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Özgün Araştırma / Research Article

Awareness of Sexual Health in Mothers Who Have Children with Learning Disability

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Zihinsel Engelli Çocuğa Sahip Annelerde Cinsel Sağlık Konusunda Farkındalık Oluşturma

Abstract

Aim: The individual and social benefits of sex education should not be ignored. This study was conducted to examine the effect of education on sexual health to mothers of children with educable mental disability. **Material and Method**: The Single Group Pretest-Posttest Model, which is one of the quasi-experimental study methods, was used in this study. The universe of the study consisted of all the parents of children who attended a Special Education Vocational Training Center (School). No sampling procedure was employed in the study. Instead, the mothers of the students who were attending the Special Education Vocational Training Center and agreed to participate in the study were enrolled in the study. Necessary permissions were taken from the ethics committee, the institution where the study was conducted, and the mothers. **Results**: The study was carried out first by the administration of the questionnaire forms, then parents' training, and finally by the re-administration of the forms one month after the training. Of the mothers participating in the study, 18.2 % stated that their children asked them questions with sexual content, 66.7 % said that children must be given sex education, and 36.3 % thought this education should be provided by instructors. 30.3% of mothers stated that they can learn the necessary information about sexual education by attending conferences and seminars. **Conclusion:** The level of knowledge of mothers about sexual development of the child generally changed after the education. In line with these results, families should educate their children with mental disabilities on sexual health.

Kewords: Sexual Health, Education, Mentally Retarded Child, Mothers, Nurse.

Öz

Amaç: Cinsel eğitimin bireysel ve toplumsal yararları olduğu göz ardı edilmemelidir. Bu çalışma, eğitilebilir zihinsel yetersizliği olan çocukların annelerine "cinsel sağlık" konusunda verilen eğitimin etkisini incelemek amacıyla yapılmıştır. **Materyal ve Yöntem:** Bu araştırmada, yarı deneysel (Quasi-Experimental) çalışma yöntemlerinden biri olan "Bir Grup Pre-Test Post-Test Modeli" kullanılmıştır. Araştırmanın evrenini Denizli Çamlık Özel Eğitim Mesleki Eğitim Merkezi (Okulu)'ne devam eden bütün öğrenci velileri oluşturmaktadır. Çalışmada örneklem hesabına gidilmemiştir. Denizli Çamlık Özel Eğitim Mesleki Eğitim Merkezi (Okulu)'ne devam eden, çalışmaya katılmayı kabul eden, öğrencilerin anneleri çalışma kapsamına alınmıştır. Araştırma için etik kuruldan, çalışmanın yapıldığı kurumdan ve annelerden gerekli izinler alınmıştır. **Bulgular:** Araştırma anket formlarının uygulanması, annelere yönelik eğitim, eğitimden bir ay sonra tekrar anket formlarının doldurulması şeklinde yürütülmüştür. Çalışmaya katılan annelerin % 18.2'sinin çocuklarının kendilerine cinsel sorular sorduğunu, % 66.7'si cinsel eğitim verilmesi gerektiğini ve bu eğitimi ise % 36.3 oranında eğiticilerin vermesi gerektiğini ifade etmişlerdir. Cinsel eğitim konusunda ihtiyaç duyulan bilgileri annelerin %30.3'ü konferans ve seminerlere katılarak öğrenebileceklerini ifade etmişlerdir. **Sonuç:** Annelerin çocuğun cinsel gelişimi hakkındaki bilgi düzeyleri genel olarak eğitim sonrası istendik yönde değişmiştir. Bu sonuçlar doğrultusunda aileler zihinsel engelli çocuklarına cinsel sağlık konusunda eğitim vermelidir.

Anahtar Sözcükler: Cinsel Eğitim, Eğitim, Engelli Bireyler, Anneler, Hemşire.

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INTRODUCTION

Parents in many countries as well as in our country have avoided pronouncing the term sex education until recently. Sex-related issues are generally referred implicitly, sometimes overlooked, and sometimes met with anger and even with disapproval (İşler ve Gürşimşek, 2018). Sex education is a lifelong process that deals with providing information, attitude development, beliefs, values, relationships, and privacy (Siecus 2004).

The individual and social benefits of sex education should not be ignored. By means of sex education, the child learns to show respect for his/her own body and the body of the opposite sex. This results in the establishment of healthy and appropriate relationships between the child and individuals of his/her own gender and the opposite sex in the later stages of life. An individual who receives education about his/her sexual development at early ages and creates a strong ground in this sense knows his/her responsibilities for his/her body. Knowledgeable individuals are more successful in resisting indecent offers and oppression coming from their friends (Çalışandemir, Bencik ve Artan, 2008). Parents are responsible for providing the child with their first education on his/her sexual development, familiarize the child with the subject, and follow up the information that the child receives from external factors (Markwei, 2019). In a study by Ceylan and Çetin on sex education, all the parents participating in the study stated that sex education was indispensable. However, parents did not know how to approach their children (Ceylan ve Çetin, 2015). However, in some social settings, discussions about sexuality and children present sexuality education as inappropriate for children's development (Robinson ve ark., 2017). According to another study, parents stated that the provision of sex education to children was necessary and that this education had to be provided by parents. It was determined that the majority of preschool children have asked their parents about their sexuality, most of the parents support sexual education, and parents' attitudes towards child sexual education are similar, and inadequate (Tuğut ve Gölbaşı, 2019). The sexual development process of individuals with learning disability in adolescence is indeed a delicate and complex issue because most individuals with disabilities rely on their families to meet all their physical, social and psychological needs (Hamby ve ark., 2019).

Since individuals with learning disability who have inadequate sexual knowledge are more vulnerable to every kind of abuse, families feel anxious and alarmed (Reynolds, 2019). The conditions challenging families of these children in adolescence are the problems of dealing with the child's curiosity and self-care about his/her own sexuality (Diken, 2017). The physical changes associated with puberty in children with disabilities in the adolescence stage are also accompanied by the changes in their sexual behavior. Sexual behaviors vary by the intelligence level of the disabled person and therefore his/her educable status (Karaca ve ark., 2016). In the literature, studies emphasize that children with learning disability generally do not know where and when they can exhibit sexual behaviors, and they lack psychosocial-sexual development (McDaniels ve Fleming, 2016).

Individuals with learning disability cannot obtain accurate and necessary information from their friends or books. They also have difficulty in their observational learning process. Therefore, these adolescents need guidance from their parents and teachers.

METHODS

Aim and Design

This study aimed to raise awareness of sexual health in mothers who have children with learning disability. The study employed a single group pretest-posttest design, which is one of the quasi-experimental study methods.

The Universe and the Sample

The universe of the study consisted of all the parents of the students who were attending a Special Education Vocational Training Center (School). The study did not employ a sampling procedure. The total number of students attending the Special Education Vocational Training Center was 217. All the mothers of the students who were attending the Special Education Vocational Training Center and agreed to participate in the study were enrolled in the study (Figure 1).

Figure 1. Sampling flow chart

First meeting – Pretest Stage	•	58 mothers agreed to fill out the pretest form.
	•	19 mothers did not agree to fill out the pretest forms; however, they wanted to join the training.
Training stage	•	77 mothers joined the training.
Posttest stage (One month after the training)	•	12 forms were incomplete.
	•	13 mothers did not agree to fill out the form.
	•	The study was completed with 33 mothers.

The place of research

The study made Special Education Vocational Training Center (School).

Data Collection Tools

Family Information Form: The form is made up of family and child information sections. The family section consists of 12 questions and the child section consists of 14 questions.

Sexual Health Knowledge Questionnaire: It consists of 23 items and is a 3-point Likert-type scale. Each item is responded with one of the "yes", "no", or "uncertain" options. Each correct response is scored 1 point, whereas incorrect or "uncertain" responses are not scored. The maximum score that can be obtained from the questionnaire is 23 points. High scores indicate that parents have a high level of knowledge. The questionnaire was developed by the researchers. For the content of the questionnaire, 2 experts from the field of child health and diseases nursing were consulted.

Implementation of the Study

Pretest stage: The participants were informed about the pretest and the information forms and questionnaires were administered in this stage.

Training stage: The mothers were trained on "sexual health for children" by the researcher.

The content of the training: communication with the child; individual rights; sexual development; creating an environment of trust for the child; private body parts; who can see the private body parts and under which circumstances can they be seen; and safe persons for children. The training was held in the training hall of the school. The presentation took about 45 minutes. After the presentation, additional time was given for a question-answer and discussion session. Mothers who could not ask any questions within the group were privately interviewed after the training.

Posttest stage: The mothers were re-administered the sexual health knowledge questionnaire one month after the training (Sampling Flow Chart).

Data Analysis

The data were analyzed using SPSS (Statistical Package for Social Sciences) (SPSS 20.0, SPSS, Chicago, IL) statistical software package. Numbers and percentages were used for the analysis of the data collected in accordance with the purpose of the study.

Ethical Considerations

Before starting the research, approval was received from the university's ethics committee (Decision Number: 60116787-020/81513, 06.12.2017). In addition, written permission was received from the institution where data were collected. The parents were also informed, and their verbal consent was obtained during the data collection procedure.

Limitations of Research

The findings obtained from the research can be generalized only to individuals in the province where the research was conducted.

RESULTS

54.5 % of the mothers participating in the study were aged 40 or below, 51.5 % were elementary school graduates, 90.9 % did not have a job, 54.5 % had less income than expenses, and 15.2 % had a consanguineous marriage (Table 1).

Table 1. Descriptive Information About the Mothers

Variables		n	%
Age	40 and below	18	54.5
	41 and above	15	45.5
Education	Elementary school	17	51.5
	Middle school	6	18.2
	High School	9	27.3
	University and higher	1	3.0
Employment	No	30	90.9
	Yes	3	9.1
Income level	Less income than expenses	18	54.5
	Equal income and expenses	13	39.4
	More income than expenses	2	6.1
Consanguineous marriage	Yes	5	15.2
	No	28	84.8
Gender of the child	Female	16	48.5
	Male	17	51.5

18.2 % of the mothers reported that their children asked them sex-related questions. 45.5 % of the mothers were found to respond to the most frequent sex-related question as "I don't want to answer it because it is too embarrassing." 24.2 % of the mothers reported that their child wondered when s/he would get married. 27.3 % of the mothers stated that their child exhibited inappropriate sexual behaviors, while 33.3 % of them did not want to respond to this item. 66.7 % of the mothers stated that children must be given sex education and 36.3 % said that this education should be provided by instructors. 30.3 % of the mothers stated they might get the necessary information about sex education by participating in conferences and seminars (Table 2).

Table 2. The Views of the Mothers On Their Children's Sexual Health Education

Topics	Variables	n	%
What mothers understand from sexual health education term	Organizing environments for girls and boys to have them adopt behaviors in society appropriate for their roles	17	51.5
	Informing people about sexual relations	9	27.3
	Informing people about sexual organs and their functions	5	15.2
	Informing people about the reproduction system	1	3.0
	Other	1	3.0
Views on providing children with sexual health education	Should be given	22	66.7
	Should not be given	2	6.1
	No idea	9	27.3
Topics that should be included in sexual health education syllabus	No idea	19	57.6
	Appropriate behaviors and attitudes in the society	6	18.2
	The importance of sexuality	3	9.1
	Self-protection	3	9.1
	Love, respect, morals	1	3.0
	Understanding privacy	1	3.0
Sexual health information sources of mothers	Participation in conferences and seminars on the topic	10	30.3
	Doctors	6	18.2
	Participation in continuous education programs on the topic	6	18.2
	No idea	6	18.2
	Self-learning from the Internet	3	9.1
	I don't want to get information from any of them because I feel ashamed.	2	6.1
Who should give the child sexual health education?	No idea	11	33.3
	Instructors	9	27.2
	Doctors	3	9.1
	Parents	3	9.1
	Teacher-family	3	9.1
	Father	2	6.1
	Mother-doctor	1	3.0
	Mother	1	3.0
Whether the child asks sex-related questions	Yes	6	18.2
	No	27	81.8
The topic that most attracts the child's attention	I don't want to answer it because it is too embarrassing.	15	45.5
	When will I get married?	8	24.2
	No questions, yet.	4	12.1
	We don't prefer talking on this topic.	2	6.1
	Adolescence period	2	6.1
	Opposite sex	1	3.0
	Kissing	1	3.0
Observing inappropriate sexual behaviors in the child	Yes	9	27.3
	No	13	39.4
	No response from the mother	11	33.3
Inappropriate sexual behaviors exhibited by the child	No response from the mother	28	84.8
	Wants to kiss	2	6.1
	Touching breasts	1	3.0
	Sitting somewhere and rubbing his/her body	1	3.0
	Rubbing himself/herself or requesting somebody else to do it	1	3.0
Mothers' reactions when they meet inappropriate behaviors	No response from the mother	23	69.7
	Saying it is inappropriate and should be private	4	12.1
	Warning and saying it is a shame	3	9.1
	Telling off the child	3	9.1
Views of the mothers on giving the child information about contraception	Yes	19	57.6
	No idea	13	39.4
	No	1	3.0

When the distribution of percentages of mothers' responses to sexual education before and after the study was examined; in general, the responses of the mothers after the training changed in the direction we wanted (Table 3).

Table 3. Knowledge Levels Before And After The Education Of The Mothers From Sexual Health Knowledge Questionnaire

	Pre-education						**Post-education**					
Sexual Development	**I agree**		**I do not agree**		**Undecided**		**I agree**		**I do not agree**		**Undecided**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
My child can touch his own body	27*	81.8	2	6.1	4	12.1	31	93.9	-	-	2	6.1
My child can ask questions about genitals	24*	72.7	9	27.3	-	-	26	78.8	6	18.2	1	3.0
My child can ask questions about breasts	21*	63.6	12	36.4	-	-	23	69.7	7	21.2	3	9.1
My child can watch with interest when he sees someone taking a bath	9	27.3	24*	72.7		-	12	36.4	19	57.6	2	6.1
My child can play house /, parents and play different roles	22*	66.7	11	33.3	-	-	23	79.7	5	15.2	5	15.2
My child can sometimes touch his genitals while he is very excited, nervous, scared	8*	24.2	25	75.8	-	-	16	48.5	15	45.5	2	6.1
My child can talk to friends about sexuality	13*	39.4	20	60.6	-	-	16	48.5	15	45.5	2	6.1
If my child is a girl, he can say he's a boyfriend	28*	84.8	5	15.2	-	-	30	90.9	-	-	3	9.1
My child might want to be alone when he gets dressed	25*	75.8	8	24.2	-	-	27	81.8	-	-	6	18.2
My child may want to be alone while taking a bath	25*	75.8	8	24.2	-	-	25	75.8	6	18.2	2	6.1
My child may say that he has heard shame jokes and sayings and may wish to repeat them	17*	51.5	16	48.5	-	-	22	66.7	8	24.2	3	9.1
My child may wonder the difference between sexes	25*	75.8	8	24.2	-	-	28	84.8	3	9.1	2	6.1
My child can imitate one of the opposite sex by role	16*	48.5	17	51.5	-	-	20	60.6	5	15.2	8	24.2
My child can examine the reproduction of animals	15*	45.5	18	54.5	-	-	19	57.6	11	33.3	3	9.1
My child can kiss other children	18	54.5	15*	45.5	-	-	10	30.3	19	57.6	4	12.1
My child can kiss adults	16	48.5	17*	51.5	-	-	8	24.2	18	54.5	4	12.1
My child may let other children kiss him	14	42.4	19*	57.6	-	-	8	24.2	21	63.6	4	12.1
My child may let adults kiss him	15	45.5	18*	54.5	-	-	6	18.2	21	63.6	6	18.2
My child can ask questions about genitals	28*	84.8	5	15.2	-	-	30	90.9	3	9.1	-	-
My child can ask questions about breasts	29*	87.9	4	12.1	-	-	30	90.9	3	9.1	-	-
My child can watch with interest when he sees someone taking a bath	31*	93.9	2	6.1	-	-	32	97.0	1	3.0	-	-
My child can play house /, parents and play different roles	29*	97.9	4	12.1	-	-	30	90.9	1	3.0	2	6.1
My child can sometimes touch his genitals while he is very excited, nervous, scared	5	15.2	28*	84.8	-	-	2	6.1	30	90.9	1	3.0

* positive response

DISCUSSION

The study was carried out to create awareness of sexual health in mothers who have children with learning disability. The sexual lives of disabled individuals are often ignored. There is a general public assumption that disabled individuals are not sexually active. However, disabled persons have sexual needs, too and sexuality is an important factor for the life quality of disabled people (Cangöl ve ark., 2013).

Sex education programs are designed to have the individual understand his/her physical, emotional, and sexual development; develop a positive personality notion; acquire a gentle perspective on human sexuality and the rights, opinions and behaviors of others; develop positive behaviors; and value judgments (Bayram Değer, Balçı, 2018; Er ve ark., 2016). This study found that mothers considered sex education as "the organization of environments that help boys and girls acquire behaviors appropriate for their roles in the society" and "providing individuals with information about sexual intercourses". İşler and Gürşimşek, the majority of the parent's evaluated sexual education as necessary for children to support development and protect themselves from sexual abuse although parents did not talk with their children about sexual issues, parents that had spoken felt uncomfortable and inadequate (İşler ve Gürşimşek, 2018). In addition, mothers defined sexuality as sexual intercourse (İşler ve Gürşimşek, 2018; Er ve ark., 2016). These results suggest that especially women in Turkey do not have adequate and accurate information about sexuality and sex education.

Sexual health and sexual life are two of the health needs of the individual in all age and developmental periods. When "sexual health" is mentioned in the society, the first thing that comes to the mind is "a satisfied and safe sexual life". However, according to the Sexuality Information and Education Council of the United States (Tepper, 2001), "sexual health" is defined as a lifelong process that addresses sex education, information, attitude development, beliefs, values, relationships, and privacy (İşler ve Gürşimşek, 2018).

By providing sex education to individuals who need special education and having the individuals gain behaviors appropriate to their genders and the society, parents, caregivers, and teachers of these individuals can feel relieved (Tepper, 2001). More than half of the mothers in the study stated that their children should be given sex education. However, when mothers were asked about "the topics that can be included in the sexual health education program", more than half of them responded as "I do not know". Very few of the mothers responded to this item as "appropriate behaviors and attitudes in the society" and "self-protection".

During the developmental processes of the disabled children, difficulties may arise due to the deviations from the norms. The problems may get even worse particularly because of the sexual development and related problems. As the psychosexual development of disabled children is not fully understood, the kind of sexual health education that should be given to these children is not known (Murphy ve Roy, 2006). Unfortunately, disabled individuals are often unable to obtain any information about sexuality. Even though sexuality is a universal human characteristic, sexual expression of disabled people is often met with severe negative reactions (McCann ve ark., 2019; Gümüş ve Altinsoy, 2015). In order to avoid these negative reactions, both the individuals and their families should be educated on issues such as meeting the sexual needs of individuals who need special education in appropriate mediums, opposite-sex orientation, physical change in adolescents, and the hygiene of sexual organs (McCann ve ark., 2019; Lockhart ve ark., 2009; Girgin-Büyükbayraktar ve ark., 2017; Schaafsma ve ark., 2015). Studies emphasize that the main reason for the lack of sex knowledge stems from the fact that this information is usually obtained from hidden, inadequate, and wrong sources (Çetinkaya ve ark., 2007; Kukulu ve ark., 2009; Civil ve Yıldız, 2010; Gürsoy ve Gençalp, 2010).

The great majority of the mothers (81.1 %) in this study stated that their children did not ask them questions about sex issues. Due to cultural understanding, children's sex-related questions have always been ignored because sex has always been a taboo. Studies report that mothers do not give any sex information to their children until questions arise. In addition, most mothers say they feel ashamed while answering children's questions (İşler ve Gürşimşek, 2018).

According to a study conducted by Siyez and et. al. on university students, more than half of the students found themselves inadequate in sex-related issues (Siyez ve ark.,2018) and 99.2% of the students stated that sex-related issues were not discussed in their family because they were considered a "shame" (Gürsoy ve Gençalp, 2010). Similarly, the mothers in this study were found to respond to the most frequently asked sex-related question of their children as "I don't want to answer it because it is too embarrassing". In addition, mothers responded to the item "do you see inappropriate sexual behaviors in your children" as "No" or "I don't want to respond to it."

In Turkish society, sex has been associated with shame and sin. In addition, traditional attitudes and taboos are known to be influential on this topic. Taboos are created by families and society. Even though they have different levels of education and belong to different cultures, most parents maintain their traditional attitude regarding this topic. For this reason, most children cannot get appropriate, adequate, and accurate information about sex from their family during their education lives (Kukulu ve ark., 2009; Gürsoy ve Gençalp, 2010; Akın ve Özvarış, 2004). Individuals with learning disability can easily be fooled since they have difficulties in distinguishing between what is true and what is not. For this reason, when determining the educational needs of individuals with learning disability about sexual development, we must be sensitive about the perceptions and expectations. Misconceptions and excessive expectations should be carefully determined in the analyses about sex education requirements (Er ve ark., 2010). A large proportion of the mothers who participated in the study stated that their children should be informed about contraception and sex (66.7 %). As is shown by many studies, disabled children need sex education (Tepper,2001; Gürol ve ark., 2014; Kök ve Akyuz, 2015). However, studies on this subject are limited. A study by Gürol et al. found that all parents who have children with learning disability ignored their children's sex education. In addition, mothers, especially those who have children with learning disability, stated that sex education was necessary for their children and that they thought this education could be given by an institution such as a rehabilitation center (Gürol ve ark., 2014). Another study reported that parents did not know how to solve problems related to the sexual development of their children with learning disability in the adolescence period (Kök ve Akyuz, 2015). 33.3 % of the mothers participating in the study stated that they did not know who should give sex education to their children, while 27.2 % of the participants stated that the education should be given by specialists. People generally think that children with learning disability do not have a sex life and family planning should not be included in sex education syllabus. They even keep their children with learning disability away from their healthy siblings for fear that they will be subjected to sexual harassment. These findings are thought to be a guide for nurses, rehabilitation centers, and schools working with children with learning disability in giving primary importance to the sex education of these children, creating awareness in families and children about this issue, maintaining healthy sexual development, and protecting these children (Gürol ve ark., 2014).

The most accurate information about sexual health should primarily be provided by families (Tutar-Güven ve İşler, 2015). For this reason, healthcare workers and especially nurses have an important role in parental education. The study of Earle emphasized that sex-related problems among disabled people should be addressed in a more holistic framework. Nurses can achieve this goal as much as possible by facilitating the expression of sexuality, helping people to talk about it, providing accessible information and services, and recognizing the sex-related needs of disabled individuals (Hall, 2018).

In general, mothers' level of knowledge about the sexual development of the child changed after the training. Similarly, there was an increase in the knowledge level of parents after the training and their interactions with their children were found to increase as well (Finan ve ark., 2016). Most parents of children with learning disability in Turkey ignore sex education needs of their children for fear that they can give wrong information to the children (Boyacıoğlu ve ark., 2018). In fact, parents are the most appropriate source of counseling for all children. Parents should be aware of their children's sexual development; in addition, they should adopt attitudes and behaviors appropriate to the development and needs of the child (Kök ve Akyuz, 2015).

The Use of Results in Practice

Due to the norms of the Turkish society, mothers avoid talking about sex and sex education with their children. Mothers, who were unable to get enough information from their parents, are also incompetent in providing information to their children. Mothers want to be educated, but they do not know how to access information. Nurses who have responsibility for protecting and improving community health also have important roles in protecting and improving the health of individuals with learning disability and their families.

For this reason, especially school nurses can help parents to increase their awareness, knowledge, and skills by providing training and rehabilitation support on issues such as sexual

health and sexual development of disabled children during adolescence.

Sexual health education programs should be organized for families who have children with learning disability. Thus, parents will be able to exhibit appropriate approaches to their children and provide the information they need. For this reason, mothers and fathers should attend sexual health education seminars and accessible information sources should be created.

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