



RESEARCH PAPER**Home-based sexual Education for Children with Intellectual and Developmental Disability (IDD)**

Dr. Amna Arif ¹ Dr. Zahida Parveen*² Saba Abdullah ³

1. Assistant Professor, Department of Education, University of Management and Technology, Lahore, Punjab, Pakistan
2. Assistant Professor, Department of Special Education, Division of Education, University of Education, Lahore, Punjab, Pakistan
3. M.Phil. Special Education, Department of Education, University of Management and Technology, Lahore, Punjab, Pakistan

Corresponding Author

Zahida.parveen@ue.edu.pk

ABSTRACT

This study was qualitative and used an exploratory research design. The sample of the study included 15 parents of children with IDD recruited using a purposive sampling technique. The tool for data collection was a self-developed semi-structured interview. The findings of the study revealed parents perceive that sexual education helps in appropriate interaction with the opposite gender and development of a sense of right. Parents also face some common changes such as attraction for the opposite gender, prominent physical changes, psychological changes, and emotional changes. The study revealed some basic problems included communication barriers, lack of knowledge and skills to talk about sexual education, inadequate content on sexual education, family values as taboos to discuss sexual matters, health-related problems, problems in managing anger and frustration, and not aware of the strategic measure. This study emphasizes the need for future interventions to overcome challenges.

KEYWORDS Challenges, Children with Intellectual & Developmental Disabilities, Parents, Sexual Education, Training

Introduction

Sexual issues are always a concerning matter to discuss with a child. These sexual matters are the spread of AIDS, pregnancy, various body changes, and gender differences. Prevention of violence with an intimate partner, support in dating, appreciation of sexual diversity, healthy relationship developments, child's sex abuse prevention, social and emotional learning, and promulgation of media literacy are the factors of healthy SE (Eva & Lisa, 2021).

Acknowledging the sexual development of the child and getting aware of the developmental features of the child are the responsibilities of his family. There is no need to wait for such questions from the child. Parents are supposed to own the responsibility to provide information on SE to set an instance for the child. This includes requesting the child's school to provide and support SE (Çalışandemir, Bencik & Artan, 2008).

Children with IDD are often ignored in sex education. It is not covered properly in the curriculum of special education. Every day challenges of daily parenting including habitual stress and such parenting responsibility requires essential care to provide for children with serious developmental difficulties, especially with ID. There is a critical

impact of such stress on parent development which resulted later in developmental and psychological outcomes for the children (Kirby, 2005).

Regardless of explicit limitations which restrict sexual knowledge & experiences of children with ID, many individuals wish to get the ability of sexual health education with an exploration of self-sexual expression. Parents have two important roles of consistent caretakers and sexuality educators for the active daily living of their child with IDD. This is much needed for the parents to comprehend their role as sex educators. This includes helping the child with IDD in expressing or exploring self-sexuality. A more directive style of support and motivation is shown for a child with ID by his mother as compared to the mother of a normal child (Blacher, 2013).

Sexuality is an essential human right since it affects people's social, emotional, and physical well-being. For individuals with intellectual and developmental impairments, sexual orientation, and its crucial health implications have been ignored, both today and historically (Center for Reproductive Rights, 2016). Increasing health professional training on sexual health and development for the ID/DD population can have a positive impact on the health and safety of the community (Murphy et al., 2016).

Literature Review

According to Dionne and Dupras (2014), ID/DD people were not recognized as sexual beings or capable of sexual activities until the 1970s, and over fifty years later, it is clear that sexuality and SE for this group are still absent. This persistent absence of sexual health education derives from the perception of ID/DD people as asexual and unable to comprehensive sex education. The refusal to acknowledge an ID/DD person's sexuality limits access to education and the tools available to educate them. This has resulted in far too many ID/DD people never receiving any kind of SE. Minimal SE for ID/DD teenagers, on the other hand, might have far more severe consequences than a lack of awareness of their sexual development (Sinclair, Unruh, Lindstrom, & Scanlon, 2015).

According to Swango-Wilson, A. (2008), Instruction is a means of promoting the capacity to make appropriate decisions and empowering the person with an intellectual disability. Administrative abilities will improve an individual's capacity to make informed decisions and then support the judgment to behave in the best interests of one's health and well-being. Not only will education help to reduce exposure, but it will also help to reduce improper sexual expression. Individuals with ID, the ID community believes, may learn to make decisions and create connections based on a shared language to convey these decisions with help and practice. Individuals with ID must be permitted to take part in decisions that affect their lives. The need for sex education has been acknowledged by parents, professional service providers, and healthcare experts.

Vescolani,(2009), explained here sex training courses' goal is to educate persons with ID about sexuality. Making Proud Choices, which is a complete curriculum, and making a difference, which is an abstinence program, are the other two curricula by the same writers. Be honored of yourself! Be responsible! The target audience is teenagers aged 13 to 19. The program is broken down into six 50-minute sessions that take place over one to five days or several weeks. The objectives are to "decrease unprotected sex among sexually active inner-city kids," "delay initiation of sex" among those who have not yet had sex, and assist teenagers in making "proud and responsible sexual decisions."

Persons with disabilities, particularly those with mental disabilities, are rarely granted sexual autonomy, and reproductive decisions are regarded outside the scope of their mental skills. Because of their contradictory ideas on sexuality, persons with mental

disabilities frequently doubt the value of sex education for them. As a result, children with intellectual or developmental disabilities are frequently omitted from both home and school sex education. However, the risk of sexual assault is real and is acknowledged by caregivers/family, which frequently leads to decisions such as hysterectomy or abortions being performed without the permission of the person with a mental handicap (Kothari, 2014).

Material and Methods

Research Design

This study used the qualitative exploratory research design. Qualitative research refers to the naturalistic inquiry process in which an in-depth understanding of social phenomena is done (Ahmad et al, 2019).

Sample and Sampling Technique

The sample of the study was the parents of children with intellectual and developmental disabilities (N=15). The parents had belonging to the various districts of Punjab. Out of the total parents of children with IDD, there were males (N=2) and females (N=13). The researcher involved both genders for relevant qualitative data. The researcher used a purposive or judgmental sampling technique to collect data from the sample (N=15). A purposive sample is defined as the one whose characteristics are relevant to the study and are explained for a rationale (Chittaranjan, 2020).

Table 1
Districts for data collection

Districts	Sample
Lahore	06
Narowal	03
D.G Khan	02
Faisalabad	01
Gujranwala	03
Total	15

Instrumentation

A self-made semi-structured interview guide was developed to collect relevant data from the participants. This instrument contained two parts. One was about demographic information of parents and their children with IDD and the other was open-ended questions (N=16). The validity of the instrument was assured by three experts from the relevant field.

Data Analysis

After data collection, the data was analyzed through thematic analysis. Additionally, qualitative data is analyzed through thematic analysis. In thematic analysis, the researcher finds the common themes emerged regarding sexual education.

Results and Discussion

The demographic details of the sample and thematic analysis is in the following.

Table 2
Demographic information of Sample

Variables	%
Respondents	
Mothers	87%
Fathers	13%
Cities	
Lahore	40%
Narowal	20%
D.G. Khan	13%
Faisalabad	7%
Gujranwala	20%
Qualification of Parents	
Below metric	27%
FA	20%
MA	53%

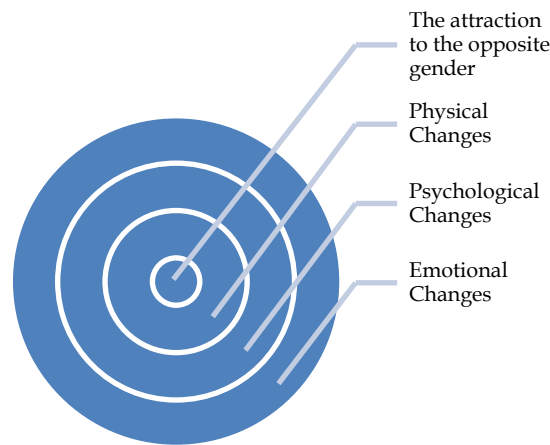


Figure 1: Changes during the stage of puberty reported by Parents

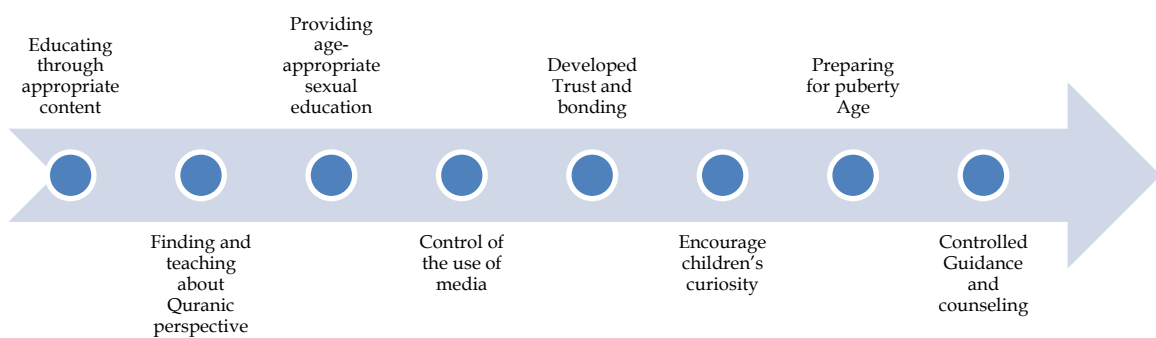


Figure 2: Efforts delineated by parents to provide Sexual Education

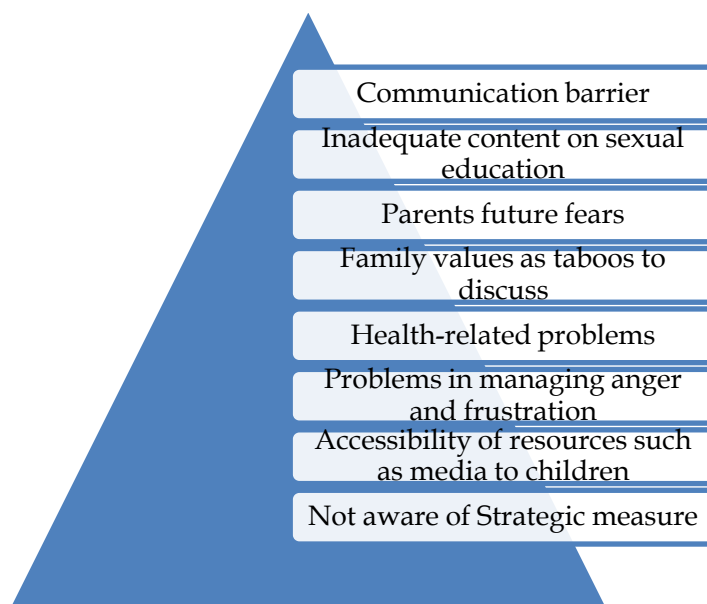


Figure 3: Problems faced by parents of children (IDD) in home-based sexual education

Discussion

The study was intended to investigate those challenges which are experienced by parents regarding home-based SE of their child with an intellectual and developmental disability (IDD). SE is a very sensitive topic to discuss both by teachers and parents. However, SE at home requires appropriate expertise, skills, and knowledge to deliver at home. Parents require specific mastery to discuss a sensitive topic with children with intellectual and developmental disabilities who are already experiencing challenges due to their limited and restricted mental capacity. Their children have already less adaptive behavior skills and parents need to cope-up with numerous challenges as well as with the intellectual disability of their child. In such conditions, parents require to deliver the best of their knowledge about SE. The perception of the parents reveals that SE has a lot of importance for children with IDD. Sex education is well known to parents whom they deliver to their children and they believe it to be delivered by the school (WANKASI & Idubamo, 2021). According to the parents of children with IDD, SE is the right of children to explore and express their sexuality in appropriate ways. Additionally, children with IDD require appropriate interaction with the opposite gender as a part of their SE.

Moreover, parents are the primary educator, and play a crucial role in the SE of their children. There is a non-deniable role of the parents in delivering SE to their children with IDD. The challenging responsibility of families is sexuality education and particularly for Muslim communities who have transitioned to modernity (Rouhparvar, 2022). Additionally, parents with higher educational backgrounds have enough content available for the delivery of SE. However, parents' perceptions indicated also that providing sex education is unnecessary for IDD children. Although, parents have the desire to discuss sexual behaviors parents feel uncomfortable and embarrassed. They don't have the knowledge and skill to discuss (Triece et al., 2008).

There are common physical, psychological and emotional changes in children with intellectual and developmental disabilities during the stage of puberty. Gender-wise physical changes, prominent physical changes, reproductive Organs size change, and weight gain during puberty are the most common changes among children with IDD. The

stage of Puberty is the period of developing reproductive function and secondary sexual characteristics in a child (Zhu, 2021). Additionally, behavioral problems, fear from parents, shyness, stubborn behavior, change in liking and disliking, and psychological Upset during the menstrual cycle are common emotional and psychological problems in children with IDD. The stage of puberty is often changed with adolescence'. It covers psychological, cognitive, social, and physical (Wolf & Long, 2016).

Moreover, there are problems that the parents of children with IDD face during puberty. These problems include communication problems, unavailability of content, and lack of training and awareness. Parents of children with IDD put their efforts into delivering SE to their children with IDD. Age-appropriate basic concepts of SE for children with IDD are necessary for the children. Encouragement, guidance and counseling, and motivation are the key efforts that parents perform for their children's betterment. The best strategies include encouragement, motivation, involvement of the child in social activities, provision of internet and audio-visual aids, storytelling, and other digital media resources that are the best to deliver SE to children with IDD. Relationship and intimacy, body image, gender roles, sexual identity, sexually transmitted infections, sexual decision-making, contraception, and reproductive health are the topics that are covered by SE (Debanjan & Sathyanarayana, 2022).

Conclusion

The study concluded that this study is a kind of fair direction for the parents of children with IDD regarding home-based SE because SE is a concerning matter to discuss with the child. This study is beneficial for the parents of children with IDD to improve their strategies and have awareness about home-based SE as parents are the primary sex educators. Home is the foundation for IDD children where they can comprehend more about SE. SE is important to empower children against several vices. Mothers recognize the need for children to be informed but a lack of adequate knowledge makes the problem. Therefore, there is a need to enlighten mothers and indeed parents on the concept of sexuality education and empower them with the skills necessary to pass it on to their children. Additionally, this study is very useful for teachers of children with intellectual and developmental disabilities to deliver school-based SE. In this way, many hidden factors could be revealed to children with IDD. Understanding body parts, their physiology, making understanding of different relationships in home and community, peer interactions, making friends, social circles as well as differences of genders and their roles are the common areas to be discussed and convey to children with IDD.

Recommendations

The following recommendation are furnished on the basis of the findings of the study:

1. Schools and institutes should plan training for parents to guide their children with intellectual disabilities regarding SE.
2. Awareness sessions regarding home-based SE must be arranged through workshops, seminars, conferences, or by using social media.
3. The appropriate content to provide home-based SE must be developed by involving religious institutes with academia.

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