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Original Article



Parents' attitute towards the sexuality of their adolescents with mental deficiency: a qualitative research

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Abstract

Objectives: This research aims to evaluate parents' opinions about the sexuality of their children with mental deficiency (MD).

Methods: This research was conducted using the phenomenological method, and it involved the parents of children (n=27) enrolled at a special rehabilitation center in Sakarya Province between February and March in 2018. Individual interviews were conducted using the semi-structured interview technique. Data were analyzed through descriptive analysis by using MAXQDA Plus.

Results: Four themes emerged from the parents' opinions about the sexuality of their children with MD, as follows: 1) "Not aware/ignoring" (statements showing the parents' being unaware of the problem or showing that they are not thinking about it), 2) "Feeling incompetent/stigmatized" (statements showing that the parents do not know what to do when their children exhibit sexual attitudes), 3) "Trying to prevent it" (statements regarding limiting their children's actions), and 4) "Calling for help" (statements regarding their feeling incompetent and their need for help from someone who is knowledgeable about dealing with their situation).

Conclusion: The parents lack sufficient knowledge about their children's sexuality. They are also uncomfortable in facing criticism from others when problems related to their children's sexuality arise. Moreover, they try to prevent their children from exhibiting problematic sexual behaviors. They also want to seek help from specialists in dealing with concerns related to their children's sexuality.

Keywords: Mental deficiency; mother; sexuality; sexuality education; qualitative study.

According to the American Association of Mental and Developmental Disabilities, a disability is a visible limitation to the functioning of individuals. Due to a disability, at least two adaptive skills (e.g., communication skills, academic skills social skills, utilization of social services, self-management, self-care, and ensuring health and safety) are inadequately developed, and individuals with disabilities lack leisure time; these deficiencies become evident in these individuals before they reach the age of 18.[1] The disability rate worldwide is 15%, and 1% of this population consists of individuals with mental deficiency

(MD). Among the individuals with MD, 85% have mild MD.^[2]The Turkey Disability Survey (2002) showed that 12.29% of the total Turkish population exhibit deficiencies, of whom 0.48% has MD. Of the mentally disabled population, 20.54% can be educated and 26.49% can be taught; moreover, 18.32% and 19.66% suffer from heavy and very heavy MD, respectively.^[3]

Adolescents with MD face many issues, one of which is sexuality.^[4] Their sex life is often an area that is ignored if not unknown. Experiencing sexuality is one of the fundamental rights of these individuals.^[5] However, there are different views



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What is presently known on this subject?

• Each developmental stage brings with it certain challenges to families raising children. Such challenges may be difficult to overcome, especially when families raise children with deficiencies. One of the most difficult areas that families deal with is the sexuality of children.

What does this article add to the existing knowledge?

 Parents stated that they have insufficient knowledge of their children's sexuality, that a feeling of being stigmatized arises from the possible reactions of other people towards their children's behavior, and that they need expert help.

What are the implications for practice?

Health professionals, especially psychiatric nurses and midwives, are expected to propose solutions to the problems faced by parents whose adolescents suffer from MD.

as regards the sexual life of adolescents with MD. One view is that adolescents with MD do not have a sex life; the less these individuals have sexual life, the better.[5-8] Another view is that adolescents with MD also go through the processes similar to those normal adolescents experience, except that their progress is slow. This view argues that adolescents may have physical and MD, but there is no obstacle in emotions. Thus, adolescents with MD should also experience a sexual life just like their normal peers. [6,8] Research showed that adolescents with mild MD display characteristics similar to those of normally developing adolescents; however, adolescents with moderate MD need help, and those with heavy MD have little control over their sexual drive.[9-11] Adolescents with MD cannot access information about sexuality just like their normal peers. For instance, they cannot obtain accurate and relevant information about sexuality from their limited number of friends and from other sources, such as books. In addition, due to their dependence on their parents, they cannot learn through observation and through experience by independently establishing friendships or by having sexual intercourse.[12,13]

MD affects not only individuals, but also their family members, especially their mothers, as well as the environment and society.[14,15] Every developmental period is a traumatic experience for families. These developmental periods are difficult to overcome, especially in children with deficiencies. [6] Due to reasons such as the failure of children to develop normally, these families encounter unexpected situations with which they do not know how to cope, and only a few professionals can lend them support.[8] During adolescence, individuals with MD experience problems related to the developmental characteristics seen in their normal peers, and these problems often manifest in the form of sexually inappropriate behaviors. These problematic behaviors include kissing, hugging without permission, touching their own genitals, holding hands, touching the body and genitals of another person, and masturbating in open areas.[16,17] In such situations, affected families are usually helpless in dealing with the negative reactions they receive from their environment. One of the most difficult areas parents deal with is the sexual harassment their children with MD experience from other children who have noticed their sexual behaviors. Adolescents with severe MD display a more pronounced inability to express themselves, so

the emergence of such harassments or cases of rape adds to the challenges they face. [8]

Quantitative methods are generally used in studies involving parents of adolescents with MD. Comparative studies on parents of adolescents with normal development and with MD show that the latter group experiences more difficulties and that they need more psychological support. In Turkey, parents are more vulnerable in terms of mental and emotional health; however, qualitative studies investigating their thoughts and experiences are limited. Therefore, in this study, parents were given the opportunity to express their inner feelings, thoughts, and experiences about their children's sexuality. The data obtained in this study are important in understanding the attitudes of the parents of adolescents with MD who display problematic sexual behaviors. Understanding these attitudes is presumed to contribute in determining the problem areas and in identifying solutions.

Materials and Method

Aim

This study aims to determine the opinions of parents about the sexuality of their adolescents with MD. Our research questions are as follows:

- 1. What are the parents' thoughts about the sexuality of their children with MD?
- 2. What attitude do parents show when their children with MD display sexual behaviors?
- 3. What concerns do parents have about their children's sexuality?

Research Design

This research focuses on the experiences of parents regarding the sexuality of their adolescents with MD. Generally, experience studies are qualitative research, which are a non-numerical assessment and interpretation of observations to investigate the meaning and variety of relationships. [18,19] A qualitative research aims to gain an understanding of how people make sense of their lives, to outline the interpretation process, and to describe how people interpret their experiences. [19] This research design is a reductive, explanatory, and interpretative process carried out by a researcher to observe people in their natural environment and to examine the occurrence as well as explain the basic characteristics of individual social events and phenomena. [20,21] Generally, there are four types of qualitative research approaches: phenomenology, ethnography, grounded theory, feminist approach, and other approaches, including action research, can be included in this group.^[22] In the present study, the phenomenological method was employed. Phenomenological studies investigate the meaning of individuals' experiences about an event or aim to understand a concept or event more clearly. In phenomenological research, the main data are obtained through an in-depth interview between the researcher and a participant.

Place and Time of Research

This study involved the parents of children enrolled in a private rehabilitation center in Sakarya Province between February and March in 2018. This rehabilitation center was established with the aim to optimize the physical, mental, and social conditions of individuals with MD so they become self-sufficient and adapted to the society. In this center, 400 children were registered, 300 of whom were active learners. The center caters to children diagnosed with mild/moderate/heavy MD, cerebral palsy, trisomy 21, and Williams Syndrome.

Participants

Among the parents included in this study, 18.5%, 22.2%, and 59.2% had children with mild, moderate, and heavy MD, respectively. The criterion sampling method, which is a purposeful sampling method, was used to determine the study sample. This sampling method is the study of all situations that meet a predetermined set of criteria. These criteria may be set by researchers, or a pre-determined list of criteria may be used. ^[23,24] In this study, the researchers set the criteria, as follows: being able to understand questions and express opinions; having a child diagnosed with MD, living with their children; and having children aged 11–18 years. Fifty parents met these criteria and were invited to participate in this study; 27 parents agreed to participate (n=27; F: 23, M: 4; response rate: 54%).

Data Collection Tools

Data were collected using a demographic information form and an interview form, which the researchers created based on the literature. [25,26]

The interview form consists of four semi-structured subheadings:

- 1. What do you think about the sexuality of your children with MD?
- 2. What do you think and feel when your child exhibits a sexual behavior?
- 3. What do you do when your child exhibits a sexual behavior?
- 4. Do you need support on dealing with the abovementioned problem? If so, in what specific area do you need support?

Procedure

The work commenced after the necessary permissions were obtained. A poster about the study was posted in a strategic location in the rehabilitation center. Parents who were in the waiting room while their children take classes were also informed about the study by the interviewers (OS and ZDK), and they were invited to participate. Parents who gave their verbal and written consent were led to a private room where no parent–child interviews are usually held or to a special education teacher's room (OS); only the parents and the inter-

viewer were allowed in the room to avoid interruption during the interviews. A suitable physical environment was provided for a comfortable and effective meeting. The interviews were conducted individually in an in-depth and face-to-face manner, and a particular attention was given in respecting the privacy of the parents. During the interviews, the parents were encouraged by the interviewer whenever they seem stuck when talking about a subject. The interviewer took care not to be judgmental and approving of the parents' responses on a subject matter. The in-depth interviews were conducted by a special education teacher (OS) who has been working for 12 years with children and adolescents who have special needs, together with a researcher involved in this study (ZDK). An audio recording of the interview could not be taken because the parents did not give their consent. With the approval of the parents, notes were taken by the interviewers during the interviews. Considering the memory factor, the interviewers recorded in writing the parents' statements at the end of the interview. The documents were encoded in MAXQDA Plus, a qualitative data analysis software. In this way, thematic coding of the interview documents were carried out more systematically than when manual analysis is done. This phase was carried out by two other authors (NKÖ and NEB). The authors who conducted the analysis are trained in qualitative research (Qualitative Research Methods and Qualitative Data Analysis with MAXQDA) and have experience in qualitative research. Each individual interview lasted 30-45 minutes.

Statistical Analysis

Data analysis is the process of revealing the meaning of a dataset. This process involves combining, reducing, and interpreting what people say and what the researcher sees and reads. Data analysis can also be expressed as the process of making sense of certain observations.[19] In this study, descriptive statistics was used to analyze demographic data, and descriptive analysis was used to analyze qualitative data. For data analysis, the seven-step analysis method developed by Colaizzi for phenomenological studies was used. The steps were as follows: 1) The relevant literature was read before and after each interview. These readings will guide the researchers during the analysis. 2) The information obtained from the interviews is recorded in writing and seen in full. 3) After the qualitative dataset is prepared, data analysis begins. 4) The formulated meanings are grouped into codes, themes, and categories. 5) The results achieved are combined with rich and comprehensive life experiences. 6) The basic notional structure of the investigated phenomenon is defined. 7) The findings are confirmed by re-interviewing some participants and by validating the results obtained with the participants' own experiences. [27] The data obtained from the interviews were first written liter-

ally by the authors who collected the data (OS and ZDK) and were analyzed by the other authors (NEB and NK). MAXQDA was used for thematic coding. The themes obtained were supported by direct quotations and interpreted afterwards. The

themes that were formed were created using the Code-Sub-Code-Sections Model of the MAXQDA software (Fig. 1). Information on the codes are presented in Table 1. In evaluating the appropriateness of the themes and codes, we asked for assistance from two academicians who were interested in this research subject.

Reliability and Validity

What is important in qualitative studies is not the dimensions of a phenomenon but rather its existence and meaning. As regards the validity of a study, the important factors to consider include long-term face-to-face interviews, impartiality of the researchers, flexibility (i.e., adding questions to and removing questions from the question quide), assessment of the study process by an external expert, and directly quoting the participants when presenting the results.[24] In this study, examples of sentences taken from the parents' answers to the interview questions (i.e., direct quotations) were presented in order to ensure external validity, that is, the transferability of the study. Throughout the study, the researchers tried to obtain objective and pure data. Themes, categories, and sub-categories emerged from the analysis. The findings were presented along with direct statements given by the participants. In addition, this research was assessed in various dimensions by experts. Given the flexibility of this study, different questions were added to the questions in between interviews. As regards external credibility, the researchers should express their position clearly. The setting of the research and the characteristics of the participants should also be clearly described, and the method used in data analysis should be defined. Furthermore, how the interview was conducted, what devices were used, how the analysis was made and its conceptual framework should be explained in detail. [24]

This research was conducted in accordance with all external reliability principles.

Ethical Dimension of the Study

This study was conducted in accordance with the Helsinki Declaration. Before the interview, permission was obtained from the directors of the rehabilitation center where the study was conducted. Also, an ethics committee approval was obtained from the Provincial Directorate of the National Education to which the rehabilitation center is affiliated. In addition, verbal and written informed consent was obtained from the participants. The parents' names are not indicated anywhere in the text; instead, each parent is given a nickname.

Results

Characteristics of the Participants

Among the participants, 85.2% were female parents (n=23), 81.5% (n=21) were married, 44.4% (n=11) were primary school graduates, 70.4% (n=18) described their economic status as mid-level, and 74.1% (n=19) were jobless. The average ages of their parents and children were 45.7 ± 8.3 and 15.48 ± 2.56 years, respectively. Of the children with MD, 40.7% were girls and 59.3% were boys (Table 2).

Themes

From the individual in-depth interview texts containing the parents' opinions about the sexuality of their adolescents with

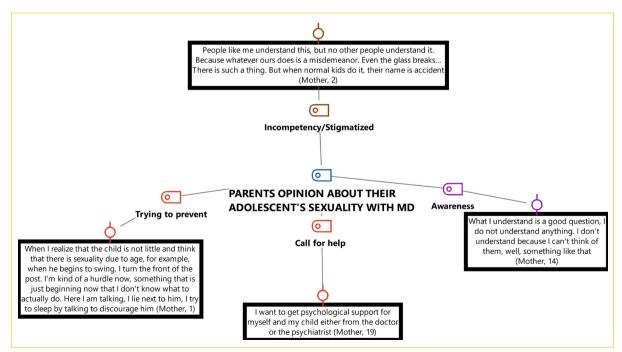


Figure 1. Themes.

Table 1. The themes and Codes					
Themes	Codes				
Not aware/ignoring	- Privacy				
	- Aggressive behavior of the child				
	- The child's shyness				
	- Absence of sexuality due to disability				
	 Not understanding the child's sexual behavior 				
	- Marriage request				
Feeling	- Community view				
incompetent/	- Prejudice				
stigmatized	- Embarrassment to society				
	- Religious pressures				
	- Judgmental attitudes				
	- Making fun of the child				
	- Exclusion of the child from settings				
Trying to prevent it	- Sexual questions				
	- Sexual curiosity				
	- Masturbation (Playing with Sex Organs)				
	- Ignoring child's Behavior				
	- Prohibition				
	- Not accepting their child's sexual needs				
	- Showing the sexual organs				
	- Uncontrolled ejaculation				
	- The sterilization of children				
	- Sexual violence				
Calling for help	- Sex education				
	- Consultancy				
	- Sexual abuse				
	- Building interdisciplinary relationships				
	- The lack of education				

MD, four main themes were identified: "Not Aware/Ignoring," "Feeling Incompetent/Stigmatized," "Trying to Prevent It," and "Calling for Help" (Fig. 1).

Theme 1. Not Aware/Ignoring: This theme is related to the parents' lack of awareness about the sexuality of their adolescents with MD. Specifically, they are unaware of the problems related to their children's sexuality, they are having difficulty thinking about their children's sexuality or are not previously thinking about such an issue, and they are pretending that their children do not have sexuality.

"How much can be given sexuality? You know, we can control or there is a time when there should be a mahram but he doesn't know. What will happen even if it is given?... I don't understand. Oh my god he doesn't understand anything but he knows the existence of his penis, how can he know it? I was asking to myself." (Mother 2)

"Because you see a different change of interest towards the environment in the child due to its extra nature, but we actually call it such a thing, namely deception of the devil, we do not see it right

now." (Father 1)

"I don't know what I need to understand from his reactions, that is, his behavior. Here I do not know how to behave." (Mother 2)

"They don't understand anything about sexuality anyway." (Mother 5)

"But no matter what I tell my child, I can't do anything right now because there is nothing in her perception." (Mother 6)

"I never thought about it. We talked to the nurse before, but it didn't work for me. The nurse said take something with a feather and we will do something in the bathroom with child. We did not do anything at all." (Mother 10)

"A good question is what I understand, I don't understand anything. I don't understand because I can't think of them, so something like that." (Mother 14)

"Well, we don't understand anything because we've never experienced anything like that." (Father 4)

"I think it's about the child's understanding, I don't know how much she can understand." (Mother 16)

"Sometimes he does something like this, he wet the sheet. I don't know if he's doing this consciously." (Mother 17)

"I don't know why. I do not know if it is due to sexuality or if there is another problem." (Mother 22)

"Well, I don't know. He sometimes jokes that she says I want to get married." (Mother 23)

Theme 2. Feeling Incompetent/Stigmatized: This theme is related to the fact that the parents felt inadequate because they do not know what to do when their children with MD exhibit sexual behaviors, and this feeling of inadequacy is amplified by the negative reactions they receive from their environment. Some participants expressed the possibility that their children's sexual behavior could be evaluated differently from the sexual behavior of other children and hence the concern about being stigmatized.

"You know, people like me understand this, but another person says what was happening. Because whatever our children do would be a fault. Even if the glass breaks ... There is such a thing. But when normal children do it, it's an accident." (Mother 2)

"I'm scared I'm scared that someone will hurt their child." (Mother 7)

"But I don't know what to do either. They will take the child to a psychiatrist and have a small dose of a pill, and I don't want to do that." (Mother 8)

"Normal children were making fun of my child. Let the good people don't make fun of my child, and no one should make fun of them. Believe that these children do their own work." (Mother 12)

"He uses it as a thing. Look, I lower my pants. Look, he uses it as a threat. I got out of school early yesterday because I was busy. Since I was not there, I do not know to whom he reacted there anymore. For example, I saw that the children were making fun of him and they were talking like "take your pants down, let's take it down"... I mean, he did it that way too." (Mother 13)

Table 2. Characteristics of the parents							
Parents no	Parents' age	Marital status	Education	Income status	Which is the disabled children	Child's age	
Mother 1	34	Married	Primary school	Medium	2	18	
Mother 2	46	Married	Primary school	Good	2	18	
Mother 3	52	Married	Primary school	Medium	2	18	
Mother 4	47	Married	High school	Medium	3	16	
Father 1	59	Married	High school	Good	4	17	
Mother 5	47	Married	Primary school	Poor	3	14	
Mother 6	52	Single	Illiterate	Medium	7	17	
Mother 7	40	Single	Primary school	Medium	1	18	
Mother 8	31	Single	High school	Good	2	11	
Mother 9	33	Married	Illiterate	Good	2	12	
Mother 10	55	Married	Postgraduate	Medium	3	12	
Mother 11	37	Married	Illiterate	Medium	3	13	
Mother 12	37	Married	Illiterate	Medium	1	18	
Mother 13	48	Married	High school	Medium	3	12	
Father 2	42	Married	University	Medium	1	14	
Father 3	60	Married	University	Medium	3	18	
Mother 14	56	Married	Secondary school	Medium	2	18	
Mother 15	52	Single	High school	Good	3	15	
Mother 16	49	Married	Secondary school	Medium	3	16	
Mother 17	37	Married	High school	Good	2	11	
Mother 18	41	Married	Primary school	Medium	4	18	
Mother 19	52	Married	Primary school	Medium	3	18	
Mother 20	55	Married	Primary school	Medium	7	18	
Father 4	38	Married	Primary school	Medium	3	15	
Mother 21	42	Married	Primary school	Medium	2	13	
Mother 22	40	Single	Illiterate	Good	2	13	
Mother 23	52	Married	Primary school	Medium	3	17	

"Since I myself do not know such a thing, I do not know how to approach." (Mother 16)

"So it's problematic after all. The child is in depression, for some reason, I'll take it to the psychologist." (Mother 17)

"Just because he is doing this because of his deficiency situation. Actually, the normal child does this, but I thought mine is doing it because of autism, but then with the support of our teacher, I realized that this is not the case." (Mother 19)

"Because people say such things that I have to hide it. Our people are very ignorant. It is such a bad influence from the child while passing by. They don't put normal children and MD children in the same environment." (Mother 20)

"I'm scared. I am afraid that my child will rape other children. My child can cause me trouble out of nowhere. Neighbors have little girls. I was afraid that he would do something to them. Then if she rapes, if she gets the girl pregnant, what do we do next?" (Mother 21)

Theme 3. Trying to Prevent It: This theme is about the attitudes of the parents when their children exhibit sexual behaviors. It is noteworthy that most of the parents restricted

these behaviors and that they considered their child's actions morally inappropriate. A few parents had attempts to divert their children's attention.

"When I realize that the child is not small, I think that there is sexuality due to age, for example, when I start to shake, I was turning directly in front of him. Somehow I'm interfering with his actions right now I don't really know what to do as it's just getting started. Here I am talking, I lie next to him, I try to put him to sleep by talking to give him up." (Mother 1)

"Sometimes I feel such things in him, I go to the room and he is trying to do something. I was reacting from the beginning, saying what you are doing, don't do it, it's a shame, then he was immediately embarrassed." (Mother 2)

"You say don't do it. I don't want that thing. I do not want my child's bad morals." (Mother 3)

"I ignore it. Sometimes it happens very rarely, which, for example, is playing with his penis. For example, what are you doing he say I am nothing anything and immediately collects this is how we ignore himself and divert his attention." (Mother 4)

"I always warned, warned, I force him leave that handling. You

will not. I said shameful and sin." (Mother 7)

"But since this is his girlfriend, they always sit next to him and hold hands, then we separated them by force." (Mother 8)

"For example, he kisses everyone, he kisses the lips, I say no." (Mother 9)

"Once I told him what are you doing, then he got up and his father said don't touch the child anyway, close the child where you see it, ignore the door. I am doing that now." (Mother 10)

"But her father said that I would not marry my daughter to someone else. So I know you absolutely do not want it." (Mother 14)

"When I first saw it, I reacted to him, saying don't do it, take your hand out of there. Actually, this was a very wrong behavior I did." (Mother 19)

"We had our child operated. Because he was watching the little girls or something. We couldn't prevent this, so we went to the doctor. The doctor also made me sign the consent form. We sterilized it with my own will." (Mother 21)

Theme 4. Calling for Help: Under this theme are the requests of parents to seek help from an expert because they feel inadequate about what they can do about their children's sexuality. Nearly all of the parents expressed their desire to be educated on this subject. However, one mother emphasized that psychiatrists' attitudes were far from informative. Another mother mentioned that other members of the society should also be educated on this subject.

"I think we should get an education about it." (Mother 1)

"You know, of course, I would like to get help from an expert and that process will be easier." (Mother 2)

"It would be better for the child if there was such a knowledgeable person on this subject, that is, an educated person herself." (Father 1)

"I wish a professional could educate my child. But first, we must be trained." (Mother 4)

"I especially want education to prevent my child from being abused. Because my child can better understand what is right and what is wrong in this way." (Mother 5)

"It may be what I do not know, it should be given with the expert." (Mother 6)

"I want child psychiatrists to be involved, but unfortunately, their number is very low in our country." (Father 2)

"We go to the doctor with these thoughts; here the doctor prescribes medication. Of course, we numb the children. It is more important to be informed about this issue." (Mother 10)

"But other people should also be informed about these issues. We can learn from the computer to some extent. But expert one on one is great." (Mother 11)

"He wanted everyone, so he didn't know what it was. Education should be given about this. I want it." (Mother 12)

"I can tell as much as I know. Again, it would be better if it was explained by an expert." (Mother 15)

"Maybe, it might be useful to give it by a specialist. The family

does not know something, the child does not know something..." (Mother 16)

"I would like to receive psychological support from either the doctor or the psychiatrist for both myself and my child..." (Mother 19)

Discussion

In this title, the findings obtained from the participants were discussed both among themselves and by comparing with the available literature through themes.

Not Aware/Ignoring

This theme came to the fore. Some parents stated that they did not know what sexuality meant in relation to the condition of their children; thus, they ignored the sexual behaviors their children displayed.

In studies that examined the sexuality of children with MD, some variables in parents (e.g., gender) and in children (e.g., MD levels) were evaluated. Gürbüz (2018) found that more male parents than female parents noticed such behaviors as "masturbating, playing with the[ir] genitals, and rubbing their genitals" in their children.[17] It was also found that the parents were less aware of the sexual problems of their girls than those of their boys. Meanwhile, Kijak (2013) found that adolescents with severe MD had certain sexual experiences, although they do not have sufficient knowledge about sexuality.[7] Baines et al.[13] (2018) also found that most of the adolescents with mild and moderate MD had sexual intercourse at the age of 19-20. Contrary to these findings, the participants in the present study stated that their children had not engaged in sexual intercourse. Some parents stated that their children masturbated only and that they did not engage in sexual intercourse in any way. Our findings are supported by many studies, which showed that adolescents with MD are indeed unaware of their sexuality. [6,7,17,28] The majority of the participants who stated the abovementioned observations were mothers, and the majority of the children of these parents had heavy MD. Even if these children have sexual urges or sexual experiences, their mothers may have overlooked them possibly because of these mothers' instinct of avoiding prejudices against their children apart from the fact that parents in general are less aware of their children's sexuality. In Turkey, sexuality is a taboo, and parents generally prefer to be indirectly interested in their children's sexuality, and parents of children with MD are thought to have more difficulty dealing with this concern.

Moreover, the participants stated that they talked less about sexuality with their adolescent children with MD. Consistent with our results, Pownall et al.^[29] (2012) found that compared with normally developing adolescents, those with MD share fewer sexual concerns with their mothers and that these sharings started at a later age. Also, the participants of the present stated that they felt uncomfortable discussing their children's

sexuality. This finding is consistent with that of Taleporos and McCabe (2002).^[30]

The participants further stated that adolescent children with MD exhibit gender differences in terms of sexual behaviors. Similarly, Bernert and Ogletree^[28] (2013) found that women with MD withdrew themselves because they feared the negative stigmatization related to gender. Chou et al.^[31] (2015) also found that men and women with MD have different sexual attitudes and experiences. The study states that both men and women with MD have very limited opportunities to develop romantic relationships and a healthy sexual identity.

Feeling Incompetent/Stigmatized

Recent studies on stigmatization of individuals with deficiency and their families showed that individuals with deficiencies had experienced inequality and social exclusion, were severely discriminated, and were exposed to negative attitudes due to their external appearance; these studies also showed that they had a habit of seclusion, they lacked social support, and they could not meet the educational needs of individuals with deficiencies; the families of these individuals were also exposed to stigmatization. [32,33] Similarly, the parents in the present study stated that their children with MD were socially excluded and were stigmatized based on the slightest negative behaviors they displayed.

Trying to Prevent It

Individuals with MD may acquire inappropriate sexual behavior as they reach puberty. Therefore, special attention must be given to the sexual development and sexual problems experienced by children with developmental issues.[34] These adolescents, especially those with heavy MD, may need more support to explore their sexuality and sexual relationships.[34] Adolescents with deficiencies may desire to engage in sexual intercourse, but this desire may be restricted by their parents. The lack for privacy for the expression of their sexuality and the restrictions they encounter may lead some children to engage in unsafe or illicit activities, such as the display of sexual behaviors in public places.[17,35] Some of the respondents stated that when their children display sexual attitudes, they try to restrict such behaviors, and this finding is consistent with that reported in the literature. Since the hormonal development in adolescents with MD does not differ from that in their peers, these two groups have similar sexual interests and desires.[4,17] However, the literature showed that male adolescents with MD are more interested in sexuality than their female counterpart. In addition, boys and girls who have higher intelligence levels display an increased interest in sexuality. Unfortunately, an increase in sexual desire leads to sexual abuse.[35] Most participants stated that they were afraid that their children would rape another person or that they would be raped by someone else, a concern that has been frequently mentioned in the literature. [6,8,15,17,29] This

fear on the part of the parents can be seen in the following statements:

"I'm scared I'm scared that someone will hurt their child."

"I'm scared he might rape other children. My child can bring trouble on my head. Neighbors have little girls. What do we do if she then gets the girl pregnant if she rapes?"

Individuals with MD may also experience pleasure from sexual abuse. Moreover, the pleasure they receive can make them more eager for sexual intercourse. The difficulties of this vulnerable group in terms of language, speech, or vocabulary and their limited cognitive abilities can further increase the risk of abuse, making it more difficult for them to explain and detect abuse. [37]

Calling for Help

Many of the participants stated that they want their children with MD to be educated about their sexuality. Consistent with this finding, Gürol et al.[38] (2014) found that the parents of adolescents with MD should receive education on their children's sexual development. Similarly, Yıkmış et al.[39] (2009), who determined the expectations of the investigated families from the special education center they attend, found that their participants wanted information about the sexual development of their children during the training meetings held for them. The most reliable counselors for all children with or without MD are their parents. The most accurate information about sexuality, about which contradictory information are provided in different sources, should be given first by their families. [40] For this reason, parents should take the lead in educating their children about sexuality. Although sexuality and sex education are important for adolescents with MD in their acquisition of sexual knowledge, Yacoub and Hall^[41] (2008) found that this factor did not lead to sexual practices, and support should be provided individually because each individual is different. According to Hayashi et al.[42] (2011), although appropriate programs were developed for adolescents with MD, sexual knowledge is lacking due to limited access to these programs. Adolescents with MD may face some risks, such as abuse in the areas of sexual and reproductive health, and dealing with this risk can be a burden for parents. Therefore, health professionals (e.g., nurses and midwives) whom parents can consult play an important role.[43] Our participants wanted their children with MD to receive sexuality education to ensure that their children could protect themselves from sexual abuse. The participants in the study of Gürol et al.[38] (2014) expressed the same concern. In line with these findings, Euser et al.[11] (2016) found that adolescents with mild MD and individuals dealing with adolescents could prevent sexual abuse by receiving adequate education and support. According to Nyokangi and Phasha^[44] (2016), sexuality education should be intensified in order to prevent sexual violence. The parents who participated in their study did not want their children to be given sexual education due to the latter's attitudes, beliefs, and behaviors. A similar finding was obtained by Brown and

Pirtle^[45] (2008). Although parents encourage their adolescents with MD to learn and although they wanted to teach their children about sexual education from an early age, they may have difficulties conveying information due to uncertainties about the place, timing, and manner of presenting the information their children want.[30] In this study, the parents stated that if their children were given access to sexual education programs, the latter would experience a nearly normal sexual life. Although the physical stages in the sexual development of adolescents with MD are similar to those of normally developing adolescents, they progress more slowly. In providing sexual education to adolescents with MD, attention should be given to their cognitive development characteristics, and individualized education should be provided.[40] Brown and Mc-Cann^[46] (2018) stated that sexual education should be given to adolescents with MD so that they can express their sexuality and meet their individual needs. Meanwhile, Eastgate et al.[47] (2012) found that adolescents with MD have limited social environments and friendships and therefore find a few opportunities for sexual relations. Individuals with MD cannot acquire most of the concepts and skills that their normally developing peers spontaneously acquire from their family and friends even without systematic learning.[48] Moreover, they stated that children with MD cannot acquire information by observing their environment compared with their peers, and sexuality education should be given to them by a specialist at the right time. Dekker et al. [49] (2014) found that individuals with MD have less knowledge and experience compared with their normal peers, and their ability to express their feelings and thoughts is limited. The present results showed that parents want to get counseling and that their children should be provided with sexual education in a simple language at the right time by professionals. A study emphasized the importance of providing parents with specific gender education programs so they in turn can provide sexual education to their adolescents with MD.[50]

Conclusion

Parents of adolescents with MD lack sufficient knowledge about their children's sexuality, and they try to prevent or ignore their children's sexual behavior because they become so concerned with the social pressure toward their children's sexual behavior. In addition, the parents stated that they wanted their children and themselves to learn from experts. Midwives, psychiatric nurses, counselors, and special education teachers collectively play important roles in improving public health and reproductive health.

In order to create self-confidence in children by removing the sexual needs of adolescents with MD from discrimination and neglect, they should raise awareness with their roles of health educators by evaluating their sexual health. Parents should be given sexual education to ensure that knowledge is transferred to their children in the best possible way. Since parents have high demands for information from healthcare profes-

sionals and teachers, continuous sexual education programs may be prepared. Society should be aware of the existence of adolescents with MD and that these individuals experience sexuality instinctively.

Limitations

Even if the same conditions are obtained in other studies, the results are not the same and the number of participants is small, showing the limitation of qualitative research in terms of individuals and the environment having a dynamic that changes over time. Given that the data obtained are limited to the opinions of 27 volunteers, generalizations could not be made. Another limitation is that the research data consists of the questions in the semi-structured interview form developed as a data collection tool and the researcher notes.

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