



Language Development for Young Tube-Fed Children

Robert Porter MBA, Ed.D., Katherine Porter M.A. CCC - SLP

LANGUAGE DEVELOPMENT CHALLENGES IN THE HOME ENVIRONMENT OF THE CHILD WHO IS TUBE FED

Contact Info: Rporter5@capellauniversity.edu - (217) 714 - 2114

Abstract

Young children learn about their world through participating in a variety of activities. The first participation from birth is a child's connection and bonding to their mother through nursing or bottle feeding.

This activity repeats when the child communicates through crying (C. D. Rudolph, 1994, "Feeding Disorders in Infants and Children," p. S117). As time passes, the language builds from crying to words.

For young children, food and the activities surrounding or immediately a part of eating are a vehicle that builds vocabulary acquisition and development. Without food as a routine opportunity for children to interact with their environment, the likelihood of language delay increases.

The goal of this study was to identify any potential issues and challenges present in the homes of young tube-fed children surrounding their altered mealtimes from a language development perspective and orientation. The working theory sought to distinguish and or determine if the tube-feeding lifestyle, with all of its encumbrances, alters a child's quantity and quality of mealtime-centric language development routines.

This ethnographic qualitative research study evaluated the home environments of tube-fed preschool-aged children in order to document the impact tube feeding may have on language development. Each of the families selected to participate have children with language delays documented on their individual education plan/individual family service plan. The study utilized 3 detailed questionnaires followed by a telephone interview with the parents to expand upon and document their comments.

The results showed a similarity to what this researcher experienced rearing his tube-fed child and to the experiences of the families from Townsley and Robinson's *Food for Thought: Effective Support for Families Caring for a Child Who Is Tube Fed*. This study expands their research in the direction of language development.

The analysis found a correlation suggesting that tube feeding can profoundly affect a child's exposure to traditional language-rich opportunities normally centered on meals. Notably, many of the parents stated they wished they knew more about the connection and recognized the loss of language development for their child; moreover, several expressed the importance of this information for other parents and professionals serving children who are tube fed.

Methodology

"Language learning is not really something that the child does; it happens to the child . . . and the difference between a rich and stimulating environment and an impoverished environment may be substantial in language acquisition"

Chomsky, N. (1988). *Language and problems of knowledge: The Managua lectures*. (p. 134).

- What: Documenting the occurrences** →
1. Family demographic information
 2. Tube feeding interactions and experiences
 3. Evaluating the child's IFSP or IEP
 4. Interview about the child's Language growth
- When:** February – April 2014
- Where:** USA
- Why:** Researchers correlation and empirical experience. The study looked for existence (recognition), frequency, and parental responses.

Questions

1. What are the specific patterns of language deficit based on the lack of eating together as a family?
2. Is this pattern found in the child's IFSP or IEP? **Answer – YES!**
3. How does the act of eating change a child's willingness to participate in a learning activity?
4. How does the parent address their child's language development needs?
5. What are some of the issues faced by families of children who are tube fed?

What we found

- Tube-fed children often do not participate in family meals.
- TV and other technology is often used to manage a child's anxiety or time.
- Single parents have a harder time.
- There is a high level of guilt, frustration, and lack of professional understanding.
- Early language development is poor.

Results



Answers for Question 1 & 2

What are the patterns of language deficit(s) observed based on a lack of eating together as a family? See Chart →

- These families have significantly altered traditional meal time routines to accommodate the needs of their child on Home Enteral Tube Feeding (HETF)?
- **Parent Comment:** *We typically don't indicate it's time to eat...sometimes we show him the syringe full of food...and we might tell him it is time to eat. We don't draw much attention to the fact that he is feeding. He tends to get uncomfortable.*
- Observation of behaviors, verbal direction from parents, and routine based repetition offers children rich opportunities for language growth. These opportunities are missing or substantially less frequent in the homes of children on HETF.
- Each of the parents indicated their children have similar difficulties asking and answering questions, making their wants and needs known.

Answers for Question 3

How does the act of eating change a child's willingness to participate in a language learning activity?

- To answer this question it has to be framed from a tube-fed perspective.
- In short, oral eating for a child on HETF can be a terror filled proposition they dread. For the parents it can be a battleground over the hard and consequential choices they face on behalf of their child. Drs. Townsley and Robinson's (2000) research revealed that this conflict for the parent often begins in their doctor's office.
- **Parent comment:** *"Two doctors say the opposite things to us. One says 'yes' feed her, the other says 'no - nothing by mouth'" (p. 38)*
 - **Parent comment:** *"Meal times devolve into battles. Over time these battles wear us down (the parents and the child) - not to mention their siblings (other family members). Many times we hope we can make up language ground in therapy because we're just surviving otherwise. And none of our doctors seem to know what to do...or realize the impact this environment has on his desire to engage."*

Fear may dominate the mind of the child and his or her gag reflex / oral sensitivity may shut off any desire to make the attempt. What follows is fatigue brought about because the child's early skill development was missing and the constant effect of reinforcement is subsequently and predictably absent.

Conclusions

- This research has established some understanding of what struggles are present in the homes of children on HETF.
- This study has identified opportunities for improvement and identified some successful strategies that might succeed in Early Intervention programs.
- The study established an association between impoverished language development and tube feeding.
- The study discovered that the parents affirmed a link between what their child has lost in not participating in mealtime routines and conversations to the levels of language development for their child.
- The study showed significant levels of stress and sometimes profound levels of scheduled activity.

Practical Management	Social Management	Emotional Management
<ul style="list-style-type: none"> -Administering the feed -cleaning the stoma site -flushing tubes -monitoring caloric and nutrition intake -etc. 	<ul style="list-style-type: none"> -Accessing support services -access to education and therapy -going out -going on vacations -coping with social situations like family meal times -etc. 	<ul style="list-style-type: none"> -Coping with the feelings of guilt and anger -coping with other peoples reactions -helping their child to cope with their emotions -overcoming feelings of loss -coping with underinformed professionals

Language Area	Named Skill	Example of Language Deficit Observed during the tube-feeding routine.
Receptive Language Skills	Following Directions	Child does not understand multiple step directions such as "Put your toy away and come to the table."
	Identifying Vocabulary	Child does not understand key words such as "wait, almost, open, pour, formula, or other food name".
	Understanding Questions	Child does not demonstrate understanding of "Do you want to eat?"; "Do you want to hold the syringe?"
Expressive Language Skills	Making Choices	Child is not able to demonstrate understanding to the caregiver/parent, that he/she has a preference/want/need.
	Requesting	Child is unable to ask for food, for feeding to wait/stop, or for someone or something to accompany him during feeding.
Pragmatic Language Skills	Answering Questions	Child is not able to answer the "who, where, how, what, when" regarding his/her wants, needs, or feelings.
	Labeling	Child is not able to effectively and meaningfully talk about what he/she sees and does.
	Making Choices	Child is not able to indicate what he/she wants or what he/she wants to happen.
Pragmatic Language Skills	Greetings	Child does not participate in the opening or closing of an interaction.
	Playing / Interacting with toys	Child does not manipulate/explore toys, which are a real source of pleasure and learning for a child.
	Turn taking	Child and Parent do not have the experience and pleasure of sustained back and forth verbal or nonverbal interactions.

Answers for Question 4 & 5

How does the parent address their child's language development needs?

What are some of the issues faced by families of children who are tube fed?

- **Parent comment:** *"We try to encourage him but it is a constant struggle. If we don't try to get him to eat, he will never get off of tube feeds. When we do push, he shuts down. But we try. We talk to him and play games. We take him to private therapy and he sees a speech therapist at school."*

Every child represented experiences increases in stress, anxiety, and frustration surrounding meal times. For children who are tube-fed, their natural curiosity and willingness to explore is stunted.

- **Parent Comment:** *"I wish she would ask for different things."*
- **Parent comment:** *"My six year old (non HETF child) is constantly asking me questions. 'Mommy, why this; why that.' She is two years younger than our (HETF) son and seems to have very natural joy learning about her world. Our (HETF) son is not that way. I have lain awake at night crying - trying to figure out how to reach him; how to pour into him these things - the knowledge and language - and ignite that natural curiosity. I hope and pray he gets it. I don't know... I just don't know."*

Expectations and routine become security and control measures

- **Parent Comment:** *"We do the same thing every day. If we change his routine he gets anxious. We try to introduce new foods but mostly we stick to the things he likes."*

Recommendations

- **PARENTS AND PROFESSIONALS NEED TO KNOW THIS INFO!!**
- First - read this study. Why? Because the study captured and clarified information specific to the language development of the child on Home Enteral Tube Feeding (HETF).
- Next steps... We recommend a mixed methodology study where language development interventions might be measured. We are interested in advancing these opportunities and leading other studies.
- We recommend that the findings of this research be published / discussed in professional journals and promoted to the teachers, professionals, and parents of children on HETF.

How this research began...

As educated parents of a child who is tube fed, we noticed a lack of interest in food related learning in our child and subsequently began utilizing non-food items to encourage learning and socio-cognitive development. This seemed to help facilitate his language growth. Sadly the professionals were the least informed in this area and thus our journey, to this end, began.