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Rural families' thoughts about sexual development of their adolescents with neurodevelopmental disorders

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Abstract

The study aims to determine rural families' experiences regarding sexual development of their adolescents with neurodevelopmental disorders. Thus, semi-structured interviews were conducted with 14 parents. Since the interviews included privacy issues, they were conducted one-to-one with the parents. The phenomenological method was used, depending on the research purpose. Inductive analysis was utilised in the analysis of the data obtained from the semi-structured interviews. Validity and reliability were included in all stages of data collection, breakdown and analysis. As a result, the families stated that their children exhibited inappropriate socio-sexual behaviours during adolescence; they strive to teach their children sexuality issues, although they do not know how and they generally prefer carrying their children along to prevent sexual abuse. Also, due to not knowing much about sexuality, they generally received their relatives' support and requested comprehensive sexuality education (CSE) from special education teachers and other experts, especially about distinguishing good and bad people, menstruation and hiding sanitary pads. Although the literature reports that sexuality and its education are generally taboo, families in this study explained their thoughts on sexuality in full detail without tabooing. This makes the study different and meaningful, when compared to similar ones. The study was conducted in an eastern Turkey city with difficult access to special education. Thus, experts in rural areas are recommended to prepare and give necessary CSE programmes to families and individuals with special needs by conducting similar studies. These studies can be conducted not only with special education perspective but also in different disciplines. It is a basic human right for all individuals to receive CSE, thus as another recommendation, experts should give all children these courses in schools.

Keywords: Comprehensive sexuality education, individuals with neurodevelopmental disorders, parenting education, phenomenological design.

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1. Introduction

The World Health Organisation (WHO, 2010) describes sexuality as a basic dimension experienced with interactions of biological, psychological, cultural, moral, socio-economic and religious foundations, containing sexuality, gender, sexual identity and orientation, eroticism, love and reproduction. Subsequently, it became much more than the WHO's definition and started to be mentioned with as human rights; and sexual rights based on human rights took place in the Declaration of Sexual Rights. According to this declaration, to which Turkey is a party, all individuals have the right to experience sexuality and receive comprehensive sexuality education (CSE). Thus, through this declaration, it is accepted as the most basic right that individuals with neurodevelopmental disorders (IWNDD) having special needs receive CSE. However, studies reveal that IWNDDs have insufficient sexuality knowledge, which creates problems. The literature shows that adolescents with autism and Down syndrome know less about privacy, compared to typically developing peers, struggle in displaying appropriate sexual behaviours and benefit less from CSE (Ginevra et al., 2016). Among its main reasons are deficiencies in social communication, e.g., inadequate understanding and reasoning in cognitive dimensions, inadequate communication and deficiencies in understanding social expectation (Dewinter et al., 2013). These cognitive and social skills' deficiencies can make sexual abuse inevitable for them. Sexual abuse is a concern for families, thus CSE becomes important. While providing them CSE, family participation is also important, which experts support (Ballan, 2012). As the literature emphasises this importance, studies in Turkey and different parts of the world report that parents (Altundag & Cakirer-Bayram, 2019; Ariyantia & Royanto, 2017; Ballan, 2012; Dupras & Dionne, 2014; Gurol et al., 2014; Guven, 2021; Gokgoz et al., 2021; Holmes et al., 2016):

- lack knowledge on sexuality education (e.g., sexual development and adolescence):
- do not know how to teach sexuality education at home:
- request help from experts regarding sexuality education; and
- worry about the issues on sexuality education (e.g., sexual abuse and unwanted pregnancy).

Based on these literature findings, it is aimed to determine the experiences of rural families with difficulties in accessing special education in a developing city of Turkey, regarding sexual developments of their adolescents with neurodevelopmental disorders. These interviews aim to identify families' deficiencies in the subject and develop an education programme according to their needs. Therefore, such a study was needed. This study is important due to it being the first to reach families in rural areas with difficult access to special education, and providing education according to the findings revealed after the interviews. With these requirements, the following questions were sought to be answered:

1. What are the experiences of rural families regarding sexual developments of their adolescents with neurodevelopmental disorders?
2. What are CSE requirements of rural families for their adolescents with neurodevelopmental disorders?

2. Method

2.1. Research model

The study used the phenomenological design which tries to reach the essence of experience by questioning experiences relating to the phenomenon (Ersoy, 2016). In this design, it was tried to reveal families' experiences with their children's lives regarding the phenomenon of sexuality and the meaning they attribute to these experiences (Creswell, 2007).

2.2. Study group

The participants were determined by criterion sampling based on purposive sampling, and the following criteria were included:

1. Being a mother, father and/or primary caregiver voluntarily participating in the study.
2. Having a child between 11 and 18 years with a diagnosed neurodevelopmental disorder.

Based on the purpose, semi-structured interviews were held one-to-one with 14 parents meeting the criteria, and Table 1 presents the participants' details.

Table 1. Demographic information of parents

Parents' code name	Age	Education status	Child' diagnosis	Childs' age & sex	Parents' job
Geno	60	Illiterate	Down syndrome	18/ B	Housewife
Angel	45	Illiterate	Intellectual disability	14/ B	Housewife
Anna	59	Primary school	Down syndrome	18/G	Housewife
Leyla	45	Primary school	Intellectual disability	18/ G	Housewife
Nora	41	Primary school	Intellectual disability	16/ B	Housewife
Nargis	40	Primary school	Intellectual disability	14/ G	Housewife
Maria	37	Primary school	Intellectual disability	18/ G	Housewife
Canan	38	Primary school	Down syndrome	14/ B	Housewife
Maral	40	Primary school	Intellectual disability	15/ B	Housewife
Silva	49	High school	Down syndrome	18/ B	Housewife
Nar	51	High school	Down syndrome	15/ B	Housewife
Seta	60	High school	Down syndrome	18/ B	Housewife
Nur	59	Graduate	Down syndrome	18/ G	Retired
Can	60	High school	Intellectual disability	18/ B	Retired

B: Boy, G: Girl.

As Table 1 shows, the majority of the participants are women and primary school graduates. Only one man participated in the interviews. While only one was a university graduate, two stated to be illiterate. Also, only two were retired and the others stated to be housewives.

2.3. Data collection tools

2.3.1. Semi-structured interview form

Before the interviews, firstly, data collection tools were developed depending the purpose. The researchers developed a semi-structured interview form through the literature. This form was sent to three health and education experts on special education and CSE, and finalised. In this process, interview principles were determined; then, pilot interviews were conducted with two parents and voice recordings were taken. The pilot interviews were listened and transcribed. After transcribing, the questions were seen to work and the interviews were held with the participants.

2.3.2. Personal information form

The personal information form asks families basic questions about age, education level, their children's diagnosis and professions. The participants filled it with a pen before the interview. The illiterate participants' forms were filled by the researcher. This form was prepared by taking expert opinion, similar to the semi-structured interview questions.

2.4. Data collection

The interviews were conducted by the researcher. In this study, there is a researcher role as a participant. The researcher has worked as an education coordinator in a rehabilitation centre for more than 2 years, and the participants' children receive services from this institution. The interviewer took different qualitative research methods and courses during graduate education, conducted qualitative researches and her studies are published in international journals. After the pilot interviews, interviews were held between 23.9.2018 and 28.11.2018. Before the interviews, the parents filled the personal information form and mutual participant agreements were signed. After all these procedures, interviews were conducted. The interviews were conducted one-to-one in the guidance service centre. A voice recorder was used during the interviews and before the interview, and the interviewed parent was informed that a voice recorder would be used.

2.4. Data analysis

When analysing the semi-structured interviews' data, inductive analysis approved by phenomenological method was used. In the inductive analysis, the steps specified by this method and suggested by Moustakas (1994) were followed. At this stage, the data was firstly transcribed into a Word document on a computer; for the first reliability (verification), 30% were randomly selected among the recordings, listened by the researcher and transferred to the interview form. Depending on the question, coding and code list were created. Based on the code list, coding reliability was checked by another expert. Themes and sub-themes relating these codes were arranged for the last time without any changes in the codes. Lastly, considering the themes, the last reliability, inter-coder reliability, was evaluated and presented.

2.5. Validity and reliability

Considering the study's validity and reliability, participant confirmation was conducted for credibility after the data breakdown. Opinions were received from experts conducting qualitative research and working on CSE. Data were collected at a certain time. Coding and reliability checks were made with experts at each data breakdown step. For transferability, the purposive sampling method was used; qualitative data were presented as descriptions. For consistency, all the data collection details were included by using the personal information form and making in-depth interviews. For verifiability, the process specified in the data breakdown was conducted. For the study's reliability, the formula of inter-coder reliability = Agreement / (Agreement + Disagreement) x

100, defined by Miles and Huberman (1994), was utilised. Using the inter-coder reliability formula, independent coders' reliability was assessed and the reliability was found to be 100%. All participants were presented under a code name, and ethics committee approval for the study was obtained from the university.

3. Results

This section presents the themes and sub-themes created by including Moustakas' (1994) phenomenological data analysis relating to the interview questions. After this analysis, eight themes and their sub-themes were seen to emerge. The themes and sub-themes were tabulated and supported with interview quotations. First, the parents informed about adolescent behaviours they observed in their children. Table 2 presents the parents' thoughts.

Table 2. Adolescent behaviours observed by parents

Adolescent behaviours observed by parents	Frequency (*f*)
Introversion	4
Bursts of anger	3
Interest in the opposite sex	3
Romantic images	1
Interest in heart drawings	1
Flirting	1
Watching love movies	1
Touching the opposite sex	1
Stubbornness	1
Difficulty in communicating	1
Saying to be a father	1
Starting to take care of himself/herself (e.g., brush hair)	1
No behavioural change	1
Inappropriate socio-sexual behaviours	
Masturbation	2
Wetting	1
Showing private body parts in public spaces	1
Undressing in public spaces	1
Showing sanitary pads	1
Hugging	1

Under the theme of adolescent behaviours observed by parents, the subthemes were introversion (four), bursts of anger (three), interest in the opposite sex (three), romantic images (three), touching the opposite sex (one), stubbornness (one), difficulty in communicating (one),

saying to be a father (one), starting to take care of himself/herself (one) and no behavioural change (one).

Four participant parents stated to observe a behavioural introversion in their children who newly entered adolescence. Angel said: '*..Of course, when a child grows up, the voice changes, well, ours has the habit of locking himself in the room. He isolates himself...*' and stated her child became lonely and introverted.

The parents also expressed their thoughts on their children's inappropriate socio-sexual behaviours in general and stated their children displaying inappropriate socio-sexual behaviours. The sub-themes were masturbation (two), wetting (one), hugging (one), showing sanitary pads (one) and private parts (one) and undressing (one) in public spaces.

Two of the mothers with boys stated that their children masturbated in public spaces. Canan said: '*…Well, he can do, I don't say anything, but he does it when with someone else, it puts me in trouble, even though I just, I warn, I say 'don't do it when with someone else, do it when alone, don't do that', but he still doesn't listen to me. Teacher lady, he is bored and he does it a little bit of boredom…*'. Nargis said: *'…My daughter needs to be talked one-to-one, well, about not showing private parts to others. No matter how much I explain, she doesn't listen...*' and expressed that the child showed her private parts to others.

Relating to the theme of parents' thoughts on sexuality, Table 3 presents the sub-themes: thoughts on their children's sexuality, CSE knowledge level and thoughts on their children receiving this education. Under the sub-theme of thoughts on their children's sexuality, the parents expressed that 'my child does not have sexuality (one)' and 'my child does not understand sexuality (one)'.

Table 3. Parents' thoughts on sexuality

Parents' thoughts on sexuality	Frequency (*f*)
Parents' thoughts on their children's sexuality	
My child does not have sexuality	1
My child does not understand sexuality	1
Parents' CSE knowledge level	
I have no idea	6
Parents' thoughts on their children receiving CSE	
My child should receive CSE	4
My child shouldn't receive CSE	1
Undecided	1

Seta, one of the parents who stated so, said: '*… I don't think Leo knows anything about sexuality. They don't understand… Teacher, I support raising the awareness of families. I say firstly parents ...*' and expressed that her child did not understand sexuality.

When asked about their CSE knowledge level, six parents stated to not know CSE. Maral said: '*…as I said, children cannot express themselves because we don't really know anything, at least if we know what to do, we can help children, because they won't be able to ask for help about it. If we do*

our best, it will be easier for our children. So, we expect such things. We expect you, the educators, to enlighten us. We may of course be uninformed about these issues…' and requested information.

Regarding the sub-theme of thoughts on their children receiving sexuality education, the parents stated that 'my child should receive sexuality education (four)', 'should not receive CSE (one)' and 'I am indecisive (one)'. Nur said: '*… It is very appropriate, very necessary, so I don't think mine is any different from other children. Even more so, our children should be given this education beforehand so that they don't suffer*…' and expressed her opinion about her child receiving CSE.

Approaches to giving CSE were questioned and Table 4 shows the answers. Relating to this theme, the parents stated to give sexuality education under the following sub-themes: parent–child nights (11), being a model (one), teaching with material support (one), ignoring (one) and being understanding/patient (one).

Table 4. Parents' approaches to provide CSE

Parents' approaches to provide CSE	Frequency (*f*)
Parent–child nights	11
Being a model	1
Teaching with material support	1
Ignoring	1
Being understanding/patient	1

Anna explained how she taught personal hygiene through being a model, which is under CSE's scope: '*… first they gave me wax. I had no other choice. I did it to set an example. Then I told my daughter 'my daughter, look, I did it, it didn't hurt, it is your turn now, you will get used to it after the first time.' When just getting used to it, she said it would hurt and didn't want to come when it was time. I said 'look, you'll smell bad.' I said 'it is necessary.' She said 'no, I don't want.' Then, my sibling said 'why do you hurt yourself? Try epilating.' Now she uses that, one by one, it hurts, but she now uses that*'.

Table 5 includes family members and others who support the parents when giving CSE. The parents stated to receive support from older sister (three), father (two), uncle (one), siblings (one) and cousins (one) within the scope of family members during CSE.

Table 5. Parent supporters while providing CSE

Parent supporters while providing CSE	Frequency (*f*)
Family members	
Older sister	3
Father	2
Uncle	2
Sibling	1
Cousin	1

Others who support the parents when giving CSE	
Teacher	2
Psychologist	1
School counsellor	1
Parents' friend	1

Nur said: '*For example, I cannot explain questions such as why they are kissing lip to lip, older sisters stepped in then. For instance, when İlim first menstruated, saw that blood, she was very scared. "Mom, what's going on, something is happening to me, come run". We also experienced these, but our sister was with us then, sister talked to her immediately "look, it happens to me too. This must happen so that we can become beautiful, we grow up, some things will change, some organs will change in our body"*…' and stated to get her sister's support.

Under the theme of CSE subjects that the parents wanted their child to receive, they requested education on the following sub-themes: menstruation cycle, not hugging strangers, hiding sanitary pads and staying away from strangers within safety skills (11), which Table 6 shows.

Table 6. Subjects that parents want to teach their children in CSE

Subject that parents want to teach their children in CSE	Frequency (*f*)
Staying away from strangers	11
Menstruation cycle	1
Not hugging strangers	1
Hiding sanitary pads	1
Safety skills	1

Maria said: '*I don't know how to keep my child stay away from strangers. I say 'this is a stranger, don't talk to her', but my child still wants to talk*…' and requested such education under CSE.

Table 7 shows the thoughts on who they want to get CSE from. This theme's sub-themes were as follows: family members should give (six) and other people should give (six).

Table 7. People from whom parents want to get CSE

People from whom parents want to get CSE	Frequency (*f*)
Family member should give	
Parents	2
Mother	2
Sibling	1
Cousin	1
Other people should give	

Child' teacher	2
School counsellor	2
Psychologist	2

Maral said: '*From teachers and educators. Yes, it is, well, a taboo and not talked much about, so we want someone knowing it best so we can learn it correctly. Because of misinformation, we learn wrong too ...*' and asked teachers to give CSE.

Also, during the interviews, the families spoke about providing a safe environment. Regarding the theme of approach in providing a safe environment, the sub-themes were as follows: carrying children along (five), chatting at the end of the day (one) and not letting children leave home (one). Seta said: '*Since Turgut is a very beloved person, even someone he doesn't know says "come, I am your sister's friend", he believes that. So, we always stay close to him*'.

4. Discussion

In the literature, there are different studies where parents of children with neurodevelopmental disorders share their thoughts on their children's sexuality needs.

Behaviours such as interest in the opposite sex and bursts of anger reported in typically developing adolescents in the literature (Bambury et al., 1999; Boyacioglu et al., 2018; Byers et al., 2013; May & Kundert, 1996; May et al., 2017) were reported by the parents in this study. For instance, the parents stated that with adolescence, their children were interested in the opposite sex. As known, children show biological and sexual maturation during adolescence. In such a period when the body's hormonal structure completely changes, its physical structure differs fast, the social roles change rapidly and radical changes occur in feelings and behaviours. Feelings, such as loving, being loved, proud, being happy, distress, anxiety, uneasiness and being offended, and moods, such as self-confidence and insecurity, may periodically cause ups and downs in them. During adolescence, adolescents experience their first flirtation and sexual experiences. Essentially, adolescents' interests and curiosities in romantic relationships are quite normal and a necessity for their development (Cinsel Yasam & Sorunlari, 2007; Santrock, 2016). Namely, IWNDDs, like typically developing peers, enter adolescence and display similar behaviours (Byers et al., 2013; Corona et al., 2016; May et al., 2017; Sullivan & Caterino, 2008; Schaafsma et al., 2017; Pecora et al., 2020). This study also reveals that these individuals exhibit similar adolescent behaviours just like TDIs.

In this study, the parents stated that their children display inappropriate socio-sexual behaviours. The parents especially expressed their children's masturbation and undressing behaviours in public spaces. Studies in the literature present that adolescents with intellectual disabilities and autism exhibit similar unsuitable socio-sexual behaviours (Byers & Nichols, 2014; Gokgoz, Deliktas-Demirci & Kabukcuoglu, 2021; Hellemans et al., 2007; Hill, 2018; Puglise et al, 2020). They report the lack of sexuality education for children as this negative situation's reason (Guven, 2021; Kalyva, 2010; Koller, 2000; Sullivan & Caterino, 2008; Sweeny, 2007). Also, studies show that when IWNDDs gets CSE, inappropriate socio-sexual behaviours decrease, they can have healthy sexuality and learn how to react in situations such as sexual abuse (Gkogkos et al., 2019; Turner et al., 2017; Puglise et al, 2020). Accordingly, this study once again shows the necessity of giving these individuals CSE.

The parents of the current study stated that their children did not receive CSE but they generally wanted their children to receive it, expressed positive opinions towards CSE also defined it as 'sex-positive', and often verbalised the topics to include under this education as reducing inappropriate socio-sexual behaviours and distinguishing good and bad people. In studies in the literature, parents

demand education on similar subjects (Dupras & Dionne, 2014; Graff et al., 2018; Gurol et al., 2014; Molin et al., 2015; Silverio Marques et al., 2017; Swango-Wilson, 2011). The results, showing parents from different parts of the world requests teaching similar contents to typically developing individuals, prove how important it is for these children.

The majority of the parents in the study are primary school graduates or illiterate, with a small number of male participants. The number of participants from rural towns or villages is also quite high. Considering all these, the fact that the parents stated to be far from taboos and prejudices towards CSE, want expert help on the issue and expressed a positive attitude towards CSE lead this study to different results comparing the similar studies.

By participating in this study, the parents expressed to want their children to receive CSE, but did not know how to teach sexuality at home. They stated to talk about issues on sexuality through 'parent–child nights' as a teaching method. The parents stated to inform their children about adolescence by generally talking with concern, but also receive support especially about changes relating adolescence from people, e.g., primarily parents, sisters and uncles. It is revealed that the parents actually strive for sexual education in this process. In a study on the concerns of a group of families in Canada about the sexuality of their children with intellectual disabilities and their sexuality education needs, most parents stated to have difficulty being a sex educator and need to listen to their children instead of advising them in order to be a good sex educator (Molin et al., 2015). This study's result has similarities with the literature and shows that although parents generally do not know what education to give, they do the correct applications in the literature (Hill, 2018; Silverio Marques et al., 2017).

The literature shows that teaching sexuality with visual support and social stories will facilitate the teaching process, especially for children with autism (Ariyantia & Royanto, 2017; Guven, 2021; Holmes et al., 2019; Pecora et al., 2020). In this study, the families reported that they taught with material or visual support during CSE teaching process and it was effective. Especially for IWNDDs having difficulties in their safety-related skills and expressing sexual needs, due to the inadequacies they experience in communication skills (Pugliese). In expressing possible abuse-related situations, they may encounter (Pugliese et al., 2020) or cope with and adapting to changes in adolescence. Teaching with visual support (Ariyantia & Royanto, 2017) and providing visual support was seen to facilitate teaching and reduces parents' anxiety about sexual issues. Similarly, teaching with visual support was a very important finding of this study and it was important that the families reported to successfully teach the relevant issues.

According to the findings of a study with families having children with disabilities, 93% of the parents consider safety skills as a very important part of children's education (Argan & Krupp, 2010). Sexual abuse is the biggest problem that the parents in this study often expressed their fears of. The majority stated to prefer not staying far from their children and carrying them along everywhere because of it. Parents take many precautions to protect their children against personal safety threats. These can be to warn children to stay away from safety threats and teach them how to act when facing with these threats (Guven, 2021; Gokgoz et al., 2021; Holmes et al., 2019; Miltenberger, 2008). These become even more critical for children with disabilities, for example, because children with intellectual disabilities do not have the skills and knowledge to protect themselves in dangerous and harassing situations (especially sexual harassment), and they struggle in distinguishing acceptable and unacceptable interactions (Wurtele, 2009; Holmes et al., 2019). Researchers highlight that combating victimisation should include developing overcoming (coping) strategies, involving families in the education and training process (Frisen & Holmqvist, 2010; Gokgoz et al., 2021), strengthening self-sufficiency skills, teaching the necessity of reporting events to adults, making sure students have someone to talk safely in their lives and creating classes without bullying

(Crothers et al., 2006). Briefly, teaching IWNDDs safety skills is predicted to serve them to live in safe environments and reduce parents' anxiety. Thus, individuals with neurodevelopmental disorders should be taught safety-related skills, starting from an early period, to protect themselves from sexual abuse. Teaching such skills under CSE is important for them to be healthy individuals.

5. Conclusion and future directions

Consequently, the literature reports that parents have an educator's role in their children's sexuality education (Altındag & Cakirer- Bayram, 2019; Boehning, 2006; Girgin-Buyukbayraktar et al., 2017; Holmes et al., 2019; Konuk-Er et al., 2016; Guven, 2021; Gkogkos et al., 2019). Thus, the literature states that it is critical for parents to drop prejudices and be open to cooperation with partners providing services to their children in the CSE process (Holmes et al., 2019; Meaney-Tavares & Gavidia-Payne, 2012). This study reveals that although parents live in rural areas and have low education levels, they support their children's sexuality education and correctly fulfil their responsibilities on CSE without realising. Also, dissimilar to the findings of most studies, it is among this study's important results that the families directly stated to not taboo sexuality and to need education. To prevent IWNDDs from exhibiting inappropriate socio-sexual behaviours at following ages and ensure their safety, teaching under CSE should be started at an early age. Experts should be able to provide CSE services to families by reaching every part of Turkey where special education cannot be accessed. Scientific research on the subject should be conducted by experts from different disciplines, not only through special education perspective. By providing school–family cooperation, a systematic CSE can be given. Thus, children can exhibit appropriate socio-sexual behaviours, sexual abuse and unwanted pregnancies can be prevented. CSE should be offered as a compulsory course to all children in schools in Turkey. By providing in-service trainings on CSE to special education teachers, studies can be conducted with scientific-based applications.

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