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Case Report

Feeding Tubes, Bonding, and CHARGE Syndrome: A Case Study Reflection and Concerns

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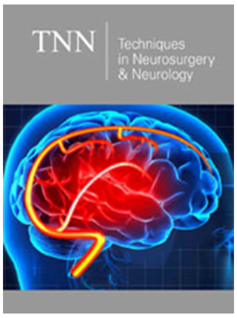

Abstract

Tube feeding technology has greatly impacted the livelihood of children with low incidence disabilities such as CHARGE syndrome. Technology development increases have made tube feeding effective and efficient for relaying liquid nourishment into the bodies of little ones in need of sustenance, but has feeding efficiency left many children without appropriate sensory stimulation resulting in the abatement of foundational developmental skills? A case study reflection from one mother regarding the use of older technologies resulting in developmental gains is compared with her observations of children currently feeding with pump technology. This mother opines for supportive training for parents and school personnel to deliberately spend time in face-to-face bonding and nurturing while feeding with pump technology. Research is needed to weigh the positives of modern feeding devices with the potential of negating typical developmental opportunities for children with comorbid sensory loss such as those with CHARGE during feeds.

Keywords: CHARGE Syndrome; Feeding tubes; Feeding pumps

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Introduction

Chris was born in 1982 with multiple congenital anomalies and many years later was diagnosed with what we now know to be CHARGE syndrome. At birth his severe unilateral cleft lip and palate were the only obvious signs of physical abnormality. Feeding became a real issue for him immediately and thus the road to eating began for Chris, his mother and medical professionals. This article is a single case study reflection on both positives and negatives associated with feeding technologies used for children with charge.

Case Presentation

CHARGE is an acronym for six areas of anomalies. These six anomalies are as follows: C=Coloboma, H=Heart, A=Atresia of the choanae, R=Retardation of growth and development, G=Genitourinary, and E=Ear anomalies [1]. CHARGE became an accepted syndrome in 2004 when the CHD7 gene was discovered [2]. Chris was born with all six of these anomalies and saving his life was of utmost importance to his mother. Feeding was at the forefront of concerns for all stakeholders in Chris' life. Immediately after birth it was noted that Chris could not suck. A myriad of tools was used to support him: typical baby bottles with larger holes in the rubber nipples, glass capillary tubes of formula dropped down his throat, rubber nipples used for baby lambs placed on cola bottles to name a few. Fearing aspiration after feedings, Chris' mother would sit with him in a wing back chair resting him on her left arm to position him upward so that formula could flow down his throat appropriately. At four weeks of age, he had a lip adhesion surgery, but still could not suck, swallow, or gain weight. At approximately six weeks of age, Chris' mother took him to his pediatric otolaryngologist because he was losing weight and she desperately believed more was wrong with him.

Chris was admitted to the hospital where tests revealed he also had severe reflux. A gastrostomy surgery including a fundoplication procedure was performed. A bladder type catheter was inserted to be used as a feeding tube for Chris. A metal clamp with a screw for closing off the tube between feedings was a part of this feeding apparatus. Formula via syringes was prescribed in certain amounts per hour for feedings followed by cleansing of the tube with water. Chris began to slowly gain some weight. The positive aspect of this type of feeding procedure for Chris was not only the support with weight gain, but the fact that his mother held him for each feeding and was able to bond with him during feedings like typical children do as they nurse or bottle feed. The catheter feeding apparatus required his mother to be within twelve inches of him at all times during feeds. Because of the vision and hearing losses associated with Chris' CHARGE, his mother was able to directly engage in deliberate sensing with him in tandem with feeding him. As he gained weight, he became more active and alert as she deliberately involved him in appropriate mother : baby cuddling, kissing, and singing. As he grew, she was able to mix baby food with fresh goat milk she purchased from a local farmer. She used the plunger on the syringe to gently push typical age-appropriate nourishment into Chris' body.

As young Chris fed with his tube, his mother felt it important for him to experience sensory touch in his mouth hoping that he could experience taste as his stomach filled with food. It made sense to her that he might at some point learn to eat from working his mouth with sensory soft foods in tandem with his satisfaction of feeling full of his liquified diet. Medical professionals prescribed specialized swabs for moisture in his mouth. Chris's mother started his sensory mouth moisturizing with the swabs, but soon moved to the use of candy suckers, honey and jarred baby food fruit on her fingers. She gently rubbed the inside of his mouth and lips with sweet foods as she fed him through his feeding tube. As he grew, he was expected to sit at the table in his highchair with the family and she tube fed him with hope and expectation that he would eventually physically eat for himself. Chris finally learned to eat and swallow soft food and his feeding tube was removed at age 3.5 years.

Discussion

Chris' mother is a professional special educator and is certified in dual sensory impairment. She has observed many children with feeding pumps which must be quite advantageous for school personnel and mothers who struggle with swallowing and feeding issues. She is particularly concerned though about her observations of children sitting alone or lying-in bed as their pumps feed them. Children with vision and hearing loss must have deliberate engagement with their senses to grow developmentally. So, while the feeding pumps may be an efficient way to have children with CHARGE syndrome feed, their teachers and parents must be trained in doing so in inclusive typical school and family feeding scenarios. The old bladder catheter feeding apparatus may be outdated with the development of more modern technical feeding devices, but it offered an opportunity for close feeding, bonding, and communication opportunities for Chris. His mother's hands were on him as he drank in food, mother talk, family talk, and loving touch for hours daily. She recalls to this day the feel of the metal clamp between her ring and middle fingers on her left hand as she extended the tube into the air above Chris as he lay cuddled in her left arm. Her right hand and arm filled the syringe with age-appropriate nourishment and massaged his mouth and lips with differing textured sweet foods. Chris is now thirty-eight (38) years old. He lives independently and is a college graduate. His medical fragility is still evident and has included numerous cardiac and other surgeries including the excision of a fistula most likely related to his catheter feeding tube. His mother wonders if his cognitive abilities were a result of the extensive close times they spent together during his early developmental years. She is concerned for children she observes feeding from technology devices and not receiving hours of daily face-to-face interaction. She concedes professionally that there is no denial that feeding pump technology is a wonderful attributing factor to the livelihood of children with CHARGE syndrome. She worries that developmental delays may be exacerbated by lack of intensive time spent in parent : child feeding times particularly in early developmental years. All children with CHARGE have varying issues within the syndrome and cannot be quantified as equal in their sensory losses. With that said, clearly the syndrome, by definition, includes severe comorbid losses in need of deliberate interventions by adults to support developmental progress for those born with CHARGE. Have the modern technology supports for tube feeding helped children live, but impacted developmental growth? Answering this question is worthy of future research because children with CHARGE syndrome represent some of the lowest of low incidence disability categories and deserve others to better understand how to support their development trajectory appropriately leading to as much independence as is possible in their later lives. You may ask yourself as you read this opinion article regarding feeding tube technology how this author has so much information regarding Chris, his mother and his syndromic feeding issues. You see, this author is she. I am Chris' mother.

References

1. Pagon RA, Graham JM, Zonana J, Yong SL (1981) Coloboma, congenital heart disease, and choanal atresia with multiple anomalies: CHARGE association. J Pediatr 99(2): 223-227.
2. Hartshorne TS, Hefner MA, Davenport SLH, Thelin JW (2011) CHARGE syndrome. San Diego, Plural Publishing.