Early Turner Syndrome Feeding Experiences

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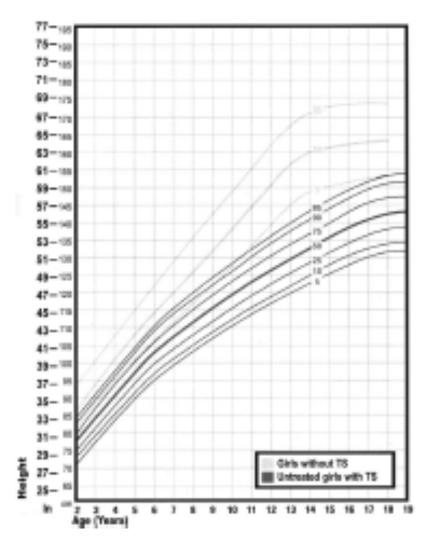




Turner Syndrome

- X chromosome disorder characterized by:
 - Short stature
 - Hearing loss
 - Early: conductive
 - Late: sensorineural
 - High arched palate & retrognathia
 - Learning disabilities
 - Ovarian dysgenesis

Growth



Turner Syndrome Feeding

- Difficulties due to inefficient sucking and swallowing refluxes
 - Impaired oral motor function
- Dysfunctional tongue movement
 - Poorly developed chewing skills
- Prevalence: 74%
 - From birth through 6 months-3 years of age
 - Slow rate, poor appetite, frequent vomit, suck & swallow problems
 - Difficulty introducing solids: poor chewing, vomiting

(Donaldson, Gault, Tan & Dunger, 2006; Frias & Davenport, 2003; Starke, Wikland, & Moller, 2003)

Feeding Study

- In-home interview, feeding observation (video recorded), and *Feeding Assessment Schedule*
- Mother of infants with Turner Syndrome
 - Introduced bottle feeding earlier and solids later
 - Only 4 of 10 had received advice about managing feeding
- Infants with Turner Syndrome
 - Very poor suck-swallow sequence coordination
 - Tongue dysfunction: poor chewing, fewer chewing attempts

Research Questions

 How common are early feeding disorders in girls with Turner Syndrome?

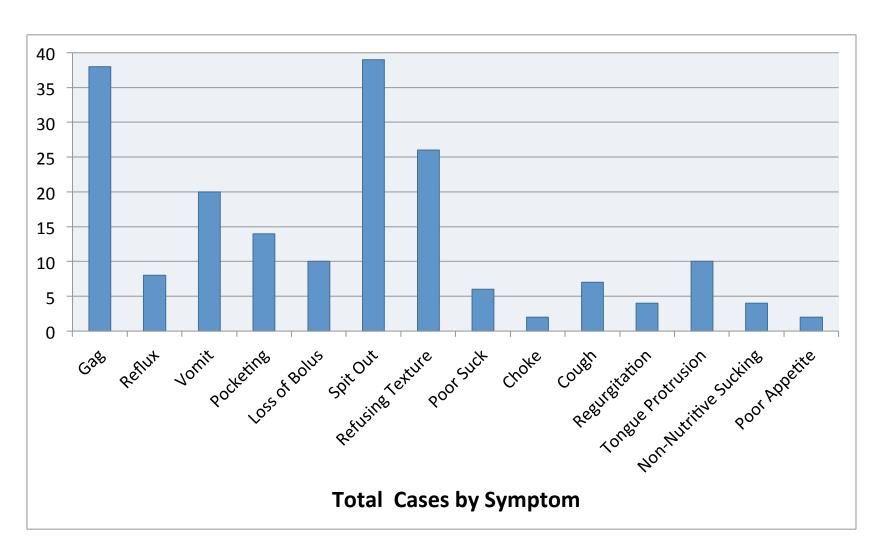
 When do these difficulties occur, and what characterizes trouble with feeding?

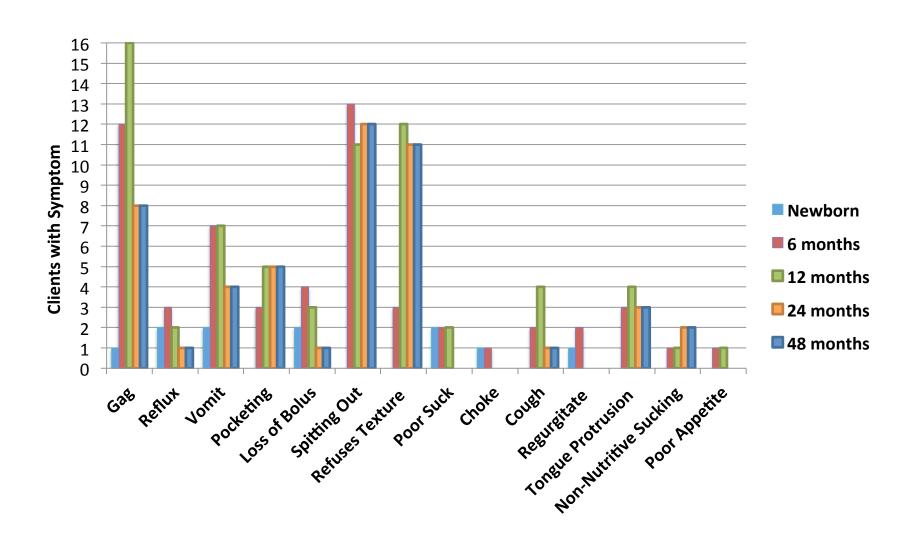
Current Study

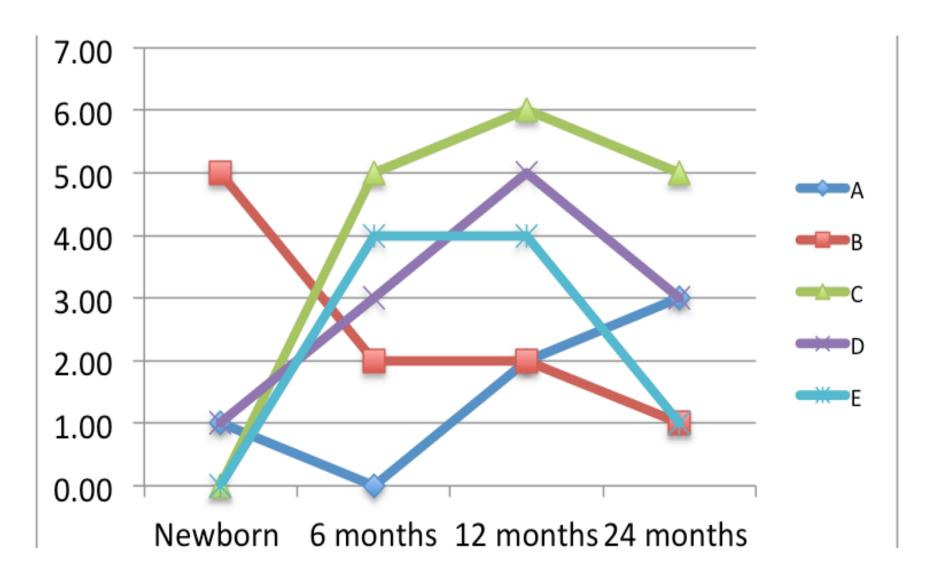
- 41 participants from CIDD Turner Syndrome Clinic, 2010-2013
 - Longitudinal, cross-sectional design
- Clinical observation, parent questionnaire, Schedule for Oral-Motor Assessment
- Ages
 - Newborn
 - 6 months
 - 12 months

- -24 months
- -48 months

	Number of	Mean	Feeding	Mean Symptoms
	Participants	Age	Difficulty	per Child
		(months)		
Newborn	8	1.63	25.00%	1.34
			(n=2)	
6 months	22	6.5	59.09%	2.77
			(n=13)	
12 months	28	11.82	39.00%	2.43
			(n=11)	
24 months	23	22.39	47.83%	2.09
			(n=11)	
48 months	7	48.00	0.00%	0.86
			(n=0)	







Conclusions & Implications

 Higher rate of feeding problems than expected from typically developing infants

Utility of adaptive feeding equipment

 Educating families and care providers about feeding concerns upon diagnosis

Team Members

- Family
- Client
- Geneticist
- Pediatrician
- Nutritionist
- Speech Language Pathologist
- Lactation Consultant

- Counselor
- Occupational Therapist

Questions?

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References

- Donaldson, M. D. C., Gault, E. J., Tan, K. W., & Dunger, D. B. (2006).
 Optimising management in turner syndrome: from infancy to adult transfer. *Archives of Disease in Childhood*, 91, 513-520. DOI: 10.1136/adc.2003.035907
- Frias, J.L. & Davenport, M.L. (2003). Health supervision for children with turner syndrome. *PEDIATRICS* 111(3), 692-702. DOI: 10.1542/peds.111.3.692
- Hjerrils, B.E., Motensen, K.H., & Gravholt, C.H. (2008). Turner syndrome and clinical treatment. *British Medical Bulletin 86*, 77-93. DOI: 10.1093/bmb/ldn015
- Mathisen, B., Reilly, S., Skuse, D. (1992). Oral-motor dysfunction and feeding disorders of infants with turner syndrome. *Developmental medicine and child neurology, 34*(2), 141-9.

References

- Ramasamy, M. & Perman, J.A. (2000). Pediatric feeding disorders. *Journal of clinical gastroenterology, 30*(1), 34-46.
- Ranke, M. & Saenger, P. (2001). Turner's syndrome. The Lancet, 358, 309-314.
- Starke, M., Wikland, K. A., & Moller, A. (2003). Parents' descriptions of development and problems associated with infants with Turner syndrome: A retrospective study. *Journal of Paediatric Dhild health 39*, 293-298.
- Zajac, D. (October, 2015). Common Syndromes[PDF Slides]. Lecture conducted at University of North Carolina, Chapel Hill, NC