

# Nurses' Challenges of Caring for Children with Intellectual Disabilities in Acute Care Settings\*

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## ABSTRACT

**Objective:** The purpose of this study is to better understand the challenges of nurses who care for children with intellectual disabilities (ID) in acute care settings.

**Materials and Methods:** This is a descriptive and cross-sectional study that included 94 nurses working at pediatric wards who agreed to participate in the study. The researcher-designed, expert-evaluated survey assessed participants' demographics and challenges while caring for children with ID. Data analysis involved descriptive statistics, correlations, and multiple linear regression analysis to determine the factors that affect the experiences of nurses who provide care for children with ID.

**Results:** The nurses reported that they encounter various challenges while caring for a child with an ID in the hospital. These are patient and family-related challenges, nurses-related challenges, health professionals, and health system-related challenges.

**Conclusion:** Communication and handling challenging behaviors of children with ID were specified as the most important issues. The nurses also reported that they did not have enough knowledge and education about caring for children with ID. Understanding the challenges and experiences of nurses are important for the development of services for children with intellectual disabilities at the hospital. There is a need for training, institutional arrangements, and policies to increase the quality of care for children with ID.

**Keywords:** Children, intellectual disabilities, nursing, hospital, acute care

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## INTRODUCTION

A large number of children worldwide are born physically and mentally ill or get a disease later and become disabled (1,2). Intellectual disability (ID) involves significant limitations in both intellectual functioning and adaptive behavior, which includes many social and practical skills requiring special care and rehabilitation (3). Although ID is not a disease, children with ID show many health problems, more than other children (3,4), such as epilepsy, asthma (3), eating problems (5,6), obesity (7), and pneumonia (3). Due to these health problems, they need more care and are hospitalized frequently (3). Despite the increased utilization of health care services by children with ID

and their families, they experience poorer health outcomes (3).

Children with ID may have significant and complex care needs (8). Studies in the literature emphasize that nurses feel inadequate, fearful, and anxious while providing care to children with ID (9-12). These challenges experienced by nurses while providing care to children with ID may also negatively affect the healthcare services provided to these children (8). Identifying the challenges that nurses face in the care of children with ID is one of the primary steps necessary to increase the quality of health care received by these children and their families.

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Children with ID are often hospitalized to be provided with health services in our country. Although pediatric nurses take care of these children in pediatric wards, no study has been found by the authors to determine the challenges faced by pediatric nurses while caring for them in Turkey. This study aimed to better understand the challenges of nurses who care for children with ID.

## MATERIALS AND METHODS

### Aim and design

This study used a cross-sectional descriptive survey to better determine the factors affecting the nurses' challenges in caring for children with ID during hospitalization.

### Research questions:

1. What are the challenges of nurses in caring for children with ID during hospitalization?
2. What are the factors affecting the nurses' challenges in caring for children with ID during hospitalization?
3. What is the level of predicting the descriptive characteristics of the challenges experienced by the nurses while caring for a child with ID?

### Participants

Participants for this study were nursing staff working at a pediatric ward in Turkey. To be included in the study, participants were required to have been caring for the children with ID for at least 6 months. The study participants were recruited through emails, announcements, and word of mouth. The sample size was determined as 135 for multidimensional linear regression analysis based on 14 variables with a significance level of 0.05, a power of 80%, and a medium effect size of 0.15 in the GPOWER 3.0 statistical analysis program. Ninety-four of the nurses could be reached through an online platform.

### Data collection tools

Data were collected through an electronic, researcher-developed, expert-evaluated survey. Researchers used studies on knowledge and attitudes about children with ID in healthcare to inform the survey item and scale development. This study was approved by Koç University's Ethics Board.

**The Sociodemographic Form:** It consists of 8 questions including the sociodemographic characteristics of the nurses who agreed to participate in the study.

**The Nurses' Challenges for Care of Children with Intellectual Disabilities Scale (NC-CCIDS):** The scale was developed based on a review of the literature on the experiences and challenges of nurses in the care of children with ID when they are hospitalized (8,9,12). The scale was reviewed by a panel of 10 experts (nurses, psychologists, and counselors) about children with ID. It was evaluated with the content validity index for the opinions of the experts. The content validity index of the items (I-CVI) was in the range between 0.99-1.00, and the content validity index of the scale (S-CVI) was between 0.99. If the I-CVI and S-CVI values are above 0.80, it indicates that there is an agreement between the expert opinions (14). In this study, the

I-CVI and S-CVI values were above 0.80, indicating that there was agreement among the experts and that the scale measured the subject adequately. The final survey consisted of 27 items. Twenty-seven items asked nurses to rate the degree to which they have faced or anticipate facing challenges in the care of children with ID when they take care of the children in the hospital. These items were rated using a 4-point Likert scale anchored with endpoints 1- "not at all" to 4- "extreme". The Kaiser-Meyer-Olkin coefficient (KMO) of the scale was 0.761 and the Barlett test result was  $X^2=1237,057$ ,  $p=0.001$ . Explanatory factor analysis was conducted to determine the factor structure of the scale consisting of 27 items. In the explanatory factor analysis, the scale has a structure with three sub-dimensions. As a result of the explanatory factor analysis, the factor loads of the child and family-related challenges sub-dimension were in the range of 0.36-0.63, the factor loads of the nurses-related challenges sub-dimension were in the range of 0.36-0.84, and the factor loads of the system related challenges sub-dimension were in the range of 0.32-0.55. After the analysis, the total variance presented is 46.33%. The presented variance ratios of the sub-dimensions are, respectively; 27.07% for "the child and family-related challenges" sub-dimension and 10.27% for "the nurses-related challenges" sub-dimension, and 8.98% for "the system-related challenges" sub-dimension. The reliability coefficient of the scale is  $\alpha=0.888$ .

### Ethical considerations

Ethical approval was obtained from the University Social Sciences Ethics Evaluation Committee (No:2020.333.IRB3.120; 5 September 2020) and participants signed a consent form. The research was conducted with those who agreed to participate by clicking on the "I agree to participate in this research" option. All nurses were informed about the purpose and procedure of the study through Qualtrics. The research was conducted by the principles of research and publication ethics.

### Data analysis

The SPSS 23.0 package program was used for the analysis of the data. Mean and percentage calculations were used for evaluating the descriptive data. The Shapiro-Wilk test was used to determine the normality of scale scores. Mann Whitney U and Kruskal Wallis tests were used to compare the mean scores of The Nurses' Challenges for Care of Children with Intellectual Disabilities Scale (NC-CCIDS) according to sociodemographic characteristics. Using the Bonferroni-corrected Mann-Whitney U test, which measurement caused the difference according to the work period and the unit they work in as a pediatric nurse was determined. Multiple linear regression analysis was used to determine the factors that affect the experiences of nurses who provide care for children with ID. To decide which independent variable to be included in the model (to determine if there are multiple correlations), tolerance, VIF, and condition index values were used. Independent variables below the VIF value of 10, above the tolerance value of 0.2, and below the condition index values of 15 were included in the regression analysis. Results will be evaluated at a confidence interval of 95% and a significance level of  $p<0.05$ .

## RESULTS

Nurses' challenges in caring for children with ID during hospitalization are shown in Table 1.

The sociodemographic data of the nurses are shown in Table 2. It was determined that the nurses were not homogeneous in terms of sociodemographic characteristics ( $p>0.05$ ).

There was no statistically significant difference between the total mean scores of the nurses from the scale and their age, education level, duration of employment, the hospital type they work in, the frequency of caring for the child with ID, the education about the care of the child with ID, the unit where they received training in the care of the child with ID, the presence of an ID person in their own family ( $p>0.05$ , Table 2). In addition, a statistically significant difference was shown between the gender of the nurses and their duration of employment as pediatric nurses and the total scores they got from the nurse-related challenges sub-dimension of The Nurses' Challenges for Care of Children with Intellectual Disabilities Scale (NC-CCIDS) ( $p<0.05$ , Table 2). There was a statistically significant difference between the unit, in which the nurses work, and the total mean scores collected by the nurses from the child and family-related challenges

sub-dimension ( $p<0.05$ , Table 2). Additionally, a statistically significant difference was reflected between the situation where the nurses find the knowledge about the care of a child with ID sufficient and the total score and the mean scores, they got from the nurses-related challenges sub-dimension ( $p<0.05$ , Table 2). Using the Bonferroni-corrected Mann-Whitney U test, which measurement caused the difference in the employment period worked as a pediatric nurse was determined. Since there are three pairs of comparisons in the analysis, the accepted significance level ( $p=0.05$ ) should be divided by three to determine the new level of significance. The new level of significance is  $0.05/3=0.016$ . As the result of the test, there was a statistically significant difference between nurses working as pediatric nurses between the period of 0-5 years and 11 years and over according to the duration of their employment ( $p<0.001$ ). It was found that the total mean scores of nurses with a duration of employment of 11 years or over collected from NC-CCIDS during Hospitalization was higher and the nurses faced challenges more often. In addition, which measurement caused the difference according to the unit they worked in was determined using the Bonferroni correct Mann-Whitney U test. Since there are six pairs of comparisons in the analysis, the new level of significance is  $0.05/6=0.008$ . According to the test results, it was determined that the difference was caused by the nurses working in the pediatric

**Table 1: Nurses' challenges for caring children with intellectual disabilities during hospitalization (N=94)**

Challenges	Mean±SD
1. Communicating with the child	2.48 ± 0.71
2. Not fully able to understand the child's symptoms	2.28±0.67
3. Taking the child's history	2.28±0.83
4. Determining the situations that child likes/dislikes	2.38±0.60
5. Child having unpredictable behaviors (repetitive and aggressive behaviors, etc.)	2.52±0.69
6. Family attitude (collaborative/non-supportive)	2.21±0.77
7. Family not having enough information about the child's disability	2.20±0.63
8. Family members not accepting the child's disability	2.04±0.81
9. Role conflict between family and healthcare professionals in providing care	2.17±0.68
10. Interventions by family members making the care process difficult-Family members interfering with the care process	2.21±0.65
11. Unwillingness of team members to provide care for the child	1.88±0.77
12. Team members avoiding talking to family members	1.79±0.76
13. Fear of hurting the child while providing care	2.04±0.67
14. Lack of experience in providing care for a child with intellectual disabilities	2.07±0.76
15. Lack of knowledge about providing care a child with intellectual disabilities	2.16±0.70
16. Feeling inadequate in providing care for a child with intellectual disabilities	2.14±0.74
17. Absence of a social worker in the institution	2.17±0.94
18. Absence of a psychologist in the institution	2.10±0.97
19. Inadequate legal regulations/procedures for providing care for a child with intellectual disabilities	2.45±0.86
20. Very short service visitation periods	1.97±0.93
21. Having not appropriate physical environment (quiet, with less stimulus) for a child with intellectual disabilities	2.60±0.80
22. Inadequate communication between nurses	1.88±0.80
23. Absence of a primary physician responsible for the child's treatment	2.27±0.96
24. Making unnecessary interventions	2.00±0.80
25. Having high patient-nurse ratio	3.15±0.81
26. Having limited time while caring for a child with intellectual disabilities	3.01±0.81
27. Lack of guidelines for the care of a child intellectual disabilities	2.98±0.80

SD: Standard Deviation

**Table 2: Evaluation of challenges factors scores according to sociodemographic characteristics of nurses (N=94)**

Variables	Nurses' Challenges for Caring Children with Intellectual Disabilities During Hospitalization						
			Patient and family related challenges score	Nurses related challenges score	System related challenges score	Total score	
	n	%	Mean±SD	Mean±SD	Mean±SD	Mean±SD	
Age	20-29 years	47	50.0	22.78±4.19	11.35±3.56	26.00±5.76	60.14±0.28
	30-39 years	21	22.3	22.57±3.15	11.85±0.69	27.85±7.22	62.28±8.71
	40 years and above	26	27.7	24.66±4.93	13.00±4.00	27.33±8.14	65.00±16.82
	Test value			$\chi^2: 1.292$	$\chi^2: 0.615$	$\chi^2: 0.200$	$\chi^2: 0.058$
				<i>p: 0.524</i>	<i>p: 0.735</i>	<i>p: 0.905</i>	<i>p: 0.972</i>
Gender	Female	92	97.9	22.75±4.16	11.96±3.29	26.44±5.86	61.16±10.63
	Male	2	2.1	24.00±8.48	17.50±0.70	32.00±1.41	73.50±10.60
	Test value			<i>U: 85.500</i>	<i>U: 10.000</i>	<i>U: 32.000</i>	<i>U: 28.000</i>
	** <i>p</i>			<i>p: 0.864</i>	<i>p: 0.031*</i>	<i>p: 0.115</i>	<i>p: 0.093</i>
Education level	Associate Degree	8	8.5	24.00±2.32	10.37±2.55	23.25±3.95	57.62±7.22
	Undergraduate Degree	54	57.4	22.16±4.80	12.14±3.78	26.42±6.14	57.74±11.87
	Graduate Degree	32	34.0	23.50±3.30	12.40±2.65	27.62±5.56	63.53±9.14
	Test value			$\chi^2: 4.253$	$\chi^2: 3.233$	$\chi^2: 4.573$	$\chi^2: 3.600$
				<i>p: 0.119</i>	<i>p: 0.199</i>	<i>p: 0.102</i>	<i>p: 0.165</i>
Total employment duration in the profession	0-5 years	35	37.2	22.54±4.39	11.36±3.69	25.27±6.19	59.18±10.51
	6-10 years	24	25.5	22.25±2.76	11.62±2.06	26.12±5.02	60.00±7.23
	11 years and above	35	37.2	25.00±4.30	12.60±2.96	30.80±7.49	68.40±13.01
	Test value			$\chi^2: 4.699$	$\chi^2: 3.428$	$\chi^2: 0.324$	$\chi^2: 1.172$
				<i>p: 0.095</i>	<i>p: 0.180</i>	<i>p: 0.850</i>	<i>p: 0.557</i>
Employment duration as a pediatric nurse	0-5 years	52	55.3	22.26±3.78	11.46±3.18	25.60±5.65	59.33±9.13
	6-10 years	15	16.0	22.80±3.34	11.40±2.50	28.00±7.38	62.20±9.73
	11 years and above	27	28.7	25.75±4.57	13.00±3.26	29.25±7.67	68.00±14.98
	Test value			$\chi^2: 1.316$	$\chi^2: 5.802$	$\chi^2: 0.152$	$\chi^2: 0.625$
				<i>p: 0.518</i>	<i>p: 0.050*</i>	<i>p: 0.927</i>	<i>p: 0.732</i>
Hospital type they work in	Public hospital	77	81.9	23.47±3.72	12.00±2.94	27.39±6.34	62.76±10.01
	Private/foundation hospital	17	18.1	19.33±3.51	9.66±3.05	22.66±4.04	51.66±8.14
	Test value			<i>U: 637.000</i>	<i>U: 572.000</i>	<i>U: 530.000</i>	<i>U: 592.500</i>
	** <i>b</i> <i>p</i>			<i>p: 0.863</i>	<i>p: 0.415</i>	<i>p: 0.220</i>	<i>p: 0.542</i>
Unit they work in	Pediatric internal medicine/ surgery	53	56.4	23.71±4.73	12.60±3.72	27.60±5.90	63.92±12.21
	Pediatric intensive care	26	27.7	21.57±2.77	11.65±2.57	25.57±4.80	58.80±6.06
	Pediatric oncology	8	8.5	20.62±3.96	9.87±3.22	21.12±3.44	51.62±5.60
	Other	7	7.4	22.57±3.15	12.28±2.21	28.57±7.89	63.42±9.21
	Test value			<i>t: 4.892</i>	<i>t: 1.790</i>	<i>t: 2.316</i>	<i>t: 3.751</i>
				<i>p: 0.027*</i>	<i>p: 0.181</i>	<i>p: 0.128</i>	<i>p: 0.050</i>
The frequency of care for the child with intellectual disabilities	Every day	17	18.1	22.00±4.12	11.00±3.05	27.28±9.03	60.28±14.27
	1-2 days a week	23	24.5	21.60±4.33	11.40±3.64	28.60±4.82	61.60±11.05
	3-4 days a week	17	8.1	22.40±2.79	11.20±3.03	23.20±4.08	56.80±5.97
	1-2 days a month	30	31.9	24.50±3.39	12.50±2.58	28.16±5.07	65.16±8.54
				<i>t: 2.393</i>	<i>t: 5.906</i>	<i>t: 2.559</i>	<i>t: 1.186</i>
				<i>p: 0.664</i>	<i>p: 0.206</i>	<i>p: 0.634</i>	<i>p: 0.880</i>
The training received related to the care of the child with intellectual disabilities	Yes	24	25.5	22.95±3.88	11.70±2.99	26.70±6.23	61.37±10.34
	No	70	74.5	22.71±4.34	12.21±3.48	26.51±5.77	61.44±10.93
	Test value			<i>U: 800.000</i>	<i>U: 789.500</i>	<i>U: 809.500</i>	<i>U: 802.500</i>
				<i>p: 0.728</i>	<i>p: 0.660</i>	<i>p: 0.791</i>	<i>p: 0.745</i>
The unit where they received training related to the care of the child with intellectual disabilities (N= 24)	University	14	58.3	23.71±3.93	11.92±3.02	27.35±6.12	63.00±10.88
	In-house trainings	8	33.3	22.12±4.18	11.50±3.50	23.62±5.23	57.25±9.80
	Other	2	8.3	21.00±1.41	11.54±3.46	34.50±3.53	66.50±4.94
	Test value			<i>t: 1.544</i>	<i>t: 0.275</i>	<i>t: 5.060</i>	<i>t: 1.533</i>
				<i>p: 0.462</i>	<i>p: 0.872</i>	<i>p: 0.080</i>	<i>p: 0.465</i>
Finding the knowledge about the care of a child with intellectual disabilities sufficient	Yes	40	42.6	22.12±3.56	10.65±2.69	25.75±5.62	58.52±8.70
	No	54	57.4	23.25±4.60	13.14±3.42	27.16±6.00	63.57±11.63
	Test value			<i>U: 876.500</i>	<i>U: 629.000</i>	<i>U: 900.000</i>	<i>U: 783.000</i>
				<i>p: 0.118</i>	<i>p: 0.001*</i>	<i>p: 0.168</i>	<i>p: 0.023*</i>
The presence of a person with intellectual disability in the family	Yes	4	4.3	24.00±3.16	10.50±0.57	23.75±1.89	58.25±5.25
	No	90	95.7	22.72±4.25	12.15±3.41	26.68±5.95	59.28±10.90
	Test value			<i>U: 139.500</i>	<i>U: 114.000</i>	<i>U: 125.000</i>	<i>U: 149.500</i>
				<i>p: 0.446</i>	<i>p: 0.214</i>	<i>p: 0.302</i>	<i>p: 0.567</i>

\*Kruskal Wallis Test; \*\*Mann Whitney U Test; SD: Standard Deviation

internal medicine units and the difference was statistically significant ( $p < 0.001$ ).

The total mean score of the nurses collected from NC-CCIDS was  $61.42 \pm 10.73$ . It was found that the mean score of the NC-CCIDS Child and Family-related challenges sub-dimension was  $22.77 \pm 4.21$ , the mean score of the NC-CCIDS Nurses-related challenges sub-dimension was  $12.08 \pm 3.35$  and the mean score of NC-CCIDS System-related challenges sub-dimension was  $26.56 \pm 5.86$ .

As a result of the analysis, variables that statistically and significantly affect the challenges that nurses face while providing care to a child with ID (gender, employment duration as a pediatric nurse, the unit they work in), and find the knowledge about the care of a child with ID sufficient were included in the regression model (Table 3). According to the association between variables in multiple regression analysis, the effect of nurses' introductory characteristics on the challenges they face while caring for a child with ID was specified as a model. According to the model, the challenges faced by nurses who are male, nurses working as pediatric nurses for 11 years or more, nurses working in pediatric internal medicine and surgical units, and nurses who do not find the level of knowledge about caring for a child with ID sufficient, are increasing. The variables in the model explain 13.5% of the challenges faced while caring for a child with ID and are statistically significant. In addition, it was reflected that the unit where nurses in the model work significantly affect the frequency of challenges faced while caring for a child with ID ( $p < 0.05$ , Table 3).

## DISCUSSION

The nurses reported that they had various challenges while caring for a child with an ID in the hospital. These challenges experienced by the nurses are discussed under three headings: patient and family-related challenges, nurses-related challenges, and system-related challenges.

### Child and family-related challenges

Most of the nurses indicated that they had some challenges in providing care due to the situation of the child and the family. It was found that nurses generally have problems in communicating with the child, taking the history of the child, determining the symptoms, and managing the child's challenging behaviors.

### Communication with children

In this study, one of the most experienced challenges faced by nurses was communication with the children. The nurses stated that they had challenges while they were taking the health histories of children, determining their symptoms and what they like or do not like. Similarly, communication is stated as an important problem by mothers of children with ID (14,15) and nurses in the literature (15). It was found that communication difficulties with these children were related to the lack of education and experience of nurses (16,17). As a result of the studies, it is stated that training nurses starting from undergraduate education will increase the nurse's self-confidence in care and the quality of care of children. In addition, it has been emphasized the importance of teaching nurses about communication strategies with children with ID and collaboration with other professionals with in-service training (18,19).

**Table 3: The Level of prediction of nurses' descriptive characteristics of challenges faced while caring for a child with intellectual disabilities (N=94)**

	The Nurses' Challenges for Care of Children with Intellectual Disabilities Scale						
	Model 1						
	Unstandardized Coefficients $\beta$	Coefficients Std. Error	Standardized Coefficients Beta	t	p	95% Confidence Interval	
						Lower	Upper
Gender <sup>a</sup>	10.729	7.374	0.145	1.455	0.149	-3.924	25.382
Employment duration as a pediatric nurse <sup>b</sup>	-2.648	2.495	-0.112	-1.061	0.291	-7.606	25.382
Unit they work for <sup>c</sup>	5.673	2.289	0.264	2.479	0.015	1.125	10.220
Finding the knowledge about the care of a child with intellectual disabilities sufficient <sup>d</sup>	2.761	2.303	0.128	1.199	0.234	-1.815	7.337
R			0.367				
R <sup>2</sup>			0.135				
F			3.465				
p			0.011				
Durbin Watson (1.5-2.5)			1.947				

<sup>a</sup>The female gender is coded as "0" and the male is coded gender as "1".

<sup>b</sup>Employment periods of 10 years or less are coded as "0" and 11 years or above are coded as "1".

<sup>c</sup>Nurses working in pediatric intensive care, pediatric oncology and other units were coded as "0" and nurses working in pediatric internal and surgical units are coded as "1".

<sup>d</sup>Nurses who find their level of knowledge sufficient were coded as "0" and those who do not find it sufficient as "1".

### Unpredictable /challenging behavior of children

In this study, nurses also indicated that they had challenges in handling unpredictable/challenging behaviors and were afraid of harming the child while providing care. This finding is supported by the existing kinds of literature which identified nurses experiencing fear and anxiety while providing care to these children (11,12). When the child is hospitalized, situations that change the child's routines may cause an increase in these challenging behaviors (16,20). The lack of knowledge and experience in controlling these behaviors are the reason for nurses' fears and concerns (12,16) and this is consistent with the findings of our study.

### Mothers' approach

Nurses reported that the mothers' approach is a factor affecting the care process in our study. Factors such as the family's attitude (collaborative/non-supportive), the family's insufficient knowledge about the child's disability, the family members not accepting the child's disability, the conflict of roles between the family and healthcare workers about providing care, the interventions of the family members that make the care process difficult were the challenges experienced by the nurses while caring for the child with ID. In the qualitative study of Peter Lewis; "Nurse-parent relationships" was determined as an important theme. It is emphasized that establishing a good relationship with the family will make the nurse feel more self-confident in caring for the child with ID (20).

### Nurses-related challenges

More than half of the nurses in our study felt inadequate in caring for a child with ID. They thought that their knowledge and experience were insufficient to provide care for a child with ID. In the other studies, nurses indicated that they did not consider themselves competent and this situation was due to a lack of knowledge and experience (16,17,21). When experience and education increase, nurses' self-confidence increases, and they reflect a more positive attitude toward the children with ID and their families (8,20).

### System-Related Challenges

The nurses experienced challenges in the care of the child with ID because of the working conditions, other members of the team, and the health policies of the institution in this study.

### Working Conditions

Nurses stated that having limited time when caring for a child with ID and caring for a high number of patients has caused challenges in our study. The nurse shortage is still an important issue in our country. The treatment and care of children with ID may take longer than usual. Because the nurse does not have enough time, they might avoid caring for these children (16,20). Different studies in the literature have also shown that caring for a child with ID requires a longer time and the nurse does not have enough time to communicate with children or families (14,16,22,23). In addition, nurses may have difficulty managing some difficult situations while caring for them due to the lack of special educators or other team members (8,24). Units should have

a senior ID nurse for advice. Such experienced nurses can provide information and can support health care staff (24).

### Team

The nurses stated that the absence of psychologists or social workers, and specialists about ID in the team caused challenges arising from the system. Caring for a child with ID requires a team approach. The importance of having a psychologist, social worker, doctor, and special educator on the team is prominent. However, team members are insufficient in our country. There are not any nurses or other health workers specially trained in this field in the hospitals. Intellectual disabilities liaison nurses might bridge the relationship between nurses and families of children with ID (20). The care provided by the multidisciplinary team will affect the quality of care given to the children with ID and their families.

### Legal and Ethical Procedures

The nurses also indicated that guidelines and legal regulations/procedures for the care of children with ID are inadequate and negatively affect the care. There is no guideline that can be used by nurses who care for these children (25). In the study of Oulton et al., nurses indicated the lack of government and institutional policies for special needs children as situations that negatively affect care (16).

## CONCLUSION

In this study, communication with the children was one of the most experienced challenges and another one is feeling inadequate while providing care for a child with ID by nurses. This study demonstrates that key areas of need are maximizing the strategies that nursing staff use to care for children with ID in the hospital, determining individualized strategies, especially to foster communication with children with ID and their families, developing guidelines, and coordinating with other healthcare professionals. Additionally, since the care of children with ID takes more time, the workload of the nurse and the number of patients should be considered.

### How might this information affect nursing practice?

Previous research emphasized limited knowledge about ID among healthcare professionals and proposed that increased knowledge would lead to an increased quality of care. This study shows the areas where pediatric nursing staff have difficulty caring for children with ID. More education regarding caring for children with ID is needed in graduate and undergraduate programs as well as continuing education at the hospital. Additionally, it is seen that multidisciplinary approaches to caring for children with ID are necessary. So, this study identifies that there is a need for training, institutional arrangements, and policies that will enable nurses working in pediatric wards to increase the quality of care for children with ID.

### Limitations of the study

The limitation of the study is the difficulty in reaching the required number of nurses due to the collection of data during the Covid-19 period.

**Ethics Committee Approval:** This study was approved by the ethics committee of the University Social Sciences Ethics Evaluation Committee (No:2020.333.IRB3.120; 5 September 2020)

**Informed Consent:** Written consent was obtained from the participants.

**Peer Review:** Externally peer-reviewed.

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