

## ORIGINAL ARTICLE

# Parents' Perspective of Sexuality among Down Syndrome Children

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## ABSTRACT

**Introduction:** Sexuality matters are always neglected, and are viewed as a taboo subject that is not discussed openly in Malaysia. Hence, sexuality issues among people with disabilities remain shrouded in prejudice and myths. Individual with Down syndrome have the same sexual experiences and needs as other typically developed children. The deficiency on cognitive ability among Down syndrome children is a major challenge for them to understand the concept of sexuality. The purpose of this preliminary qualitative study was to explore the perspectives on the topic of sexuality among Down syndrome children. **Methods:** The purposive sampling method was used to recruit respondents, based on the following criteria: i) Parents (father or mother) who have Down syndrome children aged from 8-17 years, and ii) able to communicate in the Malay or English language. A total of five respondents were included in this study. The respondents were the parents of Down syndrome children who were receiving occupational therapy interventions at three community-based rehabilitation centres in Kuala Selangor. The data were collected using semi-structured interviews, which were recorded using an audio recorder. The data were then transcribed and analysed using the Interpretative Phenomenological Analysis (IPA). **Results:** The study revealed the perspective of parents on sexuality issues among Down syndrome children in relation to readiness, puberty, sexual desires, cultural norms and vulnerable groups. **Conclusion:** Findings of this study could use as a baseline in developing a module to assist parents in managing their concerns.

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## INTRODUCTION

Down syndrome is a common condition among infants and children besides autism and hyperactive disorder. It is important to note that the significant impact experienced by individuals with Down syndrome is genetic abnormality leading to mental disorders and impaired physical development (1). In addition, other problems, such as respiratory disorders, gastrointestinal malformations and congenital heart disease also overshadow Down syndrome (2). Due to these diverse health problems and disabilities, it is necessary that parents focus their attention and energy, especially on managing these Down syndrome children with regard to their activities of daily living (ADL), school and leisure. However, in giving their full attention to these children, parents often, either deliberately or inadvertently, ignore one aspect of the essential components of an

individual which is sexuality. Intellectual disability in Down syndrome children increased the challenges in addressing sexuality topic with this population.

Sexuality is the one of the main component in a human being as it plays an important role in the social health, and mental, psychological, and physical aspects of an individual (3). There are researches that show that adolescents with Down syndrome develop hormones just like any typical adolescent (4). Even though the sexuality and reproductive organs of children with Down syndrome are similar with typically developed children, unfortunately, their cognitive development is not. The intellectual disability suffered by Down syndrome patients adds to their challenges when it comes to sexuality issues. Some of them are unable to identify the parts of the body, and also have difficulty in understanding the concept of private body parts. Pecuelas (5), in his case report, mentioned how a 25-year-old Down syndrome woman was confused between her buttocks and vagina. What is often overlooked by parents, therapists and educators is the fact that children with Down syndrome will grow up

and become mature. The desire to be in pairs and share affection will be there, and if all their desires to pair and make love do not receive the right guidance, it will create a lot of complications later. Basic education on sexuality will help these children form healthy relationships with other people, thereby avoiding unpleasant situations (6). All of these facts have increased the need to focus on sexuality issues among Down syndrome children.

The reaction of parents to sexuality issues among children with disabilities tends more towards the negative. In general, it is a taboo subject when it comes to discussions about sexuality issues, especially when it involves people with disabilities. When it comes to sexuality issues, certain individuals or groups refuse to take responsibility out of fear (7). Previous researches have proven that most parents assume an overprotective role, and treat these persons as “if they were infants and asexual” (8). Besides, some parents are not comfortable discussing and educating their children about sexuality. Chen and Chen (9) found that 50% out of 384 parents involved in a child sexual abuse prevention program in China expressed unpleasant feelings about sexual education, believing that it might overexpose their children to information about sex. In addition, there are also parents who are concerned about being too open in discussing sex with their children as this might encourage them to experience it for themselves (10). Apart from that, among other barriers reported in previous studies in discussing sexuality topic were lack of knowledge (10) and inadequate time (11). To date, there is lack of info regarding sexuality issues among children with special needs in Malaysia setting.

This preliminary study intended to explore the sexuality issues and concerns perceived by parents with Down syndrome children.

**MATERIALS AND METHODS**

A qualitative, phenomenological research was conducted. Phenomenological research is about the experience of life and its meaning, which can only be known through the individual who has passed through it (12). The purposive sampling method was used to recruit respondents for the study. Five respondents who have children undergoing occupational therapy intervention at community-based rehabilitation (CBR) centres in the Kuala Selangor area were involved in this study. The inclusion criteria included; i) Parents (father or mother) who have Down syndrome children aged

from 8-17 years, ii) Able to communicate using Malay or English language. Ethical approval was obtained from the Research Ethical Committee of Universiti Teknologi MARA (UiTM) 600-IRMI (5/1/6).

In this study, the data were collected through face to face semi-structured interviews. Interview questions were developed based on previous literatures which included parents’ understanding on the term sexuality, awareness of puberty stage, teaching methods used in addressing sexuality related matters and issues and concerns faced by these parents. Audio recordings were made throughout the discussion sessions, and these were then transcribed by using Microsoft Excel. Researchers contacted respondents for further clarification and explanation for any unclear information found in the transcript. Data were then processed by using six steps of Interpretative Phenomenological Approach (IPA) analysis.

**RESULTS**

A total of 5 respondents/parents with Down syndrome children participated in this study. All the respondents gave their views on sexuality issues among children with Down syndrome. Table I shows the profiles of the respondents in this study. The five respondents involved in this study were aged between 35 to 53 years, where 4 of them were females and one was male. All the respondents were parents of Down syndrome children aged between 10 to 17 years. Three out of the five respondents were working, where two of them were civil servants, one was involved with the private sector, while the other two respondents were housewives. The demographic profile also showed that two out of the five respondents were university graduates, while the three other respondents were holders of the Malaysian Certificate of Education (MCE).

Table II illustrates the themes and subthemes for this study.

**Theme 1: Readiness**

The interviews with the parents regarding their readiness to teach or expose their children to sexuality issues indicated that this was something that they were concerned about. Under this theme, the age of the child and the priority given to the activities of daily living (ADL) emerged as the subthemes.

All the parents highlighted that their child’s age was the reason why they were not prepared to expose their

**Table I: Respondents Profile (n=5)**

Respondents	Age	Relationship to child	Child’s Age	Child’s Gender	Occupation	Parent’s educational level
P1	35	Mother	10	Male	Executive private sector	Degree
P2	36	Mother	11	Female	Housewife	MCE
P3	45	Mother	16	Female	Housewife	MCE
P4	53	Mother	17	Female	Government servant	MCE
P5	41	Father	12	Female	Government servant	Diploma

**Table II: Themes and Subthemes**

Themes	Subthemes
Readiness	Age of the child
	ADL priorities
Puberty	Parent's concern about physical changes
Sexual Desire	Asexual or a having strong sexual drive
Cultural norm	Taboo topic
	Women's role
	Remain single/unmarried
Vulnerable Group	Sexual crime
	Unwanted pregnancy

child to sexuality issues. Two parents indicated that they would begin teaching the aspects of sexuality when their child reached the appropriate age. The respondents used age as the indicator to begin teaching sexuality matters as they felt that their children would be incapable of understanding if they were not at the stage of puberty. Apart from that, the parents felt that self-management and ADL were more important at a young age compared to the aspects of sexuality. However, based on the respondents' answers, sexual hygiene was also included as one of the activities of daily living.

### Theme 2: Puberty

Puberty is a very important phase in the biological development of the human body. The respondents expressed concern that their children were unable to understand the physical changes that were taking place in them.

### Theme 3: Sexual Desire

The parents who were interviewed in this study indicated that they believed that their children did not have sexual desires due to their cognitive ability. Two parents perceived that marriage and having intimate relationships were impossible for their special needs children. They felt that children with Down syndrome are not able to take responsibility and make decisions.

### Theme 4: Cultural Norm

From the interview, the parents also highlighted how society perceived sexuality among special needs children. The first was on how the topic should be discussed, and the second was the idea that the topic should be taught by the woman or mother in the family. It was also highlighted that the social taboo attached to special needs children meant that they would remain single throughout their life. The topic of sexuality was a very uncomfortable topic to be discussed openly between the parents and their children. There were parents who clearly told how uncomfortable they felt teaching their children about this issue.

### Theme 5: Vulnerable Group

Through the interviews, the parents also acknowledged that their special needs children were vulnerable to fall victim to sexual crimes and unwanted pregnancies. Almost all the parents interviewed believed that girls

with Down syndrome were more vulnerable to abuse compared to boys. Among the parental concerns were unwanted pregnancies and rape involving children with disabilities. There were parents who found it difficult to trust other individuals, including family members, to care for/monitor their children.

Table III shows the supporting quotes for the development of these themes.

## DISCUSSION

The objective of this study was to explore the sexuality issues raised by parents with Down syndrome children. Readiness, both mental and psychological, plays an important role, especially for parents with special needs children. The parents in this study stated that they were not ready to expose or teach their children about sexuality because of the children's age, and their priority was more focussed on teaching them to be independent in the activities of daily living.

Over the past few decades, parents have been of the opinion that young children should not be exposed to the topic of sexuality as it can have a detrimental effect on the child (11). Exposure to unhealthy sexual information can lead to unhealthy relationships and wrong notions about sex (13). The current study showed that most of the parents felt that the right time to teach or expose a child to sexuality issues was when the child reached puberty, and it would be easier to explain to the child once the menstrual cycle began. However, this might just be an excuse for parents to escape the reality that they have to teach their children about these issues. Report by Balter, van Rhijn and Davies (14) in their study to assess the attitude of pre-school teachers towards the development of sexuality in childhood, where it was found that these teachers supported the introduction of sexual education in the early years (0–6 years).

Self-management and ADL were issues that were given priority by these parents. All of them asserted that it was more important to prioritise the teaching of the ADL to their children at a young age rather than topics pertaining to sexuality. Improvement in self-care and problem-solving can assist their children to cope efficiently with difficulties in their life (15). This would allow their children to manage themselves and be independent, especially in the ADL. Teaching about the ADL includes managing the hygiene of genital parts, especially after urinating or defecating. What these parents did not realize was that when they taught their children about genital hygiene, they were indirectly exposing their children to sexuality issues. This might have been due to the fact that these parents were unclear about the definition of sexuality (10).

In early adolescence, every human being, whether male or female, will experience the puberty phase. The parents who were involved in this study felt that the puberty phase in the lives of their children was a major

**Table III: Supporting Quotes**

Themes	Supporting Comments
Readiness	<p>“At the moment, I feel there is no need to teach my son. I never think about it because he is still too young for that. He doesn’t know anything. I am afraid he cannot understand it (sexuality) if I teach him now. We, me and my husband, never talk nor discuss about this issue of sexuality. Maybe in the future, when the time is right. Maybe.” (P1)</p> <p>“I am not sure when I will teach her. Maybe a year from now. She is just eleven years old. Maybe when she is 12 years old, I’ll teach her. Maybe. I have to be ready when the time comes.” (P2)</p> <p>“I already taught her since she was young, so that thing (ADL), she will do it until she becomes an adult. At that time, I was thinking that I must teach her about self-management, rather than wait until she is 11 or 12 years old. I started teaching her when she was 5 years old.” (P4)</p> <p>“I think she is able to manage herself because she was taught from an early age. I always supervise her. I ask her if she has washed her genital parts correctly every time after she has urinated, defecated or taken a shower; sometimes I do the inspection. It has become a routine. So far, I am satisfied with her ability in managing her hygiene.” (P2)</p>
Puberty	<p>“Girls will usually have significant body shape changes compared to boys. These changes will be more pronounced during puberty. I have a hard time imagining how these kids feel when these changes happen to them. Trying to give understanding to normal children alone is quite challenging, let alone to children with Down syndrome. Although my son is a boy, I am still worried. I still worry about how I will explain to my son when he reaches puberty later.” (P1)</p> <p>“What I am worried about her is whether or not she can handle the physical changes, her menses during menstruation. Although her mother taught her about it, the concern is still there.” (P5)</p>
Sexual Desire	<p>I am aware that my son, when the time comes, will grow up like other human beings. It’s just...in terms of sexual desire, I don’t think he has it. It is impossible for him to have it (sexual desire). Because my son...he is still struggling in life even to manage himself. I don’t think he ever thinks about sex. His mental ability...it is not like a normal person. He is a disabled person. A special child. I believe he have no sexual desire.” (P1)</p> <p>“I don’t think she has it (sexual desire). She has a friend, a boy at school, but I believe they are just friends. I don’t think my daughter knows about love, sex. She doesn’t know about sexual desire at all. She is just friends with that boy. That’s all. But even though they are friends, she never lets the boy touch her.” (P4)</p> <p>“No. I think it is impossible (marriage). My son, I don’t think he’s capable of having a girlfriend, not to mention getting married. I don’t think he is able to tackle any women in the future (laugh). Actually, I will not allow him to get married if he (her son) wants to. Marriage is not an easy thing. I think he is not able to shoulder the responsibilities as a husband and father. It is because of his intelligence problems. So, it’s better if he takes care of himself only.” (P1)</p>
Cultural Norm	<p>“Sometimes when we want to say that thing (genital part), we are not comfortable. For example, women, our breasts are referred to as “the upper” and our vagina is referred to as “the lower”. We do not mention the body part correctly because sometimes when we want to say it, it feels embarrassing, and to explain it will be more problematic.” (P2)</p>
Vulnerable group	<p>“I’m not sure my daughter understands or not things related to sexuality or anything that involves sex. So, I was worried that a bad person would take advantage of my daughter. It would be even worse if my daughter did not realize she had been the victim of a rape.” (P2)</p>

concern. Undoubtedly, during the puberty phase, men and women will experience significant physical changes, including the growth of pubic hair, enlargement of the breasts for teenage girls, and voice changes for teenage boys (8). In addition, teenage girls will experience the menstrual cycle for the first time. Although it sounds normal, but for the parents involved in the current study, they were worried as to whether their children would be able to accept the physical changes and how they (parents) were going to cope with this situation.

Most of these parents were worried about how their children would feel during this phase. They believed

that the first menstrual cycle would make their daughters confused and scared, and that they would have a difficult time in explaining to their children about the puberty phase due to their intellectual disability. The parents’ concerns with regard to their adolescent daughters with intellectual disabilities included hygiene issues, menstrual symptoms, menstrual suppression and parental burden (16). One mother in this study informed that she had great difficulty when her daughter experienced menstruation for the first time, and complained of severe stomach ache and was unable to describe the cause or location of the pain. Likewise, she also encountered difficulties in explaining to the

daughter the purpose of wearing a pad, and had to make sure that she (daughter) wore one during her menses. This finding was in contrast with the study conducted by Chou and Lu (17), which stated that no parents in their study mentioned about difficulties in managing their daughters' menstruation, even though their daughters needed considerable assistance. However, they further elaborated that it happened because instead of seeking support from outside the family or from practitioners, the mothers in their study used fate as a coping mechanism, based on Taiwanese cultural values (17).

Sexual desires are different between individuals (18). When discussing sexual desires, there were various reactions from the parents involved in this study. There were those who thought that their child was asexual or had no sexual desire. It was possible that these parents hardly believed that their children would have sexual desires when they still needed help from their parents or family members with their daily routine (19).

The parents in this study revealed that they felt their child was asexual as he or she did not know what sexual desire was. It was thought that because of their intellectual disability, these children had no feelings for individuals of the opposite sex and no lust (20). Although some of their children showed an interest in individuals of the opposite sex, these parents stated that their children were unable to understand their own feelings and confused the desire of wanting to make friends with the desire to make love. In addition, these parents felt that their children were not able to take on any responsibilities and take care of others. Many people with intellectual disabilities do not marry, have children, or have personal relationships that are intimate (21).

The majority of the parents in this study did not agree to their children having their own families due to their intellectual problems. Most of them felt that their children would not be able to take on the responsibilities of having a family, among which would be the ability to manage the family in terms of generating an income, managing the household finances, as well as owning and caring for children (acceptable parenting skills). Marriage between persons with learning difficulties increased the fear of risks, and the welfare of their children as a result of inadequate parenting (22). Besides, according to the parents, all these children were said to be still struggling to manage their own lives in terms of ADL. Therefore, in the opinion of these parents, it would be impossible for them to allow their children to get married and take on heavier responsibilities. These results were in line with a study conducted by Aunos (23), which found that 75% of the parents in his study were against their children marrying and raising children due to their perspective that their children would be unable to provide adequate basic care, and a safe home environment, and would have poor judgement and negative interactions.

Social norms play an important role in influencing a person in decision making. These parents were worried about how the views of society on sexuality issues would affect their child. It is common knowledge that sexuality is a taboo issue in Malaysian society, and in Asian society in general. The parents involved in this study stated that they felt uncomfortable teaching their children about sexuality, especially in relation to the genitals (24). Due to the feeling of discomfort with sexuality issues, most parents use inaccurate terms when teaching their children about the genitals. The use of inappropriate terms when naming private parts will lead to negative effects. Substituting other terms for the genitals will cause confusion to the children (25). A reasonable approach for tackling this issue would be for parents to deal with all these unnecessary and uneasy feelings when teaching their children about genitals (25).

The cultural norm in Southeast Asia, especially in Malaysia, with regard to the role of women in marriage, is that in any situation, women are expected to help their husbands to earn money for the family and, at the same time, to manage the household and the children. This statement was supported by Hwang (26), who found that although women now play a role as workers and help with the family income, the belief still remains that women should be responsible for raising the children and running the household. The findings of the current study indicated that mothers shouldered the heavy burden of educating their children on sexuality. This situation was exacerbated when the mothers had to teach their sons how to clean their genitals. Although these mothers felt uncomfortable, they still had to do it out of a sense of responsibility. The parents could more easily identify with the need of their child of the same sex for sexual information, and they felt more confident about meeting that need (27). However, there were also suggestions from the respondents that the burden of educating their children about sexuality should be borne by both parents together (6).

The current study revealed that all the parents held the same view and agreed with the cultural norm in Malaysia that disabled persons should remain single and not get married. The parents who were involved in the study clearly stated that they would not allow their child to marry, even if the child wanted to get married. Their reasons were closely related to the intellectual level of their children, as discussed earlier. They believed that their child would not be a good parent or spouse because of that intelligence disability.

Children with disabilities are vulnerable to becoming victims of criminal misconduct (28). The parents involved in this study also voiced their concern regarding this issue, and claimed that children with special needs were vulnerable to be victims of sexual abuse or crimes (i.e., rape) due to their intellectual impairment. This anxiety was not only experienced by parents with daughters, but

was also felt by those with sons, as cases of sodomy have become more prevalent in Malaysia. However, to reduce the risk of their children, especially their daughters, falling victims to criminal misconduct, the parents in this study agreed that the daughters should be made more aware of the issue of sexuality. In the same way, Chen, Dunne and Han (29) held the view that daughters have to be taught how to take care and defend themselves from any threats, including verbal and non-verbal threats. This includes the dos and don'ts of what can be done to their bodies by others. This is very necessary so that the child will always be alert to the actions of others toward them. Similarly, Paine and Hansen (30) suggested that a child's disclosure of sexual abuse is a crucial component in stopping the abuse. In addition, besides avoiding becoming victims of crimes, there were also parents who thought that their daughters needed more sexual awareness because of their menstrual cycle and obvious changes to their physical body. This was necessary to enable the children to understand what was happening to them, and thus, prevent their daughters from experiencing confusion (24).

Apart from that, the thing that worried the parents regarding their child was unwanted pregnancy. Usually this will happen when a girl is raped. When this happens, the psychological impact on the rape victims and their families is very high. This is because an unwanted pregnancy will produce an unwanted child. Taking into account the fact that the mother of the child is a disabled person, the burden of caring for the baby will fall on other family members. It has been reported that families with disabled children undergo more stress compared to families with typical children, and the issue of safety is one of the reasons for the stress (31). In addition, fear and anxiety related to this incident (unwanted pregnancy) made it difficult for the mothers in this study to trust others, even their family members. There were mothers who were willing to manage everything concerning their daughters, rather than hand over the task of managing them to their elder son or husband. The issue of trust not only involved activities that took place at home, but also those that occurred outside, especially in public places. This finding supported the study by Kvam (32), which stated that children around the globe are at risk of being sexually abused by family members or relatives.

## CONCLUSIONS

This study successfully revealed the concerns of parents of children with Down syndrome in relation to sexuality issues. The finding of this study indicated that readiness, puberty, sexual desire, cultural norm and being in vulnerable group were found to be parents' main concerns in tackling sexuality issues for their Down syndrome children. Findings of this study could use as a baseline in developing a module to assist parents in managing their concerns.

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