



# Swallowing Related Problems of Toddlers with Down Syndrome

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Accepted: 28 August 2022 / Published online: 12 September 2022

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## Abstract

The study was aimed to define swallowing related problems of toddlers with Down syndrome (DS) by comparing toddlers with typically developing children (TDC). A total of 127 children (96 DS, 31 TDC), and their mothers included in the study. The presence of chewing disorders, food selectivity, drooling, coughing during swallowing was scored as ‘absent’ or ‘present’. The Pediatric version of the Eating Assessment Tool-10 (PEDI EAT-10) was used to determine dysphagia symptom severity, and the Turkish version of the Feeding/Swallowing Impact Survey (T-FS-IS) was used to measure the impact of swallowing disorders on caregivers. Mothers of DS reported higher rates of chewing disorders (n=39, 40.6%), drooling (n=30, 31.3%) and coughing during swallowing (n=50, 41.7%) than mothers of TDC (p<0.01). The mean PEDI-EAT-10 score of children with DS was higher than TDC (p=0.006). There were significant differences between groups in terms of T-FS-IS. Moderate to strong correlations were detected between PEDI-EAT-10 and total and subscale scores from T-FS-IS (p<0.001). This prospective study defines swallowing related problems of toddlers with DS. The study results highlight the importance of early investigation of (i) swallowing concerns in children with DS, and (ii) caregivers’ quality of life to define swallowing problems and plan an appropriate swallowing related management program.

**Keywords** Down syndrome · Swallowing · Feeding · Parent-report · Mothers

Down syndrome (DS) is a chromosomal abnormality, of which the estimated prevalence is reported as one in 800 births in Turkey (Turkey Ministry of Health, 2018).

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This population experiences a wide range of problems related to neurological, cardiac, gastrointestinal and pulmonary systems (Bull, 2018). In addition, structural and functional abnormalities regarding craniofacial region are also seen in DS, which affect oral motor, swallowing and feeding functions (van Dijk & Lipke-Steenbeek, 2018; Stanley et al., 2019; Narawane et al., 2020; Jackson et al., 2016, 2019).

Feeding and swallowing difficulties include a broad framework from sucking problems to chewing problems, poor swallowing coordination to airway aspiration. There are several studies conducted in DS to describe swallowing related problems (Stanley et al., 2019; Narawane et al., 2020; Jackson et al., 2016, 2019). In a retrospective study in infants aged between 0 and 6 months, 57% of infants were reported to have clinical signs for feeding and swallowing disorders, and 55% had oral and/or pharyngeal phase of swallowing problems (Stanley et al., 2019). Another retrospective study indicated that sucking, bolus formation and control problems, oral and pharyngeal residues were the most frequent problems in DS with 4 months of age (Narawane et al., 2020). In another retrospective videofluoroscopic swallowing study of children with DS with a mean age of 2 years, 56.3% had airway protection problems, which resulted in airway aspiration (Jackson et al., 2016).

It was known that swallowing difficulties are common in children with DS, but majority of studies investigated this issue with retrospective study designs with small sample sizes and relatively young age groups. Toddler period, which represents the ages between 1 and 3 years, is a transitional period from infancy to preschool years, and is an important period for several reasons. First of all, this time period is critical for motor, intellectual, social, and emotional development of children (Mahmoud et al., 2021). Feeding and swallowing problems in early childhood may be markers for future developmental and health problems, and may result in parental stress (van Dijk & Lipke-Steenbeek, 2018; Lindberg et al., 1994). Feeding and swallowing functions are among the main activities of daily living of children, and parents of those especially aged between 1 and 3 years have a primary role during mealtimes. Successful feeding function and ensuring adequate nutrition are perceived as indicators of competence for parents (Silverman et al., 2021). The disruption of this process, and the increase in the burden of parental care regarding feeding and swallowing difficulties due to (i) their signs (i.e., coughing, choking, vomiting, etc.), (ii) the need for preparation of appropriate foods and liquids for children, (iii) increased meal preparation time and mealtime duration, (iv) negative interactions between children and parents, (v) feeling of incompetence may result in increased parental stress (Hewetson & Singh, 2009; Taylor et al., 2022). Therefore, early identification of feeding and swallowing difficulties is important to benefit from this developmental period, and to develop potential management plan including both children and their parents (Arts-Rodas & Benoit, 1998; Wieseke et al., 2008; Prasse & Kikano, 2009). For appropriate and timely management of feeding and swallowing difficulties, parental collaboration is necessary (Smith et al., 2015). Parental experiences may provide valuable insights to define feeding and swallowing difficulties, and improve management approach. Therefore, it is important to define swallowing difficulties with prospective study designs by parental report. Accordingly, this study was planned to describe general swallowing related problems including chewing disorders, food selectivity, drooling, dysphagia symptom severity of toddlers with DS by comparing

toddlers with typically developing children, and also the impact of swallowing disorders on caregivers of children.

## Method

The study was performed at Hacettepe University Faculty of Physical Therapy and Rehabilitation. The study protocol was approved by the Non-Interventional Clinical Research Ethics Committee (Approval number=GO21/409).

Children with a diagnosis of DS who aged between 1 and 3 years, and their mothers as primary caregiver were included in the study as study group. The study excluded children under the age of 12 months, children who received feeding and swallowing evaluation before, and children who received any feeding and swallowing related training and/or orofacial therapy. Typically developing children who aged between 1 and 3 years, and their mothers were included as control group.

All evaluations were conducted by online due to the COVID-19 pandemic. The evaluation form was electronically sent to the mothers of children via Google forms, and an informed consent form was provided from mothers who agreed to participate in the study by clicking the start button of the evaluation form.

Descriptive information including child's age (month), height (cm), weight (kg), sex and mother's age (year) was noted. In terms of history of the child's feeding and swallowing function, transition time to additional food (month), duration of meal-time (min), number of meals, initial teething time (month) and number of teeth was recorded.

The presence of chewing disorders, food selectivity, drooling, coughing during swallowing was questioned, and documented as 'absent' or 'present' according to parent-report.

The Pediatric version of the Eating Assessment Tool-10 (PEDI EAT-10) was used to determine the dysphagia symptom severity of children. It has sufficient content and criterion-based validity, excellent internal consistency with a Cronbach's alpha value of 0.87 and excellent test-retest reliability (Serel Arslan et al., 2018). It is a 10-question parent reported tool of which each question was scored between 0 and 4. Example questions from PEDI-EAT are including 'My child does not gain weight due to his/her swallowing problem', 'Swallowing liquids takes extra effort for my child', 'Swallowing solids takes extra effort for my child', 'Food sticks in my child's throat and my child chokes while eating'. The score '0' indicates 'No problem', and score '4' indicated 'Severe problem'. The scores of each question were added up to calculate total score of the PEDI-EAT-10. Higher scores show severe swallowing disorder. The normative data indicates that a PEDI-EAT-10 score of 4 or more demonstrates abnormal swallowing function with a sensitivity of 91.3% and specificity of 98.8% (Serel Arslan et al., 2018).

The Turkish version of the Feeding/Swallowing Impact Survey (T-FS-IS) as a quality of life instrument was used to measure the impact of swallowing disorders on caregivers of children (Serel Arslan et al., 2018). It was developed and validated by Lefton-Greif et al in 2014 (Lefton-Greif et al 2016). The Turkish translation study was performed in 2018, and it was found that the T-FS-IS has sufficient construct

and discriminant validity, and excellent internal consistency and test-retest reliability (Serel Arslan et al., 2018). The T-FS-IS has 18 questions, and three subscales including daily activities, worry and feeding difficulty. The subscale ‘daily activities’ reflects quality of life of caregivers regarding daily activities, i.e. ‘It is hard for my family to make plans or go out to eat’. The worry section indicates caregivers’ concerns about children’s well-being, i.e., ‘I worry that my child will never eat and drink like other children’. The feeding difficulty section reflects the challenges during delivery of care specific to feeding/swallowing, i.e., ‘It is hard to feed my child because I don’t know how long these problems will last’. Each question was scored between 1 to 5 points. The score ‘1’ indicates ‘Never’, and score of ‘5’ indicates ‘Almost always’. All scores from each replied question were summed and divided into total replied question number for total score. To maintain subscale scores, scores from all replied questions within each subscale were summed, and then divided by the total number of replied questions in the subscale. Higher scores indicate low quality of life.

### Statistical Analysis

The IBM-SPSS for Windows version 20 (IBM Corp., Armonk, NY, USA) was used for statistical analysis. Visual (histogram and probability graphs) and analytical methods (Kolmogorov-Smirnov/Shapiro-Wilk tests) were used to examine the conformity of the variables to the normal distribution. Descriptive statistics were calculated as a number/percent (n/%) for qualitative data and mean  $\pm$  standard deviation for quantitative data.

The Mann-Whitney U test was used to compare groups. The non-parametric Spearman correlation coefficient was used to determine correlations between PEDI-EAT-10 and T-FS-IS. A Spearman correlation coefficient less than 0.30 shows weak, between 0.30 and 0.70 shows moderate, and greater than 0.70 shows strong correlation (Mukaka, 2012). A p-value of less than 0.05 was used as statistical significance.

### Results

A total of 127 children and their mothers participated in the study. There were 96 children with DS and 31 typically developing children. The mean age of mothers of children with DS was  $33.29 \pm 6.39$  (min=20, max=47) years, and mean age of mothers of typically developing children was  $33.90 \pm 5.93$  (min=26, max=40) years. No difference was found in terms of mothers’ age between groups ( $p=0.710$ ). Table 1 represents demographic characteristics and information regarding the history of the child’s feeding and swallowing function. No difference was detected in terms of the age and sex between groups ( $p>0.05$ ). The height and weight of children with DS was significantly lower than typically developing children ( $p=0.016$ ,  $p=0.006$ , respectively).

In terms of history of the child’s feeding and swallowing function, no difference was found in terms of transition time to additional food and duration of mealtime between groups ( $p>0.05$ ). The number of meals of children with DS was higher,

**Table 1** Demographic characteristics and information regarding the history of the child's feeding and swallowing function

	Down syndrome (n=96)		Typically developing children (n=31)		p
	Mean ±SD	min- max	Mean ±SD	min-max	
<b>Age (month)</b>	23.57±4.38	18–32	25.66±3.93	18–29	0.228
<b>Height (cm)</b>	80.57±6.95	65–97	88.75±2.75	86–92	0.016
<b>Weight (kg)</b>	10.43±2.48	4–17	13±1.04	11.50±14	0.006
<b>Feeding related charac- teristics</b>					
Transi- tion time to addi- tional food (month)	6.46±1.65	3.5–14	5.90±0.82	3–8	0.227
Meal- time duration (min)	26.97±15.70	5–60	21.95±9.73	10–40	0.400
Number of meals	5.34±1.83	3–10	3.77±0.99	3–7	<0.001
Teeth- ing time (month)	11.03±3.19	6–21	7.68±1.90	4.5–13.0	<0.001
Number of teeth	5.78±6.99	3–20	20.37±4.13	12–26	<0.001
<b>Sex</b>	<b>Number (Percentage)</b>		<b>Number (Percentage)</b>		
Female	51 (53.1)		18 (58.06)		0.678
Male	45 (46.9)		13 (41.94)		
<b>Chew- ing disor- ders</b>	39 (40.6)		2 (6.5)		<0.001
<b>Food selectiv- ity</b>	49 (51)		22 (71)		0.071
<b>Drool- ing</b>	30 (31.3)		0		<0.001
<b>Cough- ing during swal- lowing</b>	40 (41.7)		0		<0.001

initial teething time was later and number of teeth was less than typically developing children ( $p < 0.01$ ).

The 40.6% ( $n=39$ ) of mothers of children with DS reported chewing disorders, while only 6.5% ( $n=2$ ) of mothers of typically developing children ( $p<0.01$ ). Mother of DS reported higher rates of drooling ( $n=30$ , 31.3%) and coughing during swallowing ( $n=50$ , 41.7%) than mothers of typically developing children ( $p<0.01$ ). No difference was found in terms of food selectivity between groups ( $p=0.071$ ).

The mean PEDI-EAT-10 score of children with DS was  $6.05\pm 7.91$  ( $\text{min}=0$ ,  $\text{max}=36$ ), and the mean PEDI-EAT-10 score of children with typical developing was  $0.50\pm 0.70$  ( $\text{min}=0$ ,  $\text{max}=2$ ) ( $p=0.006$ ). A percentage of 41.7 ( $n=40$ ) of children with DS had abnormal swallowing function according to the PEDI-EAT-10.

The mean scores for mothers of children with DS in daily activities, worry, feeding difficulties and total score from the T-FS-IS were  $2.09\pm 0.92$ ,  $2.35\pm 1.06$ ,  $1.78\pm 0.99$ , and  $2.11\pm 0.91$ , respectively. The mean scores for mothers of children with typical developing in daily activities, worry, feeding difficulties and total score from the T-FS-IS were  $1.70\pm 0.73$ ,  $1.57\pm 0.50$ ,  $1.34\pm 0.49$ , and  $1.53\pm 0.47$ , respectively. There were statistically significant differences between groups in terms of all subsections and total score of T-FS-IS (Table 2).

There were moderate to strong correlations between PEDI-EAT-10 and daily activities, worry, feeding difficulties and total score from the T-FS-IS ( $p<0.001$ ) (Table 3).

## Discussion

The current study focus on children with DS aged from 1 to 3 years to describe swallowing related problems in this particular group of children by comparing aged and sex matched healthy peers. Children with DS aged between 1 and 3 years had significantly lower anthropometric measures, later teething time and fewer teeth. Children with DS have experienced significantly higher rates of coughing during swallowing (41.7%), chewing disorders (40.6%), and drooling (31.3%). Almost half of DS had abnormal swallowing function, and quality of life of mothers related to swallowing function were worse than mothers of healthy peers. The dysphagia symptom severity of children with DS was found to be related to quality of life of mothers.

Swallowing problems are commonly seen among individuals of all ages with DS (Nordstrøm et al., 2020). In this study, we investigated swallowing related problems in children with DS aged between 1 and 3 years. Children with DS in this age group had lower anthropometric measures compared to healthy peers. Although overweight could be a concern for many children with Down syndrome after the age of 4 years (Nordstrøm et al., 2020; Osaili et al., 2019), lower height and weight of children with DS compared to healthy peers should not be underestimated. The study reported the growth charts of Turkish children with DS showed that growth velocity reduced especially between 6 months and 3 years (Tuysuz et al., 2012). Therefore, possible reasons including poor feeding ability, swallowing disorders or accompanying diseases such as heart defects or gastrointestinal problems related to lower growth parameters in this age group should be considered and handled to maintain appropriate growth.

When looking at the history of the child's feeding and swallowing function, transition time to additional food and mealtime duration were similar with healthy peers, however number of meals per day was higher, teething time was later, and current

**Table 2** The Turkish Feeding/Swallowing Impact Survey scores of groups

Turkish Feeding/Swallowing Impact Survey	Down syndrome (n=96)		Typically developing children (n=31)		p
	Mean ±SD	min-max	Mean ±SD	min-max	
Daily activities (1–5)	2.09±0.92	1–4.80	1.70±0.73	1–3.40	0.039
Worry (1–5)	2.35±1.06	1–5	1.57±0.50	1–2.71	<0.001
Feeding difficulties (1–5)	1.78±0.99	1–5	1.34±0.49	1–3	0.034
<b>Total (1–5)</b>	<b>2.11±0.91</b>	<b>1–4.72</b>	<b>1.53±0.47</b>	<b>1–2.55</b>	<b>0.01</b>

**Table 3** The correlations between the Pediatric version of the Eating Assessment Tool-10 (PEDI-EAT-10) and the Turkish Feeding/Swallowing Impact Survey (T-FS-IS) in Down syndrome

	T-FS-IS Daily activities		T-FS-IS Worry		T-FS-IS Feeding difficulties		T-FS-IS Total	
	r	p	r	p	r	p	r	p
<b>PEDI-EAT-10</b>	<b>0.65</b>	<0.001	<b>0.69</b>	<0.001	<b>0.67</b>	<0.001	<b>0.76</b>	<0.001
<b>T-FS-IS: Daily activities</b>			<b>0.67</b>	<0.001	<b>0.65</b>	<0.001	<b>0.82</b>	<0.001
<b>T-FS-IS: Worry</b>					<b>0.71</b>	<0.001	<b>0.91</b>	<0.001
<b>T-FS-IS: Feeding difficulties</b>							<b>0.87</b>	<0.001

**Swallowing Related Problems of Toddlers with Down Syndrome**

teeth number was lower. Mothers reported higher rates of coughing during swallowing (41.7%), chewing disorders (40.6%), and drooling (31.3%). In literature, chewing disorders in DS was mentioned due to hypotonic tongue and lips, inefficient lingual lateralization, and impaired oral motor function (O'Neill et al., 2005; In't Veld et al., 2020). As a result, chewy and firm food textures were frequently mentioned as difficult to manage for children with DS (Ross et al., 2019). Addition to these possible factors, teething time and number of teeth could also be a factor for chewing disorders in DS. Almost a third of children with DS have experienced drooling, which has several complications including dehydration, infection, hygienic problems, perioral maceration, and social isolation (Leung & Kao, 1999). The possible factors caused chewing disorders may also have contribution to saliva control in these children.

Food selectivity was the most common reported problem by mothers for both groups as 51% for DS, and 71% for typically developing children. Food selectivity, which is characterized by food refusal, is defined as the consumption of a limited variety of food (Bandini et al., 2019). Toddlers are in a period to learn to self-feeding, try new foods and textures, and thereby food selectivity could also be seen in typically developing children (Fishbein et al. 2006). Although food selectivity was previously reported in typically developing children, our study shows that toddlers with DS also experienced food selectivity, which may result in varying degrees of feeding difficulties.

One of the most frequently reported problems was coughing during swallowing in children with DS. Complementary to this result, almost half of DS had abnormal swallowing function, and dysphagia symptom severity was found to be higher compared to their healthy peers. In literature, non-oral feeding was reported as 13–40% of children with DS during infancy period (Ergaz-Shaltiel et al., 2017), 52% of children aged between 6 and 12 months.<sup>7</sup> In our study conducted in the age group between 1 and 3 years prospectively, children with DS also experienced problems in pharyngeal phase of swallowing. From infancy to toddlers period, children with DS have a risk of swallowing disorders, therefore clinical dysphagia symptoms during meals should be taken into account, and if necessary swallowing function should be assessed in detail. In this context, parental report is crucial and valuable for defining swallowing difficulties, and planning appropriate and timely management.

Caregiving for a child who has a developmental disability causes high level of stress and decreased quality of life, and several factors including disability level of the child, behavioral problems, difficulty of caregiving for a child with a develop-



mental disability, disability specific factors (Plant & Sanders, 2007). Swallowing disorders could be one of the contributing factors for quality of life of caregivers. However, there is no study showing the swallowing related concerns of caregivers of children with DS. To our knowledge, this is the first study to examine the impact of feeding and/or swallowing issues of children with DS on their mothers. The quality of life of mothers of children with DS was worse than mothers of healthy peers, and dysphagia symptom severity of children with DS was found to be related to quality of life of mothers which shows that increased dysphagia severity is related to higher problematic perceptions of parents, and decreased dysphagia severity is related to lower problematic perceptions of parents. The mothers of children with DS had insufficient time for daily activities, worry about well-being of their children, and difficulties about caregiving to feeding difficulties to their children, of which all were also related to each other. Caregiver's features (i.e., sex, status), child's age, sex and accompanying diseases were found to be associated with burden of caregivers of DS (Alam El-Deen et al., 2021). Our study results highlight that feeding and/or swallowing issues affect not only children with DS, but also mothers of DS. Thus, parental concerns should be considered and evaluated during management plan of children with DS.

This study has some limitations. It provides experiences of mothers of toddlers with DS related to swallowing function, but clinical and/or instrumental swallowing evaluation is lack to confirm parent report findings. The problems such as chewing disorders, drooling, and airway protection problems faced by children with DS were quite different from each other, therefore each problem, and contributing factors should be investigated separately. In addition, children with DS frequently experience medical comorbidities including neurologic, cardiac, gastrointestinal, pulmonary, etc. (Desai, 1997). However, comorbidities were not questioned within history taken in this study, thus comorbidities associated with DS could also be recorded in future studies to investigate their contribution to swallowing and feeding functions.

## Conclusion

This prospective study describes experiences of mothers of toddlers with DS related to swallowing function by comparing toddlers with typically developing children. Toddlers with DS suffer from higher rates of food selectivity, coughing during swallowing and abnormal swallowing function, chewing disorders, and drooling, and quality of life of their mothers were worse than mothers of healthy peers. The study results point to the importance of early investigation of feeding and swallowing concerns as well as caregivers' quality of life to define the problems and plan an appropriate management program.

**Acknowledgements** Special thanks to the mothers who participated in the study.

**Funding** No funding.

## Declarations

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from the participants who participated in this study.

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Clinical trial number**= This study does not require a clinical trial number because it is a study conducted through online surveys that does not involve any intervention.

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