Original Article

Development and Validation of the Sexual Development Knowledge Assessment Scale for Adolescents with Intellectual Disability

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Abstract

Aim: We aimed to develop and validate of the Sexual Development Knowledge Assessment Scale (SDKAS) in adolescents with intellectual disability.

Methodology: This methodological study was conducted with 350 adolescents with intellectual disability of the ages 12-18. The structure of SDKAS was examined using exploratory and confirmatory factor analysis and internal consistency tests were conducted for reliability. The concurrent validity was confirmed using paralel form and test-retest analyses.

Results: The exploratory factor analysis revealed six factors. The internal consistency were verified with a Cronbach's alpha of 0.829. There were significant correlations between the test-retest scores (p<0.05). As the adolescents' sexual development knowledge level (SDKAS) increases, the parents report lower negative opinions about the sexual development characteristics of their children (parallel form) (r=-0.752, p<0.001). These results support SDKAS as a valid and reliable measure of sexual development knowledge in adolescents with intellectual disability.

Conclusions: The opinions expressed by this scale, which is based on children's self-report, will enable the enrichment of the sexuality education topics created for the sexual development of children with ID in adolescence.

Keywords: Adolescents; Intellectual disability; Sexual development; Sexual health

Introduction

Sexual health is the positive enrichment, support and strengthening of personality, communication and love by considering sexual life as a whole in terms of psychological, mental, physical and social aspects. It is also the ability of the individual to express his/her sexual problems without fear of sexually transmitted infections, force, discrimination violence or unwanted pregnancies WHO, 2015). Today, sexuality and sexual health are still accepted as normal for individuals with typical development and can be denied for individuals with intellectual disabilities (ID) (Carter et al. 2022; Goli et al. 2020). However, one of the themes covered within the scope of the third of the Sustainable Development Goals, "Assuring a healthy and quality life at all ages" is sexual and reproductive health. Within the scope of this theme, it is reported that the need to set separate targets, differentiated policies, strengthen practices and create health programs for the disabled, considering the 2030 perspective (Galati, 2015).

Sexual development in Children with ID

Sexual developmental issues and knowledge of adolescents with ID may often be ignored. Adolescence encompasses a period in which

both children and their parents live e a number of changes. Sexual developmental changes in children with puberty can cause extreme anxiety and panic (Robinson et al. 2017). Some studies suggest that in children with ID, these changes are usually associated with some challenges (Arfe-ee et al., 2014; Thompson et al., 2014). Adolescents with identity are vulnerable to sexual abuse by caregivers, family members, close friends and other people; this is higher than in typically developing children (Clatos and Asare 2016). Adolescents with ID are frequently the victims of sexual abuse due to factors such as the existence of persons that want to take advantage of these adolescents' disability, their inability to express themselves adequately and because they are the product of a society that basically ignores adolescents with ID (Bakermans-Kranenburg et al. 2016; Wissink et al. 2015, 2018). Sexual abuse can have long-term consequences, such as non-compliance, risky sexual behaviors, and serious consequences, such as unwanted pregnancy, sexually transmitted infections, and human immunodeficiency virus (HIV/AIDS) (Wissink et al. 2018). The fact that especially mentally retarded adolescents are more likely to be neglected or abused reveals the importance of studies conducted to investigate the sexual development of these adolescents (Malvaso et al. 2020).

Most studies on adolescents with ID are carried out by working with their parents. These adolescents are dependent upon their caregivers (most likely their parents) for protection and meeting their needs. The degree of dependency grows in adolescents with ID. On the other hand, even though the problems of adolescents with ID can be identified and the support of their parents can be enlisted, it is a fact that their parents may not always be by the child's side (Barak-Levy and Atzaba-Poria 2020). This can leave adolescents with ID vulnerable to sexual abuse and exploitation. Because of this, one of the most important things the parents of these adolescents wish for is to be sure the child can practice self-care and protection when he/she is alone (Kurtuncu and Kurt 2020). It is vital for this reason that these adolescents' knowledge about sexual health and development is explored (Gurbuz and Eratay 2020).

The Current Study

Sexuality has an important place in the lives of children with ID. For this reason, inclusive, innovative education programs that are continuous and aimed at their physical, emotional, social and sexual development should be created and included in the content of individualized education programs. In the individualization of these trainings, it is necessary to evaluate the sexual development knowledge level of children. In addition, determining the problems experienced in the sexual development of individuals with ID in adolescence is undoubtedly possible by identifying the problems related to this period. Their development during this period will be best reflected by the children themselves. Because of this, there is a need for developing a new measuring tool based on self-reporting for evaluating the knowledge of adolescents with ID about sexual development (Nair et al. 2017). In this methodological study, our aim was to develop and validate the Sexual Development Knowledge Assessment Scale in adolescents with ID. The hypotheses of the research are as follows:

H_1: The Sexual Development Knowledge Assessment Scale in adolescents with ID is a reliable measurement tool.

H_2: The Sexual Development Knowledge Assessment Scale in adolescents with ID is a valid measurement tool.

Methods

Participants: In this study, 350 adolescents with ID of the ages 12-18 were recruited into the study from three different therapy and rehabilitation centers. The mean age of the adolescents with ID (n=350) was 14.36±0.49 (12-18); 40.3% were girl and 59.7% were boy. In this study, 43.2% of the adolescents were with mild ID (51-70 intelligence quotient), and 56.8% were with moderate ID (36-50 intelligence quotient). Intelligence quotient (IQ) of the adolescents were obtained from the data they reported to the institution they received education after being evaluated by clinicians. Because of the difficulty the adolescents with severe or very severe ID had with understanding the

questions, these adolescents were excluded from the study ("Special Education Services Regulation" 2018; Schalock et al. 2011). None of the adolescents had speech or visual disabilities.

Development of items: We drafted a set of 35 items based on qualitative findings from a prior study (Kurtuncu & Kurt, 2020). The qualitative study identified important needs for transitions using data from interviews with mothers of children with ID. Content analysis of the qualitative data has led to a theoretical framework; In this context, the issues that mothers of children with intellectual disabilities want their children to have information about sexual development have emerged. Mother identified several issues to promote the sexual development knowledge of their children; lack of information, educational needs, sexual behaviors and the social challenges in these studies. The authors revealed items in the themes and statements of the participants. The authors worked with a specialist with special education expertise to ensure that the items were appropriate for children with expressive intellectual disabilities. Some items needed to be visually supported. The fact that these images were from real photographs would make it easier for the children to understand the expressions. Images were created from real photos. The first author prepared draft scale items using accepted criteria for questionnaire development (Sudman and Bradburn 1982). The same author arranged the items according to accepted criteria in order to reduce measurement errors (Dillman 2000).

Expert provider review: The objective of this scale was explained to the experts, namely, 10 academicians (pediatric nursing, psychiatric nursing, and child development). The experts were asked to review the items. It was also stated that experts could add items that should be included in the instrument according to their field of expertise. To assess content validity, experts rated each item's relevance and intelligibility with the scale using a 4-point ordinal rating scale. Content validity index was calculated with items given 3 or 4 points by experts (Table 1).

Pilot study: Preliminary application was made to examine the comprehensibility of the form formed after expert opinion by children with intellectual disabilities. In the preliminary application, it was studied with 10 children. Scale items were administered to the children by the researchers. Children were informed that feedback would be received for expressions that were not understood. No negative feedback was received that would change the general structure of the form. The data of the children in the pre-application were not included in the data within the scope of the scale development.

Data collection: The data were collected over the period January- March 2021 with a "Descriptive Data Form, the "Sexual Development Knowledge Assessment Scale for Adolescents with Intellectual Impairments- SDKAS", and the "Sexual Development Characteristics Scale of Adolescents with Intellectual Disability". With the draft, SDKAS was administered to 350 adolescents with ID of the ages of 12-18 who were enrolled in three different therapy and rehabilitation centers. The scale was readministered two weeks later to 172 adolescents and their parents also applied SDCS while their children were administered SDKAS. The adolescents completed the questionnaire in about 30 minutes.

Descriptive Data Form: This is a questionnaire with questions on the child's gender, age, and level of intelligence quotient (IQ).

Sexual Development Knowledge Assessment Scale for Adolescents with Intellectual Disability (SDKAS): This instrument is a self-reporting instrument that is used to assess how much adolescents with ID know about their own sexual development. The scale has 33 statements (some statements includes photographs) and six factors. The six factors were: Privacy, touch, concept of private space, gender differences, safety, hygiene. Each right answer rates a score of 2; responses given with the help of the developer of the questionnaire consist of 1 point given for a right answer and 0 for an incorrect answer. There are no reversely rated items. The adolescents' responses are added together for an overall score, which can vary between 0-66. The Cronbach alpha internal consistency coefficient was 0.829.

Sexual Development Characteristics Scale of Adolescents with Intellectual Disability

(SDCS): This scale was developed by Gurbuz and Eratay (2020) to determine the sexual characteristics of individuals with ID in adolescence with the views of their parents. This scale is a five-point Likert-type scale. It consists of 9 sub-dimensions and 36 questions. These subdimensions were sexual harassment, privacy and social trust, sexual satisfaction, sexual arousal, emotional change, physical development, information requirement, sharing sexual issues and sexual care. As the total score obtained from the scale increases, the parents report higher negative opinions about the sexual characteristics of their children (Gurbuz and Eratay, 2020). In the current study, Cronbach's alpha values were as follows: 0.80 in scale total score, 0.81 in information requirement, 0.81 in sexual arousal, 0.84 in privacy and social trust, 0.84 in physical development, 0.85 in sexual harassment, 0.84 in sexual satisfaction, 0.86 in sharing sexual issues, 0.84 in emotional change and 0.83 in sexual care.

Analytical Strategies: All analyzis was carried via IBM SPSS 22.0. All statistical analyses were conducted using a significance level of $p < 0.05$. The analyses to develop and validate of SDKAS in adolescents with ID as follows:

Content validity: The Lawshe content validity index determination method was used for the item basis content validity index (CVI) and the instrument basis content validity index (CVI) (Lawshe 1975).

Construct validity: An exploratory factor analysis (EFA) was conducted to test the construct validity of the instrument. The factor loading values of each items has to be at least 0.40 and the eigen value has to be at least 1 (Samuels, 2016). The confirmatory factor analysis (CFA) was conducted via AMOS 16.0 to confirm the factor structure of the EFA.

Internal consistency reliability. In order to check the reliability, Cronbach's alpha correlation coefficient was used for subdimensions and total scale. To test the quality of items, Cronbach's alpha reliability analysis, lower 27%-upper 27% item-total correlation analysis, and item-total correlation analysis were done.

Concurrent validity: The concurrent validity was confirmed using paralel form and test-retest analyses. Pearson's correlation analysis was performed between SDKAS and SDCS. To assess the reliability of test-retest, the intraclass correlation coefficient and Pearson coefficient were used. Moreover, in order to check the association between SDKAS scores and variables (age and IQ), an additional analysis was conducted was verified by Pearson correlation confidence.

Ethical Considerations: A University Non-interventional Ethics Committee granted ethical approval for conduct of the study (Date: 10/14/2020, No. 2020/20), after which permission was also obtained from the special education and rehabilitation centers. Before the start of the study, information was provided to the children and their parents about the purpose of the study, the administrative management and the teachers concerned. Written consent was received from the parents for their child's participation after first being informed of the purpose and scope of the study and about the confidentiality of data.

Results

Exploratory factor analysis (EFA): Kaiser-Meyer-Olkin (KMO) coefficient and Bartlett Sphericity test were performed to check the scale's suitability for principal component analysis. The data was suitable for EFA (KMO=0.728, $\chi 2=280.826$; $p<0.001$) (Pallant and Manual 2001). Kaiser normalization rotation method was performed in order to ensure the structure of the scale. Tabachnick and Fidell (2007) recommend looking at the correlations between dimensions when deciding which rotation method to use. If the correlations exceed 0.32, it means that there is 10% and more variance overlap between the factors, which is sufficient variance to warrant the oblique return. The correlations were over 0.32 between factors in this current study (Table 2).

Two items had less than 0.40 factor load were removed (i.e.,"Can you point to the shaded parts in the picture of the adolescents that are the parts of the body that must not be touched without permission? (Picture 1)" and "What should you do if you like somebody?") and the analysis re-run (Samuels 2016). Afterwards, a six-factor structure (Privacy, touching, concept of

private space, gender differences, safety and hygiene) comprising three items remained that had an eigenvalue greater than 1 (Figure 1). The results of the exploratory factor analysis showed that the eigenvalue of Privacy was 13.124 and explained 32.195 of the variance; the eigenvalue of Touching was 6.025, explaining 18.257 of the variance; the eigenvalue of Concept of Private Space was 4.729, explaining 12.331 of the variance; the eigenvalue of Gender differences was 3.916, explaining 10.867 of the variance; the eigenvalue of Safety was 3.058, explaining 9.266 of the variance; and the eigenvalue of Hygiene was 1.258, explaining 7.811 of the variance. The total variance explained was 58.915. It is sufficient for multicomponent constructs to have a total explained variance of between 40%-60% (Table 1).

Confirmatory factor analysis: Confirmatory factor analysis was conducted on the 33 items of the scale using the same sample (n = 350; M = 33.79, SD = 7.18). Figure 2 shows the path diagrams of the standardized results obtained from the confirmatory factor analysis. Goodness of fit criteria were: Chi-square/sd=1.34, root mean square error of approximation (RMSEA)=0.005, standardized root mean square residual (SRMR)=0.013, normed fit index (NFI)=0.91, comparative fit index (CFI)=0.96, adjusted goodness of fit index (AGFI)=0.96, goodness of fit index (GFI)=0.91. According to these results, the data from the measuring instrument displayed an acceptable fit.

Internal consistency coefficient: This coefficient of the scale was calculated separately for the six subdimensions as well as for the whole scale.

As a result of the conducted analyses, the Cronbach alpha value was 0.749 for the Gender Differences, was 0.729 for the Touch, was 0.758 for the Concept of Private Space, was 0.713 for the Privacy, was 0.751 for the Hygiene, was 0.737 for the Safety, and was 0.829 for the whole scale (Table 1).

Lower 27%-upper 27% item-total correlation: A significant difference was seen on the scale between the total scores of the Upper 27% and the Lower 27% groups (p<0.001). This significant difference between the lower and upper groups was interpreted to indicate evidence of item discrimination (Table 1).

Concurrent validity: The correlations between SDKAS and SDCS were investigated to determine the concurrent validity of the SDKAS, The higher scores of SDKAS correlated negatively with SDCS (r=-0.752, p<0.001). The higher scores of SDKAS correlated positively with the age (r=0.426, p<0.001) and IQ (r = 0.787, p < 0.05). The results were shown in Table 3.

Test-retest reliability: The tools were administered to a group of 172 adolescents with ID at 2-week intervals. The test-retest coefficients values were found to be 0.749 for the Gender Differences subscale, 0.716 for the Touch subscale, 0.711 for the Concept of Private Space subscale, 0.799 for the Privacy subscale, 0.618 for the Hygiene subscale, 0.714 for the Safety subscale, and 0.792 for the whole scale (p < 0.05) (Table 1). The intraclass correlation coefficient demonstrated high correlations between the measurements of the scale (r=0.829, p<0.05).

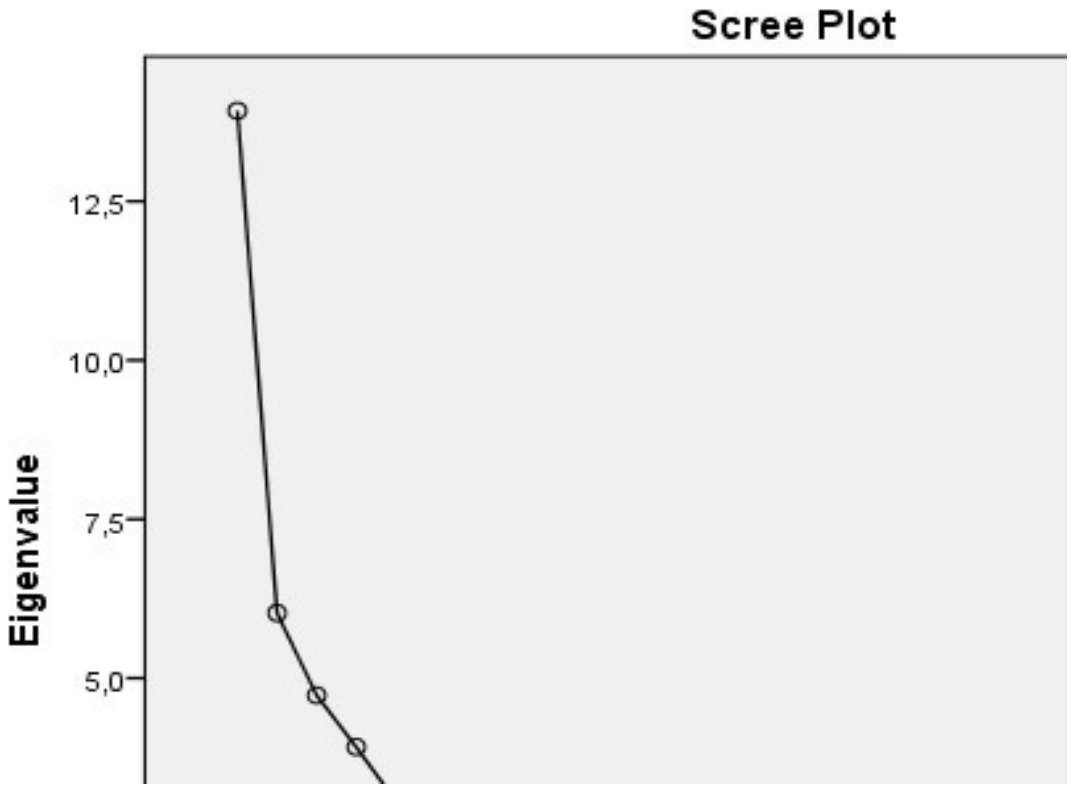

Figure 1. Slope of scree plot

Table 1. Reliability for Sexual Development Knowledge Assessment Scale

Factors	Items	Number in Experts Agreement	Factor Loading (EFA) [1]	Eigenvalue[1]	Explained variance[1]	Total variance explained[1]	Corrected Item-Total Correlations[1]	*t* (Lower 27%-Upper 27%)[2]	Cronbach's Alpha (Test)[1]	Cronbach's Alpha (Re-test)[3]
Gender differences	1	8	0.782	3.916	10.867	52.649	0.839	12.258*	0.749	0.749
	2	8	0.701				0.635	15.598*		
	3	8	0.699				0.529	7.345*		
	4	7	0.667				0.632	9.664*		
	5	7	0.659				0.554	17.270*		
Touch	6	7	0.727	6.025	18.257	44.452	0.599	12.060*	0.729	0.716
	7	10	0.729				0.572	12.631*		
	25	10	0.717				0.633	14.118*		
	26	10	0.713				0.614	13.791*		
	27	110	0.684				0.580	8.328*		
	30	10	0.673				0.622	9.295*		
Concept of private space	8	8	0.511	4.729	12.331	47.782	0.557	10.543*	0.758	0.711
	9	10	0.472				0.503	10.118*		
	10	8	0.503				0.541	9.345*		
	11	10	0.524				0.616	10.874*		
	12	8	0.565				0.512	7.328*		
	13	8	0.446				0.776	10.958*		
Privacy	14	8	0.540	13.124	32.195	40.195	0.766	12.219*	0.713	0.799
	15	10	0.560				0.645	10.480*		
	17	10	0.500				0.645	11.858*		
	18	10	0.443				0.735	12.219*		
	28	10	0.483				0.632	10.938*		

	29	**10**	**0.602**				**0.584**	**8.428***	
	31	**10**	**0.529**				**0.550**	**7.862***	
	32	**10**	**0.656**				**0.781**	**15.690***	
Hygiene	**16**	**8**	**0.663**				**0.779**	**9.958***	
	19	**10**	**0.517**	**3.058**	**9.266**	**58.915**	**0.689**	**11.239***	**0.751**	**0.618**
	20	**7**	**0.505**				**0.576**	**8.470***	
	33	**19**	**0.600**				**0.743**	**12.547***	
Safety	**21**	**8**	**0.726**				**0.679**	**9.319***	
	22	**8**	**0.705**	**3.058**	**9.266**	**58.915**	**0.756**	**11.957***	**0.737**	**0.714**
	23	**8**	**0.747**				**0.741**	**12.429***	
	24	**10**	**0.713**				**0.645**	**10.493***	
Total				**1.258**	**7.811**	**67.727**			**0.829**	**0.792**

EFA, Explanatory factor analysis; Extraction method, principal; Rotation method, Direct Oblimin with Kaiser Normalization; [1]n=350 [2]n_1=95; n_2=95 [3]n=172; *p<0.001

Table 2. Correlations between subfactors of Sexual Development Knowledge Assessment Scale

	Privacy	**Touch**	**Concept of private space**	**Gender differences**	**Safety**	**Hygiene**
Privacy	1.00					
Touch	0.332*	1.00				
Concept of private space	0.457*	0.428*	1.00			
Gender differences	0.343*	0.311*	0.427*	1.00		
Safety	0.381*	0.398*	0.325*	0.371*	1.00	
Hygiene	0.329*	0.317*	0.368*	0.326*	0.339*	1.00

*p<0.05

Table 3. Association between Sexual Development Knowledge Assessment Scale Scores age, and intelligence quotient levels of adolescents with intellectual disability

		SDKAS
Age	**Rho**	0.426**
Intelligence quotient	**Rho**	0.787**
SDCS	**Rho**	-0.752**

Pearson correlation analysis was performed. **Correlation is significant at the 0.01 level (two-tailed). SDCS: Sexual Development Characteristics Scale of Adolescents with Intellectual Disability, SDKAS: Sexual Development Knowledge Assessment Scale for Adolescents

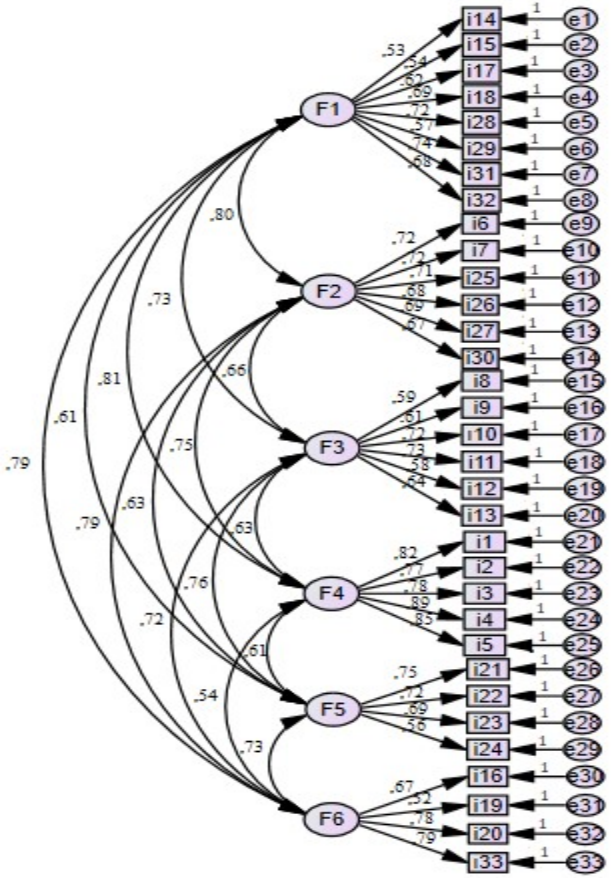

Figure 2. Standardized scores of six-factor structure of Sexual Development Knowledge Assessment Scale

Discussion

The results of this study indicate that the Sexual Development Knowledge Assessment Scale is a valid measure based on self-reporting in adolescents with ID. The exploratory factor analysis revealed six components: Privacy, Touch, Concept of private space, Gender differences, Safety and Hygiene. This structure was confirmed by the confirmatory factor analysis. The internal consistency were verified with a Cronbach's alpha of 0.829.

To our knowledge, this instrument is one of the first to be developed for assessing sexual development knowledge assessment based on self-reporting in adolescents with ID in Turkey. There is only one measuring instrument used in Turkey for assessing the sexual development of adolescents with ID; this tool is based on parent-reporting (Gurbuz and Eratay 2020). The most accurate measures, even for the assessment of ID, are those that are based on self-reporting.

Measures based on self-reporting will allow for the most accurate and effective evaluation of a child's level of knowledge about sexual development, making it possible to carry out needed interventions (Ibrahim 2021).

The authors prepared the draft scale of 35 items based on the results from some studies in the literature (Guven and İşler, 2015; Kurtuncu and Kurt 2020; Roden et al. 2020). The measuring tools in the literature that had been developed to determine the level of knowledge of adolescents with ID about sexual development contained statements and pictures that would be difficult to understand (Blasingame et al. 2015; Leighton 2019; Richards 2018). Faculty members in pediatric nursing and child development were consulted about the statements and pictures in the draft scale in terms of their suitability for adolescents with ID. After receiving the experts' opinions, the statements were tested in a pilot study with 15 adolescents with ID.

The exploratory factor analysis revealed a six-factor construct. The common concepts that could be associated with the factors were given the headings, "privacy," "touch," "concept of private space," "gender differences," "safety" and "hygiene." Another scale evaluating sexual development in adolescents with ID included factors that were named, "body parts," "public and private spaces," "adolescence," "masturbation," "relationships," "social-sexual boundaries," "sexuality," "safe sex," and "sex and the law." Because this measure contained a great many questions and included such matters as sexual relations, the descriptions of the factors in the scale in the present study are different and the number of items is less (Richards, 2018). Another measure developed in our country comprised the factors, "sexual arousal," "need for knowledge," "privacy and social safety," "knowledge about bodily development," "sexual abuse," "impulse to seek sexual satisfaction," "sharing of sexual matters," and "emotional change and sexual self-care." Since this instrument was based on evaluations made by parents, more areas of knowledge could be explored, which increased the number of factors in the scale. Both measuring tools are similar in terms of the nature of the factors (Gurbuz and Eratay 2020).

The intraclass correlation coefficient demonstrated high correlations between the measurements of the scale for test-retest stability. Due to the intellectual difficulty of the adolescents in the study, an interval of 2 weeks was seen to be sufficient. Test-retest reliability measures the consistency of a scale over time. The time that elapses between the two applications of test and retest should not be short enough to allow the responders to remember the answers they provided in the first test. These result confirms the reliability of the instrument, as a tool to assess knowledge the sexual development knowledge assessment scale for adolescents with ID, even over time (Cohen 1988).

In this study, the concurrent validity of SDKAS was confirmed using parallel form (SDCS). According to analysis of the correlation between them, as the child's sexual development knowledge level (SDKAS) increases, the parents report lower negative opinions about the sexual development characteristics of their children (SDCS) ($r=-0.752$, $p<0.001$). The high

scores on the SDKAS are associated with the excess of parents' negative opinions about their children's sexual characteristics (Gurbuz and Eratay 2020). A negative correlation between SDKAS and SDCS is supported in the literature (Kucuk et al. 2017; Top 2021). Parents with intellectual disabilities adolescents with high sexual knowledge scores have lower levels of negative opinions about the sexual characteristics of their children (Top 2021). Adolescents with ID who receive sexual development and health education and have high sexual knowledge exhibit a higher rate of correct sexual behaviors (Kucuk et al. 2017).

As a result of this study, the higher scores of SDKAS correlated positively with the age ($r=0.426$, $p<0.001$). In the scales developed for children and adolescents with ID, the compatibility between the scale and age is commonly considered to evaluate the psychometric properties (Dovgan et al. 2019; Kumar et al. 2021; McKenzie et al. 2019). Age of adolescents with intellectual impairents have a strong association with their sexual health knowledge level (Nunes et al. 2017; Obasi et al. 2019). Younger adolescents with intellectual impairents may have lower knowledge and therefore they may exhibit higher risky sexual behaviors (Nunes et al. 2017). Therefore, the correlation between SDKAS and age was examined and the positive correlation appeared to support the literature.

Determining the problems experienced in the sexual development of individuals with ID in adolescence is undoubtedly possible by identifying the problems related to this period. Their development during this period will be best reflected by the children themselves. The opinions expressed by this scale, which is based on children's self-report, will enable the enrichment of the sexuality education topics created for the sexual development of children with ID in adolescence.

Limitations: The study did not examine whether the SDKAS performed differently among adolescents with or without ID. SDKAS also needs testing among adolescents with or without ID. The sensitivity and specificity of SDKAS can be examined for the future studies.

Conclusion: Our results showed that the Sexual Development Knowledge Assessment Scale can be considered as a valid instrument based on self-reporting to assess sexual development knowledge in adolescents with ID. In addition to the general scale of the scale, structural domains are related to the measurement of sexual development knowledge of adolescents with ID. The fact that the scale items contain photographs makes it easier for these adolescents to understand and interpret the questions. Considering that the scale development study was conducted with only Turkish adolescents, the Sexual Development Knowledge Assessment Scale for adolescents with ID should also be tested for validity and reliability in other cultures. Also, the use of the Sexual Development Knowledge Assessment Scale for adolescents with ID in other disability type studies and with different data collection tools, and the interpretation of the findings as a whole, will increase the importance of the study and improve the development of the sexual development information assessment scale of children with intellectual disability in adolescence.

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