

Awareness among parents of individuals with intellectual disability about sexual health education

ABSTRACT

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Background: Most of the parents have no idea that how and when they should educate about sexual health to their typically growing children. It is important for parents to educate their children with intellectual disability about sexual health. The risk of sexual exploitation and abuse is very high in individuals with intellectual disability. **Objective:** The present study was conducted to find out the awareness among the parents of individuals with intellectual disability about sexual health education. **Materials and Methods:** Subjects for the present study were the parents of individuals with intellectual disability studying at government rehabilitation institute for intellectual disabilities, Chandigarh ($n = 100$). The present study is a cross-sectional study and subjects were selected by making use of random sampling technique. A Rating scale on "Awareness on sexual health education for parents of intellectually challenged children" developed by Lakshmi and Navya, (2014) was used. **Results:** The results revealed that there is a significant difference in knowledge, attitude, and practice among the parents of individuals with intellectual disability about sexual health education. The significant difference with respect to the gender on awareness about sexual health education (knowledge, attitude, and practice) among the parents of individuals with intellectual disability was found. No significant difference with respect to family type on awareness about sexual health education was found. **Conclusion:** Parents who live in rural locality have responded greater on the knowledge and practice than those who live in urban locality. However, parents living in urban locality have scored more on attitude over the parents who live in rural locality.

Keywords: Awareness, intellectual disability, parents, sexual health education

It is important to understand that after the enactment of the United Nations Convention on Rights of Persons with Disabilities -UNCRPD, 2008, the right to have sexual needs has been ensured. The UNCRPD views persons with intellectual disability as normal as any other individuals. The UNCRPD says persons with disabilities have the basic human right to enjoy sex as a leisure pursuit and for their sexual interests to reside on a continuum as seen in typically developing persons.^[1] It is important to know whether the parents are aware of the sexual health education of their

children with intellectual disability. Parents always plan for a perfect, healthy child and never expect a child with disability. However when they meet with such a situation, it negatively affects their attitude in the form of misery, doubt, guiltiness, denial, dishonor, etc., and this may lead to a condition of disbelief and doubt on personality and ability of their ward including their sexuality.^[2] Parents can play important role in educating their children about sexual health education and it is possible only when they

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are well aware of it. The training of parents can have a great influence which may further help their children to acquire appropriate knowledge, understanding, and skills related to sexuality and reproductive health.

The transition from childhood to adolescents as sexual beings is very challenging for those parents who have children with intellectual disability. The reason is the stigma attached to sexual feelings and desires within the community.^[3] The perception of parents having children with intellectual disability differs from the other parents of typically growing children in imparting sex education. However, mothers play a crucial role in providing sex education than fathers.^[4] Sex education is equally important for people with intellectual disabilities. However, there is an inadequacy of appropriate knowledge about effective methods and means for teaching sex education. Alike others, people with intellectual disabilities do have the right to sex education which enables them with appropriate knowledge, understanding, skills, practice, and ability to make choices and decisions related to the same.^[5,6] Earlier days people used to hesitate to talk about sex education and the condition was worse for people with disabilities than those without disabilities. However, society is now opening up to accept individuals with disabilities, still, without individualized instruction, individuals with disabilities have limited opportunities to participate in meaningful relationships and are more at risk of sexual abuse.^[7] People have tried to rule the sexuality of people with disability to control reproduction and abuse. Irrespective of ability or disability, every individual is born with his/her sexual identity, and this sexual identity is being acquainted with an individual's sexuality and indulging in it appropriately. The role of parents in imparting sexual health education needs to be ensured. Parents should be active members in all the planning related to their children with intellectual disability. The school and the teachers must involve parents at every stage of development.^[8] Empowerment in sex education is expected to minimize the threats of negative consequences from sexual behaviors. A person who is being empowered or trained about sexuality or sex education is likely to enhance the value of a relationship with people of opposite gender and helping them in making decisions relating to their sexual urges.^[9] A study found various barriers to sexuality for people with intellectual and developmental disabilities. These barriers have been found as causative factors on how a person perceives his/her sexuality, knowledge of sex and sexuality, quality of life and subsequent outcomes for meaningful adult life. The study also reports that there are huge number of experts who believe that young people need education for sexual health which needs to be delivered as early as possible in a comprehensive manner,^[10] however, the reality is the other way around.^[5] It is none other than parents who can

initiate sexual health education right from an early age. Understanding the role of parents in imparting sexual health education, the investigators intended to conduct a study on awareness about sexual health education among parents of individuals with intellectual disability.

Aims and objectives

To find out awareness among the parents of individuals with intellectual disability about sexual health education with reference to gender, locality, and family type.

MATERIALS AND METHODS

Participants

Participants for the present study were the parents ($n = 100$) of individuals with intellectual (irrespective of severity) disability studying at Government Rehabilitation Institute for Intellectual Disabilities (GRIID), Chandigarh, India. Following were the inclusion criteria-willingness to participate followed by a written consent, parents having child with intellectual disability ($IQ < 70$), male and female having minimum and maximum education of 10th and 12th, respectively. The exclusion criteria were parents who attended any workshop/seminar regarding awareness about sexual health education in the last 3 years.

Design

The present study is a cross-sectional study wherein participants were selected using random sampling technique.

Tool

For the present study, a rating scale on awareness (knowledge, attitude, and practice) on sexual education for parents of intellectually challenged children was used. This tool is developed by Lakshmi and Navya (2014) and published by National Psychological Corporation, Agra, India.^[11] It is a self-administered scale and there are 71 items (knowledge-1–20 [$n = 20$], attitude-21–39 [$n = 19$] and practice-40–71 [$n = 32$]) in the tool. The responses are to be given on five-point rating scale as “Strongly Agree, Agree, Uncertain, Disagree, and Strongly Disagree.” There is no negative scoring on the statements. The tool was tested for reliability using test-retest method which suggests 0.9500, 0.8425, 0.8412, and 0.8775 for knowledge, attitude, practice, and overall awareness, respectively.

Procedure

The administration of the tool was scheduled as per the convenience of the sample. Written informed consent was obtained from the participants. The participants were made clear about the aims and objectives of the present study. It was also made clear to the participants that their identity will be kept confidential and the collected data will

be used only for the purpose of the study. Instructions were written on the tool and the same was given verbally by the researchers to the participants and enough time was provided to them to complete the tool. Researchers were available throughout the process to look for their queries regarding understanding the item while filling up the tool. The tool was administered on parents of individuals with intellectual disability. Each participant received the tool and completed it. The study was approved by the research committee of the institute. The data collected were analyzed using Statistical Package for the Social Sciences (SPSS) (Released 2008. SPSS for Windows, Version 17.0. Chicago: SPSS Inc.).

RESULTS

Table 1 depicts the comparison of Means of fathers (male) and mothers (female) obtained by the selected sample. On “knowledge,” the obtained mean for males 79.17 and standard deviation (SD) 9.53 whereas for females, the Mean was 87.06 and SD as 10.88. The calculated “*t*” value 3.87 was significant at ($P < 0.01$) level of significance. On “attitude,” the obtained Mean for males was 74.25 and SD 9.43 whereas for females, the Mean was 80.47 and SD as 8.76. The calculated “*t*” value 5.18 was significant at ($P < 0.01$) level of significance. On “practice,” the obtained Mean for male was 128.5 and SD 16.32, whereas for female, the mean was 134.9 and SD as 13.16. The calculated “*t*” value 2.12 was significant at ($P < 0.05$) level of significance. The calculated *t*-value of knowledge, attitude, and practice were $t = 3.87$ ($P < 0.01$), $t = 5.18$ ($P < 0.01$), and $t = 2.12$ ($P < 0.05$), respectively.

Table 2 depicts the comparison of Means of type of family (joint and nuclear) obtained by the selected sample. On “knowledge,” the obtained mean of the joint family was 86.33, and SD as 11.39, whereas for the nuclear family, the mean was 82.27 and SD 10.74. The calculated “*t*” value 1.33 ($P > 0.05$) was not significant. On “attitude,” the obtained mean for joint family was 78.47, and SD as 9.72, whereas for the nuclear family, the mean was 76.94 and SD 9.62. The

calculated “*t*” value .57 ($P > 0.05$) was not significant. On “practice,” the obtained mean for joint family was 132.4, and SD as 19.17 whereas for the nuclear family, the mean was 131.35 and SD 14.5. The calculated “*t*” value 0.24 ($P > 0.05$) was not significant. The calculated *t*-value of knowledge, attitude, and practice were $t = 1.33$, ($P > 0.05$), $t = .57$ ($P > 0.05$), and $t = 0.24$, ($P > 0.05$), respectively.

Table 3 depicts the comparison of means of locality (rural and urban) obtained by the selected sample. On “knowledge,” the obtained mean of rural was 87.54, and SD as 13.77 whereas for urban, the mean was 82.18 and SD 10.29. The calculated “*t*” value 1.67 ($P < 0.05$) was found to be significant. On “attitude,” the obtained mean for rural was 74.54, and SD as 8.32, whereas for urban, the mean was 77.56 and SD 9.76. The calculated “*t*” value 1.06 ($P > 0.05$) was not significant. On “practice,” the obtained mean for rural was 118.62 and SD as 15.96 whereas for urban, the mean was 133.44 and SD 14.18. The calculated “*t*” value 3.46 ($P < 0.01$) was found to be significant. The calculated *t*-value of knowledge, attitude and practice were $t = 1.67$ ($P < 0.05$), $t = 1.06$, ($P > 0.05$), and $t = 3.46$ ($P < 0.01$), respectively.

DISCUSSION

The results of the present study show a significant difference with respect to the gender on awareness about sexual health education (knowledge, attitude, and practice) among the parents of individuals with intellectual disability. The results highlight that the mothers are more empowered than the fathers in all the domains of sexual health education i.e. knowledge, attitude, and practice. This may be because mothers may have a larger role in imparting sex education to their children with intellectual disability. The other possibility of having reported such results may be because mothers are the primary caregivers who look after all the needs of their child with intellectual disability. Children with intellectual disability are often attended by their mothers, hence, it so obvious that they have a close relationship with their mothers than the fathers. Similar findings were reported by another study which reports that awareness of mothers has a major role in providing sex education to their children.^[12] The results of the present study suggest that mothers are more aware than fathers on sexual health education for their children with intellectual disability. Findings of a study suggest that mothers, particularly those with sons, agreed that sex education is important.^[13] A critical review of the literature found that parents are willing to have a dialogue with their children about sex education provided they are given appropriate support in terms of motivation, knowledge, and skills to lead the discussion.^[14] Another critical analysis of sex

Table 1: Comparison of means of awareness on sexual health education among parents with respect to gender

Domain	Gender	n	Mean	SD	t	Significance level
Knowledge	Male	47	79.17	9.53	3.87	0.000
	Female	53	87.06	10.88		
Attitude	Male	47	74.25	9.43	5.18	0.001
	Female	53	80.47	8.76		
Practice	Male	47	128.5	16.32	2.12	0.035
	Female	53	134.9	13.16		

SD – Standard deviation

Table 2: Comparison of means of awareness on sexual health education among parents with respect to family type

Domain	Family type	n	Mean	SD	t	Significance level
Knowledge	Joint	15	86.33	11.39	1.33	0.184 (NS)
	Nuclear	85	82.27	10.74		
Attitude	Joint	15	78.47	9.72	0.57	0.573 (NS)
	Nuclear	85	76.94	9.62		
Practice	Joint	15	132.4	19.17	0.24	0.807 (NS)
	Nuclear	85	131.35	14.5		

NS – Nonsignificant; SD – Standard deviation

Table 3: Comparison of means of awareness on sexual health education among parents with respect to locality

Domain	Locality	n	Mean	SD	t	Significance level
Knowledge	Rural	13	87.54	13.77	1.67	0.098
	Urban	87	82.18	10.29		
Attitude	Rural	13	74.54	8.32	1.06	0.292 (NS)
	Urban	87	77.56	9.76		
Practice	Rural	13	118.62	15.96	3.46	0.001
	Urban	87	133.44	14.18		

NS – Nonsignificant; SD – Standard deviation

education for people with autism spectrum disorders highlights that people with disabilities must have the right to sexuality education regardless of their cognitive functioning.^[15]

No significant difference with respect to family type on awareness about sexual health education (knowledge, attitude, and practice) among the parents of individuals with intellectual disability was found. However, there is a difference in the Mean in all the domains (knowledge, attitude, and practice) with respect to family type. The results suggest that the joint family is more aware of sexual health education of individuals with intellectual disability than the nuclear family. This may be because the person with intellectual disability living in a joint family has wider scope to interact with many other family members. This interaction enables the family members to have detailed information about persons with ID in contrast it is lacking or sometimes missing in the nuclear family. The significant difference with respect to the locality on knowledge and practice of sexual health education was found. However, no significant difference was seen in the attitude domain of sexual health education. The results suggest that the locality plays an important role in the awareness about sexual health education among parents of individuals with intellectual disability. It was interesting to see that parents who live in the rural locality have responded greater on the knowledge and practice than those who live in urban locality. A new finding has emerged from the present study as parents living in the rural locality have scored more on knowledge and practices about sexual health education than those living in an urban locality. This finding questions

and breaks the conventional thought that people living in the urban locality have a greater awareness. Such a result must have been due to technological advancement which has dramatically changed all walks of life including people living in a rural setting. However, parents living in the urban locality have scored more on attitude over the parents who live in rural locality urban.

Parents have favorable attitudes about sex education for their children with intellectual disability as they believe it would ensure their safety against any sexual abuse.^[16] Parents want their children to be educated about sex education by the teachers whereas school is in the view that basic sex education must be imparted by the family. Furthermore, it adds that the education of parents cannot be a single factor that influences the attitude of parents but that there are several other factors like socioeconomic status, locality of residence and family structure, etc., which needs to be taken into account.^[17] Sex education needs to be taught within the formal education system; however, the role of informal sex education cannot be ignored as this has also been found equally beneficial. With adequate education and training, parents can be equipped to impart informal sex education which can be a cost-effective affair also. There should be educational programming that can focus on sexuality development (which includes bodies, their rights, and how to interact in society) of individuals with disability.^[18] A study reported the need for adequate knowledge, attitude, and practice among the parents to deal effectively with the sexuality issues of adolescents with intellectual disability.^[19] This creates a ground for developing suitable tools for assessment and intervention

programs for effective management of individuals with intellectual disability. The findings of the research suggest equal opportunity to have sex education for students with intellectual disability needs to be ensured in public schools. Further, they suggest that many students do not receive sex education.^[20] However, there are good numbers of teachers who believe that sex education can help students with intellectual disability. The majority of the parents do not support sex education at the lower primary level saying “the children are very young” which is not convincing enough. Sexual development is a sequential development; thus, it needs to be introduced appropriately. Adequate sex education will help the children in understanding their sexuality. If appropriate sex education will not be provided by the parents, there is a chance that someone else might teach them the wrong way.^[21]

Research reveals that there is a dire need to empower parents for sex education of their children with disability.^[22,23] Parents must be involved not only in sexuality education choices for their children but also be a part of any other related programs to help their children in all walks of their life. Based on the findings of this study, it is recommended that awareness of the parents is mandatory for improvement and by imparting training on sexual health education, they can provide the right information to their child.^[24] Today’s parents are favoring sex education for their children. The responsibility of teaching sex education should not be left only on mothers.^[25] Findings of research suggest that having a proper orientation and sensitization program for the parents to make them understand the importance and skills to impart sexual health education for their children with intellectual disability is important.^[26] Considering appropriate perspective of sexuality among persons with disabilities has become an integral part of education. This will help persons with disabilities to have proper understanding of sexuality and realize their potential better.^[27]

Limitations

The study was cross-sectional and limited to only one institution, thus, it questions the larger generalization of the findings that emerged from the present study. The sample of the present study was selected only from one institution and was not approached through the house-to-house method. However, these samples were representing the rural and urban community. Awareness about sexual health education should have been compared with the parents of children without disability or other disability, to draw a comprehensive finding. Education of parents was capped as a minimum and maximum of 10th and 12th respectively as the tool was in the English language. Parents having higher education were not included assuming it might influence

the awareness of parents. In future, comparative study, experimental study or longitudinal study may be conducted to dig into the detailed findings.

CONCLUSION

The objective of the study was to find out the awareness among parents of individuals with intellectual disability about sexual health education. However, the small sample and the exploratory nature of the study raise difficulties when making a broader generalization. Through the awareness of sexual health education, people with intellectual disability will be able to achieve autonomy and increase their control over their lives. The combination of formal and informal education options would best serve all the needs of the individual in their least restrictive environment. Based on the results, it may be suggested that the policymakers should understand that there is a need to provide more information regarding sexual health education to the parents of individuals with intellectual disability. Thus, provisions are to be made for empowering parents through training to further train and empower their children with intellectual disability.

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Conflicts of interest

There are no conflicts of interest.

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