SEXUAL HEALTH EDUCATION TO EMPOWER WOMEN CAREGIVERS OF CHILDREN WITH AUTISM- A CASE STUDY APPROACH

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Abstract: This paper attempts to explore the challenges faced by women caregivers of children with Autism, with regard to their child's sexuality; and, document their experience of being empowered with knowledge about sexual health education,to deal with the sexual development and sexual behaviours of their children through an intervention program,. It draws on a small qualitative study, based on interviews and in-depth correspondence with women caregivers of children with Autism from Bangalore city. This paper reveals a plethora of issues that they deal with on the personal front, as well as in the family and in the society, as their children with Autism grow up; and also how gaining knowledge about sexual health has empowered them to overcome the challenges they face. The implications of these findings lay an emphasis on the need and importance of sexual health education for women caregivers of children with Autism.

Keywords: Children with autism, Intervention program, Sexual health education, Women caregivers

Introduction: Autism is a pervasive developmental disorder that adversely affects every aspect of a child's development such as psychological and behavioural functioning, language acquisition and communication, social skills, sensory integration, motor functioning, cognitive abilities, imagination and even sexual expression (Cunningham and Schreibman, 2008; American Psychiatric Association, 2000; Wetherby and Prizant, 2000;Cohen and Volkmar, 1997). These symptoms can be present in a variety of combinations, ranging from mild to severe; hence autism is referred to as a spectrum disorder (Minshew, Sheeney and Bauman, 1997; Bristol et al., 1996).Present statistics in India reveals that between the ages of two and nine, 1 out of every 66 children has Autism (Deshmukh, et. al, 2013).

Providing care for a child with Autism often causes family disruptions, parents are at a significantly increased risk of experiencing psychological difficulties (Bouma and Schweitzer, 1990) and perceived parental competence and marital satisfaction are found to be lower in parents of children with autism (Rodrigue, Morgan and Geffken, 1990). Frequently, mothers find it necessary to reduce or end outside employment to be full time caregivers for their children with autism (Freedman, Litchfield and Warfield, 1995).These mothers face certain unique challenges, as many of them take care of male children, because there is a higher incidence of Autism among males, owing to the genetic nature of the disorder (Bryson, 1997). The fathers may not be able to support their spouses with care giving activities at home, because they are often forced to work overtime in order to compensate for the decrease in the family income (Cidav et. al., 2012).

Children with autism exhibit a wide range of sexually inappropriate behaviours and deviant characteristics as they grow up, due to their lack of social skills, and poor understanding of social rules. They have been found to display an interest in sexual interactions, sexual self stimulation and often engage in sexual behaviors that include touching oneself, non-consensual touching of others, masturbating in public, and disrobing (Gilmour et. al., 2012; Hellemans et. al., 2007; Ruble and Dalrymple, 1993; Haracopos and Pedersen, 1992).Such behaviours may pose difficulties for mothers when they spend time with their children at home, and also in public situations, especially when un-informed people may misunderstand or be judgemental of their child's behaviour.

Mothers of children with poor daily living skills, may be responsible for continuous care-giving, and may have to provide assistance with a range of personal activities such as bathing, toileting and dressing. As children attain puberty, care giving issues become more complicated and stressful for the mothers to deal with. The increased care-giving demands and difficulty in dealing with the child's sexual development, especially if the child is of the opposite gender- may lead to increased psychological distress. Dealing with severe and sensitive problems on a regular basis is definitely a major source of stress for many caregivers (Domingue, Cutler and Mc Tarnaghan, 2000; Marcus, Kunce and Schopler, 1997).

The doubts and worries caused by the sexual behaviours and sexual development of their children and the ignorance about how to train the child in aspects of personal and genital hygiene, private and public behaviours, and appropriate social behavior complicate matters further for mothers. Knowledge on matters related to sexual health and behaviours of children with autism can help alleviate stress levels in mothers. However, open discussion of sexuality and sexual health are widely considered a taboo in the Indian society, therefore acting as a barrier in gaining the much required knowledge on sexual health matters. Most often sexual health education for girls

and women does not go beyond understanding the physiology and functioning of the female sexual organs. Due to cultural and traditional norms in society, it is considered inappropriate for women to talk about or seek information on male reproductive health. Incorrect information gained from unreliable sources and the many negative myths regarding sexuality, sexual activity, pubertal changes of boys and masturbation have the potential to create misunderstanding in the minds of female caregivers, making them less likely to adopt healthy practices and attitudes towards promoting sexual health of their children with autism.

The case studies discussed in this paper highlight the challenges and dilemmas facedby women caregivers, specifically with regard to sexual health and pubertal changes in their children with autism. It focuses on their silent struggles as individuals who are frequently isolated within their families in handling the sexuality of their growing children. The case studies further document their feedback after attending an intervention program on sexual health education specifically catered to understand the various aspects and needs of children and adolescents on the spectrum. There is very limited research evidence to document women caregivers' personal struggles. Hence through this paper, the authors wish not to present broad generalizations butto enable readers to look closely into the lives of a small sample, just to give a glimpse of the actual struggles faced by umpteen women caregivers of children with autism, as this is a grossly under-researched area in India.

Methodology:

Objectives: The study aims to-

1. Document the challenges faced by women caregivers specifically with regard to sexual health and pubertal changes in their children with autism through case studies.
2. Establish evidence that gaining knowledge about sexual health will empower women caregivers of children with autism to overcome the challenges they face in this area.

Sample: Three women caregivers of children with autism from three special schools in the city of Bangalore, who showed their willingness to share their experiences and struggles in care-giving, were selected for the study.

Method: The investigator identified the respondents, established rapport with them and assured them that confidentiality about their identity will be maintained. The respondents were asked to attend a comprehensive sexual health education program conducted by the investigator for a period of 8 weeks, covering 8 different modules, that each lasted three hours. The concepts to be taught to the children and the methodologies that can be employed to teach the same to children with Autism were addressed. At the end of each session the respondents would ask questions and seek clarifications regarding matters they found difficult to deal with, especially about the inappropriate sexual behaviours of children with Autism at home and in public places. The investigator addressed the following topicsduring the intervention program:

1. Understanding sexuality and the need for sexual health education
2. Characteristics and behaviours of children with Autism in relation to sexuality
3. Healthy lifestyle: hygiene, nutrition and fitness
4. Puberty and changes that accompany it in males
5. Puberty and changes that accompany it in females
6. Masturbation and its management
7. Sexual safety skills and prevention of abuse
8. Importance of leisure activities in reducing undesirable sexual behaviours

Various teaching techniques such as lectures, group discussions and power-point presentations, and visual aids such as flash cards, posters, puppets and models were employed to explain these concepts to the respondents.

On completion of the intervention program, the investigator explained to the respondents the need for documenting these case studies and sought written consent from them. Owing to the sensitive nature of the topic being researched, the investigator conducted multiple in-depth semi structured interviews with the respondents. The interviews were audio recorded with permission, and translated from Kannada (the local language) into English. The contents of the interviews were further analyzed and categorized under sub-themes such as socio-demographic details of the family, diagnosis and other details of the child with autism, behaviours manifested by the child with autism, specific areas of struggle for the caregivers, knowledge on sexual health education gained from the intervention program and its impact on them.

Case : 1: SH is a mother of a 14 year old son with autism. She moved to Bangalore with her family four years back in search of better treatment facilities and a good special school for her child. SH had to leave her previous lucrative job after her second son was diagnosed with autism. Her elder daughter and husband are not able to help her much in care giving. She has taken the responsibility upon herself to do all that she can for her son with autism.

On asking her about her child with autism, she said that he was generally a quiet boy, with limited ability to communicate through speech.But over the last one year he has become moody and aggressive. But her number one problem with the child is with regard to masturbation and an increased interest in sexual activities. She says, "I know he is growing up. But I

don't know how to deal with him. He suddenly slips his hands into his pants at the mall or in the parking lot, sometimes even in the restaurants. He is almost 5 ft and 7inches, and no one will excuse this behaviour in public. The most difficult part for me to deal with is that he looks 'normal' like any other typically growing teenager. I feel very awkward and ashamed when he does such things". On asking how she deals with it, she said thatmost often she would hit him on his hand and pull his hand out sternly. She has reduced taking him out often. She says, "On the days when he goes to school, he is fine, because he is kept busy. I find it very difficult to handle him during holidays. He enjoys being idle and keeps fondling his genitals. I am afraid he will harm his body by masturbating repeatedly. He gets very angry when I interfere and ask him to stop."

She said that she struggled with this issue and found it very difficult to discuss it with others, including her husband, as she did not want others to judge her child. She said that the other important reason for her moving to Bangalore was to be far away from other acquaintances and relatives in her home-town who prodded her with questions about her son. She says, "their endless questions and advice to me upsets me sometimes. I used to become frustrated when my child displays inappropriate behaviors and others begin to judge him as well as me." She expressed that she did not know where to get help regarding the sexual behaviours of her son. She started worrying about the fact that someone may misunderstand her son's 'unintentional but inappropriate behaviour' and label him a sexual offender.

When the school suggested she attend the intervention program, SH agreed. She says that she has understood her son's behaviour. And will work on various aspects to train him to express his sexuality and sexual behaviours appropriately. She said, "I know it is his right to express his sexuality, it is his right to be educated too. If I don't teach him, he may not learn. And the sooner I teach him, the better it will be for him as well as for me. He is already a grown up boy, but before his adult years, I wish to train him in the right way." On asking her about the impact of the intervention program on her, she says, "sometimes I used to feel my life is like a long bad dream, and I hope to wake up from it someday" but at other times, "I feel I have learnt so much through my experiences of dealing with this autistic child. I have become a better person. I have learnt so much even through this program. Earlier I could not accept that my son with special needs has sexual needs and desires too. But now I feel that I am his educator and advocate. I will teach him what is right and I will also stand up for his rights." She also mentioned, "Personally, this program has helped me know more about sexual health, andovercome those challenges that I was struggling with silently, whilst providing care for my son. Many myths about the sexuality of children with autism have been busted only by gaining knowledge about sexual health education tailor-made for them specifically."

Case : 2: MB is a 43 old mother of a 16 year old son and a 11 year old daughter. The daughter was diagnosed with autism at the age of 5. MB's husband then decided to move to another country for his work, as he could not come to terms with 'his' child having a disability, and also because they needed more finances to provide for the special child. MB managed her household by herself, caring for her two children and seeking treatment and therapy for her daughter. She says, "only God knows how much I have run around alone, from hospitals to special schools, and from one therapist to another- trying to find a remedy to my daughter's condition." Although her husband supports her financially, she says, "I'd rather be content with what I have and have him live with me, than have much and struggle alone!"

MB's daughter displays certain behaviours that are inappropriate. She would remove her clothes when she felt uncomfortable. Upon much insistence and careful vigilance while outdoors, MB monitors her daughter's behaviours. But while at home, she refuses to listen and becomes unreasonably angry and aggressive. She would scream and hit her head against the wall or door.

When she was around ten years of age, she started showing signs of approaching puberty. She would frequently touch her budding breasts and open her shirt or dress to look inside. Upon seeing these seemingly sexual behaviours, MB decided to send her teenage son to a boarding school. She said, "it was one of the most painful decisions I had to take in my life- I had to send away a sensitive and affectionate son to a boarding school, and I had to look after a daughter who was becoming more difficult to handle each day".

MB mentioned that after her son left home, her daughter started taking advantage of the situation, and refused to wear clothes altogether. She sometimes even refused to use the toilet, even though she had been toilet trained previously.

Eventually, MB had to socially isolate herself. Neither could she bring any friends or relatives home, nor could she visit anyone because of her daughter's inappropriate behaviours. She said, "I started feeling so angry and frustrated. I couldn't go anywhere, or have anyone over. Some days, even when I was burning hot with a fever, I had to manage all the household work myself. I also had to stop my maid because I felt very embarrassed by the mess my daughter would make sometimes. She would pass urine anywhere around the house.

Over time, MB noticed that her daughter's problem behaviours increased in variety and in intensity. She would sometimes touch her genitals and smell her fingers in the presence of others. She would also insert objects into her vagina. She would get terribly upset when MB interfered and insisted on her removing it. Unable to handle these issues by herself, MB sought help from her daughter's special school, who directed her to attend this intervention program on sexual health education.

After attending the intervention program, MB expressed "I now understand how important it is to be consistent in molding my child's behaviours for the better. Since we lived alone, I would sometimes let her have her way around the house. I have understood my child better after attending this program." She also said, "others may sometimes think that mothers with autistic sons struggle more than a mother like me with an autistic daughter- as I will be more competent to deal with sexuality issues- by virtue of being a woman. But each child with autism is different, we mothers have our own struggles to deal with all the time. Sometimes, they are so personal that we cannot share it with anyone, including our spouses."

MB said that she will prepare specific teaching material for her daughter and prepare her for menarche. Talking about hysterectomy, she said, "many times in the past I have considered hysterectomy for my daughter. But now I have understood the role the uterus plays in a woman's life with regard to overall health and wellbeing. I also became aware that removal of the uterus will only leave her more vulnerable to abuse. People can take undue advantage of her as she will not have chances of becoming pregnant." On asking her about the usefulness of the intervention program, she said, "As a mother of a child with autism, I face many problems. But the problem of managing sexuality related behaviors are the most severe and sensitive and by far the most difficult to deal with. I used to feel very helpless thinking about my daughter's behavioural issues, but now I feel some sort of a confidence in knowing that I know about sexual health and I can teach and lead my child in the right way." She also mentioned that such programs on sexual health education should be made available for other mothers such as herself, as they may have previously never had a chance to learn so much about sexual health, sexual development and sexual behaviours- because our society is closed to discussing these topics openly.

Case: 3: KN is the maternal grandmother of a non-verbal male child aged 13, diagnosed with Pervasive developmental disorder and moderate intellectual disability at the age of 4. The child was previously living with his parents. His diagnosis led to differences of opinion and conflicts between the couple, eventually ending their marriage through divorce when he was just 7 years old. The child was then looked after by his mother, who was depressed and could not cope with the challenges of looking after him alone. Her belief in karma made her spend long hours trying to find out the cause of her misfortune. She believed that some wrong that she did in her previous life has landed her in her current predicament. She was advised psychiatric treatment to cope with depression and general medication to stabilize her failing health. The child's behaviour problems worsened over time. KN recalls, "My grandson did not seem very different from other children his age initially. But when his parents divorced and his mother started showing clear signs of depression and moodiness, his behaviours changed for the worse. He did not understand what was happening around him, but he was very upset that his mother was sad and sick most of the time." Unfortunately, the mother of the child chose to end her life by taking an overdose of some medication. The maternal grand-mother KN then took the child into her care when he was 11 years old. KN is 68 years old, single, and the sole caregiver of this child. She says, "After his mother's death, he seemed to have lost interest in doing anything. I sometimes have to help him even with his personal care- including bathing him. He also had severe trouble with sleeping and started having seizures occasionally." Over the last two years, as he is growing up, KN notices a lot of changes in him. "I know he is becoming a big boy sooner than others. I can see his facial hair appearing and voice changing. But I don't know how he will handle the changes in his body. And I don't know how I can help him. I am not well educated and there is no man around to help him. I had only one daughter, and I have no experience of dealing with a teen age boy. I see him fondle with his genitals sometimes. It upsets me." She expresses concern over the fact that he does not know it is a private behaviour. He has no qualms about touching himself in her presence. She mentioned that she feels humiliated at such times and would cry secretly. She then attended the intervention program. It helped her understand the pubertal changes in boys, the need to give them privacy and train them to identify when and where they can touch themselves intimately. She says, "I was not aware of the many changes that occur in the male reproductive system, and why they experience erections often. I was assuming that he has a problem, but now I know that he is going through normal development." On matters relating to privacy, she said, "I would keep him right next to me the whole day, as I was afraid of letting him be alone. Now I understood that is the reason why he has performed some sexual behaviors

in my presence.I will give him privacy and his personal space. That will solve issues for the two of us." KN has also resolved to teach him about his body, hygiene and self care at the earliest so that he will be independent. She hopes that he will be able to handle his personal needs by himself after her time. She says, "I will look after him as long as I am alive. But I have decided to make an effort to teach him all that he should know, so that he can be independent and live with dignity later." Finally, on being asked about the impact of the intervention program on her, she said "I feel very relieved that I now know about these issues relating to sexual development. Being a single caregiver, I was very stressed out before by his behaviours and by my own ignorance on this issue. Now I feel a little more competent to teach him and help him to go through this phase of life as smoothly as possible".

Discussion and Conclusion: All three cases demonstrate that women care givers of children with autism face unique challenges. They face difficulties in family life as they may be struggling to find the right balance between caring for the child with autism, and being present physically and emotionally for other family members. Research shows that parenting a child with autism requires an inordinate amount of time, effort and energy, and may have detrimental effects on marital relations (Piven, et. al., 1991).

Women caregivers also find it difficult to approach others for help regarding sexuality related issues as it is a sensitive subject. Here in India, girls are brought up with certain ideals and values- such as shouldering responsibilities, and bearing all the family burdens- without sharing the 'inside story' with others- in order to protect the family honor. The societal constraints of not discussing sexual issues restrains women folk from mustering the courage to gain knowledge and seek help to solve these sensitive problems that leave them in much stress and heartache. In general, women caregivers report having less knowledge about sexual health because they are restricted by cultural norms and taboos (Bastien, Kajula and Muhwezi, 2011).

Possessing knowledge dispels ignorance and provides the basis for any form of education. Many parents themselves agree that the knowledge they possess about sex and sexuality may have been obtained from unreliable sources such friends, media or books. This type of knowledge is clearly insufficient to deal with the sexual health issues of individuals with Autism. Researchers like Brown et al. (2005), Darling and Baxter (1996), and Seligman and Darling (1989), have reported that parents need information about the nature of their child's disability, as well as about the programs, treatments and services that provide additional knowledge and support to meet the family members' needs.

Through personal observation, the investigator gathers from the interviews that the women caregivers find it safe and comfortable to attend a sexual health education program in a group within a formal set up, rather than have a one-on-one session with a counselor in an informal set-up, as they don't feel singled out. They reported a feeling of consolation in knowing that other women caregivers in the group may also be going through similar struggles. Therefore there is a definite need to provide sexual health education to the parents of children with autism through formal group intervention programs, especially focusing on the needs and problems faced by women caregivers, so as to alleviate their stress and empower them to handle challenging situations in the care giving scenario.

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