

Perceived Barriers and Concerns of Mothers in Providing Sexuality Education to Children with Intellectual Disabilities A Qualitative Study

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Abstract—Sexuality education is an essential component of holistic development of children and adolescents. Children with intellectual disabilities experience physiological and emotional changes similar to normally developing children; however cognitive limitations, communication difficulties and impaired adaptive functioning increase their vulnerability to sexual abuse, exploitation and inappropriate social behaviours. Mothers as primary caregivers play pivotal role in providing sexuality education to their children. However, many mothers have inadequate knowledge and confidence while discussing sexual health topics; also associated with certain degree of cultural stigma and personal inhibitions associated with such topics, may be more pronounced among mothers of children with intellectual disabilities.

A qualitative research design was adopted wherein twenty mothers of children with intellectual disabilities attending a special school were identified as the accessible population using purposive sampling. Finally, eighteen mothers were included in the sample. Data were collected using in-depth semi-structured interviews until data saturation was achieved. The interviews were audio-recorded, verbatim transcripts were prepared and analysed using the Braun-Clarke thematic analysis. Major barriers identified included developmental and cognitive limitations of the child, communication difficulties, behavioural challenges, lack of parental confidence and inadequate knowledge, time constraints and limited institutional support. Major concerns expressed by mothers included children's vulnerability to abuse, fear that children may be unable to report inappropriate experiences, uncertainty regarding developmental readiness for sexuality education, fear of triggering curiosity in children and concerns about exposure to inappropriate media content.

The study highlighted that mothers recognize the importance of sexuality education for children with intellectual disability but encounter multiple challenges in providing it. Strengthening caregiver education, implementing supportive policies, improving institutional support and promoting collaboration among families, educators and healthcare professionals may help parents provide developmentally appropriate sexuality education for upholding the rights and dignity of children with intellectual disabilities.

Index Terms—Intellectual disability (ID), mothers, perceived barriers and concerns, sexuality education.

I. INTRODUCTION

Human development is a dynamic process that encompasses biological, psychological and social domains. According to Maslow's hierarchy of needs, physiological and safety needs form the foundation of healthy development of an individual of which sexual development is an inevitable part requiring timely guidance about body awareness, privacy and personal safety for holistic development and well-being [1]. However, for children with ID, navigating sexual development can become challenging although they experience pubertal and sexual changes similar to other normally developing children [2]. Global prevalence estimated that approximately 1–3% of the population lives with intellectual disability which is also a significant contributor to Years Lived with Disability worldwide [3][4]. In India, 1.5 million individuals are classified under intellectual disability [5]. Children with ID face a heightened risk of sexual

predation while restricting their ability to identify and disclose such acts.[2][6]

Mothers as primary care givers are often key figures in guiding children through puberty-related changes and matters related to safety and personal boundaries. Mothers having children with ID particularly experience unique challenges and there are limited Indian studies conducted in this domain. Therefore, the present study aimed to explore perceived barriers and concerns of mothers in imparting sexuality education to their children with intellectual disabilities.

II. METHODS

A qualitative descriptive research design was adopted. The study was conducted at selected special school of Western Maharashtra. Twenty mothers of children with ID attending that were identified as study population through purposive sampling and eighteen were finalised as study sample. The sample size was determined also based on data saturation as new themes emerged till the eighteenth participant. Inclusion criteria were mothers of children in age group of 6 to 18 years diagnosed with ID; ability to communicate in Hindi, English and Marathi and willingness to participate in the study was also taken into account. Mothers with severe illness, psychological distress and male care givers were excluded.

A self-constructed semi-structured interview guide was used. In-depth interviews which lasted for 30-45 minutes each were conducted in the school ensuring privacy and observations were noted in the field notes. The tool consisted of socio demographic data of the mothers, basic details of the children with ID, open ended questions about opinions, experiences and challenges mothers face while discussing sexuality education with their children having ID and audio recording of interview responses and field notes.

Content validity and finalisation of the tool was established by a panel of experts in this speciality. Yvonna S. Lincoln and Egon G. Guba criteria was used to ensure trustworthiness of the data. Approval was obtained from the Institutional Ethical Committee prior to data collection and ethical considerations of the study were ensured through the study. A pilot study was conducted among mothers of children with

ID who met the inclusion criteria but were not included in the study sample.

Data Analysis- For data analysis, Braun and Clarke’s six-step thematic analysis approach was used.

III. RESULTS

1.Socio-Demographic profile of the study sample

Table I: Distribution of sample as per socio-demographic data n=18

Variable	Category	Frequency (f)	Percentage (%)
Age in years	<25	0	0
	25-30	2	11.1
	30-35	5	27.8
	35-40	7	38.9
	>40	4	22.2
Education	Illiterate/ Primary	0	0.0
	Secondary	3	16.7
	Higher Secondary	3	16.7
	Graduate	8	44.4
	Post-Graduate	4	22.2
Occupation	Working	4	22.2
	Housewife	14	77.8
Family Type	Nuclear	10	55.6
	Joint	8	44.4
Income Level	₹1,59,586 and above	3	16.7
	₹79,756 to ₹1,59,585	2	11.1
	₹59,795 to ₹79,755	12	66.7
	₹39,830 to ₹59,794	1	5.6
	₹23,870 to ₹39,829	0	0
	₹7,989 to ₹23,869	0	0
	≤₹7,988	0	0
No of Dependents	One child	3	16.7
	More than one child	7	38.9
	One child and in laws/parents	2	11.1
	More than one child and in-laws/parents	6	33.3

Table I illustrates the socio demographic characteristics of the study sample. The majority (38.9%) were in the advanced age group of 35–40 years age. Most participants (44.4%) were graduates and predominantly (77.8%) housewives. More than half (55.6%) belonged to nuclear families. The majority of them (66.7%) had family monthly income of ₹59,795 to ₹79,755. Most of them (83.3%) reported a high number of dependents i.e more than one child with disabilities or one child and parents/in laws living with them or more than one child and parents/in laws living with them.

2. Description of demographic variables of the children with ID-

Table II: Distribution of children with intellectual disabilities as per demographic data n=18

Variable	Category	Frequency(f)	Percentage (%)
Age in years	5 to 10	6	33.3
	10 to 15	10	55.6
	15-20	2	11.1
Gender	Male	10	55.6
	Female	8	44.4
Disability percentage	<40	01	5.55
	40-80	13	72.22
	>80	04	22.22
Associated Disabilities	Yes	12	66.7
	No	6	33.3

Table II demonstrates the characteristics of children with intellectual disabilities in terms of age, gender, percentage of disability and associated disabilities. The majority (55.6%) of children were aged between 10 to 15 years, predominantly males (55.6%). The major disability percentage was 40-80% with 66.7% children having associated disabilities.

3. Thematic Analysis- Table III and IV show the details of themes and subthemes identified.

Table III: Perceived Barriers

Theme	Description	Supporting Quotes
Lack of parental confidence and knowledge	Mothers’ low confidence due to limited knowledge, lack of prior exposure and discomfort in discussing sexuality.	<ul style="list-style-type: none"> • “Honestly, I feel shy to talk about such things. In our family, we never openly discussed these matters.” • “I don’t know how to start the conversation. I don’t know what to explain and how to explain it.” • “With my limited knowledge, I try to explain to him. He understands a little. But he cannot express himself.”
Time constraints and work burden	Multiple responsibilities such as employment, household work, caregiving and health issues limit mothers’ time and energy to provide	<ul style="list-style-type: none"> • “My health is not good. I have a lot of household work. I am also undergoing treatment.” • “I feel I do not have enough time. I am

Theme	Description	Supporting Quotes
	sexuality education.	working. School teachers must also teach these things.” <ul style="list-style-type: none"> • “I come back home from work at 6 pm... I do not get time to talk about all this.”
Developmental-Cognitive limitation	Child’s poor ability to understand sexuality education due to delayed mental development, leading to postponement of teaching.	<ul style="list-style-type: none"> • “He does not understand many things yet. Perhaps when he grows older, we can explain it to him.” • “Although he is 14 years old, his mental age is around 2 years.”
Communication barrier	Limited expressive ability and non-verbal status of the children which posed difficulty for mothers to explain concepts or confirm understanding.	<ul style="list-style-type: none"> • “He does not speak much. So I don’t know how much he understands.” • “He cannot express properly. He only tells if

Theme	Description	Supporting Quotes
		someone hits him.”
Behavioural challenges	Hyperactivity, short attention span and aggression hindering communication process and teaching efforts.	<ul style="list-style-type: none"> • “He doesn’t sit at one place and listen. Even if I try to explain something serious, he starts shouting. It becomes difficult. Then I leave it.”
High dependency and severe disability	Complete dependence for daily activities made sexuality education seem less urgent compared to basic survival skills.	<ul style="list-style-type: none"> • “She is completely dependent on me. She cannot do anything on her own. During menstrual cycles I don’t even send her to school.”
Family resistance and cultural inhibition	Discouragement of family members on sexuality education, believing it unnecessary or inappropriate. Cultural taboos and lack of openness about sexuality that prevented	<ul style="list-style-type: none"> • “My mother-in-law says, ‘What is the requirement to teach these topics to children?’” “They do not support, ma’am. They do not like discussing these topics.”

Theme	Description	Supporting Quotes
	mothers from discussing the topic.	
Inadequate structured professional support	Mothers' expression of need for training, workshops and professional guidance to teach sexuality education effectively.	<ul style="list-style-type: none"> • "There should be classes for us parents also." • "I feel I do not have enough time. I am working. School teachers must also teach these things." • "If someone teaches us step by step how to explain, it would help." • "Professional guidance for parents should be provided."

Table IV: Perceived Concerns

	Description	Supporting Quotes
Safety and vulnerability concern	Mothers' fear about their children were vulnerability to sexual abuse and unable to protect themselves.	<ul style="list-style-type: none"> • "My main concern is that if something wrong happens to him, he may not be able to explain."

		<ul style="list-style-type: none"> • "We are always worried someone may take advantage."
Fear of inability to report abuse and future safety	Mothers' worries regarding their children inability to report abuse and anxiety about their child's future safety.	<ul style="list-style-type: none"> • "He cannot explain clearly if something happens." • "I worry about what will happen when we are not there."
Exposure to inappropriate media content	Mothers' concerns about children accessing sexual content online and showing inappropriate behaviour.	<ul style="list-style-type: none"> • "He was watching inappropriate videos with his friends. If I am not nearby, he again watches such content."
Concern about comprehension and mental readiness	Doubts of mothers about their child's poor comprehension and mental readiness for the topic.	<ul style="list-style-type: none"> • "She has no mental development according to physical development." • "Maybe when he grows a little more and understands better."
Fear of social judgement and stigma	Mothers' fears about criticism and misunderstanding from	<ul style="list-style-type: none"> • "I am afraid he may repeat those words outside."

	society if children discuss sexuality openly.	<ul style="list-style-type: none"> • “Sometimes I feel scared about what people might say if I teach him these.”
Fear of triggering curiosity	Mothers’ concerns that sexuality education might increase curiosity or inappropriate behaviour.	<ul style="list-style-type: none"> • “Sometimes I think if I explain too much, he may become more curious in those matters.” • “She may become curious if I teach her more about sex education.”

IV. DISCUSSION

A major barrier identified in this study was mothers’ limited confidence and lack of structured knowledge regarding how to discuss sexuality-related topics. Many participants were uncertain about the appropriate timing and methods for discussing sexuality education. Similar findings were reported by Kamaludin K et al., where mothers acknowledged the importance of sexuality education but felt inadequately prepared [7].

Caregiving burden further limited mothers’ ability to provide consistent guidance and supervision related to sexual education. A systematic review has reported similar findings highlighting high levels of stress, anxiety and psychological burden among parents of children with intellectual disabilities [8]. The intensity of burden on care givers was also proportional to increasing severity of disability. Similar findings were reported in a recent descriptive study conducted in India [9].

Child-related barriers such as cognitive limitations, communication difficulties and dependency on care

givers for basic needs further make sexuality education discussions difficult. A cross-sectional study conducted in 2023 also had shown similar findings like poor reporting skills in these children due their intellectual limitations [2]. These children often require repeated, simplified and customised teaching approaches to understand concepts related to privacy, boundaries and appropriate behaviour. These findings are consistent with studies conducted by Gupta B.[10] The most prominent concern expressed by mothers was fear of sexual abuse, exploitation and their child’s inability to protect themselves. Mothers were particularly worried about future safety in their absence. These concerns are supported by evidences showing limited abuse resistance knowledge among children with intellectual disabilities and significantly higher risks of violence, sexual abuse and maltreatment compared with their non-disabled peers [6][11].

Concerns regarding inappropriate sexual behaviours in public and fear of increased sexual expression were also reported by mothers. Similar concerns have been documented among Indian parents of children with intellectual disabilities [12]. Participants also highlighted the lack of professional guidance, school involvement, and structured educational resources. These challenges were also reflected in an Indian study conducted in 2024[10].

Despite these barriers and concerns, mothers expressed willingness to educate their children when provided appropriate support. These findings highlight the need for culturally sensitive, disability-adapted sexuality education training (SET) that empower mothers and their children with ID. These interventions have proved to significantly enhance knowledge and self-protection skills among these children [10].

V. RECOMMENDATIONS

- Appointment of nurse counsellor in schools to provide guidance to children and parents.
- Inclusion of disability- sensitive teaching modules for children with disabilities in the curriculum of Child Health Nursing.
- Conduct workshops for teachers and parents in special schools.

- Emphasis on longitudinal, interventional nursing research for deeper understanding and bridging the gaps

VI. LIMITATIONS

The present study was conducted in a single special school established under aegis of Indian Armed Forces, implicating limited generalizability. This has also restricted sample size to eighteen. A larger sample size could have generated richer data. The data was collected in a span of fifteen days and the experiences and perceptions might reflect the participants views during that particular time.

VII. CONCLUSION

Sexuality education for children especially vulnerable group like children with intellectual disabilities is a developmental, protective and a rights-based necessity. In the present study, demographic profile of mothers of children with intellectual disabilities except occupation (working women) did not significantly influence their perceived challenges. This suggests that the barriers and concerns are systemic rather than individual deficits. They understand the importance of sexuality education but they require institutional collaboration and structured nursing interventions to help them educate and guide their children. Thus, sexuality education is a shared responsibility of parents, educational institutions and health care professionals.

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REFERENCES

- [1] Maslow AH. A theory of human motivation. *Psychological Review*. 1943;50(4):370–396.
- [2] Jojo N, Nattala P, Seshadri S, Krishnakumar P, Thomas S. Knowledge of sexual abuse and resistance ability among children with intellectual disabilities. *Child Abuse Negl*. 2023; 136:105985. doi:10.1016/j.chiabu.2022.105985.
- [3] Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities*. 2011;32(2):419–436.
- [4] GBD 2019 Mental Disorders Collaborators. Global, regional, and national burden of mental disorders in 204 countries and territories, 1990–2019: findings from the Global Burden of Disease Study 2019. *Lancet Psychiatry*. 2022;9(2):137–150.
- [5] Government of India. Office of the Registrar General & Census Commissioner. *Census of India 2011: Data on Disability*. New Delhi: Ministry of Home Affairs, Government of India; 2011.
- [6] Fang Z, Cerna-Turoff I, Zhang C, et al. Global estimates of violence against children with disabilities: an updated systematic review and meta-analysis. *Lancet Child Adolesc Health*. 2022;6(5):313–323.
- [7] Kamaludin K, Ismail NA, Rahman NA. Mothers' experiences in providing sexuality education to children with intellectual disabilities: a phenomenological study. *Malays J Med Health Sci*. 2022;18(6):45–52.
- [8] Cheng AWY, Lai CYY. Parental stress in families of children with special educational needs: a systematic review. *Front Psychiatry*. 2023; 14:1184377. doi:10.3389/fpsy.2023.1184377.
- [9] Baliga N, Bene M, Naik N. The weight of compassion: a cross-sectional study exploring caregiver burden and quality of life among primary caregivers of children with intellectual disability in Goa, India. *J Contemp Clin Pract*. 2025;11(11):381–390.
- [10] Gupta B. Sex education training as a capacity-building tool for mothers and children with intellectual disability. *J Psychosex Health*. 2024;6(3).
- [11] Mailhot Amborski AE, Bussi eres EL, Vaillancourt-Morel MP, Joyal CC. Sexual violence against persons with disabilities: a meta-analysis. *Trauma Violence Abuse*. 2022;23(5):1532–1545.
- [12] Menon P, Sivakami M. Exploring parental perceptions and concerns about sexuality and reproductive health of children with intellectual disability in Mumbai. *Front Sociol*. 2019; 4:58.