



Measuring feeding difficulties in toddlers with Down syndrome

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ABSTRACT

Early feeding problems occur frequently across the population, but have a higher incidence in children with Down syndrome (DS). Early identification can possibly be improved with the help of a valid screening instrument based on caregiver reports. In a previous study, we investigated the concurrent validity of the Dutch version of the *Montreal Children's Hospital Feeding Scale* (MCH-FS, SEP in Dutch) in a sample of typically developing toddlers, and we found a correlation between the score on the instrument and observed behavior during a regular meal. The current pilot study was a replication in a sample of children with DS (aged 1; 0–3; 0) and their primary caregivers ($n = 32$).

The results showed that children in the sample did not score higher on the SEP than children in their respective norm groups. In addition, when caregivers reported more symptoms of feeding problems on the SEP, children showed more food refusal and negative affect during the observed meal. This suggests that the screening instrument is particularly associated with negative mealtime interactions. This is in contrast with earlier results, which mainly indicated a relation with eating skills.

1. 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, 1994). 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) reported 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 (Faulks, Collado, Mazille, Veyrone, & Hennequin, 2008; Van den Engel-Hoek, 2006). 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 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 et al., 2003) and that children with DS 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 Kritzing (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.

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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 -0.46 , 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. 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, Diddens, & Korzilius, 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 et al. (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 et al. (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.

1.1. 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)?

2. Method

2.1. 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 g 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.

2.2. 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’). In these cases, 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 et al. (2016), which is based on earlier observational instruments (e.g. Young & Drewett, 2000; Van Dijk, Hunnius, & 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

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