

Sexuality Education in Girls With Intellectual and Developmental Disabilities and Role of Mothers

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The present research was conducted to investigate the strategies used by mothers to give sexual education to their girl child with Intellectual Developmental Disabilities. The study also revealed that what type of problems mothers usually face while trying to educate their girl child about their sex. A mixed descriptive approach was used for this study. It was hypothesized that mostly mothers do prefer to use modeling techniques as compared to oral communication methods to educate their girls. By using purposive sampling method thirty mothers whose girls are enrolled in different special schools of Karachi were selected as samples. It was kept in view that all the girls whose mothers were selected for the study must be between the ages of 10 -18 years (i.e., start of puberty to adolescence). A structured questionnaire, which served as the instrument of the study was designed by using adaptations from instructional manual for parents of Florida Developmental Disability Council. Findings showed that mothers used both modeling and verbal instructions for sexuality education and preferred that both schools and parents should collaborate on providing this education. In the light of obtained results, it is recommended that mothers need support and guidance from school administration and from other professionals to provide sex education to their girl child.

Keywords: Sexuality education, intellectual developmental disabilities, modeling techniques, oral communication, puberty, adolescence

In our country no guidelines have been provided about the provision of sex education. However, in neighboring country people have realized the need of the implementation of such educational programs especially for girls. The problem is that even many literate and professionally equipped people consider it useless and a type of

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education which is against our constitutional and religious ideology. Talking about sex in Pakistan especially in public is prohibited. The word sex education often appears as social taboo. If a person chooses to talk about it or tries to initiate some helping program, then he/she can get a death sentence for it or face legal consequences from the society's professionals. The biggest misunderstanding that people consider is that if one is talking about sex then it means that he/she is only referring to sexual intercourse. Recently, the government forced a private school system to remove all the sex education related material from its curriculum (Shah, 2014). Even the education minister was shocked to hear about the lessons and responded as "sex education for girls? How can they do that? That is not part of our curriculum, whether public or private" (Shah, 2104).

Our society needs to change its paradigms about sex education and related issues for the betterment of future generations. Sex education is not about getting engaged in sexual activities, but it is a map or detailed set of instructions about human sexuality. According to the Sexuality Resource Center for Parents (SRCP), the process of sexual education informs one about body images and how one feels about his or her own body type, learning of own identity, knowledge of sexual anatomy, getting aware of different feelings and emotions, recognition and acceptance of responsibilities, and sexual orientation. Sex education also develops awareness related to the reproduction rights and health conditions.

According to the Future of Sex Education (FOSE), topics like anatomy, physiology, personal health and safety, relationships, pregnancy, and birth must be included while designing a detailed inclusive sex education program. The importance and need of sex education program is undeniable for all children. But due to the increase in sexual crimes against girls such programs must be offered especially to girls between puberty and 18 years of age, so they get aware of health and hygiene problems. Provision of sex education not only makes girls able to attain sound health but also works as an alarm for them to avoid abusive situations.

The planning and implementation of sex education programs is also important for the girls with intellectual and developmental disabilities. These girls are quite vulnerable to sexual abuse and in many cases the person who abuses them is from their close circle. Below average level of Intelligent Quotient, lack of social communication, and adaptive skills makes girls with Intellectual and Developmental Disabilities (IDD) an easy victim of sexual abuse. Therefore, it is essential that these girls must learn about their body type, grooming, identity, sexual rights, and values.

Parents and school administrations do have the realization of the graveness of this issue, but cultural and societal pressures stop them to take step for the planning. The role of parents especially mothers cannot be overlooked for the smooth implementation of the sex education program. As an initiative parents must be advised about the process of sexuality education of their child with IDD (Ballan, 2001). Many mothers of girls with IDD seem to complain about the development of their child and many mothers feel uncertain about management of their girls' sexual development (Ballan, 2001).

Mothers often feel fear that during puberty and adolescence, their daughters might exhibit inappropriate behavior on feeling sexual impulses which can lead them to exploitation. Consequently, mothers get over protective, which triggers anxiety symptoms in them and they feel helpless.

The present study was also designed to focus on problems and needs of mothers who are tackling the developmental stages of their girls. The study looked into the process of smooth covering of developmental stages and what strategies are used by mothers. The study covers the developmental factors which come across in the duration between puberty and adulthood. The factors include identification of body image, changes in the features of body, period of adolescence, social skills in adulthood, and avoidance of abuse. The study also explores mothers' expectations towards school professionals and society to help her in during developmental period of her girl child. The following research questions were designed for the study:

1. What strategies are being used by mothers to provide sexuality education to their girls at home?
2. What do mothers perceive about sexuality education, and how they expect the role of school administration and other professionals in the provision of sexuality education?

Following hypotheses were formulated for the study.

1. Techniques of modeling and verbal instructions are both significantly used by mothers instead of using only verbal instructions with their girls.
2. Mothers give significant preference to themselves to provide sexuality education to their girls instead of collaborating with school professionals for it.

Method

Research Design

In the study, the design was based on mixed method descriptive approach. Both qualitative and quantitative techniques were used to gather data. Information about the demographical factors like age, education, and occupation were also collected in order to find any relation between the variables.

Participants

A sample of 30 mothers of girls with intellectual and developmental disabilities was selected. The inclusion criteria required participation of those mothers who have a daughter aged between 10 to 18 years (age of puberty to adolescence). Only those mothers were selected who volunteered to participate in the study. Simple random sampling method was used for selection from different special schools located in the Karachi city.

Instruments

A structured questionnaire which served as the instrument was designed for the present study. The adaptations were made in the questionnaire from the instructional manual for parents or caregivers of individual with developmental disabilities. The manual was designed by Baxley and Zendell (2005) to provide sexuality education for children and adolescence with developmental disabilities. The manual was sponsored by the United States Department of Health and Human Services, Administration of Developmental Disabilities and the Florida Developmental Disabilities Council. The manual was basically designed for the parents of children with intellectual and developmental disabilities. The manual offered variety of techniques which parents can use in order to help their children resolve all the issues they face during the time period of puberty to adulthood, regarding their sexuality.

The instrument of this study was designed by adapting all the factors mentioned in the manual. But it was kept in view that all the adapted items were in accordance to local needs and scenario. The language used in manual was English, but for the better understanding of mothers it was adapted and designed in Urdu language. The first section of the questionnaire contained the items which were used to collect all the demographic information about the mothers and girls with intellectual and developmental disabilities. The second section

comprised of five small sections containing total 35 items. The five sections include: Recognition of Body Differences and Similarities (9 = items); Changes in the Body (5 = items); Adulthood (8 = items); Social Skills (5 = items); Avoidance of Physical and Sexual Abuse (8 = items). The third section contains the two major questions related to the hypotheses of the study. A five-point Likert scale with response options ranging from *Always* to *Never*, was used to collect responses from both second and third sections.

The fourth section of the instrument consisted of open-ended questions (also adapted from the manual) that allowed mothers to express their fears and problems regarding sexual education in a qualitative manner. The questions in this section, were used to investigate techniques that mothers use at their home to teach girls about developmental changes in the body, the need of proper sexuality education curriculum, and development of program by the collaboration of public and private sectors to empower mothers. After adaptations were made, it was necessary to validate the content of the instrument before administering it on the target sample. Therefore, a pilot study was conducted on ten mothers of girls with IDD. After analyzing results from pilot study, necessary changes were made in the questionnaire. Then, the finally designed questionnaire was applied on the target sample group. In order to report the reliability, Cronbach's alpha reliability coefficient was used. The results showed consistency between the devised questionnaire as the value appeared $\alpha \geq .9$ which shows reliability is excellent or next to good.

Procedure and Analyses

The questionnaire was distributed among the mothers. The mothers were asked to fill the questionnaire according to their own individual understanding. Continuous assistance was provided by the researcher to the mothers during the whole procedure. Mothers filled the questionnaire and returned it back to the researcher. For convenience of mothers the questionnaire was initially prepared in Urdu language, then for the analysis reasons again it was translated into English. Then the researcher tabulated the data and analyzed results with the help of percentages. While hypotheses were tested by using the chi-square statistical method.

Results

As the instrument comprised on four sections. The findings of first, second and third parts of data, which were the quantitative parts

are following. While, the responses of forth section which was the qualitative part will be discussed in the discussion.

The results obtained after the analysis of demographic data revealed that 36% of respondent mothers belonged to the age group of 40 years. It can also be observed from the data that 50% of mothers held only matriculation certificate which might have worked as an agent to hold them back to think according to the changing societal needs and do adaptations for both them and their child. According to data, 63% mothers and their daughters lived in a joint family system. Data also revealed that 83% of the respondent mothers were house wives.

Section two consisted on five basic and thirty five sub-constructs. All the constructs were carefully adapted to measure mothers' perception regarding sexuality education. Overall, 66% mothers always talked to their daughters about sex and only 56% of them always talked about the issue and problems related to it.

Recognition of alike and differences. Recognition of body areas was always taught by 73% mothers and only 13% mothers used the correct name of the area for recognition. 57% mothers always used mirrors to perform the activity while 58% mothers use child's own picture, and 60% mothers used dolls for the same purpose. 84% mothers marked that they always tell their girls about the body differences of boys and girls.

Changes in the body features. Sixty seven percent mothers always try to know about their girls own body perception. 90% mothers insisted their girls to get dressed in a proper way. 20% mothers accepted that they never talk about menstruations with their girls not even at the beginning of puberty.

Period of adolescence. Majority of the participants that is, 86% mothers always made their girls wear undergarments. Only 4% mothers never asked their girls to not touch their private parts in front of others. 67% mothers told their girls to not talk about their feelings, needs and problems with everybody and only talk to particular person on whom they have confidence, or they feel close, especially family members. 73% mothers asked their girls to maintain their personal space and privacy

Social skills. Most of the participants (90% mothers) taught their girls to respect both others and themselves. 86% mothers told their girls about the difference between talking to an elder and to a friend.

Avoidance of Physical and Sexual abuse. Eighty percent mothers told their girls to not sit alone. 76% mothers taught their girls about good and bad touch. 70% mothers consulted professional if their daughters showed constant irresponsibility in self and health care issues.

Section three was formulated to measure the two hypotheses for the study.

Table 1

Comparison of Verbal Instructions and Both Verbal and Modeling Techniques

Description	Modeling and verbal instructions both	Verbal instructions	Total
Observed (o)	18	5	23
Expected (e)	23	23	23
D = (o - e)	-5	-18	-
D2	25	324	-
D2 / e	25/ 23 = 1.08	324/ 23 = 14.08	15.17

As shown in Table 1, $\chi^2 = 15.17$ (calculated value) on same ($df = 1$ & significance = .05) which is greater than the tabled value which is 3.84. Therefore, the null hypothesis is rejected. Table shows that techniques of modeling and verbal instructions both are significantly used by mothers instead of using only verbal instructions with their daughters.

Secondly, it was assumed that mothers give significant preference to themselves to provide sexuality education to their girls instead of collaborating with school professionals for it. Which is again rejected as the Table 2 clearly shows mothers preferences.

Table 2

Preferences of Mothers for Providing Sexuality Education

Description	Collaboration of mothers and school professionals	By mothers only	Total
Observed (o)	21	06	27
Expected (e)	27	27	27
D2 = (o - e)	-6	-21	-15
D2	36	441	-
D2 / e	1.33	16.33	17.66

Table 2 shows that value of chi-square is 7.66 (calculated value) on same ($df = 1$ & significance = .05) which is greater than the tabled value which is 3.84. Therefore, the null hypothesis is rejected.

Discussion

All children show curiosity about sex which is a normal behavior. Almost in all the families, parents do feel uncomfortable to talk about sexuality related issues and problems with their children. Similarly, it is a big task for the parents of children with intellectual and developmental disabilities. As evident from the results that 73% mothers talk about sexuality related issues and 13% mothers avoid telling the real name of body parts, consequently it gets harder for the child to recognize the same body area when any other person uses its name. Therefore, mother and caregivers must understand that they are not helping their child by not telling the real name. There has been a little acknowledgment of sexuality as a natural experience throughout the life span of individuals with developmental disabilities (Richard, Miodrag, & Watson, 2006). However, parents must understand that individuals with developmental disabilities have similar needs and desires as other children often exhibit (Richard et al., 2006). The mothers need to perform all the activities with the thought in mind that their children are real human beings who can encounter real life situation while dealing with the sexuality issue.

It is also very important to know about the child's perception about his or her body, since in this study it was revealed that 67% mothers investigate about their girls' perception about her own body and 84% mothers talk about body differences to their girls, while, 90% mothers ask their girls to wear clothes properly. It means 6% mothers are creating behavioral issues in their daughters by not telling why they are asking them to wear the clothes in proper manner. Individuals with intellectual and developmental disabilities are so naive that they never understand double or hidden instructions. Therefore, in order to train them or for their better understanding one must provide clear and short instructions to them.

Parents are found to possess educator skills (Walker, 2001) so mothers who complain that they are not able to explain to their daughters about sexuality related issues must need to change their strategy instead of quitting. The results of frequencies show that most mothers practice teaching personal hygiene and health care skills to their daughters. Also, mothers do help their daughters by talking to them about their needs, feelings and problems and save them by

telling them to keep their needs and problems limited to particular persons of family (in most cases only mothers).

The results revealed that very few mothers prepared their girls for puberty related issues at the start of this period as most of the mothers accept that they do not talk about the menstruation signs avoid the topic because they are unable to answer the questions their daughters ask. Most of the mothers do not talk openly as societal pressure, cultural and religious values make things complicated, and also mothers' family background and limited beliefs do not allow mothers to get involved in their child's sexuality education (Woody, 2008). Many mothers are often uncertain about what girls should know (Ballan, 2001). Professionals found that mothers often show confused, anxious and ambivalent attitude towards the sexuality of their children (Ballan, 2001).

One of the hypothesis, which stated that mothers preferred to provide sexuality education to their daughters by themselves and do not want any other person to do so got rejected and it appeared that mothers do want a collaboration with the professionals to provide their daughters sexuality education. The same phenomenon was put into the fourth open ended part of the instrument to get the clear picture of mother's needs and limitations. The results of open-ended part with detailed answers showed variety of needs and understanding levels of mothers. As a question was put that, should mothers provide sexuality education to their girls? One of the mother responded:

“It's solely mother's responsibility and mothers know better”

Another mother responded as,

“Don't think so, because it is mother's responsibility to take care of their child's needs. There is no need to take others' support. A mother can be a better guide. Child should only share problems to their mothers”.

But on the other hand, the testing of similar hypothesis produces different results and shows that mothers need extensive helping program in this issue. The responses of second open ended question make this outcome clear as many mothers responded positively to take help, stating:

“Yes, government or private sector institutes must initiate a program”.

Another opinion came as:

“We need a comprehensive informative program”.

Another assertive response was given by a mother along with a suggestion which was:

“Informative workshops must be provided to all mothers but on initial basis, but kindly arrange special corners/counters for mothers in hospitals which starts guiding them from initial level, that from where they can start and how they can minimize the intensity of their girl’s conditions”

Another mother responded:

“A workshop program must be arranged for both mothers and their daughters, so they may practice all the information and activities together”

Another mother responded:

“Kindly offer an awareness program. The program must contain detailed information about the physical and sexual education”.

Similarly, the second hypothesis of the study also got rejected which was designed to find the method mothers used to provide sexuality education at home, it was predicted that mothers used modeling techniques along with verbal instructional methods for their daughters’ complete understanding. The girls with intellectual and developmental disabilities have limited capabilities to understand any issue because of their limited communication and adaptive skills. But from the results derived from the analysis it appeared that mothers preferred to use verbal instructional methods.

The very similar idea was put in to the form of a question in open ended descriptive questions. The responses gathered from mothers were a little ambiguous since most of the mothers from the total sample claimed that they used many activities. Some used phrases like “Particular method”, but didn’t explain what they mean by the word “particular”. Many mothers used the words like different and repetition of activities in their answers. Only two responses out of the total stand different:

A mother revealed that she uses different characters and stories to solve her girls’ problems and issues related to body image and identity. She makes her own stories and characters who have problems similar to her girl and that’s how she explains the situation to her girl via story.

Another mother responded that, “I tell my daughter how to do it, observe her how she is doing and if she is doing it wrong I show her doing it by myself”.

It is clear that children with developmental disabilities gain physical maturation on the same rate as other children of same age unless their condition is severe. Children with intellectual and developmental disabilities learn more when sexuality information is repeated and reinforced both at home and school (Ballan, 2001).

Conclusion

From analysis of all the results it can be concluded that, mothers do want to provide sexuality education to their girls. Factors which make them restricted is their family culture and belief and to some extent their educational level. The need is that sexuality education must be provided to the girls with intellectual and developmental disabilities. Public and private sectors must design and implement a program in collaboration, to empower mothers to help their children.

Recommendations

Like girls, boys with intellectual and developmental disabilities have the same need to get sexuality education to function in the society, so a study can be replicated to cater the boys’ needs and to investigate the father’s importance to initiate a sexuality education program for boys with IDD. Government can introduce sexuality education program in schools. Curriculum for the provision of sexuality can be designed according to the age level and cultural background. With the collaboration of public and private sectors, an extensive training program of sexuality education techniques can be initiated for parents of exceptional children.

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