CHILDREN WITH FEEDING TUBES

Part 1: THE ISSUES

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Children who receive all or part of their nourishment through a tube create special challenges for therapists and parents. There is a tendency for others to view the tube as an enemy of progress – as something to be gotten rid of. Children are often referred to a therapist with the specific request to get the child off the tube and onto oral feedings as rapidly as possible. When the transition to oral feeding is not made rapidly, everyone feels like a failure. With many children, the emphasis has been placed on the feeding process, rather than on the development of skills that could support feeding. This is rather like putting the cart before the horse. Let us review the special questions, issues, and problems that are presented when a child has a severe feeding problem that requires tube feeding.

Why are feeding tubes recommended?

Tube feedings can be initiated for a wide variety of reasons. Premature infants under the gestational age of 33 weeks or 3 pounds have not reached the stage of development where strong sucking and swallowing patterns can support oral feedings. Some children have such severe respiratory or cardiac problems that they do not have the energy to suck and swallow. Because the respiratory system and the feeding system use the same passageway in the upper portion of the pharynx, difficulties with swallowing or breathing can cause a child to aspirate, or draw food or liquid into the lungs rather than into the esophagus. Other children may lack the neurological coordination required to organize the collection and movement of food in the mouth, and to propel it to the back of the tongue and the pharynx for swallowing. Sucking and swallowing may be very slow or very uncoordinated, and the child might be unable to take in enough calories before becoming exhausted. Still other children experience severe gastrointestinal difficulties that cause food to be refluxed and vomited. Surgical procedures to prevent reflux may increase the discomfort of swallowing and result in a reduced desire to eat.

What characteristics are seen in children who are tube-fed?

Children who are tube-fed have many characteristics in common with other children with feeding problems. Other characteristics appear to be unique to the child with a severe feeding disorder. The severity or special combination of these characteristics prevents the infant from achieving many of the developmental feeding abilities that would be seen normally at 1-2 months of age. Two of more of the following physical and sensory behaviors have been observed consistently in infants under 18 months who have been placed on tube-feedings:

Hyperextension of the neck, accompanied by scapular adduction and shoulder girdle elevation is seen as the primary movement characteristic of many of these infants. These tone and movement patterns strongly influence the infant's feeding and respiratory abilities.

Respiratory difficulties are observed with high frequency. These generally reflect the incoordination of sucking and swallowing patterns with breathing. Respiratory control problems contribute to fearfulness and caution as a general approach to new or unsuccessful experiences. Respiratory problems may become exaggerated when the child produces excessive mucous that collects in the pharyngeal airway. Infants with primary respiratory dysfunction related to prematurity or cardiac disorders are often unable to coordinate a suck-swallow-breathe pattern. Their energy is directed toward the breathing portion of this triad. The baby temporarily may have an absent swallow reflex, or may refuse to take the nipple when it is offered.

Dysfunctional and disorganized sucking patterns are characteristic of the majority of tube-fed infants with prematurity or neurological dysfunction. A clear sucking rhythm is often lacking. Movements may be further disorganized when touch or pressure is applied to the tongue with a nipple or spoon. The disorganized infant may use a rapid, non-nutritive suck with the bottle, or may forget to pause for breathing in the suck-swallow-breathe cycle.

Swallowing disorders preclude the development of successful oral feeding. The infant may have difficulty using the tongue and lips to organize the bolus of food or liquid in the oral cavity and project it backward for the swallow. Small amounts of food may drip over the back of the tongue without causing a swallowing reflex to be elicited. When the swallowing reflex fails to occur, the airway is open and unprotected, and the upper end of esophagus does not open to allow the passage of food. Aspiration of the food into the lungs is the natural consequence. Some children have a swallowing reflex that is delayed. Instead of the pattern triggering from the backward movement of the tongue and the stimulation of the anterior pillars of fauces, the reflex will be elicited after food or liquid has collected in the valleculae or pyriform sinuses. Although the swallow occurs, a portion of the bolus may be aspirated before or after the swallow.

Hypersensitive responses to oral stimulation occur frequently when the infant has been deprived of positive sensory input to the mouth. When sensory input is provided, it may be experienced as very strong and uncomfortable. Since many children require invasive procedures such as suctioning and tube-insertion, a belief that the mouth is an unpleasant place can develop. The infant avoids using the mouth to explore and learn because it is uncomfortable. He becomes wary and watchful of anyone who approaches his mouth, assuming that the sensory input will be intensely uncomfortable

Sensory defensive responses to facial and oral stimulation occur as a primary difficulty in some children. Defensive responses are strongly negative, and throw the child immediately into a fight-or-flight reaction. The child's basic perception is one of danger, and the sensory stimulus is often perceived as an attack. Sensory defensiveness may occur as a response to touch, movement, smell, taste, and texture in food.

Gastroesophageal reflux occurs when the muscles at the lower end of the esophagus fail to contract enough to prevent reflux or backwash of stomach contents into the esophagus and pharynx. Reflux often results in vomiting. Reflux is unpleasant for the child and caregivers. Constant acid irritation of the esophagus can reduce the infant's desire to take food by mouth because of the discomfort.

Delayed gastric emptying is observed when food remains in the stomach and is not efficiently emptied into the small intestine. This condition contributes to gastroesophageal reflux and to a reduction in appetite. When the stomach contains a substantial amount of food from the last meal, children aren't hungry when the next meal is offered.

Gagging, retching, and nausea occur when the gastrointestinal system is under severe stress. These symptoms are most common as a side-effect of medication, or gastrointestinal surgery. Children whose reflux has been stopped with a fundoplication may begin to retch during or between tube feedings. This unproductive heaving and gagging is extremely distressing to the child and family, and strongly reduces the desire to eat. When gastric emptying is delayed, a pyloroplasty may be added to the fundoplication, creating an open valve at the bottom of the stomach to enhance gastric emptying. Some children experience rapid dumping of stomach contents into the intestines following this procedure. Sudden changes in blood sugar and autonomic nervous system symptoms such as sweating, pallor, and nausea may accompany tube feedings.

Eating aversion is the result of a complex interplay of sensorimotor, gastrointestinal, and environmental responses. It is a term used to describe children who simply do not want to eat. It is typically perceived as a behavioral issue, with the child confronting adults with a strong refusal to accept enough food to be

adequately nourished. The term infantile anorexia is occasionally used to describe these children. However, a large number of these children have subtle sensorimotor and gastrointestinal characteristics that make eating uncomfortable. These children may choose a non-eating behavior to reduce or prevent discomfort. This choice may become strong and unbending when the child experiences pressure from others to eat.

Failure-to-thrive is the end result of physical, sensory, metabolic, or environmental eating difficulties. The child does not gain grow adequately with oral feeding. Tube feedings may be initiated as a temporary measure to increase the child's nutritional status and improve growth.

What types of feeding tubes are recommended for children?

Tubes can be divided into two general categories: those that are inserted through the oral-pharyngeal area (i.e. nasogastric tubes, orogastric tubes), and those that are not (i.e. gastrostomy tubes, jeujenostomy tubes). This is an important distinction therapeutically. The insertion and presence of a tube in the nose, mouth, or pharynx may actually compete with goals of an oral-motor treatment program. Since one of the goals in the program is to develop a sense of pleasure and enjoyment with use of the mouth, this will become more difficult if tubes must constantly be inserted or remain in the naso-pharyngeal area. It is also uncomfortable for some children to actively suck and swallow with the tube in place. Added breathing difficulties can arise when one small nostril of an infant is occluded by the tube. Although the nasogastric tube is usually the first tube a child receives, it has many disadvantages when used as a long-term procedure.

If the child is a candidate for surgical procedures, the insertion of a gastrostomy tube can enable nourishment to be supplied in a way that does not conflict with oral-motor treatment goals. The area of invasion for the tube is separated from the oral-pharyngeal area. It becomes much easier for the child to discover the pleasurable aspects of the mouth. Because there is no longer a tube taped across the face, the child looks less ill, and the parents are subjected to fewer stares and questions.

There are disadvantages to the gastrostomy tube that must be considered. Surgery is risky for some children, even when it is done without general anesthesia (i.e. PEG procedure). Some children develop a mild irritation and leakage around the tube site. This can be uncomfortable for the child and of concern to the parents. A gastrostomy procedure can increase the risk of gastroesophageal reflux or make an existing reflux disorder more severe. When reflux is present or suspected, more extensive surgery is usually combined with the insertion of a gastrostomy tube. The most common procedure, the Nissen fundoplication, creates a wrap of stomach tissue around the lower esophageal sphincter to prevent the refluxing of stomach contents into esophagus. When the gastroesophageal reflux is a symptom of a more extensive disorder of the gastrointestinal system, severe side effects can result. Many children with neurological dysfunction show poor motility of the entire system. The stomach empties too slowly, and movement of digested food through the intestines may be slow or reduced. The fundoplication may contribute to gagging, retching, gas bloat, nausea, and other major discomforts that reduce the child's interest in taking food orally.

If reflux is severe, a tube may be inserted directly into the jejunum at the top of the small intestines, bypassing the stomach. This eliminates the risk of refluxing food from the stomach. Stomach acids and other secretions may, however, still be refluxed.

Some children are unable to absorb adequate nutrients through the intestinal walls because of shortening of the intestinal tract or lack of intestinal motility. Nutrients can be given through a central line that goes directly into the blood stream. This is referred to as hyperalimentation or TPN (total parenteral nutrition).

How do families perceive the feeding tube?

Feeding tubes are given to support life, and to make it easier for the child to grow without the risk of malnutrition, excessive fatigue, or aspiration. Theoretically, the introduction of the tube should be a positive event, one that supports growth and learning. When children and their families have gone through an extended period of difficult feeding, they may welcome the tube. Tube feedings offer an opportunity for the child to be well-nourished without pressuring the child to eat more or eat faster. Risks of aspiration and chronic respiratory illness are reduced. Parents often express relief and acknowledge that they and their child are happier since tube feedings were initiated.

The tube may be perceived negatively by some families and professionals who become deeply discouraged when the tube is recommended. If neurological problems underlie the feeding difficulties, there is often a strong, unspoken fear that once a child has been given a tube, the tube will required forever. In a sense, the tube is seen as an outward symbol of their fear that their child is very different from others. Somehow if the tube would go away, it would mean

that the child was less handicapped, or more like other children. The tube often represents the failure that many mothers feel when they are unable to feed their baby. In our culture, there is a strong emotional connection between feelings of adequacy as a woman and a mother, and the ability and enthusiasm with which our children eat. When a child can't or won't eat in a way that meets our expectations, we feel let down and wonder where we have failed. Even when there is objective evidence that the child's feeding problems are unrelated to issues of mothering, there is often a nagging inner voice that tells us that if we were smart enough, or creative enough, or persistent enough, our child would be able to eat. The tube may become the final symbol that often says, "I've failed".

The introduction of a tube is frequently made prior to a referral for treatment for feeding problems. If the child has been receiving therapy, the family may be encouraged to drop treatment for feeding problems once the tube has been given. This verifies their suspicion that the doctor believes the child will never eat by mouth. The tube as a nutritive support can be a friend and not an enemy. It can allow the child to gain improve nutritional status while simultaneously learning how to eat in a safer and more comfortable way.

Do tube feedings ever reduce the child's ability or desire to eat orally?

When tube feedings are initiated immediately after birth, the infant lacks the opportunity to build associations between positive sensations in the mouth and the reduction of hunger, or the social interaction with another person that surrounds a meal. If oral feedings become possible at a later time, the prime associations and motivations to take food by mouth will be missing. The child may see no relationship between learning to handle food in the mouth and the satisfying inner feelings that come after a good meal. This can become a greater barrier to the establishment of oral feedings than the original sensorimotor problem.

Tube feedings may initiate or increase gastroesophageal reflux. When reflux occurs regularly, esophageal irritation and pain can result. As this becomes associated with mealtimes, the young child may connect eating with being uncomfortable. This reduces the desire to taste food and eat by mouth.

When total tube feedings are initiated in a child who has been taking food orally, the mouth may go through many changes. The stimulation provided by touch to the mouth, feeding utensils (i.e. nipples, spoons, cups) ,and food often disappears from the child's sensory experience. Small sucking and swallowing movements that may have been present, but inadequate to support nutrition, are no longer stimulated and practiced. Over time, they appear to be forgotten and do not occur when a nipple or food is placed in the mouth. Negative and invasive stimulation to the face and mouth continues or increases as suctioning, intubation, tube insertion, and other life-enhancing procedures are carried out. Gradually the mouth becomes unfamiliar with touch, taste, texture, and other stimuli that had pleasurable associations.

The face and mouth can become physically hypersensitive to touch and taste when a child has not experienced this type of input for a long time. It is as if the nervous system increases its sensitivity to search for input that has been withdrawn with the addition of tube feedings. When sensory input is provided, it is perceived as invasive, uncomfortable, sudden, and intense. The infant dislikes the way things feel and taste in the mouth. If there are problems with physical coordination, the baby may be unable to put fingers, fists, and toys in the mouth. He is unable to participate in the exploration that is the primary path to learning in the infant and young child. Because most of the sensory input that is given is provided by another person, the infant becomes cautious about allowing anyone near the mouth.

Much of the sensory input that is provided by others is uncomfortable and unpleasant. Suctioning and insertion of a nasogastric or orogastric tube occurs frequently for many medically-at-risk infants. With each invasion of the oral space, the child strengthens a belief that sensations in the mouth are dangerous and unpleasant. An unending circle begins as the infant erects barriers against anyone who would provide oral stimulation or offer food.

How can parents support the child's desire and ability to eat orally?

Children who receive tube-feedings should have the opportunity to develop comfortable and safe oral-motor skills through a specialized therapy program. However, there are many things that parents can do to support the child's ability to return to some oral feeding in the future.

Children's tube-feeding mealtimes contribute to their associations with food and being fed. When mealtimes are relaxed, comfortable, and interactive, the child learns that eating can be pleasurable. An infant can be cradled in the parent's arms for a tube-feeding and receive the same interactive benefits with a caring feeder as a bottle-fed infant. Older infants and toddlers can be tube-fed during a family meal or fed in a special chair or location associated with eating.

If gastrointestinal discomfort is present during tube-feedings, special attention can be given to reducing stress associated with mealtimes. Children and their parents often anticipate retching or vomiting which adds to the overall stress level and physical discomfort. The anticipatory stress often serves as a trigger that increases both the frequency and severity of the reflux. Activities that calm and relax the child can be used to prepare the child for the meal. Music can support physical and mental relaxation. Parents can learn to recognize the child's first signals of discomfort. The flow of formula can be stopped before the child becomes distressed. Multiple pauses during the meal can reduce the triggers that initiate episodes of severe reflux, vomiting, or retching.

Loving, interactive sensory input can be provided to the child's face and mouth during play and daily care activities. Comforting touch, patting or stroking while singing, or making funny sounds together can build positive associations with orofacial input. This can prevent hypersensitivity and negative associations from developing.

If the child does not experience reflux or other gastrointestinal discomfort during the meal, oral stimulation can be provided during tube feedings. This can include sucking on a pacifier, stroking the lips, playing with mouth toys or other positive input. This is used to help the child maintain or develop oral-motor skills that can be used for oral feeding at a later point.