions for FGD were decided on the basic aspect of KAP of sexuality. It was decided to guide the participants during FGDs to discuss the following issues:

1. Knowledge of human anatomy and naming the sex organs
2. Knowledge about physiology of sex organs
3. How often do they indulge in masturbation?
4. What do they know about sexual intercourse?
5. Their concept of pregnancy and contraception
6. Their concept and readiness for marriage and having children
7. Their knowledge about behavior to safeguard themselves from sexual abuse
8. Menstrual hygiene management.

The FGDs were conducted by the researchers (BSC, PA, WA, DR, SM) and all the sessions were audio recorded. Permission was obtained from the participants for making notes during the session and one researcher (WA for males and DR/SM for females) was assigned the task of recording discussion. Later, the research team reviewed audio recording of session to find out if any information was omitted while making notes. The audio sessions were then transcribed and the records were maintained strictly confidentially.

Initially, 3 FGDs were conducted with all the participants. Although, the research team was able to engage the participants in the common FGD group, the female participants were little hesitant to share their views and it was decided to conduct separate FGD for male and female participants. Thereafter, 2 FGDs were conducted with male participants and 3 with female participants separately. FGD
with males was conducted by male research team (BSC and WA) and female research team (PA with DR or SM) conducted FGD with female participants.

**Results and Discussion**

The group came up with significant results regarding KAP about sexual acts. These participants were more vocal than the preconceived notion of shying on talking about sexuality.

Studying sexual health of PWID is very complex because of multiple reasons. First, society’s attitude and behavior toward these persons vary from culture to culture. Second, the severity of ID varies from mild to profound form. Third, ID has multifactorial etiology affecting physical hygiene, and sexual abuse. There is very little information on sex and sexuality including sexual functioning, pleasure, satisfaction, sexual fantasies, intimacy and romantic relationship, marriage and gender orientation, and so on.12 Even the Rights of Persons with Disability Act under the Section 10 (1 & 2) on reproductive rights mentions their rights to access information on reproductive and family planning and prohibition of any medical procedure which can lead to infertility. The scant existing data indicate that PWID have poor sexual health. However, they have desires and needs similar to other people without disability. Also, these persons are more susceptible to sexual abuse.14

In this study, all the participants expressed that they have desire to have sex and all male participants stated that they get erection and indulge in masturbation and named semen as “maal” (commonly used term in this age group in this region). On asking, whether they would like to get married, all of them desired to get married. All of them even named the girl with whom they would like to get married. The participants were asked, “why didn’t you get married as yet?” They stated (chorus): “we cannot get married because we are not earning money.”

The factors like social attitude, limited communication, and inability to stand trial before the law and limited access to support and services put these persons in a highly vulnerable class.15 During the FGDs, out of 13 participants, 3 participants (2 males and 1 female) took the lead and they even tried to encourage others to express their views. On being asked the female participants about the safety and security in the school, while travelling in school bus and at home, one of the female participants (WX) reported: “my elder brother (having ID, enrolled in GRIID) had tried to touch me once when I was alone at home. I didn’t like it and informed my mother who promised to instruct him not to do it again. However, when he didn’t stop despite warning from my mother, I decided to safeguard myself and hit him whenever he tried to touch my breasts. Later, I decided to avoid being alone with him and started coming down to stay with my grandparents till my mother returned. Although, I never informed my grandparents about the incident.” Another male participant (EF) stated: “a boy in the school bus tried to kiss me. I felt very angry and wanted to slap him, but stopped myself as there is camera installed inside the bus. In case I hit him, it will be recorded in the camera. This boy can complain to school principal and principal madam may suspend me from the school.”

In this study, authors used FGDs as a method of data collection. Literature search showed that there is no culturally adapted tool to assess the sexual knowledge among the PWID for Indian setting. FGD is also a preferred method for collecting personal information, feelings, perceptions, opinions, and it saves time, and offers opportunity to seek clarification. FGD in disability research has unique advantage over quantitative research design as FGD gives an access to collect information not only on the participants but also on their interactions.16

Unexpectedly, the research team found it easy to engage the participants in discussion of areas which are generally perceived very personal and where engaging even normal adolescents is difficult. This might be because the participants had known the researchers for quite some time and hence felt comfortable and were articulate.

In the first FGD with male participants, the discussion was initiated by asking them “what do they understand by sex?” Although there was initial shyness and reluctance, soon the participants were comfortable and participated in the discussion with lots of enthusiasm. The participants understood the meaning and concept of sex and all of them admitted that they had seen pornography videos on the mobile of their parents, friends, and siblings. They were also able to name sexual organs. When the participants were asked the procedure of having sex, one participant (CD) raised his hand and stated: “the man should be on top and he should make the girl ready for sex by touching her body parts and by kissing her.”

The other FGDs of female participants was led by PA and SM. The participants were asked to share any experience related to sex, sexuality, and sexual abuse. One of the female participants (OP) stated: “one boy staying in the same residential home where I am staying took me to a toilet, took off his clothes and tried to have sex with me (ganda kaam karna chahata tha), but I didn’t allow him as I don’t like him. Also, I slapped him as he was trying to force me. I am in love with another boy.” She later corrected her reply and said: “I don’t love him, but he keeps on looking at me which means he loves me.”
Another female participant (IJ) stated that: “I easily get attracted toward a boy. He has taken me to the toilet and tried to put his hands inside my trouser and told me that he wanted to marry me.” When the female participants were asked, “what would you do to safeguard yourself in case a boy tries to force you into sexual act?” Two of the participants (WX) said: “we would like to slap him, run away from the place, and would complain to the teacher and his parents.”

All female participants were well aware of menstruation and how to maintain menstrual hygiene. They were able to predict their menstruation and knew how to get and use sanitary pads. One of the girls was aware of sexual act, others refused to talk about it saying that their mother or teacher has told them not to look at boys, get too close to them, or talk to them. Same was the reply about differences in anatomy of boys and girls. One girl (OP) living in residential care institute stated that she wants to get married as she wants to have her own home. In replying to how the child is born, they replied that “it happens after marriage, there is pain in the abdomen and ladies want to eat pickles.” This shows that they were not aware of pregnancy as a consequence of sexual act. Though they were emphatic in responding about not indulging in “dirty job” and reporting it to caregivers if someone tries to do it.

There are not many studies from India which have been done in the past to explore knowledge and sexual practices among PWID. Kassa et al18 reported that there was a lack of adequate knowledge, appropriate practice, and favorable attitude of young persons with disability regarding different sexual reproductive health-related issues.

In this study, the participants belonged to mild ID group and were studying in an institute. There is a risk of sexual exploitation present for both females and males in the community. As reported in this study, a female participant had to fend herself from her brother and a male from a close associate. Hence, the PWID, both males and females, need to safeguard themselves from their family members or close associates who seem to believe that they can take advantage without being held accountable. The PWID in this study knew what were wrong sexual advances and stood against those, fending themselves and maintaining the social norms (by maintaining the respect of brother in eyes of grandparents by not revealing to them about his misbehavior). There are several myths about sexuality of persons with disability which doesn’t allow them to be treated as an independent adult. These myths include preventing sexual expression, considering them asexual, or over-sexual.18 Chrastina and Večeřová19 reviewed 47 articles on supporting sexuality of PWID and suggest that existing research focuses largely on inhibition of sexual abuse. However, attention must be given to other aspects of sexuality.19

The findings from the current study showed that PWID, both males and females, have aspirations for intimacy, marriage, and having children. A study from United States reported that among 11 to 23 years old females with mild ID, one-half engaged in consensual sexual intercourse. The study further reported that the proportion of sexually active women with mild ID was similar to the general population, after adjustment for age and race.20 The authors could not find any published data from India on sexual activities of females with ID.

In this study, the male participants knew about sexual organs, fore-play, the desire, erection, and masturbation. They knew that they need a partner for marriage. Aspiring for marriage, many had thought about a person with whom to marry, acknowledging at the same time that they need to be economically stronger to get married. They had knowledge about honeymoon after marriage and to carry forward their progeny with child birth.

The participants were further asked about their plan in case they get married. All of them stated that: “we would like to go for honeymoon on a hill station by hiring a taxi.” One of the researchers asked the participants whether they would like to take their parents with them during honeymoon. Fifty percent of them said “no” and rest did not reply. The participants who said “no” could explain the reason and said that their wives would not like it. The participants were further asked about the process of pregnancy. One participant (ST) stated: “pregnancy is possible only when husband has sex with his wife.” On further asking, whether they would like to have children, all said “yes” and preferred to have male child. Three participants explained that: “male child is a must as male had to look after the house and to continue the progeny, whereas female has to take care of the house.”

Some female participants knew about the sexual act while majority preferred not to talk about it as directed by their caretakers. The female participants were not so much aware of the sexual knowledge about pregnancy and childbirth, but their observation of eating pickles having association with pregnancy was remarkable. In this study, the females had lesser sexual knowledge as compared to male participants as they were instructed to avoid this topic by their caregivers altogether but were emphatic about protecting themselves against unwanted sexual advances. A few of the female participants were hesitant in talking and considered it “dirty job,” which conveys unfavorable attitude. On the other hand, male participants had favorable attitude and were looking forward to such experiences.

On inquiry about the number of children they would like to have after getting married, all said 1 or 2. The research team asked, “what would you do in case both the children are female?” All replied that they will accept the female child. At the end of FGD with male participants, the research team felt that the knowledge, attitude, and sexual practices among PWID are almost similar to persons with normal intelligence.

The overall findings of the study show that persons with mild ID have knowledge about sex and sexual practices. These persons are also sexually active and are indulging in sexual acts as per their statements. Authors in this study concluded that even after limitations in general intellectual functioning,
PWID have functional knowledge about human anatomy, physiology, and identification about sex organ. They are aware about sexual intercourse, ejaculation, pregnancy, and contraception, even though they have not had sex education in their curriculum and very limited societal and social media exposure. They practice masturbation for satisfaction of sexual desire, with feeling that they are not economically independent for leading a successful family life. This is the era of rights-based approach for PWID, and as per Maslow’s hierarchy of need, sex is one amongst the very basic needs of any human. This is the need of the hour to make imminent efforts in furthering dissipation of knowledge and research in this area. Appropriate training can lead a better sexual practice among PWID. Gupta (2017) mentions studying sexuality of persons with disabilities is important as it is an issue of human rights, complete rehabilitation, inclusive society, increasing life choices of disabled, full participation and equal access for them.21

Challenges

During FGDs, it was noticed that boys were keen to talk about sexuality, smiled often, and appeared willing. While girls were a little shy initially, talked freely about unwanted advances, often kept their eyes low conveying disinterest in talking, and were not very forthcoming. However, after rapport building and having known to each other, the group participated actively in second and third FGD. Limited direction in terms of limited data-based research on sexuality of PWID in Indian context was another challenge. Initially, the group started with both males and females and later it was decided to have separate FGD on sexuality because different concerns were raised. The group needed more probe questions to carry on discussion; this could be due to their limited cognitive ability.

Limitations

This study was conducted only on 13 persons with mild ID; however, conducting a comprehensive qualitative research with this sample size seems to be adequate. The collection of data using only FGDs could be viewed as one of the limitations. The other widely used method for qualitative research, namely, observation and interviews, could have been also adopted.

Recommendations

The clinicians and the other professionals working with PWID generally advocate the practice of safety and security of women from sexual assault and exploitation. Such an approach is based on the assumption that PWID have limited knowledge about sexual health. Whenever a girl with ID expresses the wish to get married, there is general discouragement presuming that she would not understand the meaning of sex, marriage, pregnancy, and so on. This approach is against the fundamental right to equality. The findings of this study are contrary to the general assumption that PWID have limited knowledge about sexuality. Further, the clinicians and caregivers are required to recognize the emotional trauma of day-to-day sexual exploitation and assault as the PWID get equally hurt and traumatized. There is a need of sensitive and appropriate sexual health care of PWID starting with proper sexual knowledge for safe sexual practices.

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