Caregivers' Experiences of Feeding and Swallowing Problems in Children with 22q11 Deletion Syndrome

Sarah Aldeghather[1], Tanya Gilroy [2], Margaret Walshe.[1]

1. Department Of Clinical Speech and Language Studies, Trinity College, Dublin
2. Speech and Language Therapy Department, Temple Street Children's University Hospital. Dublin

Background

22q11 deletion syndrome is caused by chromosomal deletion and is associated with feeding and swallowing disorders. These difficulties arise from craniofacial anomalies, cardiac disease, respiratory, gastrointestinal and neurological difficulties (1, 2). Dysphagia prevalence in individuals with 22q11 deletion syndrome is estimated to be around 30% (3). The experience of caregivers with this population is unknown and services within the Republic of Ireland to this population are thought to be lacking, as dysphagia remains an under recognized disability.

Methods

A cross sectional descriptive web based survey was conducted. Non-probability purposive sampling was used. The survey was distributed by 22q11 Ireland support group to organization members. Data was collected online using surveymonkey platform.

Research aims

To examine caregivers' experiences of dysphagia in children with 22q11 deletion syndrome and to identify caregivers' perceptions of service needs for this population in the Republic of Ireland.

Findings

Forty-three people responded to the survey. All were parents of children with 22q11 residing in the Republic of Ireland.

Feeding and Swallowing Problems

- 82.50% reported difficulties feeding their children with 22q11 deletion syndrome.
- The most frequently reported types of feeding and swallowing problems were nasal regurgitation and low weight gain.
- Most parents reported early onset feeding and swallowing problems. 68% discovered the problem during the first week of life and other 15% discovered the problem later on during the first year.
- 57% of participants reported that the feeding problem had resolved over time.
- Nasal regurgitation and the inability to extract milk from the bottle were reported by parents as the most challenging feeding difficulties.
- The prevalence of gastrointestinal problems among children surveyed was higher that what was reported in the literature. 40% had a history of gastro-oesophageal reflux and 50% had constipation requiring medications.

Services in the Republic of Ireland:

Participants were asked about the access to needed services and the answers are shown in table 1.

Table 1. Access to the needed services

The needed services	Percentage of parents who were able to access the service	Percentage of parents who were dissatisfied with the services either because of the inaccessibility or late access
Speech and language therapy	94%	30%
Clinical nutrition and dietetics	71%	15%
Psychology	34%	25%
Occupational therapy	53%	40%
Physiotherapy	63%	20%

- 27% of participants sought services abroad for a variety of reasons (See figure 1). The most preferred destination for services were the United States of America and the United Kingdom.

Conclusions:

Dysphagia in children with 22q11 deletion syndrome is under investigated. Types of feeding and swallowing problems vary widely. Most of the feeding and swallowing problems experienced by children with 22q11 deletion syndrome are early-onset problems but these resolve. According to findings, the two most needed services to treat dysphagia were speech and language therapy and clinical nutrition and dietetics. Most parents were able to access both services in Ireland, yet earlier access is needed as most problems occur early in childhood.

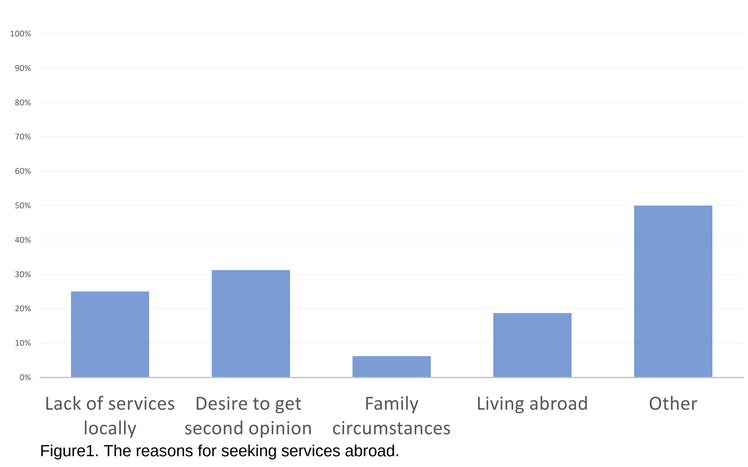

Figure1. The reasons for seeking services abroad.

References:

1. Eicher PS et al, Dysphagia in children with a 22q11.2 deletion: unusual pattern found on modified barium swallow. J Pediatr. 2000;137.
2. Sacca R ZK et al, Association of airway abnormalities with 22q11.2 deletion syndrome. International Journal of Pediatric Otorhinolaryngology. 2017;96.
3. McDonald-McGinn DM et al, 22q11.2 deletion syndrome. Nat Rev Dis Primers. 2015;1:15071.
4. Noleen Kavanagh, (2018), Child with 22q11 deletion syndrome [ONLINE]. Available at: https://static.wixstatic.com/media/b81376_b0879a17a55c4b52bcb8f5dd4e0ec2e3~mv2.jpg/v1/fill/w_567,h_852,al_c,q_90,usm_0.66_1.00_0.01/b81376_b0879a17a55c4b52bcb8f5dd4e0ec2e3~mv2.webp [Accessed 1 September 2018].

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

ESSD2018 1--13D
Session 13. Poster session 13D: Paediatric Dysphagia 3
Sarah Aldeghather
DOI: 10.3252/pso.eu.ESSD2018.2018
Poster presented at: 8th ESSD CONGRESS, DUBLIN 2018 Dysphagia: Shaping the Future
PosterSessionOnline.com