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Running head: FEEDING DIFFICULTIES TODDLERS DOWN SYNDROME

Measuring feeding difficulties in toddlers with Down syndrome

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Introduction

Feeding problems in early childhood are shown to have a negative impact on development and can be a source of caregiver stress (Lindberg, Bohlin, Hagekull & Thunstrom, 1996). Although these kinds of problems occur frequently across the population, their incidence is much higher in children with developmental disabilities than it is in typically developing children. For instance, Manikam and Perman (2000) report incidence rates of 80% compared to 25% in the typical population. It is estimated that 57 percent of infants with Down Syndrome (DS) have feeding difficulties during the neonatal period (Spahis & Wilson, 1999). These problems often remain present throughout life, but are particularly prevalent in children below the age of 7 years, for whom it is estimated that up to 80 percent have problems with eating (Pipes & Holm, 1980; Van Dyke, Peterson & Hoffman 1990). However, it should be noted that a direct comparison between these populations is complicated due to the fact that different definitions of what constitutes a feeding problem are used in these studies.

Children with DS often have anatomical and physiological anomalies, such as a smaller mouth cavity, a smaller upper jaw, dental anomalies, weaker lip tension, and stronger tongue tension (Van den Engel-Hoek, 2006; Faulks, Collado, Mazille, Veyrune, & Hennequin, 2008). This leads to oral motor problems in roughly four out of five children with DS (Field, Garland & Williams, 2003). It has also been shown that children with DS chew less effectively and that tongue protrusion is frequent, which can lead to food being expelled from the mouth and evoke a pharyngeal reflex (van den Engel-Hoek, 2006). Spoon-feeding is also more difficult, as the sucking response remains present for longer in children with DS, making it hard for them to take an active bite. There is a delay in the development of oral motor skills needed to eat solid food (Spender, Stein, Reilly, Percy & Cave, 1996). The age at which solid food is introduced is also later than it is for the typical child. For instance, Hopman, Csizmadia,

Bastiani, Engels, De Graaf, Le Cessie et al. (1998), reported that bread was often introduced around age 12 months (versus 8 months for typically developing children), pieces of hard fruit around 30 months (versus 12 months) and the first meal with meat, vegetables and/or starch around 24 months (versus 12 months). In addition, it has been shown that 45% of children with DS show selectivity by texture (Field, Garland & Williams, 2003) and that they show less self-feeding between the ages of 11 and 38 months (Spender et al, 1996). It is estimated that 57% of children with DS have pharyngeal dysphagia (O'Neill & Richter, 2013). In addition, children with DS display behavioral problems during feeding more often than typically developing children. For instance, Bhatia, Kabra and Sapra (2005) report that 55% of children aged between 2 and 6 years with DS showed behavioral problems as compared 12.5% in control group children. In addition, Lewis and Kritzinger (2004) estimated that around 30-40% of parents of a child with DS between the ages of 1 and 4 years report stress around feeding.

In order to diagnose a feeding problem, procedures such as physical examination and feeding observation are necessary (Arvedson, 2008). However, questionnaires that are aimed at the experiences of caregivers are important, because these informants offer a more 'holistic' view of the child's behavior as well as giving an impression of any caregiver stress that may have been experienced. For this reason, Ramsay, Martel, Porporino, and Zygmuntowicz (2011) developed the *Montreal Children's Hospital Feeding Scale* (MCH-FS), which consists of 14 questions and only takes a few minutes to administer and score. The MCH-FS measures parental concerns, family reactions, compensatory strategies, appetite, mealtime behaviors, oral sensory behavior and oral motor behavior. The instrument, of which French, English, and Dutch versions have been validated, has been demonstrated to have a good sensitivity and specificity (Sanchez, Spittle, Allinson, & Morgan, 2015). In a previous study (Van Dijk, Timmerman, Martel, & Ramsay, 2011), we translated the MCH-FS into Dutch and

established Dutch norms for the ages of 6 months to 4 years. The Dutch version is called the “Screeningslijst Eetgedrag Peuters” (SEP), literally translating to “Screening List Eating Behavior Toddlers”. The Dutch version distinguishes four norm groups based on age (6 months -1 years, 1-2 years; 2-3 years and 3-4 years). In a second study, which was on the concurrent validation of the instrument, we found significant moderate correlations between the total score on the SEP and infant behavior during a regular meal (the relative amount of bites, refusals and self-feeding; with correlation coefficients of $-.43$, $.67$ and $-.46$, respectively) (see van Dijk, Bruinsma & Hauser, 2016). However, the sample of this study consisted of typically developing infants between the ages of 9 and 18 months who were all born prematurely. Further research is needed into both typically and non-typically developing children before the instrument can be used in clinical settings.

In the previous study, we examined the relation between caregiver-reported feeding problems (as measured on the SEP) and various types of feeding behavior that are symptomatic of feeding efficiency and problems. We included the ability of the infant to self-feed, the speed of feeding, meal duration, the child’s food acceptance or refusal, the child’s negative affect (whining, crying, and spitting out food) and the use of coaxing. These behaviors are considered symptomatic of feeding problems (Hofman-van den Hoogen, 1998; de Moor et al., 2007; Crist & Napier-Phillips, 2001, Piazza-Waggoner, Driscoll, Gilman, & Powers, 2008; Reau, Senturia, Lebailly, & Christoffel, 1996; Whelan & Cooper, 2000). The current study was a replication study of Van Dijk, Bruinsma and Hauser (2016), this time with a sample of toddlers who have DS.

The aim was to investigate how toddlers with Down syndrome score on the SEP as reported by their parents, and whether similar correlations exist between behavior during a feeding interaction and the score on the screening instrument for this specific target group. For this reason, we used the same observational categories as in Van Dijk, Bruinsma and Hauser

(2016). We also included tongue protrusion for the DS sample, as there are indications that this hinders feeding efficiency and can lead to retching (Van den Engel-Hoek, 2006). Children with DS are one of the target groups for the MCH-FS/SEP, as they are prone to developing feeding problems and have regular pediatric check-ups, enabling early identification and referral. However, it is still unknown to what degree the results from the previous study can be generalized to the population of children with DS and can be used clinical practice with children with DS. For this reason, it is important to first investigate how scores on the instrument relate to feeding behavior of this group of children with DS. This study also addresses the empirical question of which mealtime behaviors relate to what caretakers of DS consider problematic feeding.

Research Questions:

1. Do caregivers of children with DS report more feeding problems on the SEP than parents of children from the general population?
2. Does the score on the SEP correlate with the observed feeding skills (feeding efficiency, self-feeding, and tongue protrusion) and feeding interaction (food refusal, negative behavior of the infant, parental coaxing, and mealtime duration)?

Method

Participants

A total of 32 children (23 boys and 9 girls) with Down syndrome participated in this study along with their primary caregivers. The families in question were recruited by undergraduate students from the *Windesheim University of Applied Sciences*, through their personal networks, the Dutch Foundation for Down Syndrome, social media, and speech language therapists. The families lived across the Netherlands. The inclusion criteria were that the child had DS, was

between the ages of 1 and 3 years old, and that he or she was eating solid food. The average age was 21.53 months at the moment of the observation (SD = 7.08 m). The children's birth weight was 2950 grams on average (SD: 799.9 gr), with three children having had a low birth weight (below 2 kg). Gestational age at birth was 37.50 weeks on average (SD = 2.2 w). Two children were born after a pregnancy of 35 weeks or less. In ten cases, parents reported complications at birth (not including the diagnosis of Down syndrome or minor complications such as vacuum retraction, induced labor, and non-urgent cesarean section), such as placental abruption, prematurity, or meconium in the amniotic fluid. In three cases, there were indications of asphyxia at birth (parents reported the infant was blue). 25 of the 32 children had (any type of) comorbid problems associated with Down syndrome; there were cardiovascular problems in 17 children, and other problems (eye, bowel, and thyroid problems) in 12 children. The presence or absence of feeding difficulties was not a criterion for inclusion and was not asked for until the home visit.

Measures

During the home visits, a short interview was held in which the primary caregivers were asked about the development of their child (covering the medical and developmental history). After this, they were also given a short questionnaire including the 14 items of the SEP, which were answered on a 7-point Likert scale. The scores on some of the items had to be inverted, so that high values always indicate a greater severity of symptoms. In four cases, the SEP was not filled in as instructed. In one case, parents had marked two neighboring values (for instance, '1' and '2'). Here, we used the highest value ('2', in the example). In another case, parents had indicated two values on the scale (for instance, both '2' and '6'). They had marked separate values for two types of food, which were written next to the values. Here, the middle value ('4', in the example) was taken. Two parents did not fill in item 4 ("when does

your child start to refuse food”) but wrote behind the item “does not refuse”. This was interpreted as the extreme anchor point “at the end of a meal”. In this way, all 32 questionnaires could be used for further analysis.

During each home visit, a video recording was made of a feeding session. These sessions were coded from the first feeding action (either a caregiver offering a bite or a self-feeding action of the child) until the caregiver indicated that the meal was finished. We used the same coding scheme as in Van Dijk, Bruinsma and Hauser (2016), which is based on earlier observational instruments (e.g. Young and Drewett, 2000; Van Dijk, Hunnius and Van Geert, 2009). The coding scheme has codes for giving, accepting and refusing a bite, self-feeding a bite, uttering negative affect (by the child), and giving instructions (by the caregiver). For this specific target group, we also included tongue protrusion during eating. This means that in total there were 7 behavioral categories: Give, Accept, Refuse, Self-feeding, Tongue protrusion, Negative affect of the infant, and Instructions by the caregiver (see Table 1). Adding up the frequencies of Accept and Self-feeding gives the total amount of Bites, which -when expressed relative of time—is a measure of feeding efficiency.

[insert table 1]

Five trained undergraduate students from the Windesheim University of Applied Sciences, who were following the Speech and Language Therapy bachelor program, coded the videos. Inter-observer reliability was determined by double (blind) coding 29 videos in total (random combinations of two observers each). Tongue protrusion was double coded in 18 videos. We calculated overlap and non-overlap of behavior codes within a time frame of 2.0 seconds. In order to compute Cohen’s Kappa, we took a chance overlap of .50 for all codes. Because there

were low frequencies of some codes, we combined sessions and computed average Kappas for each code. Reliability was substantial for Refuse ($K = 0.769$) and Negative behavior infant ($K = 0.752$), and almost perfect for Give ($K = 0.872$), Accept ($K = 0.950$), Self-feeding ($K = 0.925$), Tongue protrusion ($K = 0.856$), and Instructions caregiver ($K = 0.845$).

The duration of the meals varied between 6.50 to 34.75 minutes (average meal duration was 17.3 minutes). For this reason, we used relative frequencies of the behaviors described in the coding scheme (frequency divided by meal duration).

Procedure

Families were visited at home around mealtime (lunch, dinner, or a snack). During these visits, a background questionnaire was administered, the SEP was filled out, and a meal was filmed. The same (primary) caregiver was involved in all elements of the home visit (background questionnaire, SEP, feeding session). Caretakers were instructed to feed the child as they usually would, including the type of food that was offered. In all cases, the food was part of the child's food repertoire. The most common foods on offer were bread (19 times) and fruit (10 times, of which 6 times pieces of fruit, 3 times pureed with lumps and once smooth puree). Other types of food were crackers (4 times), yoghurt (twice), a mixed meal with meat and vegetables (2 times, in both cases pureed with lumps), vegetables (once, in pieces), soup (once) or cake (once). 8 children got two types of food during the same meal (e.g. bread and fruit, or soup and yoghurt). The home visits took approximately one hour and were executed between October 2015 and December 2016. Although the questionnaires should have been administered before the meal, this was reversed on some occasions ($n = 8$) when the caregiver indicated that he/she or the child could not wait. However, in all these cases, the caregiver reported the meal was representative of a regular meal afterwards. Ethical approval was requested and acquired at the University of Groningen (ppo-015-142).

Analyses

A-priori power analysis (with a two-tailed alpha of 0.05 and a minimum power of 0.80) indicated that a sample of 29 participants is sufficient to pick up large effect sizes, as was found in the previous study (Van Dijk, Bruinsma & Hauser, 2016). Because this study is primarily a replication of this, we used a similar sample size. Since the children came from two age groups (1-2 years and 2-3 years) and there was a clear age effect in the Dutch normative sample, we compared children with their own respective age groups. Independent one-sample t-tests were performed to test the average SEP-score of the 1-year-olds ($n = 23$) against the average of the normative sample of those aged 1-2 years old, and the average SEP-score of the 2-year-olds ($n = 9$) against the normative sample of those aged 2-3 years old (as reported in Van Dijk et al. (2011)). Pearson correlation coefficients were calculated across the sample ($n = 32$) between the questionnaire data and the observation categories. All tests were 2-sided with an alpha of .05.

Results

In total, 3 parents reported that their child had feeding problems, and a fourth child had just finished treatment for feeding problems. In 8 cases, caregivers reported that the meal was not fully representative of a regular meal. They reported minor deviations, such as “Usually, she eats more bread”, and “Usually, we have more people eating at the dinner table”. In one case, the parent thought the child did not feel too well and therefore ate less.

In total, 10 children did not self-feed at all, 8 children exclusively self-fed, and 14 children used combined feeding (some bites were fed by the caregiver and some bites were self-fed). Table 2 shows the frequencies of the observed behaviors of these three groups separately and

for the total sample. Clearly, the observed behaviors showed different frequencies for each of the groups, which is partly intrinsic to the coding scheme. However, because a one-way ANOVA showed that the SEP did not significantly differ between the three groups ($F(2, 29) = 1.36$; $p = .27$) and subsamples would be too small analyze separately, all further analyses are performed on the sample as a whole.

[insert table 2]

The average score on the SEP was 31.03 ($SD = 10.03$), which is in the same range as the normative sample between ages 1 and 3 years ($t = .853$, $p = .400$). When using separate norm groups for each age, t-tests showed that the 1-year-old participants did not score differently than the 1-year-old norm group ($t = 1.472$; $p = .155$) and that the 2-year-old participants did not score differently than the 2-year-old norm group ($t = -0.612$; $p = .557$).

The correlation analysis showed that the behaviors “refusal per second” and “negative affect per second” correlated positively with the total score on the SEP ($r = .591$; $p < .001$ and $r = .487$; $p = .005$, respectively). This means that in cases when a caregiver reported more general symptoms of feeding problems on the SEP, the child showed more food refusal and more negative affect during a regular meal. The associations between the SEP and the other indicators were not significant (see Table 3).

[insert table 3]

Discussion

The results of this study showed that the scores on the SEP were similar to the same-aged children in the norm sample. In the current study, we used a statistical definition of feeding problems based on a normative sample and a questionnaire based on parental perceptions. This suggests that on average, parents of toddlers with DS do not experience more feeding problems than parents of typically developing toddlers. It may be speculated that these parents have different expectations regarding the eating behavior and skills of their child. At present, DS is well defined and understood, and parents of a child with DS are educated on what to expect both medically and in terms of feeding difficulties during infancy and childhood (for instance, see Baum, Nash, Foster, Spader, Ratliff-Schaub and Coury (2008) and Bull and the Committee on Genetics (2011)). They receive regular pediatric consultations and have access to support groups. This may provide caregivers with an adequate frame of reference with regard to what to expect when raising a child with DS. A similar finding was also reported by Spender et al (1996), who found that when mothers of children with DS were asked about feeding problems, they tended not to report them. Nevertheless, a majority of these mothers admitted that they had asked for advice about feeding problems at one moment in time. This suggests that although caregivers experience problems, they appear to understand them as an expected part of growing up with DS.

Having a different framework on what to expect may explain why there were no significant associations between feeding skills of the infant (bites per minute, self-feeding and tongue protrusion) and feeding problems on the SEP. Although the observed children with DS showed relatively little self-feeding and many instances of tongue protrusion during chewing, this was not correlated with parental report of feeding problems. This suggests that parents do not experience this as problematic. What they do find problematic is the display of negative affect and food refusal. These results are partly in contrast with the previous study (Van Dijk, Bruinsma & Hauser, 2016), in which we found a correlation with skills such as self-feeding

and feeding efficiency. Refusing food is clearly related to experiencing feeding problems across both samples.

In conclusion, the results of this study suggest that the Dutch version of the MCH-FS (SEP) can be used to get a valid impression of the eating behavior of a child, in the sense that its sum score relates to the child's food refusal and negative behavior as benchmark behaviors. This means that the instrument has a certain degree of concurrent validity in a sample of toddlers with DS, but that the interpretation of the total score is slightly different than it is with typically developing children. Because the score on the SEP did not show any correlation with feeding skills, such as self-feeding and feeding efficiency, this leads to the question of whether the SEP can be used in children with DS. It is important to emphasize again that on the SEP, the caregivers provide their perspective of the feeding behavior of a child, in addition to how those feeding behaviors influence caregiver's life. For this reason, the score provides valuable information on how caregivers perceive the feeding and whether this leads to stress. However, since the SEP does not relate to feeding skills in children with DS, direct observation of eating behavior remains indispensable. The SEP includes three items on feeding skills, and it may be questioned whether these are relevant for this population of children with DS. Future research with a larger sample is needed to investigate this further.

One limitation of the current study was that in 8 out of 32 cases, the SEP was administered after the observed meal instead of before. This may have had an effect on the results, because caregivers may have been influenced by what they have experienced (even though in all cases, the caregiver reported that the meal was representative). Another clear limitation is that this study is based on a relatively small sample, which was only sufficient to pick up large effects. Because of the small sample, it was not possible to conduct separate analyses on children who eat independently and children who have to be assisted partly or fully. Though

the current analysis did not show a significant difference on the SEP between these groups, this may have been caused by a lack of power. Because these groups are possibly very different from each other, this should be included in future studies.

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Table 1

Coding scheme used for the quantification of feeding and interaction behavior

Eating and feeding

G: Give (event): caregiver brings food towards the mouth of the child ('Cleaning' is not seen as a Give, only when the food is subsequently put into the mouth.)

A: Accept (event): food goes into the mouth

X: Refuse (event): child refuses usually by not opening the mouth (Note: all Gives that are not accepted are refused.)

S: Self-feeding (event): each action by the child to bring food into the mouth (If a child is chewing on a larger piece of food, each action of bringing the food *into* the mouth is coded separately.)

T: Tongue protrusion (event): each time the tongue visibly pushes food out of the mouth.

Interaction behavior

I: Instructions caregiver (event): all parental verbal interaction that tells the child to eat (e.g. "have a bite"), the tone does not matter (includes coaxing and giving directives)

N: negative affect infant (event): all instances of starting to cry, whine or fuss, choking, rough physical behavior by the infant (includes pushing away or pulling spoon)

Table 2

Absolute frequencies of the observed behaviors

	Total sample (n =32) Average (range)	No self-feeding (n = 10) Average (range)	Combined feeding (n = 14) Average (range)	Exclusive self- feeding (n = 8) Average (range)
<i>Gives</i>	18.06 (0-68)	42.80 (14-68)	10.71 (1-27)	0 (0-0)
<i>Accept</i>	15.94 (0-68)	38.60 (8-68)	8.86 (1-26)	0 (0-0)
<i>Refuse</i>	2.13 (0-19)	4.20 (0-11)	1.86 (0-19)	0 (0-0)
<i>Self-feeding</i>	27.53 (0-102)	0 (0-0)	29.93 (9-88)	57.75 (16-102)
<i>Tongue protrusion</i>	19.23 (0-71)	23.11 (0-71)	15.00 (0-67)	21.75 (3-54)
<i>Instructions</i> <i>caregiver</i>	24.63 (0-64)	17.80 (0-29)	30.79 (5-64)	22.38 (2-61)
<i>Negative affect</i> <i>infant</i>	7.72 (0-45)	17.00 (0-45)	4.21 (0-16)	2.25 (0-8)

Table 3

Correlations between the score on the SEP and the relative frequency of observed behaviors, consumed grams, and mealtime duration

	r	p
<i>Give</i>	.112	.543
<i>Accept</i>	.011	.954
<i>Refuse</i>	.591*	.000
<i>Self-feeding</i>	-.255	.158
<i>Bites</i>	.258	.154
<i>Tongue protrusion</i>	-.048	.802
<i>Instructions caregiver</i>	.182	.318
<i>Negative affect infant</i>	.487*	.005
<i>Consumed grams</i>	.270	.135
<i>Mealtime Duration</i>	-.167	.362