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Impact of the orientation program on sexuality among parents of children with intellectual and developmental disabilities

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Abstract

Parents of persons with intellectual and developmental disabilities are usually distressed by the progressive deteriorating conditions of their children with differential abilities. Children of parents with intellectual disabilities are considered to be at risk for child neglect, and developmental and behavioral problems, due to parenting skill deficits. Years of research have demonstrated that parents with intellectual disabilities can be taught a variety of parenting skills through behavioral skills training with corresponding benefits to their children. Whereas the parents play a prima facie role in the upliftment of their children from the day they are born. On knowing the condition of their child after birth they face the vicious cycle of denial, shock, and worthlessness. This condition creates negative perceptions and stigmatizes them to the condition. They start searching for gainful resources from where they could find some practical solution for their child. In this scenario, some parents show optimism whereas some are pessimistic about the present situation they are dwelt in. The professionals in the field of disability rehabilitation play a significant role in this crisis situation of parents, helping them to resolve the issue, empowering them to come out of the crisis situation, and molding their perception positively towards the cause, by facilitating their active participation in various training programs. Parents from their own seek various training resources to meet the challenges with regard to their child with special needs. Throughout the world, there are various kinds of training programs that are aimed to reconcile the challenging situation of parents having children with different abilities. The present study seeks to understand the underlying factors that facilitate the participation of parents of children with special needs. In this study, 100 such parents including 14 fathers and 86 mothers were studied using group and single case design that includes direct observation of the parenting behavior of parents with Intellectual and developmental disabilities with IQs ranging from 35 to 49 from the preschool and primary group of students. The study is restricted to the city of Secunderabad.

Keywords: Intellectual disability, sexuality, parents, perception, awareness level, training program, empowerment

Introductions

The study aims to see the impact of the training program on sexuality on the perception and awareness level of parents of persons with intellectual and developmental disabilities. The level of awareness with regard to any matter is of much significance in forming perceptions and dealing with that particular matter. The parents are overwhelmed with the parental responsibilities in their day-to-day life, and managing and handling the children with or without disabilities become sometimes a great challenge for the parents.

According to Farrag and Hayter (2014) ^[10], sexual health education can help youngsters develop a positive view of their sexuality. Sex education covers a variety of topics that are helpful to introduce to children, including the anatomy of reproductive organs, the process of personal sexual development, sexual activity, reproductive health, contraception, personal image, values, decision-making, communication, STDs, protection against sexual harassment, unforeseen pregnancies, and also a method to protect reproductive organs in relation to health, hygiene, security, and safety (Fentahun, N., *et al.*, 2012; Irianto, K., 2014; Lawrence J, *et al.* 2000) ^[11, 14, 18]. Working together, among other parties, is necessary to address sexual health issues in children with intellectual disabilities, including but not limited to parents, teachers, and medical experts. Parental sex education of their children at a young age is one of the early preventative strategies in this topic (Wilson E.K, *et al.* 2010)

[24]. In order to encourage their children in understanding the stages of their sexual development and their attitude toward the opposite sex, parents play a crucial role in educating them about sex. This challenge becomes more and more severe with regard to the child with special needs, parenting the specific child with special needs calls upon various types of adjustments with other role models in and outside the family. In this situation, the perception and awareness level of the parents with regard to the disabling conditions and their effect on other aspects of life plays a significant role within the family, it helps to make the family function in a cohesive manner or if it is negative, then it may disrupt the functioning of the family. The parents' training program empowers the parents with positive perceptions, apt skills, and positive attitudes for the upbringing of the child with disabilities. The parents both father and mother are very much worried about the hidden potentials of their child with and without disabilities. Some of the parents are on a constant move to search for good resources from where they get practical knowledge of handling and managing their child with special needs, which becomes more complicated and diversified when the other sibling is without disabilities. In a family where there are siblings with and without disabilities, the parenting role conflict persists in a large dimension. Generally, the parents are more declined towards the progression of the child without a disability, and in this process of nurturing the one with a disability gets neglected. This type of neglecting attitude deteriorates the condition of children with special needs. Timely intervention is not given to the child with a disability, which results in more unmanageable conditions within the family. The family surviving in this condition gets broken from within, and the members curse each other for each every mishappening. The child with a disability is either admitted to a special school or stays back in their home. Special schooling procedure gets more apt for the child when the interventions are provided equitably at home, school, and community. In this post-pandemic situation, the education system has been confined at home, and children with or without disabilities are receiving education through online digital modalities. In these circumstances, parenting is of great significance, parents are facing multiple challenges in and outside the home including numerous physical and emotional distresses involving job insecurity, loss of near and dear ones, and ill health of children with or without disabilities. Along with these situations, there are myriad opportunities for exploring new pathways, new resources and avenues, and performing new social roles. In this context, the parent's role is vital to support each and every aspect of the development of the concerned child. The rehabilitation professionals are conscientiously working in close contact with the family, supporting each and every need of the child with special needs, and harnessing quality interaction among family members by arranging various training programs at special schools, home-based situations, and in community settings. It is important to acknowledge the distressing situation a family faces because of the child with special needs, the professional plays the role of the counselor in this context and helps them realize "they are not alone" and it is the task of the multidisciplinary team to acknowledge the issue. The various contextual factors that are engulfing the parents with respect to the concerned child with special needs are taken into consideration and studied in depth. Throughout the world, there are various research studies that highlight the

contextual factors that interfere with the participation of parents of children with special needs in the training program. The factors studied in the present study imbibe the quality of life of children with special needs from parental quality interaction. Parents' awareness and empowerment with regard to the issue are of much significance towards the holistic development of children with special needs. In the context of the present study, it is very important to recognize the contextual factors apart from the techniques of training that influence the behavior of parents and their response to intervention. The behavior of any kind does not occur in a vacuum. In order to understand why some parents lack parenting skills or appear not to cooperate with services, it is crucial to determine the specific "context" or ecological niche within which each family is functioning (Belsky, 1993; Bronfenbrenner, 1989) [25, 26]. The "parental interactional model" a contextual model underlies the step-by-step approach, the model incorporates ecological context and behavioral principles in analyzing the internal and external factors influencing the participation of parents in any kind of training program. The experiences of parents providing sex education to their children are described under four themes.

Hypothesis

There will be a significant impact on the perception level and awareness level of sexuality education of persons with Intellectual and developmental disabilities among the parents of persons with intellectual and developmental disabilities.

OR

There will be a significant difference in scores of the post-test in comparison to scores of the pre-test drawn through feedback from Parent respondents of PWMR / ID on administering a questionnaire to study the impact of the training program on their perception level and awareness level on sexuality-related issues.

Operational Definition

Parent of PWMR / ID: This refers to a biological blood relationship or legally acquired guardianship to care for a Person with MR/ID as a primary caretaker and having authority to decide for their child for their life span needs particularly with reference to their sexuality needs.

Parenting: The term parenting in this study refers to a set of responsibilities. Parents of PWMR/ID discharge in guiding their children through early childhood, adolescence, and adulthood life stages on sexuality development and preparing them to deal with challenges appropriately, in spite of having a disability condition.

Methodology: This study used a qualitative study with a phenomenology approach. Participants were selected using the purposive sampling method, the sample comprised parents (father & mother) of adolescent children with moderate intellectual disabilities enrolled in Special Schools, and parents were able to communicate and share their experiences in regional languages and gave their consent. The total number of participants in this study was twenty parents. Twelve mothers participated in the focus group discussion, and seven mothers and one father participated in the in-depth interview, seven of them also

participated in focus group discussions while the other one not participated. Data was collected using focus group discussions and in-depth interviews, the discussions were audio recorded and later on transcribed.

Discussion: Based on the findings of this survey, all parents concur that sex education is crucial for children with intellectual impairments since, in their experience, these kids go through the same bodily changes that other kids do during puberty. This is consistent with the findings of Gurol, A. *et al.* (2014)'s ^[13] study, which shows that all moms, particularly those who have sons, agree that sex education is vital. People have long held the misconception that children with intellectual impairments lack feelings and sexual desire, are innocent youngsters, and don't need sex education. Therefore, since they think that sex education for their children is useless, parents are frequently uninformed and occasionally overprotective. Literature of many types, which demonstrates how children with intellectual disabilities have sexual impulses, refutes these views (Gurol, A, 2014; Isler, A. *et al.*, 2009) ^[13, 15]. Children with intellectual impairments are frequently cared for by their moms on a daily basis, thus it is usual for them to have a stronger bond with their mothers than with their dads. This is consistent with what Walker, J.L. (2001) ^[23], finds that mothers have a significant role in educating their children about sex. According to Gurol, A. *et al.* (2014) ^[13], there was a different perspective on this issue since most mothers felt that teachers, not parents, should play a significant role in teaching sex education. The moms said in the interview that they rejected the notion of sex education because they thought it was unimportant or taboo, and they felt uncomfortable discussing it with their kids. In a survey including 18,000 children aged 11 to 16 years, Balding J. (1999) ^[7] found that the children thought their parents should be their primary source of sex education, followed by teachers and finally health care providers. Instead of their parents, teachers, or healthcare providers, these kids' buddies served as their primary source of sex education. Parents understood the value of a strong religious foundation in sex education. After explaining the religious laws, they claimed it was simpler to impart sex education. Parents frequently lecture their kids about inappropriate behaviors, such as embracing friends who are the opposite sex and walking about nude after taking a bath, to name a few. This is consistent with what Wilson, E.K. (2010) ^[24] states, according to which numerous parents supported their provision of sex education by turning to religious teaching or the religious community. Parents acknowledged that it was challenging to provide sex education and respond to their children's inquiries about sex, especially from their males, because of their limited awareness of sexual changes in their children (Walker, J.L, 2001) ^[23]. Parents admitted that they were unsure about how to begin teaching their children about sex as well as the appropriate terminology to employ. They came to see that their hesitation and uncertainty about how to begin providing sex education to their children was due to their ignorance of the sexual development of those youngsters. They want to do it correctly and on schedule. This presented challenges for the parents, because they had to wait until their children inquired about sex or, occasionally, until they already had a specific sex issue because teaching children with intellectual disabilities about daily activities, was challenging enough

without adding the responsibility of providing sex education (Dupras, A., and Dionne, H., 2014) ^[9]. Parents also cited a number of drawbacks of the delayed introduction of instruction in these areas, including their children's inappropriate sexual conduct and their lack of knowledge of how to care for their reproductive organs (Ballan, M.S., 2012) ^[8]. The goal of sex education were accomplished when the kids realized their faults in sexual activity and could defend themselves from abuse that may harm their physical and emotional health (Isler, A, 2009; Gunarsa, S.D, 1991; Izugbara, C.O., 2008) ^[15, 12, 16]. The development of intellectually disabled youngsters into autonomous, assertive people can be aided by good sex education. Additionally, the kids will learn social skills, have a good attitude and practice healthy sexual conduct, which will make them less vulnerable to sex abuse, STDs, and unintended pregnancies (Sweeney, L, 2008) ^[22]. It's crucial to utilize terminology that youngsters can comprehend while delivering sex education, according to Katz & Ponce (2008) ^[17]. Most of the time, parents must repeat their explanation to their children, checking to see if they comprehend it or not. In order to keep their kids from getting bored, parents need to be inventive in their explanations.

Conclusion: Parents should have discussed less sexually explicit issues with their children. The difference in delivering sex education should be regularly emphasized and conveyed gently. To prevent their children from sex abuse, parents should start sex education early and practice the technique. In order to give sex education, parents—especially mothers—play a far more significant role than fathers.

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