MATERNAL STRESS AND COPING WHEN A CHILD IS FED ENTERALLY

DISSERTATION

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By

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Abstract

While there is extensive literature on parental stress associated with parenting a child with special health needs, few researchers have looked specifically at the stress associated with parenting a child fed enterally. The purpose of this study was to explore the stressors experienced by mothers of children who were being fed enterally and the coping strategies and resources available to them by employing an exploratory/descriptive design. Data were obtained during face-to-face interviews, or interviews conducted via mail, employing a list of open-ended questions about caring for an infant/child who is fed enterally and a demographic questionnaire filled out by the mothers. A convenient sample of 40 mothers of children who were being fed enterally was recruited for the study. Through content analysis of the data from this sample of mothers, the negative and positive aspects of home enteral nutrition (HEN) and the stressors and coping strategies were delineated.

Mothers identified several important stressors. These included the social stigma associated with HEN, managing the equipment, negative emotions associated with the process, and physical problems. Mothers did perceive that their children were now able to receive appropriate nutrition and thus, sustain physical growth and development. Coping strategies identified by the mothers included: seeking social support, seeking assistance from health professionals, being flexible with the child's HEN schedule, and taking the time to care for themselves.

The stressors and coping strategies faced by mothers of children on HEN are multidimensional and encompass social and psychological components. By identifying the specific areas of stress that mothers of children on HEN deal with on a daily basis, nurses and other professionals can develop interventions that help to decrease the effect of the negative stressors. A better understanding of the ways mothers cope with these stressors allows for more accurate evaluations of these interventions. Appropriate interventions that lessen stress and allow for better coping will create the best possible environment for the feeding process to occur. This ultimately benefits the child by making the feeding process more pleasurable for both mother and child. Dedicated to my husband, who has stood behind me all the way, and to my family and friends who believed in me and kept pushing me when I wanted to give up.

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CHAPTER 1

OVERVIEW

Introduction

All parents experience stress from their roles as caregivers and socializers of children (Peterson & Mathieson, 2000). Parental stress occurs regularly, even during the positive accomplishments of childhood, and parents of children with disabilities are even more susceptible to stress. As the main caregivers of children with chronic or disabling conditions, parents need varying degrees and types of support.

In studies of children with disabilities, parental distress and family functioning impact the children in numerous ways, affecting cognitive, behavioral, and social development (Sloper, 1999). In addition, a family's perception of the stressful nature of caring for a child with a disability affects their use of resources and the level of parental stress more than the actual severity of the child's problems. Parental and child characteristics and the features of the family's social context also affect parenting stress (Halpern, Brand, & Malone, 2001).

The birth of a child with a disability is certainly an event that is considered not only stressful but is often viewed as a crisis by the parents of that child (Hughes, 1999; Reichman, Miller, Gordon, & Hendricks-Munoz, 2000). Raising a child with a disability poses many crises over the lifetime of the child. Parents must adapt to the many changing circumstances and needs of the child. Stress is often the consequence of these demands. A child with a disability can strain family finances, stress relationships, and cut families off from outside support. Families of children with chronic health problems often have a higher level of overall stress due to the fact that they are often dealing with multiple stressors at the same time (Kendall-Tackett, 2001). Parents experiencing the increased stress of raising a child with a disability often experience less social support from family and friends in dealing with this increase in stress (Brotherson, Oakland, Secrist-Mertz, Litchfield, & Larson, 1995). Social isolation or lack of informal social support can be one of the most stressful factors associated with caring for a child with a disability (Beresford, 1994). While there has been much written about the stress of raising a child with a disability, one area that is lacking in information is the stress specifically associated with raising a child with a feeding disorder who requires home enteral nutrition (HEN).

Feeding problems in children are becoming more prevalent and the use of HEN is rising. An estimated 25% to 35% of children in the general pediatric population have feeding problems (Byars, et al, 2003). Approximately 12.8% of all children in the United States, an estimated 9.4 million children, have special health care needs (Maternal Child Health Bureau, 2001). It is estimated that feeding problems are even more prominent (40%-70%) in these children (Byars, et al, 2003).

It has been estimated that HEN provides a cost savings of approximately 70% over in-patient hospital enteral feeding costs (Puntis, 2001). While HEN has positive impacts on the quality of life of caregivers of children with feeding problems, such as

a decrease in the amount of time spent trying to orally feed, easier administration of medications and decreased concern over the nutritional status of the child, it is not without complications (Sullivan, et al, 2004). Potential complications of tube feedings can be separated into gastrointestinal, metabolic, and mechanical. The most common complications are gastrointestinal and include vomiting, abdominal distention, diarrhea, and the bringing about or worsening of gastroesophageal reflux disorder (Arvedson & Brodsky, 2002).

A feeding problem is defined as a deficit in any aspect of taking in nutrition that results in undernutrition, poor growth, or stressful mealtimes for children or their caregivers. Bottei (1995) defines the nursing diagnosis of feeding dysfunction globally as "the inability to safely consume adequate nutrients to meet nutritional needs" (p. 81). A general definition of a feeding disorder is the inability or unwillingness to eat certain foods (Babbitt, et al., 1994). The causes, signs, symptoms, and severity of a feeding disorder can vary greatly both among different children and within the same child over time (Arvedson & Brodsky, 2002). Major diagnostic categories associated with feeding disorders include the following: 1) Neurologic (encephalopathies, traumatic brain injury, neoplasms, mental retardation, and developmental delays); 2) Anatomic and structural (congenital, such as tracheoesophageal fistula and cleft palate, and acquired, such as tracheostomy); 3) Genetic (chromosomal, such as Down Syndrome, syndromic, such as Pierre Robin sequence, and inborn errors of metabolism); 4) Secondary to systemic illness (respiratory, such as bronchopulmonary dysplasia, gastrointestinal, such as GI dysmotility, and congenital cardiac anomalies); 5) Psychosocial and behavioral (such

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as oral deprivation); and 6) Secondary to resolved medical conditions (Arvedson & Brodsky, 2002).

Feeding problems can manifest in many different ways, such as resistance to accepting foods, lack of energy for the work of eating and digestion, and oral sensorimotor disabilities. Prolonged difficulty in feeding can also result in cognitive impairment, emotional dysfunction, malnutrition, growth retardation, decreased energy, greater susceptibility to illness, and even death (Manikam & Perman, 2000). Even feeding disorders that are self-limiting have the potential to result in parental anxiety and distress and disruption of the parent-child relationship (Cerro, Zeunert, Simmer, & Daniels, 2002).

Whenever a child cannot meet nutritional needs orally, there needs to be an alternate method of feeding. Options available include enteral feedings through the gastrointestinal tract and parenteral feedings that provide nutrients directly into the bloodstream, bypassing the gastrointestinal tract. Multiple options for both enteral and parenteral routes now exist. Enteral feedings, usually the preferred method, can be given by means of a nasogastric, orogastric, gastrostomy, or jejunostomy tubes. Parenteral nutrition may be delivered by means of peripheral vein access (peripheral intravenous central catheter or PICC) or direct central venous access (Arvedson & Brodsky, 2002; Minard, 1994).

Enteral or tube feedings are used as the initial method of providing nutrition to infants and children who are unable to feed orally or who have excessive or unusual nutrient requirements that preclude the use of oral feedings alone. The easiest way to deliver enteral feedings is by an orogastric (OG) or nasogastric (NG) tube. If longterm (greater than 1-3 months) enteral feeding is needed, a gastrostomy tube (GT) is often preferred. Tube feedings can be provided as a continuous infusion, intermittent infusion, bolus, or overnight feeding (Murray, 2000).

For children with feeding problems, the dynamics of the feeding interaction are drastically altered. The emphasis is no longer on the pleasurable aspects of feeding but become focused on getting the child to consume enough nutritional intake to promote growth. Mothers of children with feeding problems report that they spend 4-8 hours per day attempting to feed their child compared with the approximately 1 hour reported by mothers of children without feeding problems (Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003). Enteral feedings become necessary when the child can no longer consume enough nutrition to promote growth. Although mothers can articulate the benefits, the decision to initiate enteral feeding remains difficult. Mothers describe agreeing to the insertion of a feeding tube as "giving in" (Spalding, & McKeever, 1998). By agreeing to a feeding tube, mothers perceive that they were denying their child the opportunity for oral feeding, the one normal activity (albeit difficult) in which their child engages (Guerriere, et al, 2003). Mothers also reported feelings of inadequacy and failure because they were not able to orally feed their child successfully (Hughes, 1999).

While there has been much written about the stress of raising a child with a disability, one area that is lacking in information concerns the stress associated with raising a child with a feeding disorder who requires tube feedings. There is a corresponding gap in the literature with regards to the coping resources available to the parents of a child with a feeding disorder requiring tube feedings.

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Purpose

When the decision is made to enterally feed a child, the usual feeding process is altered for both the child and parents. Mothers are most often the parent with the primary responsibility for managing the enteral feeding of their child. However, very little is known about how caring for a child who is enterally fed impacts the mother (Spalding, & McKeever, 1998). Few nurse researchers have examined the stress associated with a child fed enterally from the mother's perspective. Adams, Gordon, and Spangler (1999) concluded that mothers of children with a disability who were fed enterally had significantly more stress compared to mothers of children with a disability who were fed orally when it came to parent and family problems. Sleigh (2005) noted that mothers felt that their life was ruled by feeding times and that their feelings of not being in control or not being understood by professionals were major sources of stress.

There is some evidence to suggest that the placement of a nasogastric tube or a gastrostomy tube and the reliance on enteral feedings introduces a new set of stressors to the mother. However, these stressors have not been fully identified. Also in need of further identification are the specific coping strategies employed by mothers to manage the stressors associated with their child's enteral feedings. In addition, what is not known are the external resources needed by these mothers to successfully cope with the stress. A better understanding of the maternal stressors and the coping strategies used by mothers allows for the development of nursing interventions aimed at reducing the amount of stress confronted by these mothers. Appropriate interventions will create the best possible environment for the feeding process to

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occur and thus, ultimately benefit the child's cognitive and social development because the feeding process will become more pleasurable for both mother and child.

The purpose of this study was to explore the stress experienced by mothers of children who are being fed non-orally and to explore the coping strategies and resources available to them. The specific aims of this study were:

- To identify how mothers of children who are fed enterally feel about feeding their child by tube.
- 2. To identify the negative and positive aspects of Home Enteral Nutrition.
- 3. To determine what types of stressors mothers of children who are fed enterally experience.
- 4. To determine what types of coping strategies mothers of children who are fed enterally employ to deal with identified stressors.
- 5. To determine what types of external resources mothers of children who are fed enterally use or require in dealing with identified stressors.

Method

Design

This study used an exploratory/descriptive design. Forty mothers of children who were being fed enterally in the home were the subjects of this study. The decision was made to use mothers and not include fathers because in 90% of families of a child with a feeding disorder, mothers are the ones who are responsible for the child's nutritional intake (Carroll & Reilly, 1996). Mothers were recruited for this study if they were the primary caregiver of a child who was being fed enterally either by nasogastric or gastrostomy tube at home, spoke English, and were at least eighteen years old. Mothers were excluded if their child was currently hospitalized, also receiving total parenteral nutrition in conjunction with enteral feeding, or on mechanical ventilation or assisted breathing, as these conditions could potentially be related to the stress felt by these mothers. Data were collected using a semistructured interview (see Appendix B). Mothers were also asked to complete a demographic questionnaire after the interview was completed (see Appendix C). *Subjects*

The population of children on HEN is extremely diverse and it was the intent of the researcher to reach a diverse population of subjects. To ensure this goal, forty mothers were recruited through multiple venues. Mothers were recruited through the Mighty Medical Miracles (M3), a regional chapter of the Oley Foundation, which is the national organization that provides information and psycho-social support to consumers of home parenteral and enteral nutrition (n = 10). Mothers from M3 were contacted during monthly meetings of the support group. Information about the study and contact information for the principal investigator (PI) was also included in the Oley Foundation national newsletter to recruit a second group of mothers (n = 16) and interviews and questionnaires were done via email or regular mail, depending on the preference of the mother, since the distance was too great to travel to the home by car. Through this newsletter the PI was contacted by the Nutrition Support Nurse Coordinator at The Children's Mercy Hospital in Kansas City, Missouri. The Nurse Coordinator agreed to recruit potential subjects from within her current case load, explain the study, and set up appointments for face-to-face interviews that were conducted at Children's Mercy Hospital (n = 14). There were no significant

statistical differences noted between these groups of mothers with regard to age, race, income level, child's age, or length of time child had been on HEN.

Procedure

The study was approved by the Behavioral/Social Sciences Institutional Review Board of The Ohio State University. Approval was also obtained from the Institutional Review Board of Children's Mercy Hospital in Kansas City, Missouri. Written informed consent was obtained from each subject prior to data collection (see Appendix A). Data were either collected by face-to-face interviews or from written responses to the interview questions. Semi-structured open-ended interview questions were used to gather the richest data possible. These face-to-face interviews were audio taped for later transcription and analysis. Transcription was done by hand and performed by the PI. See Appendix B for the complete interview schedule. Questions one through eight will be discussed in chapter 3 and the remaining questions will be discussed in the following chapter. Mothers were also asked to complete a demographic questionnaire to obtain information about them and their child, such as age, race, income level, child's age, diagnosis, and length of time on HEN. See Appendix C for a copy of the demographic questionnaire. Interview questions and the demographic questionnaire were developed by a committee of researchers familiar with HEN and the use of interview techniques.

Some interviews and questionnaires were done over email or regular mail, depending on the preference of the mother, when the distance was too great to travel to the home by car (n = 16). The study was explained by telephone and the consent form was mailed to them along with a stamped envelope for return. Once the signed consent form was received by the PI, the interview questions and the demographic questionnaire were emailed or mailed to the subjects with instructions to answer each interview question to the best of their ability by writing out their responses. Responses were then mailed back to the PI and any questions that needed additional clarification were discussed over the telephone. Two mothers were contacted for clarification of the child's diagnosis and the child's age when HEN was started. It has been noted that computer-assisted self-administered interviews, when compared to face-to-face interviews, allow for an increase in perceived anonymity and make the respondents feel more at ease when it comes to reporting behaviors that could be considered socially undesirable (Newman, et al., 2002; Perlis, et al., 2004). It would be reasonable to assume that thinking of their disabled child as a burden to their family could be something these mothers might consider socially undesirable. In comparing responses to the question concerning significant burdens on the family, the number of burdens stated by those who were interviewed face-to-face was compared to the number of burdens written by those who returned interviews by email or regular mail. There were no significant differences in the number of burdens noted by either group (Mann-Whitney U = 149, p = .244).

Data Analysis

Data from each question asked during the interview were analyzed using content analysis. Content analysis utilizes a set of data-driven coding procedures, generated from the data themselves, to reduce and simplify recorded information into a set of categories that can be identified and measured to describe the presence, frequency, intensity and meaning reflected by written or verbal text (Waltz, Strickland, & Lenz, 2005). Content analysis aids the researcher in generating core constructs from interview data through a systematic method of reduction and analysis. It is especially suited to exploratory studies because it allows the researcher to get to the answers of the questions to which it is applied (Priest, Roberts, & Woods, 2002).

A content analysis was performed on each open-ended question using the eight-step technique as described by Waltz, Strickland, and Lenz (2005). In step one, the universe of content to be examined must be defined. The universe of content for this study was the tape-recorded or written responses to open-ended interview questions. For step two, the characteristics or concepts to be measured must be identified. The concepts to be measured in this study were defined by the research questions of the study as noted previously in this chapter. Step three involves selecting the unit of analysis to be employed. The units of analysis for this study consisted of words or word combinations that were indicative of complete and separate ideas or responses to each question being asked. A percent agreement for establishing the units of analysis of 80% was set a priori. Step four involves developing a sampling plan, which for this study involved analyzing the entire response to each open-ended question separately across all forty interviews. The analysis of each question was completed in the order that they appeared during the interview, with each analysis being completed before moving on to the next question. Step five consists of developing a scheme for categorizing the content and setting up clear coding and scoring instructions. The categorical decisions for this study were made inductively after the first 4 interviews (10% of the study subjects) by both researchers who would be coding the data. The categories were determined to be

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mutually exclusive and exhaustive. In step six, the categories and coding instructions are pretested. This was accomplished by coding the first ten interviews to establish intra- and interrater reliability that were above 80%, which was set a priori as the minimum acceptance rate. During step seven, coders are trained and the acceptable level of reliability is determined. For this study, there was no need to do additional training since there were no new coders used to perform the analysis. As noted before, an interrater reliability rate of 80% was set a priori. Step eight consists of performing the actual analysis. All forty interviews were first analyzed to establish units of analysis by the PI, a research nurse, and the dissertation advisor and then those units were then coded into categories.

For each individual question, the frequency and percentage of the forty subjects who gave a response that could be coded within each category was determined. Throughout the interviews, these mothers often gave more than one response in answer to each question, so results equal more than forty for many of the categories. Data from the demographic questionnaire were analyzed using the statistical package SPSS-14 (SPSS for Windows, Rel. 14.0.0, 2005).

Reliability of Data Analysis

There are three types of reliability that are considered important in content analysis. Unitizing reliability concerns the consistency in identifying the units of analysis to be categorized. Interpretive reliability (also referred to as interrater reliability) deals with the consistency in assigning those units of analysis into categories. Stability reliability refers to the reliability of coding decisions made over time. It is important for unitizing reliability to be established prior to categorization in order to establish interpretive reliability (Garvin, Kennedy, & Cissna, 1988).

Unitizing reliability was established by calculating the number of units of analysis (i.e. separate and complete responses for each question, for which a subject could have more than one for any given question), calculating the number of differences noted between the researchers, subtracting the number of differences from the total number of units to determine the number of units agreed upon, and determining the percentage of the total units that were agreed upon.

Reliability of coding decisions, which establishes stability reliability (also referred to as intra-rater reliability), was confirmed by recoding selected questions after a period of time had passed to check stability over time. Questions were chosen randomly by placing the numbers of each question in a hat and selecting ones to be rechecked. This percentage was calculated using the same method as used to determine unitizing reliability.

Limitations

There are a number of limitations that must be kept in mind when interpreting the results of the present study. One of the most important limitations of this study was the decision to interview only mothers. Although in 90% of families who have a child with a feeding disability, mothers have the primary responsibility for the child's nutritional intake (Carroll & Reilly, 1996), they certainly are not the only ones in the family who experience stress when caring for a child on enteral feedings. Another limitation was the use of a convenience sample. A convenience sample was necessary given the nature of the type of subjects used. People enter qualitative studies because they have personal knowledge of some event and are willing to communicate this knowledge to others. In order to research what it is like to deal with HEN on a daily basis, one must search out those who are currently dealing with HEN. Since there is no national registry of persons on HEN available in the United States, it was necessary for the researcher to seek out subjects from known support groups and there is no way to determine if those who expressed interest in participating in the study were different from those who did not express interest in participating.

A final limitation was the size of the sample. There are no computations or power analyses that can be done when doing a content analysis to determine a priori the minimum number of subjects required. Researchers set the number of subjects required in a study utilizing content analysis in order to achieve the purpose and of the study and by appraising the resources available to conduct the study. These resources often include the number of investigators and the financial support available (Sandelowski, 1995).

Results

The results of this dissertation are presented in a series of potential manuscripts, located in chapters two through four. The titles and abstracts of each potential manuscript are described below.

<u>Manuscript 1:</u> Baack, C.J. & Steward, D.K. (in process). Home enteral nutrition: Issues in clinical practice.

Abstract

Children who exhibit serious feeding problems often require enteral (tube) feeding methods, which become necessary from a safety perspective as well as for the provision of adequate nutrition. Parents, most often the mother, are placed in the position of learning and managing this alternative form of feeding in the home setting. When faced with the decision about whether or not to implement HEN for their child with a feeding disorder, many parents, especially the mothers, struggle. By agreeing to a feeding tube, mothers perceived that they were denying their child the opportunity for oral feeding, the one normal activity (albeit difficult) in which their child was able to engage. It is important for clinicians who work with these children in the community to be aware of the clinical issues that parents experience with home enteral nutrition (HEN). These clinical issues are presented as a synthesis of recent research findings related to maternal management of HEN.

<u>Manuscript 2:</u> Baack, C.J. Steward, D.K., Menke, E.M., Von Sadovszky, V., & Rabidoux, P. (in process). Maternal stress when a child is fed enterally.

Abstract

An estimated 25% to 35% of children in the general pediatric population have feeding problems. Mothers have reported that providing oral feedings to a child with a feeding disorder is a stressful process, but this does not always indicate that they were willing to initiate enteral feedings. Although mothers can articulate the benefits, the decision to initiate enteral feeding remains difficult. Mothers described agreeing to the insertion of a feeding tube as "giving in" and reported feelings of inadequacy and failure because they were not able to orally feed their child successfully. Few researchers have specifically examined sources of stress for mothers of children receiving enteral feeding. The specific aims of this study were to identify the negative and positive aspects of Home Enteral Nutrition and to determine what types of stressors mothers of children who are fed enterally experience.

Forty mothers were interviewed, using open-ended questions about what the hardest and easiest thing was when utilizing HEN, as well as the negative and positive aspects associated with using HEN. Mothers were also asked what it was like when they first learned that their child would have to be fed by tube and how they felt about using HEN. They were then asked to describe any significant burdens that had been placed on their families as a result of HEN. The results of this study provide insight into what it is like to make the decision to start enteral feedings. A rich description of the things these mothers felt were the hardest and most negative, the things that caused them the most stress, was obtained. At the same time, a better understanding of what was easy and most positive about utilizing HEN emerged.

<u>Manuscript 3:</u> Baack, C.J., Steward, D.K., Menke, E.M., Von Sadovszky, V., & Rabidoux, P. (in process). Coping strategies employed by mothers of children on home enteral nutrition.

<u>Abstract</u>

Health care providers mistakenly assume that the introduction of enteral feeding for a child with a feeding disorder will decrease the stress experienced by the mother, however the placement of a nasogastric tube or a gastrostomy tube and the reliance on home enteral nutrition (HEN) introduces a new set of stressors to the mother that are multidimensional and encompass social and psychological components. Coping is the process by which an individual manages events that are appraised as stressful and the emotions that these events produce. A better understanding of the strategies mothers employ in order to cope with HEN will allow the development of nursing interventions aimed at strengthening those coping strategies. The specific aims that were addressed in this study were to determine what types of coping strategies mothers of children who are fed enterally employ to deal with identified stressors and to determine what types of external resources mothers of children who are fed enterally use or require in dealing with identified stressors.

Forty mothers were interviewed, using open-ended questions focusing on how they coped with the significant burdens that HEN brought up for their families. They were also asked what they did during celebrations that centered on food. Mothers were also asked to describe what they did to take care of themselves, who they turned to for help with caring for their child on HEN and who they sought out to talk about their child. The results of this study also showed that mothers predominately used problem-focused coping strategies in dealing with the mechanics of HEN. When it came to dealing with things that were significant burdens for their families, mothers in this study used problem-focused strategies much more than emotion-focused strategies, but tended to use more emotion-focused strategies when it came to taking care of themselves. While mothers in this study turned to their family more for help in caring for their child, they sought out professionals more often when they needed to discuss some aspect of their child's HEN regimen.

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The stressors and coping strategies faced by mothers of children on HEN are multidimensional and encompass social and psychological components. This study has confirmed this and brought to light a number of the specific ways that these mothers find to cope with the every day stressors that make up HEN. A better understanding of these stressors and coping strategies will allow the development of nursing interventions aimed at reducing the amount of stress confronted by these mothers. A better understanding of the ways mothers cope with these stressors allows for more accurate evaluations of these interventions.

CHAPTER 2

HOME ENTERAL NUTRITION: ISSUES IN CLINICAL PRACTICE

Introduction

A child is assimilated into culture through the process of learning to eat. Family mealtimes illustrate a family's identity and create a sense of group membership. Food preferences are based on social and ethnic backgrounds and provide bonds between people of the same background. The ritual elements of mealtimes are symbolic and tied to emotional bonds that are created and replayed in memories, creating a sense of belonging to a group that is considered a safe refuge. Families pass dishes, recipes, and blessings down from generation to generation to create a sense of continuity (Fiese, Foley, & Spagnola, 2006; Rudolph, 1994).

For a child with a feeding problem, mealtime is altered. Feeding problems can increase the length of time it takes to eat and can decrease the enjoyment of mealtime. Mothers of children with feeding problems have reported spending five to fifteen hours per day attempting to feed their child (Craig, Scambler, & Spitz, 2003; Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003). Thus for some children with feeding problems, the time that is required to ensure that they receive adequate nutrition leaves little time for other nurturing activities. Early recognition and diagnosis of feeding problems, along with working with an interdisciplinary team, improves a child's nutritional status, physical, cognitive, and psychosocial development and also improves the interaction between the child, family, and caregivers (Siktberg & Bantz, 1999). The purpose of this paper is to provide a discussion of the clinical issues that can arise when a child requires home enteral nutrition (HEN). These clinical issues are presented as a synthesis of recent research findings related to maternal management of HEN.

Oral Feeding and the Indicators of the Need for HEN

An increasing number of children have oral-motor dysfunction resulting in feeding problems as a consequence of surviving complex medical problems including neurodevelopmental disorders, prematurity, congenital anomalies, and acquired brain injury (Adams, Gordon, & Spangler, 1999). An estimated 25% to 35% of children in the general pediatric population have feeding problems (Byars, et al, 2003). Approximately 12.8% of all children in the United States, an estimated 9.4 million children, have special health care needs (Maternal Child Health Bureau, 2001). It is estimated that feeding problems are even more prominent (40%-70%) in these children (Byars, et al, 2003).

Feeding problems can cause many difficulties, such as cognitive impairment, emotional dysfunction, growth retardation, malnutrition, decreased energy, greater susceptibility to illness, and even death (Manikam & Perman, 2000). Clinically, weight loss and poor growth are often the most noticeable. Feeding problems can also lead to poorer outcomes, more hospitalizations and an increased rate of complications (Kang, Zamora, Scott, & Parsons, 1998).

The causes, signs, symptoms, and severity of a feeding problem can vary greatly among different children and within the same child over time (Arvedson & Brodsky, 2002). These feeding problems can manifest in many different ways, such as resistance to accepting foods, lack of energy for the work of eating and digestion, and oral sensorimotor disabilities (Manikam & Perman, 2000). Whenever a child cannot meet nutritional needs orally, an alternate method of feeding becomes necessary from a safety perspective as well as for the provision of adequate nutrition. Enteral feedings are usually the preferred method. Parents, most often the mother, are placed in the position of learning and managing this alternative form of feeding in the home setting. There are numerous physiologic indicators of the need for enteral nutrition. Some of the more common indicators include an uncoordinated suckswallow-breath mechanism or inability to swallow, breathing problems, coughing, or choking during feeding, poor tongue, lip, and jaw control, excessive drooling, a history of recurrent upper respiratory infections or pneumonia, severe reflux, aspiration, and an inability to meet increased protein or caloric needs. Additionally, there are several psychosocial indicators of the need for enteral nutrition. These include failure to thrive, difficulty feeding, a long time spent feeding, stressful feedings, unexplained food refusal or severe food aversion, and an unpalatable diet or medications (Colomb, Goulet, & Ricour, 1998; Kimber & Beasley, 1999; Serrano & Mannick, 2003; Siktberg & Bantz, 1999; Smith, Camfield, & Camfield, 1999).

The Decision-Making Process

Mothers of children who have a feeding problem are in agreement that providing oral feedings to their child is a stressful process (Rouse, Herrington, Assey, Baker, & Golden, 2002; Sleigh, 2005; Spalding & McKeever, 1998). They have described mealtimes as a "battle" or "war" with a significant amount of time devoted to the feeding process. In response to maternal reports, health care providers often assume that the introduction of enteral feeding will decrease the stress experienced by mothers and will be an intervention that is embraced by mothers. However, in the majority of cases this is a mistaken assumption. Researchers who have examined the maternal decision-making process related to initiating the use of HEN have found that mothers, despite the stress that accompanies oral feeding, do not readily agree to the use of HEN (Guerriere et al, 2003; Sleigh, 2005). Mothers have reportedly taken as long as 18 months to agree to the use of HEN. Several factors contribute to the reluctance of mothers to finally agree to the use of HEN.

Mothers of children who were diagnosed with a feeding disorder believed that they were at fault for not being able to feed their child, and that if they just tried harder, they could get their child to eat enough. They felt that agreeing to a gastrostomy tube (G-tube) insertion meant "giving up" on oral feeding, something they did not want to do (Craig, et al., 2003; Rouse et al., 2002; Spalding & McKeever, 1998). They felt pressured from both medical professionals and their family members to make this decision. In addition, the use of a nasogastric tube or G-tube to provide HEN was viewed by mothers as not "normal" and the use of a surgically inserted G-tube was viewed as something permanent (Craig & Scambler, 2006; Sleigh, 2005; Thorne, Radford, & McCormick, 1997).

An important factor that delayed decision-making was the perception held by mothers that they had not been given enough information about HEN to make this important decision. Guerriere and colleagues (2003) reported that 50% of the mothers in their study received the majority of information related to the description and management of a G-tube and thus, HEN, after agreeing to have a G-tube inserted into their child. Mothers reported that they wanted more information about what the G-tube would look like, where it would be located on their child's body, how to use the G-tube, what kind of equipment would be needed, and who they would be able to turn to for help with problems. In addition, mothers wanted to be able to talk to someone who was already dealing with HEN and felt that if they had more support and more information, the decision would not be so hard to make (Brotherson, Oakland, Secrist-Mertz, Litchfield, & Larson, 1995; Guerriere, et al, 2003; Rollins, 2006).

HEN and Growth

One of the most important benefits of HEN, and the most frequently stated reason, is to improve growth through the provision of adequate nutritional intake. Numerous researchers have demonstrated that one of the benefits of HEN is an improvement in weight gain. HEN has been found to induce catch-up growth, with increases in weight, height, and skin fold thickness, when compared with baseline measures obtained before HEN was initiated (Sleigh, 2005; Sullivan et al., 2005). Children in the study by Sullivan and colleagues (2005) demonstrated a significant improvement in weight-for-age *z*-scores (-3.03 to -1.60) during the first year following the introduction of HEN. In addition, positive correlations have been found between improvements in height and weight and length of time on HEN (Craig et al., 2006; Kang, Zamora, Scott, & Parsons, 1998; Rosenfeld, Casey, Pepe, & Ramsey, 1999; Sullivan et al., 2002).

While HEN improved growth, mothers expressed concerns related to determining what parameters should be used to assess adequacy of growth, both prior to and following initiation of HEN. Mothers reported feeling confused when the initial discussions were held to consider HEN because the most important reason for initiating HEN was their child's poor growth. For many of these mothers, they had been told that their child would not grow well because of the effects of the underlying disability (Brotherson, et al, 1995; Craig, et al., 2003). Thus, inadequate growth was not perceived as a compelling reason to initiate HEN. Following initiation of HEN, mothers expressed frustration at not being able to receive accurate information related to the expectations for their child's growth potential (Craig, et al., 2003). Available evidence, albeit limited, lends support to the mothers' frustrations. In the above study by Sullivan et al. (2005) the significant increase seen in z-scores across the first year of HEN was greater than would be expected for healthy children of a comparable age. Contributing to the frustration of determining what is the expectation for a child's growth is the lack of an appropriate growth chart for monitoring growth. In most cases, the NCHS growth charts are the best available assessment tool available. Unfortunately, the NCHS growth charts are derived from healthy children and most

likely are not the most appropriate reference. (See Table 2.1 for a list of available disorder-specific growth charts).

An interesting dilemma voiced by several mothers was the fear that if their child demonstrated significant improvements in weight gain the mothers and other family members would not be able to physically handle the child (Craig et al., 2003; Sleigh, 2005). The resulting increase in the child's size could translate into the need for a mechanical hoist or an increase in the need for caregivers to assist with lifting and moving. Again, the weight gain reported by Sullivan et al. (2005) reinforces this dilemma.

HEN and Nutrition

There is no doubt that nutritional intake is greatly improved when HEN is implemented. Mothers are in agreement that HEN certainly eases the burden of providing adequate nutrition to their child (Brotherson et al., 1995; Guerriere et al, 2003; Sullivan et al., 2004; Thorne, et al., 1997). However, mothers also expressed concerns about what constitutes adequate nutritional intake for their child. Their frustration centered around receiving nutritional instruction that was based on ageappropriate standards developed for health children (Craig et al., 2003). Mothers believed that the nutritional instruction should have been individualized to meet the specific needs of their child.

Complications of HEN

While there are many benefits to HEN, it is not without complications. In order to make an informed decision about HEN, parents need to be made aware of the complications that can come about, both with the immediate post-operative period
Disorder	Reference
Preterm infants	Casey P., et al. (1990). Growth patterns of low birth weight preterm infants: a longitudinal analysis of a large, varied sample, <i>Journal of Pediatrics</i> , 117, 2, 298-307.
Down syndrome	Cronk C., et al. (1988). Growth charts for children with Down syndrome one month to 18 years of age, <i>Pediatrics</i> , <i>81</i> , <i>1</i> , 102- 10.
Cerebral palsy	Krick J., Murphy-Miller, P., Zeger, S., & Wright, E. (1996). Pattern of growth in children with cerebral palsy. <i>Journal of</i> <i>the American Dietetic Association, 96, 7,</i> 680-685.
Achondroplasia	Horton W., Rotter, J., Rimoin, D., Scott, C., & Hall, J. (1978). Standard growth curves for achondroplasia. <i>Journal of</i> <i>Pediatrics, 93, 3,</i> 435-438.
Williams syndrome	Morris C., Demsey, S., Leonard, C., Dilts, C., & Blackburn, B. (1988). Natural history of Williams syndrome: physical characteristics. <i>Journal of</i> <i>Pediatrics, 113, 2,</i> 318-326.
Prader-Willi syndrome	Holm VA. (1995). Growth charts for Prader-Willi syndrome. In Greenswag, L. and Alexander R., (editors). <i>Management</i> <i>of Prader-Willi Syndrome</i> , 2nd ed., New York: Springer-Verlag.
Noonan syndrome	Witt D., Keena, B., Hall, J., & Allanson, J. (1986). Growth curves for height in Noonan syndrome. <i>Clinical Genetics, 30,</i> <i>3</i> , 150-153.

Table 2.1: Disorder-Specific Growth Charts (Pediatric Nutrition Consultation Online,2006).

and once at home. Problems that can arise during the immediate post-operative period include post-operative respiratory problems, peritonitis, wound dehiscence, and a need for additional surgery to treat gastroesophageal reflux (Sleigh & Brocklehurst, 2004). Other problems can be divided between major complications and minor complications. Table 2.2 lists these major and minor complications (Colomb, et al., 1998; Crosby & Duerksen, 2005; Evans, Holden, & MacDonald, 2006; Godbole, et al., 2002; Sleigh & Brocklehurst, 2004). There are also some problems that are more commonly seen with a gastro-jejunal tube, such as migration or displacement of the end of the tube back into the stomach or farther into the small intestines, tube blockage with formula or medications, and a ruptured gastrostomy balloon resulting in the need for tube replacement (Godbole, et al., 2002).

Additionally, there are certain problems that, although not occurring often, can be seen with the percutaneous endoscopic gastrostomy procedure. These include the potential for esophageal perforation, severe peritonitis and the formation of a gastro-colic fistula (Nicholson, Korman, & Richardson, 2000). In addition, there are several areas of concern brought up by parents that would best be described as psychosocial complications of HEN (Crosby & Duerksen, 2005; Evans, et al., 2006; Murphy, 1997). These are listed in Table 3.3. Mothers often report that the psychosocial problems associated with HEN are more of a burden than the medical problems that arise (Enrione, Thomlison, & Rubin, 2005).

Caregiver Burdens

Children who are on HEN require a significant amount of very technically oriented care, such as 1) administering the formula (whether it be by bolus or continuous feeding via a pump), 2) monitoring the child during continuous feeding, 3) managing equipment, 4) maintaining the stoma site and replacing the tube, and 5)

Major Complications	Minor Complications
Wound Infection	Vomiting
GI Bleed/Ulceration	Diarrhea
Chronic Respiratory Problems	Aspiration
Peritonitis	Tube Entanglement
Volvulus	Leakage at Tube Insertion Site
Intestinal Prolapse	Granulation
Bowel Obstruction	Pain

Table 2.2: Medical Complications Associated with HEN

Psychosocial Complications	
Conflicts over who is in charge (Homecare professionals vs. parents)	
Judgments by homecare personnel about family lifestyles	
Loss of privacy	
Sleep Interruptions	
Activity avoidance/Isolation	
Storage space issues for all the equipment	
Problems with faulty pumps	
Problems getting needed supplies	
Restricted mobility	
Problems getting respite	
Changed relationship with child	
Missed taste of food	

Table 2.3: Psychosocial Complications Associated with HEN

training others to do the care. Mothers are most likely the person who is responsible for the technical care associated with HEN (Heaton, Noyes, Sloper, & Shah, 2005). These children often require twice as much time in total care when compared to a child with a disability who is fed orally (Heyman, et al, 2004). It certainly is not surprising to find that these mothers report a lack of support in caring for their child as well as a lack of respite care so that they can take a break from caring for their child. These mothers also report that they have to plan their life around the child and the feeding schedule and that there is little time left for their spouse or other children. They have also found that it is very difficult to combine caring for a child on HEN and working a paying job, so they end up quitting work, which often places a financial burden on an already taxed family (Enrione, et al., 2005; Heaton, et al., 2005; Rollins, 2006).

While the cost of HEN is significantly lower than hospital care, there are still financial burdens placed on the family of a child who is being cared for on HEN. One reason for this is the fact that some insurance companies will cover the cost of the equipment (pumps, tubing, syringes, etc.) but consider the formula to be "food" and will not cover the costs of it, or will only cover a portion of it. Depending on the age of the child, monthly costs can range from \$25.00 (for metabolic formula for a newborn) to \$1698.00 (specialty enteral formula for a 9½ year old). With the average costs of PediaSure, a common formula for children over the age of 12 months, being \$1.02/100 kcal, the average costs for a month of HEN can range \$510.00 (Lucas & Feucht, 2004). Eligible families can apply for state or federal assistance to help pay

for formula, but this is often based on the family's income and not all families meet the requirements.

While the time spent caring for children with HEN is greater than that required for children fed orally, this is not the only burden mothers are faced with. Mothers often find HEN to be unnatural and abnormal, and view it as a signal that they are not a "good mother." They feel that HEN makes their child's disability more visible, which increases the stigmatization and social isolation they may be experiencing. They encounter feelings of abandonment, frustration, anxiety, and fear as a result of decreased social support (Brotherson, et al, 1995; Guerriere, et al, 2003; Kirk, 1998; Rollins, 2006).

A final burden that mothers of children on HEN face is the fear that their child will always be dependent on HEN and will lose, or fail to attain, oral feeding skills (Craig, Scambler, Spitz, 2003). They also feel that by giving in to HEN, they are losing out on interaction time with their child. This interaction during feeding is very important to mothers, even though some physicians see HEN as solving any feeding issues and don't think that oral feeding still needs to be encouraged (Brotherson, et al., 1995; Mason, Harris, & Blissett, 2005).

Teaching and Learning

In making the decision to implement HEN, parents noted that there tend to be gaps in the information that is given to them concerning all aspects of HEN, but particularly concerning the practical and emotional aspects of dealing with it on a daily basis. After a GT was inserted, the parents found that they would have liked more information about the clinical aspects of HEN before making that decision. They stated that there was a need for consistent, accurate information both before and after surgery (Craig, et al., 2003; Rollins, 2006; Sleigh, 2005). Parents need to be taught not only about the technical aspects of HEN, but also the risks and complications, as well as how to prevent complications from arising (Colomb, et al., 1998). Parents also express concerns about whether physicians and nurses in their community had enough training and knowledge in the management of complications that might arise (Crosby & Duerkson, 2005).

Prior to discharge from the hospital, the parents of a child on HEN need to be trained about how to provide safe, competent care for their child. Nurses are often responsible for providing this training, as well as assessing the family's ability to meet all their medical, social, emotional, and financial needs and making any necessary referrals for any needed support (McNamara, Flood, & Kennedy, 2001; Montagnino & Mauricio, 2004). Because nurses are often responsible for providing the teaching necessary to care for children on HEN, it is important for them to keep updated on the necessary skills and to make sure that they are familiar with the equipment currently available for use in the community. It is also important to make sure that there is an open line of communication between the nurses caring for the child in the hospital and those who will be caring for the child in the community (nurses as well as physicians) to ensure that there is a smooth transition to the home environment (Chaplen, 1997; Culverwell, 2005). Because the knowledge and practices concerning HEN can differ from institution to institution, the effective establishment of HEN can be hindered (Persenius, Larsson & Hull-Lord, 2005).

In order to make the transition to home as smooth as possible, discharge planning must be done ahead of time to ensure that all the necessary equipment is available at the home prior to the child leaving the hospital. It is very important to have the local public health nurse involved with the discharge planning from the beginning (Khair, 2003). Kirk (1998) briefly discussed the problems that parents experienced in getting equipment, maintaining equipment and getting supplies delivered regularly for children on HEN in the early 1990's. Today those same problems are still being encountered, as well as others. Evans, MacDonald, and Holden (2004) found the following problems being encountered shortly after discharge from the hospital:

- 1. Getting set up with a home delivery company.
- 2. Getting equipment before discharge (obtaining the first shipment without problems).
- 3. Wrong supplies being delivered.
- 4. Getting accurate prescriptions for the correct formula.
- 5. Being adequately trained on the use of the feeding pump.
- 6. Receiving a different pump than the one trained on.
- 7. Access to help for problems.

Parents also need to be taught how to deal with emergencies, such as what to do if the GT becomes dislodged. They need to be taught how to replace it, what to do if they are experiencing problems replacing it, where to go for help, and which local hospitals know how to handle a GT when a child is involved. This is especially important if the child has a G-J tube, since these tubes need frequent maintenance and replacement (Fortunato, Darbari, Mitchell, Thompson, & Cuffari, 2005).

Parents also need to be reminded to plan for periods of time when equipment deliveries may be interrupted, such as during holiday seasons or inclement weather. Another area of teaching that should not be overlooked is how to plan for vacations. It is important for parents to plan for what supplies need to be taken, what supplies can be shipped ahead to destination, and to know the emergency contacts in the area (Culverwell, 2005).

The Interdisciplinary Team

Children on HEN need support from any different sources. These sources can include:

- primary care physicians
- pediatricians
- GI surgeons
- community health nurses
- dieticians
- nutrition nurse consultants
- speech and language therapists
- occupational therapists
- school nurses
- home care nurses
- respite care providers
- other nurse specialists (i.e. wound care specialists)
- other specialty physicians (depending on child's primary diagnosis)
- the child's family members

With so many different health professionals involved in the care of a child on HEN,

the potential exists for a lack of continuity of care and a lack of coordination of

services. The family can be left unsure of who to contact when problems or questions

arise (McNamara, Flood, & Kennedy, 2001). There is a need for one person to be

designated as the case manager, responsible for keeping the team informed and coordinating between all the care providers.

Given the frequent changes in the nutritional, clinical, and practical needs of a child on HEN, there needs to be monitoring done, to include height, weight, BMI, biochemical tests, and hematological tests. This monitoring needs to be done on a regular basis and the results need to be shared among all members of the team (Murray, 2000). When making decisions about any changes in the care of a child on HEN, it is important that the entire team working with the child be involved. It is also very important that there not be any problematic relationships between all members of the team, professionals as well as family members, with respect to control, trust, and competence (Kirk, 1998). It is only by working together as a team that the needs of the child on HEN be kept the priority.

Conclusion

When faced with the decision about whether or not to implement HEN for their child with a feeding disorder, many parents, especially the mothers, struggle. While they may understand that their child needs adequate nutrition in order to grow, they often blame themselves for their child's inability to feed orally and experience feelings of inadequacy and failure (Craig, et al., 2003; Hughes, 1999). By agreeing to a feeding tube, mothers perceived that they were denying their child the opportunity for oral feeding, the one normal activity (albeit difficult) in which their child was able to engage (Guerriere, et al, 2003; Sullivan, et al, 2000). Because of these mixed feelings associated with HEN, the decision to implement it is not an easy one and there is often a delay, for months or even years, in making the decision (Craig, et al., 2003). It is unrealistic to expect this decision to be made the first time enteral feeding options is discussed.

There are those who actively seek out assistance with feeding problems, only to be told to keep trying to feed their child orally, that their child only needs a little more time to catch up in growth. There are also those parents who have a child with a disability for which there are no established standard references for growth. It is frustrating for parents to be told not to expect their child to grow like a normal kid, only to be told that in the end, there is a need for HEN because their child isn't growing.

For many mothers of children with feeding difficulties, feeding times are considered "special" even though they are difficult. Feeding through a tube was seen as medicinal and was thought to take away the social aspects of feeding, such as the opportunity for close contact, interaction, and communication. Even after HEN was implemented, there was a desire to maintain the skills necessary for oral feeding, in hopes that their child would feed orally at some point in the future (Craig, et al., 2003). It is important to keep in mind what the symbolic nature of feeding is to these mothers and to realize that oral feeding is likely to still occur, and should be encouraged, if there are no apparent health risks associated with it. It is emotionally important to these mothers to still be able to be what they consider a "good mother," of which feeding their child in a "normal" way is a large part of.

CHAPTER 3

MATERNAL STRESS WHEN A CHILD IS FED ENTERALLY

Introduction

An increasing number of children have oral-motor dysfunction as a consequence of surviving complex medical problems, which can include neurodevelopmental disorders, prematurity, congenital anomalies, and acquired brain injury (Adams, Gordon, & Spangler, 1999). These children exhibit serious feeding problems including disorganized suck/swallow/breathing mechanisms, oral aversion, gagging, aspiration, and vomiting (Guerriere & Llewellyn-Thomas, 2001). Reliance on enteral (tube) feeding methods becomes necessary from a safety perspective as well as for the provision of adequate nutrition. Parents, most often the mother, are often placed in the position of learning and managing this alternative form of feeding in the home setting.

Mothers have reported that providing oral feedings to a child with a feeding disorder is a stressful process. However, recognition of this stress does not always indicate that mothers were willing to initiate enteral feedings (Craig, Scambler, & Spitz, 2003). Health care providers mistakenly assume that the introduction of enteral feeding will decrease the stress experienced by the mother. Available information about the caregiver burden for mothers of children on enteral feeds is often derived anecdotally or from research focusing on the clinical aspects of enteral feeding and the morbidity associated with it. Current research on the benefits of enteral feeding has centered on its association with the physical well being of the individual patient (Craig, et al, 2006).

It is possible that the placement of a nasogastric tube or a gastrostomy tube and the reliance on home enteral nutrition (HEN) introduces a new set of stressors to the mother. What need to be further identified is what these stressors are and how these mothers feel about dealing with HEN. A better understanding of the stressors involved with HEN will allow the development of nursing interventions aimed at reducing the amount of stress confronted by these mothers. Appropriate interventions will create the best possible environment for the feeding process to occur and thus, ultimately benefit the child's cognitive and social development by allowing the feeding process to become more pleasurable for both mother and child.

Background and Significance

Stress

Experiences of stress occur on a regular basis for all parents because of their roles as caregivers and socializers of children. This collective experience of stress gives emphasis to the importance of understanding how wide variations of this concept contribute to the effective or ineffective functioning of mothers and fathers. Parental stress occurs regularly, even during the positive accomplishments of childhood. Parental stress results from responding to the demands of a crisis event or

the accumulation of stressors at both the individual and relationship levels of experience (Peterson & Mathieson, 2000).

Selye (1994) defines stress as the nonspecific result of any demand on the body, producing either mental or physical effects. Lazarus and Folkman (1984) state that stress is not a single variable but a compellation of many processes and variables. They further state that psychological stress is a specific relationship between a person and their environment that is judged by that person to be challenging or exceeding his or her resources and jeopardizing his or her well-being. Whether this relationship is judged to be stressful is dependent on the cognitive appraisal that the individual gives to the specific event.

As the main caregivers of children with chronic or disabling conditions, parents are even more susceptible to stress and need varying degrees and types of support. Raising a child with a disability poses many crises over the lifetime of the child. Parents must adapt to the many changing circumstances and needs of the child. Stress is often the consequence of these demands. While there has been much written about the stress of raising a child with a disability, one area that is lacking in information concerns the stress associated with raising a child with a feeding disorder who requires non-oral methods of feeding.

Feeding Disorders

An estimated 25% to 35% of children in the general pediatric population have feeding problems (Byars, et al, 2003). Approximately 18% of all children in the United States, an estimated 10-20 million children, have some type of developmental disability or chronic health condition or disability (Committee on Children with Disabilities and Committee on Psychosocial Aspects of Child and Family Health, 1993; Newacheck, et al, 1998). It is estimated that feeding problems are even more prominent (40%-70%) in these children (Byars, et al, 2003). However, in the United States, the actual prevalence of enteral feeding in children is difficult to determine due to the lack of any national database listing those who are being treated on home enteral nutrition (HEN).

Increasing numbers of children born prematurely or with congenital abnormalities are not only surviving, but also living longer and having greater expectations for normal and productive lives. Premature infants are at risk for feeding problems due to poorly developed suck and swallow mechanisms. Feeding problems can also coincide with such conditions as mental retardation, cerebral palsy, chronic pulmonary problems, structural deficits, and neurological impairment and can manifest in many different ways, such as resistance to accepting foods, lack of energy for the work of eating and digestion, and oral sensorimotor disabilities. Prolonged difficulty in feeding can also result in cognitive impairment, emotional dysfunction, malnutrition, growth retardation, decreased energy, greater susceptibility to illness, and even death (Manikam & Perman, 2000). Even feeding disorders that are selflimiting have the potential to result in parental anxiety and distress and disruption of the parent-child relationship (Cerro, Zeunert, Simmer, & Daniels, 2002).

Experiences with feeding problems can also have a negative effect on parents and caregiving behaviors. When feeding is not pleasurable and is looked at not as a warm positive experience, but as a job to be done, significant negative consequences can result. Feeding problems impact all aspects of the environment (cultural, physical and social) of the premature or disabled child (Case-Smith & Humphrey, 1996). *Maternal Stress and Feeding Disorders*

For children with feeding problems, the dynamics of the feeding interaction are drastically altered. The emphasis is no longer on the pleasurable aspects of feeding but become focused on getting the child to consume enough nutritional intake to promote growth. Mothers of children with feeding problems report that they spend 4-8 hours per day attempting to feed their child compared with approximately 1 hour for mothers of children without feeding problems (Sullivan, et al, 2000; Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003). Enteral feedings become necessary when the child can no longer consume enough nutrition to promote growth. Although mothers can articulate the benefits, the decision to initiate enteral feeding remains difficult. Mothers described agreeing to the insertion of a feeding tube as "giving in" (Spalding, & McKeever, 1998). By agreeing to a feeding tube, mothers perceived that they were denying their child the opportunity for oral feeding, the one normal activity (albeit difficult) in which their child engages (Sullivan, et al, 2000; Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003). Mothers also reported feelings of inadequacy and failure because they were not able to orally feed their child successfully (Hughes, 1999).

While there is extensive literature on the stress associated with parenting a child with a developmental disability or a chronic health problem, few researchers specifically have examined sources of stress for mothers of children receiving enteral feeding. Mothers perceive that agreeing to the insertion of a feeding tube added to

their stress because the feeding tube was viewed as "abnormal" and emphasized or validated the child's disability or medical illness (Sullivan, et al, 2000; Guerriere, et al, 2003). The majority of mothers report that they receive inadequate preparation for the management of enteral feeding in the home environment (Chaplen, 1997; Thorne, Radford, & Armstrong, 1997; Guerriere, et al, 2003). An important source of stress identified by mothers was incorporation of the technology associated with enteral feeding into the family's daily routine and home environment (Thorne, Radford, & Armstrong, 1997; Spalding, & McKeever, 1998). Adams, Gordon, and Spangler (1999) compared maternal stressors associated with caring for a child with a disability who was enterally fed with stressors of mothers caring for a child with a disability who was fed orally. Mothers of children who were enterally fed reported more stressors, such as emotional and physical energy expenditure, having to learn and follow new safe food-handling procedures, and decreased interaction with other family members, especially at mealtimes. Mothers also noted the lack of free time as a substantial source of stress.

Mothers report that enteral feedings are time consuming and that their daily routine revolves around their child's feeding schedule. The feeding schedules prescribed by health care providers were not always compatible with the family's daily routine. Mothers also describe how they get little respite from the care of their child and that their child accompanies them on all outings and errands (Spalding, & McKeever, 1998).

Summary

Mothers are most often the parent with the primary responsibility for managing the enteral feeding of their child. However, very little is known about how caring for a child who is enterally fed impacts the mother (Spalding, & McKeever, 1998). There is a need to know more about what types of stress a mother encounters when caring for a child who is being fed enterally. It is also important to know what strategies mothers are using to best cope with these stressors. These will be addressed in Chapter 4. A better understanding of the stressors and coping strategies will allow the development of nursing interventions aimed at reducing the amount of stress confronted by these mothers.

The purposes of this study were to identify the stressors experienced by mothers of children who are being fed enterally and to describe the feelings these mothers have about dealing with HEN. The specific aims of this study were:

- To identify how mothers of children who are fed enterally feel about feeding their child by tube.
- 2. To identify the negative and positive aspects of Home Enteral Nutrition.
- 3. To determine what types of stressors mothers of children who are fed enterally experience.

Method

Design

This study used an exploratory/descriptive design. Forty mothers of children who were being fed enterally in the home were the subjects of this study. The decision was made to use mothers and not include fathers because in 90% of families of a child with a feeding disorder, mothers are the ones who are responsible for the child's nutritional intake (Carroll & Reilly, 1996). Mothers were recruited for this study if they were the primary caregiver of a child who was being fed enterally either by nasogastric or gastrostomy tube at home, spoke English, and were at least eighteen years old. Mothers were excluded if their child was currently hospitalized, also receiving total parenteral nutrition in conjunction with enteral feeding, or on mechanical ventilation or assisted breathing, as these conditions could potentially be related to the stress felt by these mothers. Data were collected using a semi-structured interview (see Appendix B). Mothers were also asked to complete a demographic questionnaire after the interview was completed (see Appendix C).

Subjects

The population of children on HEN is extremely diverse and it was the intent of the researcher to reach a diverse population of subjects. To ensure this goal, forty mothers were recruited through multiple venues. Mothers were recruited through the Mighty Medical Miracles (M3), a regional chapter of the Oley Foundation, which is the national organization that provides information and psycho-social support to consumers of home parenteral and enteral nutrition (n = 10). Mothers from M3 were contacted during monthly meetings of the support group. Information about the study and contact information for the principal investigator (PI) was also included in the Oley Foundation national newsletter to recruit a second group of mothers (n = 16) and interviews and questionnaires were done via email or regular mail, depending on the preference of the mother, since the distance was too great to travel to the home by car. Through this newsletter the PI was contacted by the Nutrition Support Nurse Coordinator at The Children's Mercy Hospital in Kansas City, Missouri. The Nurse Coordinator agreed to recruit potential subjects from within her current case load, explain the study, and set up appointments for face-to-face interviews that were conducted at Children's Mercy Hospital (n = 14). There were no significant statistical differences noted between these groups of mothers with regard to age, race, income level, child's age, or length of time child had been on HEN.

Procedure

The study was approved by the Behavioral/Social Sciences Institutional Review Board of The Ohio State University. Approval was also obtained from the Institutional Review Board of Children's Mercy Hospital in Kansas City, Missouri. Written informed consent was obtained from each subject prior to data collection (see Appendix A). Data were either collected by face-to-face interviews or from written responses to the interview questions. Semi-structured open-ended interview questions were used to gather the richest data possible. Mothers were asked how they currently fed their child, what it was like when they first learned that their child would have to be fed by tube and how they felt about using HEN. Other open-ended questions focused on the negative and positive aspects associated with using HEN, as well as what the hardest and easiest thing was about using HEN. These face-to-face interviews were audio taped for later transcription and analysis. Transcription was done by hand and performed by the PI. See Appendix B for the complete interview schedule. Questions one through eight will be discussed in this chapter and the remaining questions will be discussed in the following chapter. Mothers were also asked to complete a demographic questionnaire to obtain information about them and their child, such as age, race, income level, child's age, diagnosis, and length of time on HEN. See Appendix C for a copy of the demographic questionnaire. Interview questions and the demographic questionnaire were developed by a committee of researchers familiar with HEN and the use of interview techniques.

Some interviews and questionnaires were done over email or regular mail, depending on the preference of the mother, when the distance was too great to travel to the home by car (n = 16). The study was explained by telephone and the consent form was mailed to them along with a stamped envelope for return. Once the signed consent form was received by the PI, the interview questions and the demographic questionnaire were emailed or mailed to the subjects with instructions to answer each interview question to the best of their ability by writing out their responses. Responses were then mailed back to the PI and any questions that needed additional clarification were discussed over the telephone. Two mothers were contacted for clarification of the child's diagnosis and the child's age when HEN was started. It has been noted that computer-assisted self-administered interviews, when compared to face-to-face interviews, allow for an increase in perceived anonymity and make the respondents feel more at ease when it comes to reporting behaviors that could be considered socially undesirable (Newman, et al., 2002; Perlis, et al., 2004). It would

be reasonable to assume that thinking of their disabled child as a burden to their family could be something these mothers might consider socially undesirable. In comparing responses to the question concerning significant burdens on the family, the number of burdens stated by those who were interviewed face-to-face was compared to the number of burdens written by those who returned interviews by email or regular mail. There were no significant differences in the number of burdens noted by either group (Mann-Whitney U = 149, p = .244).

Data Analysis

Data from each question asked during the interview were analyzed using content analysis. Content analysis utilizes a set of data-driven coding procedures, generated from the data themselves, to reduce and simplify recorded information into a set of categories that can be identified and measured to describe the presence, frequency, intensity and meaning reflected by written or verbal text (Waltz, Strickland, & Lenz, 2005). Content analysis aids the researcher in generating core constructs from interview data through a systematic method of reduction and analysis. It is especially suited to exploratory studies because it allows the researcher to get to the answers of the questions to which it is applied (Priest, Roberts, & Woods, 2002).

A content analysis was performed on each open-ended question using the eight-step technique as described by Waltz, Strickland, and Lenz (2005). In step one, the universe of content to be examined must be defined. The universe of content for this study was the tape-recorded or written responses to open-ended interview questions. For step two, the characteristics or concepts to be measured must be identified. The concepts to be measured in this study were defined by the research questions of the study as noted previously in this chapter. Step three involves selecting the unit of analysis to be employed. The units of analysis for this study consisted of words or word combinations that were indicative of complete and separate ideas or responses to each question being asked. A percent agreement for establishing the units of analysis of 80% was set a priori. Step four involves developing a sampling plan, which for this study involved analyzing the entire response to each open-ended question separately across all forty interviews. The analysis of each question was completed in the order that they appeared during the interview, with each analysis being completed before moving on to the next question. Step five consists of developing a scheme for categorizing the content and setting up clear coding and scoring instructions. The categorical decisions for this study were made inductively after the first 4 interviews (10% of the study subjects) by both researchers who would be coding the data. The categories were determined to be mutually exclusive and exhaustive. In step six, the categories and coding instructions are pretested. This was accomplished by coding the first ten interviews to establish intra- and interrater reliability that were above 80%, which was set a priori as the minimum acceptance rate. During step seven, coders are trained and the acceptable level of reliability is determined. For this study, there was no need to do additional training since there were no new coders used to perform the analysis. As noted before, an interrater reliability rate of 80% was set a priori. Step eight consists of performing the actual analysis. All forty interviews were first analyzed to establish units of analysis by the PI, a research nurse, and the dissertation advisor and then those units were then coded into categories.

For each individual question, the frequency and percentage of the forty subjects who gave a response that could be coded within each category was determined. Throughout the interviews, these mothers often gave more than one response in answer to each question, so results equal more than forty for many of the categories. Data from the demographic questionnaire were analyzed using the statistical package SPSS-14 (SPSS for Windows, Rel. 14.0.0, 2005).

Reliability of Data Analysis

There are three types of reliability that are considered important in content analysis. Unitizing reliability concerns the consistency in identifying the units of analysis to be categorized. Interpretive reliability (also referred to as interrater reliability) deals with the consistency in assigning those units of analysis into categories. Stability reliability refers to the reliability of coding decisions made over time. It is important for unitizing reliability to be established prior to categorization in order to establish interpretive reliability (Garvin, Kennedy, & Cissna, 1988).

Unitizing reliability was established by calculating the number of units of analysis (i.e. separate and complete responses for each question, for which a subject could have more than one for any given question), calculating the number of differences noted between the researchers, subtracting the number of differences from the total number of units to determine the number of units agreed upon, and determining the percentage of the total units that were agreed upon.

Unitizing reliability for the individual questions was as follows: Question one (How did you feed your child today?), 96%: Question two (What was it like when you first discovered you couldn't feed your child by mouth?), 86%; Question three

(How do you feel about feeding your child by tube?), 92.3%; Question four (What, if any, are the negative aspects of feeding your child by tube?), 86%; Question five (What, if any, are the positive aspects of feeding your child by tube?), 89%; Question six (What is the hardest thing about feeding your child by tube?), 96%; Question seven (What is the easiest thing about feeding your child by tube?), 85%; Question eight (What, if any, significant burdens have been placed on your family in dealing with your child's feeding difficulties?), 88%. Each question was discussed in detail to determine why there was a difference in units of analysis. Each researcher was given the opportunity to express decisions about each unit that was different and then a consensus was reached as to what would be considered the unit of analysis used in going forward to the next step. There were no areas of differences.

Reliability of coding decisions, which establishes stability reliability (also referred to as intra-rater reliability), was confirmed by recoding selected questions after a period of time had passed to check stability over time. Questions were chosen randomly by placing the number of each question in a hat and selecting ones to be rechecked. A stability reliability rate of 95.5%, 96%, and 94% was established for questions two, three, and five respectively. This percentage was calculated using the same method as used to determine unitizing reliability.

Units of analysis (referred to as responses) were coded into the mutually agreed upon categories established during steps five and six described previously. Interpretive reliability was established in the same manner as unitizing reliability, by calculating the number of differences noted between researchers and subtracting it

from the total number of units coded to determine what percentage of units coded was agreed upon. Question one had a total of 40 responses that categorized into four concepts with an interpretive reliability of 100%. Question two had 79 responses that were categorized into fifteen concepts with an interpretive reliability of 95.5%. Question three had 91 responses that were categorized into eleven concepts with an interpretive reliability of 90%. Question four had 86 responses that were categorized into sixteen concepts with an interpretive reliability of 87%. Question five had 70 responses that were categorized into twelve concepts with an interpretive reliability of 87%. Question six had 94 responses that were categorized into sixteen concepts with an interpretive reliability of 93%. Question seven had 65 responses that were categorized into seven concepts with an interpretive reliability of 93%. Question seven had 65 responses that were categorized into seven concepts with an interpretive reliability of 93%. Question seven had 65 responses that were categorized into seven concepts with an interpretive reliability of 93%. Question reliability of 93%. Question seven had 65 responses that were categorized into seven concepts with an interpretive reliability of 93%. Question seven had 65 responses that were categorized into seven concepts with an interpretive reliability of 93%. Question seven had 65 responses that were categorized into seven concepts with an interpretive reliability of 93%. Question eight had 94 responses that were categorized into eight en concepts with an interpretive reliability of 93%.

Results

Description of Sample

The average age of the mothers in this study was 35 (range 20-55, sd = 7.605). The average age of the children being cared for on HEN was 66.7 months (range 11-235; sd = 54.7). The average age that HEN was initiated was 16.7 months (range 0-156; sd = 31.6) and the average length of time they had been on HEN was 47 months (range 6-228; sd = 51.95). Demographic data about the subjects are presented in Appendix D in Table D.1. Information about the primary diagnostic categories of the children who were on HEN is presented in Table D.2.

To start the interview, mothers were asked how they fed their child. Fourteen of the children (35%) were on a bolus feeding regimen, 12 (30%) were on continuous infusions, 7 (17.5%) were on continuous infusions only at night, and 7 (17.5%) were on a combination of bolus and continuous infusions.

Decision to Implement HEN

Mothers were asked what it was like when they first discovered that they would need to feed their child by tube. See Table D.3 for a complete list of the responses these mothers gave. While some of these mothers had mixed feelings about the need for HEN, the decision to implement HEN was a difficult one for many of them to make. The majority of these mothers (n = 17, 42.5%) responded that they were scared or worried about feeding their child by tube. Twenty-five percent (n = 10) stated that they felt devastated and overwhelmed by the idea that they would have to feed their child by tube. Many of them (n = 8, 20%) spoke about feeling like they had failed as a mother because, as one mother put it, "you show love by giving food."

While there were many negative responses to this question, there were also some positive responses. Nine mothers (22.5%) felt relieved that there would be a way to feed their child that was safe and four mothers (10%) felt that using a tube to feed their child was easier than what they had been using, which for some had consisted of total parental nutrition (TPN).

Feelings about HEN

Mothers were then asked how they felt about feeding their child by tube. See Table D.4 for a complete list of how these mothers felt about feeding their children by tube. There were also many mixed feelings about how they felt about this. Over half of the mothers stated that they were okay with feeding their child by tube (n = 23, 57.5%), while fifteen (37.5%) had negative feelings about it. Thirty percent of the mothers (n = 12) stated that they had accepted feeding their child by tube as a way of life while eleven (27.5%) still wished that they could feed their child by mouth. *Negative and Positive Aspects of HEN*

Mothers were asked to describe what they felt were the negative and positive aspects of dealing with HEN.

Negative aspects of HEN

Mothers were asked to describe what, if any, were the negative aspects of HEN. A total of 86 responses were categorized into sixteen concepts. For a complete list of the sixteen concepts that were noted to be negative aspects of dealing with HEN see Table D.5. Fifteen mothers (37.5%) felt that the social stigma attached to having a child that is not being fed orally was the most negative aspect of dealing with HEN. Dealing with all the equipment that is needed to implement HEN was noted to be a negative aspect of HEN by eleven of the mothers (27.5%). Mothers mentioned equipment in conjunction with many other problems that they encountered, such as it being difficult to travel because of all the equipment that had to be brought along, and their child's mobility being restricted due to being "attached" to the feeding pump.

Mechanical problems, such as the feeding pump occluding or their child getting wrapped up in the tubing during the night and causing an occlusion or causing the tubing to come apart and leak, were noted to be negative aspects of HEN by ten mothers (25%). Physical problems, such as infections around the GT site and seepage around the site, were noted by nine mothers (22.5%). Another negative aspect of HEN that was frequently mentioned was dealing with the schedule that their child had to adhere to (n = 7, 17.5%). It was interesting to note that one mother (2.5%) did not feel that there were any negative aspects to dealing with HEN.

Positive aspects of HEN

Mothers were asked to describe what, if any, were the positive aspects of HEN. A total of 70 responses were brought up that were then categorized into twelve concepts. For a complete list of the twelve concepts noted to be positive aspects of HEN, see Table D.6. Twenty-eight mothers (70%) noted that the most positive aspect about HEN was that their child was receiving the nutrition and hydration they needed each day. Nine mothers (22.5%) noted that if it were not for HEN their child would not be alive today, which was considered to be extremely positive to them. Knowing that their child was gaining weight was another positive aspect noted by seven mothers (17.5%). Being able to give their child accurate doses of unpalatable medications (n = 6, 15%) and the ease of using the tube as apposed to TPN (n = 6, 15%) was also noted.

Stressors Associated with HEN

To determine what types of stressors mothers of children who are fed enterally experience, subjects were also asked what they considered to be the hardest and easiest aspects of HEN. They were also asked to describe any significant burdens that they felt had been placed on their family as a whole because of their child's need for HEN.

Hardest aspect of HEN

When asked to describe the hardest aspect of feeding their child by tube, mothers in this study mentioned a total of 94 responses that could be categorized into sixteen concepts. See Table D.7 for a complete list of the sixteen concepts that were considered to be the hardest aspects of dealing with HEN. These concepts were very similar to those noted when asked about the negative aspects of HEN, but there were several differences in the way the individual concepts were prioritized.

Dealing with all the equipment that is needed to implement HEN was mentioned by more mothers than any other concept (n = 15, 37.5%). As one mother noted, her child "could not live without machines." This concept was also mentioned in conjunction with many of the other concepts noted to be hardest to deal with, such as mobility issues (n = 8, 20%) and traveling issues (n = 7, 17.5%). Mothers brought up dealing with negative feelings as the next hardest thing about feeding their child by tube (n = 10, 25%). Not only did some of these mothers have negative feelings, about HEN themselves, such as feeling like they had failed their child and feeling that their child was different or "more disabled," but for some, their child did too, such as hating the tube or being terrified of it. This was difficult for them because they felt that there was not anything they could do to "make it better or fix it." Several mothers (n = 8, 20%) mentioned missing out on the "joy of feeding our child," or were concerned that their child was missing out on the social aspects of eating. Other mothers mentioned that keeping their child on a strict feeding schedule was hard for them to deal with (n = 8, 20%).

Easiest aspect of HEN

When asked to describe the easiest aspect about their child being fed by tube, mothers in this study mentioned a total of 65 responses that fell into seven conceptual categories. See Table D.8 for a complete list of the concepts considered to be the easiest aspects of HEN.

Similar to what they felt were the positive aspects of HEN, the majority of these mothers mentioned the ability to give their child the nutrition and hydration needed to grow more often than any other concept (n = 20, 50%). Many of these mothers also stated that they felt that the actual mechanics of using the feeding tube were easy (n = 17, 42.5%).

Other concepts that were mentioned as being easy included such things as the time it took to feed by tube being shorter than what was spent trying to feed the child by mouth (n = 11, 27.5%) and the ease at which they could get their child to take medications or needed formulas that were orally offensive (n = 7, 17.5%). Some mothers mentioned that because of tube feeding their child a specified formula, they did not have to worry about whether their child was going to tolerate what they were being given anymore (n = 5, 12.5%). Several mothers mentioned that feeding their child by tube was the only thing they knew (n = 2, 5%), with one mother stating that feeding her second child by mouth felt unnatural after having spent so long feeding her first child by tube. There were three mothers (7.5%) who stated that there was nothing about feeding their child by tube that they would consider easy.

Significant burdens placed on family

When asked to describe any significant burdens that had been placed on their families as a result of their child's feeding difficulties, mothers mentioned 94 responses that were categorized into eighteen concepts. Again, some of these concepts are similar to those associated with the negative aspects of HEN and what was considered the hardest aspects of HEN, but the frequencies of the concepts mentioned were very different. For a complete list of the concepts that were considered significant burdens placed on the families of these subjects see Table D.9.

A frequently mentioned concept that mothers brought up as a significant burden for their family was the lack of trained caregivers (n = 14, 35%). As one mother put it, her daughter could not be with other people who could not feed her for more than three or four hours, so she was limited to activities that would not take longer than that. Dealing with scheduling was also noted to be a significant burden (n = 14, 35%). Many of the mothers who mentioned scheduling as a significant burden for their family stated that it was in relation to how long it took to complete each feeding and how they had to plan everything they did around the amount of time it would take to complete it. This included any trips to go shopping, trips to visit family members, going on outings with other children, and even work schedules, with some parents working opposite shifts so that there would always be someone home who could do each scheduled feeding

Several mothers mentioned problems that arose for their extended families (n = 10, 25%). Many had families that wanted to be supportive, but were afraid of the responsibility that comes with dealing with HEN, while others had extended families

that were not supportive at all. Even though all of the mothers in this study indicated that they some form of financial assistance (i.e. insurance or state medical aid), several still spoke about the financial burden that had been placed on their family (n = 9, 22.5%).

There were several mothers who felt that HEN brought up significant psychological problems for their child (n = 8, 20%), which included such things as not being able to have the normal things a two year old child would get to enjoy, being made to feel different, being excluded from activities that siblings got to enjoy because of the feeding issues, and being "treated like a baby" instead of being treated age appropriately. Other mothers noted that their sleep patterns were always being disrupted (n = 3, 7.5%) due to equipment malfunctions or fears that their child would get tangled up in the tubing or possibly vomit and aspirate during the night. One mother (2.5%) felt that there were no significant burdens placed on her family as a result of her child's feeding difficulties.

Discussion

The results of this study provide insight into what it is like to make the decision to start enteral feedings as well as what it is like for a parent to deal with HEN. While many mothers had negative feelings about their child needing to be fed enterally, there were also many that had positive things to say about this decision. Research has shown that the choice to initiate HEN is a complex, emotional, and difficult decision to make (Guerriere, et al., 2003). Even though oral feedings were often seen as a source of stress, they were not always an indication of the willingness to start enteral feedings (Craig, Scambler, & Spitz, 2003), a sentiment shared by

many of the mothers in this study. Both oral feeding problems and tube feedings are often seen as counter to what a mother views as "successful mothering" (Rollins, 2006). Many of the mothers in this study felt this same way, stating that HEN was seen as a failure on their part and that it took away their sense of normality.

Mothers in this study had mixed feelings about HEN. While many felt positive about the use of HEN, there were also others who had negative responses to it. Spalding and McKeever (1998) found that, once the decision had been made and HEN was started, some mothers felt relief that their child was finally getting the nutrition that they needed, while Craig and others (2003) found that some mothers felt the need to reevaluate the need for the GT and to continued to pursue oral feedings. Similar responses were noted by mothers in this study

In interviewing mothers of children who were being treated with HEN, a rich description of the aspects of HEN that they felt were the hardest and most negative, the things that caused them the most stress, was obtained. At the same time, a better understanding of what was easy and most positive about utilizing HEN emerged. Other researchers have found that mothers of children who required HEN had greater levels of stress than mothers of children who did not require HEN (Addams, Gordon, & Spangler, 1999; Pederson, Parsons, and Dewey, 2004). While it is important to know that there is a greater level of stress experienced, it is also important to know what types of stressors are being encountered.

Mothers in this study found that there was little time for them to spend on themselves or their families because of the limited number of people available who could care for their child on HEN and the amount of time it took to adhering to the

schedule their child was on in order to complete the feedings needed to provide adequate nutrition. This is in line with research that has shown that caregivers of children on HEN spend more time providing care to their child than those with healthy children, often planning their life around the feeding schedule and having little time or ability to spend with spouses or other members of the family (Heyman, et al., 2004; Enrione, Thomlison, & Rubin, 2005). Other issues that were perceived as stressors have included the increased financial burden of HEN, the increased trouble getting baby sitters, the loss of social support and limitations to social activities, the increased visibility of the child's disability, and problems with sleep disturbances (Colomb, Goulet, & Ricour, 1998; Kirk, 1998; Evans, MacDonald, & Holden, 2004; Heyman, et al., 2004; Heaton, Noyes, Sloper, & Shah, 2005; Rollins, 2006). While these were all noted to be areas of difficulty for the mothers in this study, many others were also pointed out to be problematic, expanding the knowledge of what is seen as burdens that families of children on HEN must find ways to deal with.

It was interesting to note that an overwhelming majority of these mothers (70%) felt the most positive aspect of HEN was that their child was able to receive the nutrition and hydration that they needed. There was no one thing that stood out so prominently when asked about the most negative aspect of HEN. There were, however more different things brought up that were negative. See Table D.10 for a comparison of the negative and positive aspects of HEN. It was also interesting to note that what these mothers felt was the most negative aspect of HEN was not what

they felt was the most significant burden placed on their family. See Table D.11 for a comparison of the negative aspects with the most significant burdens.

Implications

Research Implications

Further research needs to be done on the stress that families encounter when implementing HEN. Mothers are not the only members of the family that are affected by the stress that occurs as a result of HEN. Information must also be gathered about the negative and positive aspects of HEN that affect fathers and siblings.

By identifying the specific areas of stress that families of children on HEN deal with, nurses and other professionals can develop interventions that help to decrease the effect of the negative stressors. Longitudinal studies comparing stress levels of mothers after the implementation of HEN, comparing these levels of stress to each other over time as well as comparing them to mothers who are not dealing with HEN will increase the understanding of when best to intervene. Through the use of comparison studies between mothers who are dealing with HEN and those who are not, the best method of measuring the levels of stress can be determined so that intervention strategies can be evaluated appropriately. These can be accomplished through the use of established scales that measure parental stress and adjustment to illness, such as the Parenting Stress Index (PSI) and the Parent Experience of Child Illness scale (PECI).

It is just as important to identify the positive aspects of HEN as it is to identify the negative aspects. It may also be of help in dealing with HEN if what other mothers considered to be positive aspects of HEN is made known. Knowledge that there are positive things associated with HEN can help to counteract some of the feelings of failure associated with "giving in" to the insertion of a G-tube (Spalding & McKeever, 1998).

Practice Implications

Because the decision to implement HEN is such a difficult decision to make (Guerriere, et al., 2003), it is imperative that the procedure be explained thoroughly prior to the initiation of enteral feedings and that mothers be given ample opportunity to ask questions about what HEN entails both while in the hospital and once at home. It is also important for them to know that there is a wide range of reactions to HEN, both in society and perhaps within their own families, and that not everyone reacts the same to this technology. By being made aware of the negative and positive aspects of HEN and what may be the hardest things to deal with, these mothers will be better prepared for what needs to be done to care for their child.
CHAPTER 4

MATERNAL COPING WHEN A CHILD IS FED ENTERALLY

Introduction

The placement of a nasogastric tube or a gastrostomy tube in a child, and the reliance on home enteral nutrition (HEN), introduces an entirely new set of stressors to the child's mother that are multidimensional and encompass social and psychological components (Liley, & Manthorpe, 2003). The decision to initiate HEN is a very difficult one to make and mothers of children who require HEN experience a great deal of stress (Spalding & McKeever, 1998; Adams, Gordon, & Spangler, 1999; Guerriere, McKeever, Llewellyn-Thomas, & Berall, 2003). It has been shown that the global levels of stress felt by mothers of children with disabilities who are fed enterally are greater than those felt by mothers of children without disabilities (Adams, Gordon, & Spangler, 1999; Sullivan, et al., 2004). Information needs to be identified about how these mothers cope with the stressors they deal with in managing their child's HEN and the external resources employed by these mothers that help them to be successful.

While there have been studies published about the stress associated with parenting a child with a feeding problem (Craig, Scambler, & Spitz, 2003; Pederson, Parsons & Dewey, 2004; Enrione, Holden, & MacDonald, 2005; Rollins, 2006), there are only a few studies that have looked at how these parents cope with the stress of caring for these children at home.

Researchers have started to look at the stress associated with parenting a child receiving enteral feedings, but have yet to concentrate on the strategies that these parents employ in coping with the stressors involved in HEN. A better understanding of the strategies mothers employ in order to cope with HEN will allow the development of nursing interventions aimed at strengthening those coping strategies. Appropriate interventions will create the best possible environment for the feeding process to occur and thus, ultimately benefit the child's cognitive and social development because the feeding process will become more pleasurable for both mother and child.

Background and Significance

Stress & Coping

Coping is a process by which families manage stress. It is created and modified over time. Coping strategies involve the management of different elements of family life at the same time. These can include maintaining internal communication and organization, promoting the independence of individual members, maintaining family unity and coherence, developing and maintaining social supports, and maintaining some control over the impact of stressors and the amount of change they bring to the family (McKenry & Price, 2000). Coping is the process by which an individual manages events that are appraised as stressful and the emotions that these events produce. Lazarus & Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Put succinctly, coping is the effort to manage stress.

Problem-focused coping is directed at managing or altering the problem causing the stress. This involves defining the problem, generating alternative solutions, weighing the cost and benefits of various actions, taking action to change that which is changeable, and learning new skills, if necessary. Emotion-focused coping is directed at regulating the emotional response to the problem. This includes such tactics as distancing, avoiding, selective attention, blaming, minimizing, seeking social support, exercising, and meditating. While there is a distinction between emotion- and problem-focused coping, everyone uses both types to deal with stress (Lazarus & Folkman, 1984). Problem-focused coping strategies have been found to be more effective in reducing parenting stress in families of children with disabilities (Stoneman & Gavidia-Payne, 2006).

Coping With HEN

While the decision initiate HEN is a complex, emotional, and difficult decision to make (Guerriere, et al., 2003), research has shown that there is a considerable amount of relief felt immediately after the insertion of a G-tube because of the many perceived positive changes seen both in the child and in the lives of other members of the family (Spalding & McKeever, 1998). After some time had passed, however, mothers found that there were many changes in their lives that accompanied HEN and

that they had to develop ways in which to cope with those changes. One way of coping with HEN that they discovered was developing unique and individualized plans to meet their child's nutritional needs at the same time as meeting the needs of the rest of their family, particularly when it came to dealing with the schedule their child needed to be on. They also found that they had to become knowledgeable in the types of care that their child needed as they were expected to be the "expert" in this care. Garro (2004) reported on the coping patterns of mothers of children with feeding problems during in-patient treatment of the underlying feeding problem after out-patient treatment had proved to be unsuccessful and found that it is important to provide these families with a variety of resources, such as access to information and access to support groups, because a greater understanding of their child's medical condition helped them to cope with the stressors brought on when hospitalized. However, these children were not yet being treated with HEN.

Thorne, Radford, and Armstrong (1997) found that caregivers of children on long-term HEN needed to develop creative and flexible strategies in order to deal with the stressors of using this technology in the home. They found that successful coping encompassed many different areas, including social, emotional, and philosophical issues. They also found that support to these caregivers needed to go beyond simply guidance on dealing with skin care and nutritional concerns. They found that successful coping strategies were centered on such things as managing the gastrostomy, dealing with people and society, and maintaining normalcy in their families' lives. Other researchers have also reported that the decision to initiate HEN, while it made coping with some stressors presented to a family with a child with

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feeding problems easier, brought about other stressors for which new coping strategies had to be developed. It became a struggle between maintaining a child and family's need for normalcy against the child's health and nutrition needs, and balancing the quality of life for the family with the quality of life for the child (Brotherson, Oakland, Secrist-Mertz, Litchfield, & Larson, 1995). Researchers have also reported on the coping strategies used by caregivers of children with tracheostomies and gastrostomies who were being cared for in the home (Montagnino & Mauricio, 2004). These caregivers used support from family and friends and their own ability to redefine stressful events so that they were more manageable in order to cope with stress. Research is starting to show that there are a number of different ways that families cope with the stress associated with HEN.

Summary

Mothers are often the parent who is responsible for managing the enteral feeding of their child. Current research is still lacking in information about how caring for a child who is enterally fed impacts the mother (Spalding, & McKeever, 1998). While there is a need to know more about the stress a mother encounters when caring for a child who is being fed enterally, it is equally important to know more about the strategies mothers are using to best cope with these stressors. A better understanding of these coping strategies will allow the development of nursing interventions aimed at reducing the amount of stress confronted by these mothers, or giving them better coping strategies for dealing with stress. Appropriate interventions will create the best possible environment for the feeding process to occur and thus,

ultimately benefiting the child's cognitive and social development because the feeding process will become more pleasurable for both mother and child.

The purposes of this study were to identify the types of coping strategies that mothers of children on HEN use and to identify who mothers turn to for support.

Specific aims that were addressed in this study included the following:

- 1. To determine what types of coping strategies mothers of children who are fed enterally employ to deal with identified stressors.
- 2. To determine what types of external resources mothers of children who are fed enterally use or require in dealing with identified stressors.

Method

Design

Forty mothers of children who were being fed enterally comprised the sample in this exploratory study. In 90% of families, mothers are usually responsible for managing enteral feedings (Carroll & Reilly, 1996). Inclusion and exclusion criteria are presented in Chapter 3. Mothers were asked to complete a demographic questionnaire (see Appendix C) and participate in a semi-structured interview (see Appendix B).

Subjects

Subject recruitment is explained in Chapter 3. Briefly, mothers were recruited from the Mighty Medical Miracles (n = 10) during attendance at meetings and via the newsletter through The Oley Foundation (n = 16). A Nutrition Support Nurse at The Children's Mercy Hospital in Kansas City, Missouri assisted with identification and recruitment of subjects at this site (n = 14). No significant statistical differences were found among these groups of mothers with regard to age, race, income level, child's age, or length of time child had been on HEN.

Procedure

A thorough discussion of the procedure used for this study is presented in Chapter 3. The study was approved by the Behavioral/Social Sciences Institutional Review Board of The Ohio State University. Approval was also obtained from the Institutional Review Board of Children's Mercy Hospital in Kansas City, Missouri. Written informed consent was obtained from each subject prior to data collection (see Appendix A). Semi-structured open-ended interview questions were used to gather the data (see Appendix B). Mothers were given the option of doing either a face-toface interview or via email or public mail. The face-to-face interviews were audio taped for later transcription and analysis. Mothers were also asked to complete a demographic questionnaire (see Appendix C). A concern was that mothers who chose to respond via email or mail would feel more comfortable reporting burdens. However, there were no significant differences between these response methods when compared to face-to-face interviews. Questions nine through thirteen will be discussed in this chapter.

Data Analysis

Content analysis was used to analyze the data obtained for each interview question. A detailed description of the data analysis is provided in Chapter 3. Briefly, content analysis involves an eight-step process as described by Waltz, Strickland, and Lenz (2005). All 40 interviews were first analyzed to establish units of analysis by the PI, a research nurse, and the dissertation advisor and then those units were coded into categories. For each of the questions, mothers usually provided more than one response. An interrater reliability rate of 80% was set a priori. Data from the demographic questionnaire were analyzed using the statistical package SPSS-14 (SPSS for Windows, Rel. 14.0.0, 2005).

Reliability of Data Analysis

A description of the methods used to determine reliability is presented in Chapter 3. Unitizing reliability for the individual questions was as follows: Question nine (How do you deal with these significant burdens that have been placed on your family?), 94%; Question ten (What do you do to take care of yourself?), 86%; Question eleven (Food is associated with a lot of celebrations, how do you celebrate these occasions?), 84%; Question twelve (Who do you turn to the most for help with caring for your child?), 94%; Question thirteen (Who or where do you go to talk about caring for your child?), 98%. Each question was discussed in detail to determine why there was a difference in units of analysis. Each researcher was given the opportunity to express decisions about each unit that was different and then a consensus was reached as to what would be considered the unit of analysis used in going forward to the next step. There were no areas of difference for which 100% agreement could not be reached after discussion of differences.

Reliability of coding decisions, which establishes stability reliability (also referred to as intra-rater reliability), was confirmed by recoding selected questions after a period of time had passed to check stability over time. Questions were chosen randomly by placing the numbers of each question in a hat and selecting ones to be rechecked. A stability reliability rate of 98%, and 98% was established for questions ten and twelve respectively. This percentage was calculated using the same method as used to determine unitizing reliability.

Units of analysis (referred to as responses) were coded into the mutually agreed upon categories established during steps five and six described previously. Interpretive reliability involves placing the units of analysis into the correct categories and was established in the same manner as unitizing reliability. Question nine had a total of 54 responses that categorized into twelve concepts with an interpretive reliability of 99%. Question ten had 102 responses that were categorized into thirteen concepts with an interpretive reliability of 95%. Question eleven had 48 responses that were categorized into eight concepts with an interpretive reliability of 100%. Question twelve had 91 responses that were categorized into six concepts with an interpretive reliability of 100%. Question thirteen had 84 responses that were categorized into five concepts with an interpretive reliability of 100%.

Results

Description of Sample

Demographic data describing the mothers and children are presented in Appendix D, Table D.1 and D.2. The mean maternal age was 35 (range 20-55, sd = 7.605). The average age of the children on HEN was 66.7 months (range 11-235; sd = 54.7). The average age of the child when HEN was initiated was 16.7 months (range 0-156; sd = 31.6). Children had been receiving HEN for approximately 47 months (range 6-228; sd = 51.95). Fourteen of the children (35%) were on a bolus feeding regimen, 12 (30%) were on continuous infusions, 7 (17.5%) were on continuous infusions only at night, and 7 (17.5%) were on a combination of bolus and continuous infusions.

Coping with HEN

Information about how mothers coped with the stressors they encountered in dealing with HEN was grouped into several areas of assessment. Mothers were first asked how they dealt with any significant burdens they felt were placed on their family as a result of HEN. Mothers were then asked what they do to take care of themselves. Since food is a large part of many celebrations, mothers were asked to describe different ways that they have managed these celebrations. Mothers were also asked who it is that they turn to the most for help with caring for their child on HEN and who they turn to when they need to talk about caring for their child on HEN.

Coping with significant burdens

There were many ways these mothers coped with the significant burdens that they felt their families had to deal with because of their child's feeding problem. See Table D.12 for a complete list of these concepts.

When mothers were asked how they dealt with any significant burdens they felt were placed on their family as a result of HEN they gave a total of 54 responses that were categorized into twelve concepts. Each of the established concepts was determined to be either a problem-focused coping strategy or an emotion-focused coping strategy. There were a total of nine concepts that could be categorized as problem-focused coping strategies and three that could be categorized as emotionfocused coping strategies. Eleven mothers (27.5%) stated that they dealt with significant burdens by just dealing with them, taking things "day by day" and figuring out ways to do things so that they could "go on with life." Support from family members and other social support systems were seen as important for eight mothers (20%). Support from spouses was seen as a significant source of strength in coping with issues that arise with the medical professionals that are involved with the child's HEN as well as a way to make sure that the siblings in the family did not feel left out. Support from other family members, such as grandparents, was utilized to give these mothers time to do things with spouses or siblings that they might not otherwise have the opportunity to do. Obtaining help from medical professionals was a strategy that seven mothers (17.5%) used to deal with problems that involved the mechanics of HEN. In addition, some of these mothers also relied on the health professionals to advocate on behalf of them and their child.

Six mothers (15%) mentioned scheduling. These mothers used various strategies to cope with the effects that scheduling HEN had on their family. Some found that they had to adhere to a very strict schedule in order to lessen the effect on their family's lives, others felt the need to adhere to a schedule, but found a way to cope with the schedule in a slightly different way, such as doing everything during the daytime so that there was no need to leave the house after being attached to the feeding pump. Another mother found that it was better for her family to be more flexible with the scheduling of her son's HEN, so that he could participate in things with the rest of the family and complete his feeding at a later time in the day.

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Taking care of self

Because these mothers spent so much of their time caring for their child on HEN, they were asked what it was that they did to take care of themselves. A total of 102 responses were categorized into thirteen concepts. For a complete list of the ways these mothers took care of themselves, see Table D.13. When looking at this list of concepts that mothers used to take care of themselves, there were a total of four concepts that could be considered problem-focused coping strategies and a total of eight that could be considered emotion-focused coping strategies. There were twelve instances where mothers said that they did not do anything, or not enough of anything, to take care of themselves, which would not be considered either a problem-focused or emotion-focused strategy.

Almost half of these mothers (n = 18, 45%) looked to their social support systems, either their spouses, family members, or friends, for help in making time to take care of themselves. They utilized these support systems to provide time for them to do things that they wanted to do and to provide them with someone to talk to when they needed to vent about something.

Another way in which these mothers reduced stress or tension in their lives was through exercise. Exercise became very important to many of the mothers, especially as their child grew older and they were able to find more ways to get away for periods of time. One mother developed a unique way to ensure that she could participate in her favored form of exercise by trading her writing skills to do a newsletter and calendars in exchange for free yoga classes. Another mother utilized the nursing assistance she gets to make exercise a priority in her life. To reduce stress and tension, other mothers worked on crafts or other hobbies, such as scrap booking or writing.

Anther way these mothers reduced tension was through eating or drinking, especially what they considered forbidden foods, like cookies, that they did not like to eat in front of their child. Mothers also found ways to pamper themselves with massages, manicures and pedicures, and getting their hair done by a stylist. One mother also talked about how she had a disabling medical condition herself, so it was very important for her to take care of herself by eating healthy and taking her own medications.

HEN and celebrations

Food can be a source of security, status, identity, and social acceptability. The sharing of food centered on holidays, religious festivals, or rites of passage reflects the status of the host and creates a bond among those who have eaten together. It is in this sharing of food that individuals experience a sense of belonging (Bayer, Bauers, & Kapp, 1983). When a child is on HEN, celebrations centered on food can become difficult to deal with. Mothers in this study had many strategies that they employed to make sure that their child on HEN could still participate in celebrations. The majority of the children (n = 26) could at least have tastes of celebratory foods, but there were many other strategies used in addition to giving tastes. You will find these listed in Table D.14.

Who mothers turn to for help

When asked who it is that they turn to the most for help with caring for their child on HEN, mothers in this study mentioned family more than any other group (n

= 33, 82.5%), followed by their husband, or the child's father if not married, (n = 27, 67.5%). Other people that were mentioned when asked who they turn to for help were professionals that were involved in their child's care, the most common response being nurses, followed by respite and/or care providers. Table D.15 lists the various people that these mothers turn to for help in caring for their child on HEN. Four mothers felt that the only one that they had to turn to for help was themselves, this often being a personal choice.

Who mothers turn to when they need to talk

Table D.16 lists the various groups of people that these mothers went to when they needed to talk about their child's care. Many mothers mentioned the professionals that they have come in contact with while dealing with HEN (n = 33, 82.5%). Doctors, nurses, and hospital clinic staff members, primarily in their local gastrointestinal clinics, were mentioned most often. Most of the mothers had very positive things to say about the doctors and nurses they engage with to talk about their child's care.

While professionals were sought out the most when these mothers needed to talk to about caring for a child with HEN, other people who were sought out seemed to be spread evenly between family, support groups, and friends. Many of the mothers talked about how they often will do their own research about dealing with HEN, often times making use of the internet (n = 6, 15%).

Discussion and Implications

Discussion and implications for research

Parents of children with disabilities have often used problem-focused coping strategies in dealing with the daily stress associated with the care of a child with a disability. Mothers in this study predominately used problem-focused coping strategies in dealing with the mechanics of HEN. This is consistent with research by Thorne, Radford, and Armstrong (1997) that showed that caregivers of children on long-term HEN found that problem-solving skills were critical to managing the technical aspects of HEN. When it came to dealing with things that were significant burdens for their families, mothers in this study used problem-focused strategies much more than emotion-focused strategies, but tended to use more emotion-focused strategies when it came to taking care of themselves.

When mothers and fathers of children with autism were studied, it was found that mothers used more problem-focused coping strategies than fathers did (Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005). It has also been noted that the use of problem-focused strategies vs. emotion-focused strategies was different for mothers and fathers, with mothers experiencing a higher marital adjustment score when their partner used more problem-focused strategies (Gavidia-Payne & Stoneman, 2006). However, there is a lack of research on the use of problem-focused versus emotion-focused coping strategies used when a child has HEN. Given this gap in research on the use of problem-focused versus emotion-focused coping strategies of parents of children on HEN, one of the next steps for researchers to take is to measure the types of coping responses used by both mothers and fathers to see if they differ and to see if they mediate each others' ability to cope with stress. In this study it was noted that 67.5% of the mothers (n = 27) listed their husbands (or the child's father if not married) as the first person they turn to for help in caring for their child on HEN. This is in opposition to what was noted by Adams, Gordon, and Spangler (1999). They reported that few mothers of children with HEN found their husbands to be a source of stress relief. This is an area that needs further study to determine the extent to which fathers are involved in the care of children on HEN.

The stressors and coping strategies faced by mothers of children on HEN are multidimensional and encompass social and psychological components (Liley, & Manthorpe, 2003). This study has confirmed this and brought to light a number of the specific ways that these mothers find to cope with the stressors that make up HEN. A better understanding of these stressors and coping strategies will allow the development of nursing interventions aimed at reducing the amount of stress confronted by these mothers. A better understanding of the ways mothers cope with these stressors allows for more accurate evaluations of these interventions. Appropriate interventions that lesson stress and allow for better coping will create the best possible environment for the feeding process to occur. This ultimately benefits the child by making the feeding process more pleasurable for both mother and child. *Discussion and implications for practice*

Most of the mothers in this study saw the importance of creating time for themselves and found it to be essential for maintaining their energy and keeping a positive perspective on life. This is consistent with what other researchers have reported (Thorne, Radford, & Armstrong. 1997). However there were twelve instances where the mothers felt that there was nothing they could do to take care of themselves. It is important for this group of mothers to make taking care of themselves a priority. Nurses can help by educating them about the importance of this, as well as advocating for respite care to be made available for them.

Mothers in this study found unique ways to involve their child on HEN in celebrations. It is important that nurses educate mothers about the importance of making sure that their child on HEN is included in such celebrations so that they will develop a sense of belonging in the family. Mothers have been known to develop unique ways of meeting their child's nutritional needs while at the same time meeting the needs of the rest of the family (Spalding & McKeever, 1999) and nurses need to educate those who are making the difficult decision to initiate HEN about the fact that there are ways to fit the technological aspects of HEN into the everyday life of the family.

While mothers in this study turned to their family more for help in caring for their child, they sought out professionals more often when they needed to discuss some aspect of their child's HEN regimen. When it comes to who to turn to for help, it is important to note that the relationship that parents have with health care workers has been shown to have an impact on the parents' ability to cope with long-term illnesses in children (Nuutila & Salantera, 2006). Many gastrointestinal clinics employ a nurse as a nutrition consultant. In this role, the nurse is available to do teaching as well as to answer questions as they come up. Many expert nurses who work in this arena see themselves as an anticipatory planner, preparing parents for all the tasks that make up HEN as well as helping parents with the initial decision

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process that these parents face in deciding to implement HEN (Radford, Thorne, & Bassingthwaighte, 1997). The effectiveness of this role in the clinic needs to be studied in terms of how it affects the level of stress and ability to cope that families with children on HEN experience. It also needs to be studied on a longitudinal basis to see what types of information families need over time and how the need for information changes over time. APPENDIX A

INFORMED CONSENT

The Ohio State University Informed Consent Form

CONSENT FOR PARTICIPATION IN SOCIAL AND BEHAVIORAL RESEARCH

Protocol title: Maternal Stress and Coping When a Child is Fed Enterally

Protocol number: 2004B0368

Principal Investigator: Dr. Deborah Steward, PhD, RN Co-Investigator: Cathryn J. Baack, RN, MSN, PhD Candidate

I consent to my participation in research being conducted by Dr. Deborah Steward and Cathryn Baack of The Ohio State University and their assistants and associates.

The investigators have explained the purpose of the study, the procedures that will be followed, and the amount of time it will take. I understand the possible benefits, if any, of my participation.

I know that I can choose not to participate without penalty to me. If I agree to participate, I can withdraw from the study at any time, and there will be no penalty.

- I consent to the use of audiotapes. I understand how the tapes will be used for this study.
- I consent to the use of photographs. I understand how the photographs will be used for this study.
- If applicable, I consent to the use of email for communication purposes. I understand that confidentiality of email communications cannot be guarenteed.

I have had a chance to ask questions and obtain answers to my questions. I can contact the investigators at (614) 688-3645 or (614) 292-4978. If I have questions about my rights as a research participant, I can call the Office of Research Risks Protection at (614) 688-4792.

I have read this form or I have had it read to me. I sign it freely and voluntarily. A copy has been given to me.

Print the name of the participant:

Date:_____

Signed:

Signed:

(Participant)

Signed: _____

(Principal Investigator or his/her authorized representative)

Witness:

(when required) HS-027 (Rev. 05/01) (Person authorized to consent for participant, if required)

The Children's Mercy Hospital Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY AT THE CHILDREN'S MERCY HOSPITAL Maternal Stress and Coping When a Child is Fed Enterally

WHO IS DOING THIS STUDY?

This study is being conducted by Dr. Deborah Steward, PhD, RN and Cathryn Baack, RN MSN, PhD candidate. Beth Lyman RN, MSN is the study coordinator for the Children's Mercy site. Other health care professionals may help them.

The study personnel will not receive any direct personal financial benefits as a result of your decision.

We are asking you to be in this research study. Please read the information below

and ask questions about anything that you do not understand before you make a

decision.

WHY IS THIS STUDY BEING DONE?

Many children cannot safely eat food by mouth due to having other health problems such as cerebral palsy, developmental delays, seizures, or brain injury. They may have trouble with the suck/swallow/breathe mechanism or have trouble with gagging and swallowing food or fluids into the lung. Thus, an enteral feeding tube such as a nasogastric, gastrostomy or jejunostomy tube may be required to provide the necessary nutrients and fluid to sustain life. Mothers are most often the person who gives the feedings via the enteral tube. This form of feeding a child, via enteral tube, can be stressful to the mother.

The purpose of this research study is to focus on enteral tube feeding and determine what types of:

• stressors these mothers experience in general and in the day-to-day care of their child.

- coping strategies these mothers use to deal with stress.
- outside resources these mothers use or need to deal with stress.

WHO CAN BE IN THIS STUDY?

We are asking you to be in this study because you are the mother of a child who requires enteral tube feeding.

About 30 subjects will be in this study at 2 different places. About 15 subjects will be asked to be in this study at The Children's Mercy Hospital.

WHAT WILL HAPPEN TO ME IN THIS STUDY?

Being in this study involves participating in a one time interview with Cathryn Baack. The interview will last approximately 2 hours. It will be audiotaped unless you are not comfortable with that approach. In that case, you will talk to Mrs. Baack and she will take notes after the interview.

If you decide to be in this study the following things will happen:

- You will be scheduled a time to meet with the interviewer at The Children's Mercy Hospital.
- After giving consent, you will answer some questions about your family in general.
- You will then be asked questions about the process of enteral tube feeding with your child and how you feel about doing it.

WHAT ARE THE RISKS OF THE STUDY?

There may be certain risks in this study. These risks may include you being uncomfortable talking about your feelings about providing nutrition to your child via enteral tube feeding. You may have some sadness about some of your responses to the questions.

If you have any of these problems or other changes in the way you feel, you should tell the investigator or other study personnel as soon as possible.

There may be risks we don't know about right now. We will tell you about any new information that might change your decision to stay in the study.

WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?

There may be no direct benefit to you from being in this study. By being in this study, you may help other mothers in the future.

WHAT ABOUT EXTRA COSTS?

There is no cost to you for being in this study.

WHAT ABOUT CONFIDENTIALITY?

You have rights regarding the privacy and confidentiality of your health information. When health information includes identifiers (like names, addresses, phone numbers and social security numbers) that link it directly to an individual, it is called protected health information (PHI). Federal laws require that PHI be kept secure and private. In certain situations, federal law also requires that you approve of how your PHI is used or disclosed. A research study is one of those situations.

By signing this consent form, you are permitting the following people to have use of your PHI for the research purposes described in this form:

- The research team, which includes the study personnel listed on this form and other persons involved in this study at The Children's Mercy Hospital
- The Ohio State University Institutional Review Board and its designees;
- The Institutional Review Board at The Children's Mercy Hospital;
- Federal agencies such as the Office for Human Research Protections

Information about you that is obtained during this study will be recorded in a research record. Information in the research record will be sent to the sponsor. This record will include your name, street address, telephone number and email address.

By signing this consent form, you are allowing your information to be recorded in the research record. You are also permitting your research record to be shared with everyone listed above.

The persons and groups listed above are required by federal law or by contract to keep any PHI in your research record secure and private. While confidentiality cannot be guaranteed, it will be protected to the greatest extent possible. There also may be some situations where laws require the release of your PHI. If your PHI is shared with an organization that is not required to comply with federal privacy laws, your health information is no longer considered protected and may be used and shared freely by that organization.

You may choose not to sign this consent form and not participate in the study. You may cancel your consent to use and share your PHI at any time by contacting the study personnel listed on this form or The Children's Mercy Hospital Medical Records Correspondence Department in writing. If you cancel your consent, you may no longer participate in this study. If you cancel your consent, no more information will be recorded in your research record for study purposes. Your PHI that has already been collected for the study may still be used, however. Unless you cancel your consent, your PHI may continue to be recorded and used until the study is finished. Some information about the study may be included in your medical record. Any study information recorded in your medical record will be kept there indefinitely. In the case of a side effect or bad event, your entire medical record may

need to be reviewed. Unless stated elsewhere in this form, you may not have access to your research record or test results.

Results of this study may be made public. You will not be identified in any publications or presentations.

WHAT ARE THE ALTERNATIVES TO BEING IN THIS STUDY?

You may choose not to participate in this study.

WHAT WILL I RECEIVE FOR BEING IN THIS STUDY?

You will receive a \$20 gift certificate from Wal-Mart for participating in this study.

If the total value of compensation to you from The Children's Mercy Hospital totals more than \$600 in any calendar year, the hospital must report this to the IRS on a Form 1099 with the recipient's social security number. You will receive a copy of this tax form. If you are a Children's Mercy Hospital employee, the amount you receive will be added to your W-2.

WHAT ARE MY RIGHTS AS A STUDY PARTICIPANT?

Being in a research study is voluntary. You do not have to be in a study to receive care for your child. If you choose not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled.

You may withdraw from the study at any time without penalty or loss of benefits to which you are otherwise entitled.

WHO SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

Beth Lyman RN MSN is in charge of this study at The Children's Mercy Hospital. You may call her at (816) 855-1766 with questions at any time during the study. You may also call Mrs. Baack, the principal investigator, at (614) 688-3645 with any questions you may have.

You should call Beth Lyman if you believe that you have suffered physical injury or are sicker as a result of being in this research study.

You may also call the Chair of the Pediatric Institutional Review Board (IRB) at (816) 234-3879 with questions about injury or your rights as a research subject. The IRB is a group of people who review studies to protect the rights of research subjects.

SPONSOR AND INSTITUTIONAL RESPONSIBILITIES

It is not the policy of The Children's Mercy Hospital to compensate research participants if the research results in injury. The hospital will provide facilities and medical attention to participants if needed.

CONSENT OF SUBJECT

The purposes, procedures, and risks of this research study have been explained to me. I have had a chance to read this form and ask questions about the study. Any questions I had have been answered to my satisfaction. I consent to be in this research study. A copy of this signed form will be given to me.

Signature of Consenting Party Date

STUDY PERSONNEL

I have explained the purposes, procedures, and risks involved in this research study in

detail to:

Print name(s) of Subject

Signature of Person Obtaining Consent

Date

02/01/06

APPENDIX B

INTERVIEW SCHEDULE

Interview Schedule

1. How did you feed your child today?

2. What was it like when you first discovered you couldn't feed your child by mouth?

3. How do you feel about feeding your child this way?

4. What, if any, are the negative aspects of feeding your child by tube?

5. What, if any, are the positive aspects of feeding your child by tube?

6. What is the hardest thing about feeding your child by tube?

7. What is the easiest thing about feeding your child by tube?

8. What, if any, significant burdens have been placed on your family in dealing with your child's feeding difficulties?

9. How do you deal with these significant burdens that have been placed on your family?

10. What do you do to take care of yourself?

11. Food is associated with a lot of celebrations, how do you celebrate these occasions?

12. Who do you turn to the most for help with caring for your child?

13. Who or where do you go to talk about caring for your child?

APPENDIX C

DEMOGRAPHIC QUESTIONAIRRE

Demographic Questionnaire

- 1. What is your current age?
- 2. What is your race? (i.e. White, Black, Asian, Native American, etc)
- 3. What is your marital status?
- 4. How many people currently live in your household? What are their ages?
- 5. What is your yearly household income?
- 6. What is your highest level of education?
- 7. Do you have any health insurance or other financial assistance?
- 8. What is your child's date of birth?
- 9. What is your child's medical diagnosis?
- 10. At what age did your child start receiving enteral feedings?
- 11. How long has your child been on enteral feedings?
- 12. How long have you been feeding your child enterally at home?

13. Prior to discharge from the hospital, did you receive any training on enteral feedings?

14. If yes, who did you receive training from?

- 15. How much time was spent in this training?
- 16. What was covered during this training?
- 17. Have you ever had training in your home on eneteral feedings?
- 18. If yes, who did you receive training from?
- 19. How much time was spent in this training?
- 20. What was covered during this training?

APPENDIX D

RESULTS TABLES

Mother's Race Image: Constraint of the system	Background Characteristic	n	%
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Health Insurance or Financial Aid Yes40100	No Response	3	7.5
Yes 40 100	Health Insurance or Financial Aid		
	Yes	40	100

Table D.1: Frequencies and Percentages for Background Characteristics of the

Sample

Child's Diagnosis	n	%
Developmental Disorders (i.e. Cerebral Palsy, Premature birth)	7	17.5
Gastrointestinal Disorders (i.e. Hirschprung's disease, Esophageal atresia, GERD, Short Bowel Syndrome, Liver Oomphalocele,)	8	20.0
Genetic Disorders (i.e. Down Syndrome, Cri-du-chat syndrome, Jarcho Levin Syndrome, Partial duplicaton of 3Q)	8	20.0
Neurological Disorder (i.e. Agenesis of the Corpus Callosum, Cerebral Vascular Accident, Cervical Spine atrophy, Hydrocephalous, Spina Bifida)	10	25.0
Respiratory Disorders (i.e. Chronic Lung Disease, Cystic Fibrosis, Laryngomalacia)	4	10.0
Miscellaneous Disorders (i.e. Hypopituitarism, Nephrotic Syndrome, Failure to thrive)	3	7.5

Table D.2: Diagnoses of children on HEN

Response	n	%
Scared/Worried	17	42.5
Very scary; nervous; horrified; concerned about not knowing		
everything that went with tube; couldn't handle it		
Devastated/Overwhelmed	10	25
It was pretty devastating; overwhelming learning all the medical procedures: everything was overwhelming: my son was devastated; so		
many different feelings		
Relieved	9	22.5
Relief because that was what we were waiting for to bring him home	-	
from the hospital; as long as she was coming home it was ok; at first,		
we were relieved: grateful because she was in so much pain with the		
TPN		
Felt like a failure	8	20
I felt like I had failed as a mother; felt like I was not a good mother; I		
had failed to succeed with p.o. feeding		
Difficult	7	17.5
In the hospital it was pretty difficult because we didn't know why or		
what it was about; it was very difficult to accept that it would be long-		
term;		
Took away normal activity	7	17.5
The one normal thing we could do was breastfeed and they took that		
away; I felt robbed of that bonding moment; it compromised oral		
stimulation and the social aspects of eating; you show love by giving		
food and I couldn't do that		
Shocked/Angry	4	10
It was shocking and emotionally upsetting; I felt angry, shocked and		
cheated; shocked more than anything because she was eating, just not		
gaining weight		
Easy	4	10
After it was explained it was easier to deal with; it didn't faze us; it		
was not a big deal; it was easier than TPN		
Depressed	3	7.5
It was depressing; we were very sad;		_ _
Frustrated	3	7.5
It was frustrating		

Continued

Table D.3: Mothers' Responses to Their Child Needing Tube Feedings

Table D.3, continued

Response	n	%
Not surprised	3	7.5
She was not a good eater, so we were not surprised; she was		
developing oral aversion, so it didn't come as a surprise; she had a		
birth injury so it was not a surprise		
Want to be rid of it	1	2.5
I'd give anything to be rid of it		
Denial	1	2.5
We were in denial		
Uncomfortable	1	2.5
I was uncomfortable with it at first		
Drastic	1	2.5
I thought it was something kind of drastic		

Response	n	%
OK with it	23	57.5
It helped her gain weight so I am ok with it; it has become a way of		
life; I know she is getting the nutrition she needs so I'm fine by it; I'm		
ok with it now; I love it at this point in life; I'm grateful for the		
technology; on a good day, it doesn't bother me		
Negative feelings	15	37.5
I don't like it; at first it was strange and horrible; hate that she has to		
live this way; it is difficult; it has its frustrations; sad when around		
typical kids her age; we don't like it; wish we had never had to do it; on		
a bad day, I am angry with myself;		•
Accepted as a way of life	12	30
It has been a way of life; it's necessary; we do what we have to do;		
in the end, it's ok; I have accepted it; don't have any choice; to me, it's		
normal	11	27 5
Like for child to eat orally	11	27.5
I d like for her to eat normally; wish he didn't heed it; want to wean		
ner off ner feeds; I d rather sne eat p.o.; wish ne was normal; I would		
Or of the of the image.	0	22 E
Use quality of life was what mattered, it has bent him alive and	9	22.3
the quality of the was what mattered, it has kept fills allowed for her survival.		
it's a matter of life and death; it's tough on our schedules; we're going		
to need it long term: having him with us is what is important		
Child gets nutrition	0	22.5
She gets what she needs: we don't have to fight about food: I'm	,	22.3
happy there's a way to get things into her. I know she's getting the		
nutrition she needs: was only way for him to be home: it allows him to		
get adequate nutrition: it's the best way form him to get all that he		
needs		

Continued

Table D.4: Mothers' Responses to How They Feel About Feeding Their Child by Tube
Table D.4, continued

Response	n	%
Good aspects to it	4	10
There are some good things about it; my child is alive; we have		
learned a lot; it's been a good thing		
Problems with equipment	3	7.5
I don't like PediaSure, it's thick and sugary; We can't readily get		
stuff we need; I get emotional when things go wrong;		
Can use tube when sick	2	5
We can get nutrition and hydration in when she's sick; if she's sick, I		
can make sure she gets fluids		
Easier for child	2	5
It's probably easier for him; G-tube was a victory over TPN		
Others reactions to it	1	2.5
Other people's reactions to it bother me		

Negative Aspects of HEN	n	%
Social Stigma	15	37.5
Mostly it's the stigma; other people, most people are good, but every		
now and then you get one who just doesn't understand; it's not		
"normal", normal in quotations because I always put it in quotations,		
it's not something people see very often, they ask questions, but don't		
really understand; it's an unnatural way of life; being different; other		
children find it strange; people staring; it makes the family stand out;		
the stigma		
Equipment	11	27.5
The amount of stuff we have to lug around; we have this little pouch		
we take everywhere with us that has syringes and extensions and sets,		
and I have to make sure everything is clean and dry and it's just a pain;		
there is so much stuff to bring; having to deal with all the supplies; if I		
go anywhere, I have to make sure I have PediaSure and syringes with		
me; having to remember everything and make sure we have all the stuff		
with us; knowing how to work the machines; never being able to travel		
without the feed bag, the pump, water, extra GT, syringes, making sure		
we have electricity to plug his pump in;		
Mechanical Problems	9	22.5
Waking up with a bed full of formula; it's a hassle to make sure she		
doesn't turn the pump off at night; the tube falls out; formulas get stuck		
in the machine;	_	
Physical Problems	9	22.5
Infections around the tube site and seepage from the site; M. has		
multiple significant health issues; her mouth gets very dry; severe		
reflux and digestive problems; her tube site stinks; she has increased		
reflux and when she gets sick, it's different for us; in her case, it was		
the aspiration, keeping her from getting pneumonia; breakdown at the		
site	0	•
Emotional Feelings	8	20
It seems inordinately more complicated to have a tube fed kid		
sometimes; feeling like you're failing your child because you can't give		
them what they need through your own body naturally; it's intimidating		
and a pain in the butt; feeling that I didn't do everything for her; pretty		
much the burden; a sense of failure that we could not train P. to take a		
bottle; it s inconvenient; negative emotions related to not being able to		
give her treats and the extra work of fixing her something different		

Table D.5: Negative Aspects of HEN (Home Enteral Nutrition)

Table D.5, continued

Negative Aspects of HEN	n	%
Scheduling	8	20
The attachment to a tube for so long; having to be so organized;		
working on multiple feeding activities at the same time; just the		
everyday schedule; it is so time consuming, having to be attached to		
something all the time; you have to time everything and schedule		
everything around her feeds; family obligations impact how and when		
to feed		
Inability to Enjoy Food	5	12.5
She doesn't know the joy of food; she still craves different tastes of		
things; he misses out a lot on things, like the enjoyment of food and		
different tastes and textures;		
Location Problems	4	10
It's hard to do on the go: having to be limited to what you can and		_
can't do while eating: it's hard to do in public		
Problems for the Child	4	10
Having for her to deal with having it in all the time: her growing up	-	
and thinking she's weird, wondering what's wrong with her; her self		
esteem, the way she looks at herself, just having to be attached to		
something all the time: his friends give him a hard time about it		
because they don't understand		
Traveling	3	7.5
Traveling is a big pain, going on a vacation is a hassle, there is so	-	
much stuff to bring; never being able to travel without the feed bag.		
the pump, water, extra GT, syringes, not being able to just pick up and		
go somewhere: we just stay home, although I've taken his pole, his IV		
pole, with us to go places		
Financial Burden	3	7.5
It's expensive: one is the cost, it's huge, our insurance doesn't cover	•	
hypoallergenic formula		
Limited Caretakers	2	5
Nobody wants to baby-sit because of the tube: the burden of	_	•
constant care, without respite form someone other than your spouse		
Mobility	2	5
He wraps himself up in the tubing: she wants to move around and it		
is hard to keep her in one place while she is getting the feeding		
Sleep Difficulties	1	2.5
I don't get a full night's uninterrupted sleep because the pump		
occludes		
Cleanliness	1	2.5
I have to make sure everything is clean and dry and it's just a pain:		
Nothing	1	2.5

Positive Aspects of HEN	n	%
Nutrition/Hydration	28	70
He/She gets what he/she needs; knowing she gets the calories she		
needs; we're making sure she eats; I can manipulate her constipation		
with warm liquids; now she's adequately fed and hydrated; if she's not		
hungry or won't eat, I know I can hook her up to her tube; she's getting		
better nutrition than most kids her age		
Kept Child Alive	9	22.5
It has kept him alive; without this technology, M. would more than		
likely not be alive; she is alive because of enteral nutrition; she's alive;		
it keeps him alive; it saved her life; I hate it, but he's alive; if it weren't		
for the tube feeds and TPN he wouldn't be here today	_	
Weight Gain	7	17.5
It allows her to gain weight; my son is growing; we can keep her		
weight up; the burden of worry is gone about weight gain; seeing the		
results on the scale; she's gaining weight; he's growing wonderfully for		
his age		
Medication Administration	6	15
The ability to give medication without a fight; only positive is		
hydration and giving meds.; can give meds via the tube; giving		
medication, she doesn't have to taste it; the medicines he has to take		
which most kids take by mouth, he doesn't have to experience that		1.7
Lase of Using the Tube	0	15
It's easy, quick, and not messy; having her on the tube and formula is		
Quality Time with Child	4	10
L con spond quality time with him doing anything we want to: we	4	10
held her constantly and have a very strong hend:		
Incroase Child Development	3	75
He's growing and thriving: all of her skills have improved	3	1.5
Decreased Worries	3	75
We don't have to worry about aspirating: we don't have to worry	5	1.5
about her allergies		

Table D.6: Positive Aspects of HEN (Home Enteral Nutrition)

Table D.6, continued

Positive Aspects of HEN	n	%
Allowed Child to be Home	1	2.5
She got to come home and she still gets to eat		
Helps Others Understand	1	2.5
It helps others understand that not everybody is the same, some		
people are different and have to do things differently		
Meeting New People	1	2.5
Some of the families and professionals we have met, we have met		
some amazing people that we would not have if I had had a healthy kid		
Helped Career	1	2.5
Selfishly, it has helped my career because I can understand my		
patients a little better		

Hardest Aspects of HEN	n	%
Equipment	15	37.5
Taking the equipment with us someplace; others can just throw bottles		
in a bag and go and I can't do that, I've got all this equipment and this		
and that; all the stuff, the g-button, tube, tubing, and formula; my son		
cannot live without the support of machines and very expensive,		
specially ordered formula; keeping the supply kit ready to take along at		
all times;		
Emotional Feelings	10	25
There's this whole ritual that goes with it that's irritating; she hates		
it; my heart just breaks for her and it's frustrating; it's stressful		
anticipating whether she is going to retch; missing out on the joy of		
feeding your child; afraid she'd need it for the rest of her life; feeling		
like he'll never feed orally		
Inability to Enjoy Food	8	20
She wants to taste stuff and can't; missing the social aspects of		
eating; taking something away from him; knowing he can't do		
something orally; I want her to experience food orally; I felt she was		
missing out on something		
Mobility	8	20
Restraining her to hook her up; mobility is hard for her, she gets		
tangled up; not letting her run around with other kids; getting wrapped		
up in the tubing; she's active so it's hard to keep her down, she doesn't		
like to kit still for it and the time it takes	0	• •
Scheduling	8	20
The time it takes for everything; just the whole schedule, finding a		
time where she could be off for a little while so she can be out with her		
friends; it has become kind of a routine for us; the extra time it takes to		
do it, getting her hooked up	0	•
Problem for Child	8	20
She is just terrified of the tube; now that he's getting older, he is		
more aware; at this point, making sure it's not too disruptive for her; it		
makes him more disabled; not challenging him enough; not knowing if		
he is nungry; that s the hardest part, that it bothers him the most; seeing		
mm go urrough the nassie of it		

Table D.7: The Hardest Aspects of HEN (Home Enteral Nutrition)

Table D.7, continued

Hardest Aspects of HEN	n	%
Traveling	7	17.5
Traveling anywhere: when she's on the feeding nump it's definitely	,	17.0
hard to go anywhere: not being able to go anywhere when he's hooked		
up: coordinating getting her out of the car with the tube and backpack		
Social Stigma	6	15
The stigma is horrible; the questions you get from strangers; it's just		
not normal; other people's reactions; going out in public		
Location Problems	6	15
If we are out in public, where is some place private where we can sit	;	
it's hard to be discreet about it; feeding my child in public; where		
you're at, trying to get it done		
Physical Problem	5	12.5
His stoma site is always red and irritated; she has horrible gagging		
spells; the constant pain it causes her; the tube leaking formula and		
gastric fluid; the actual surgery, I was majorly stressed about them		
cutting my baby		
Sleep Difficulties	4	10
It keeps her from sleeping in her crib because she gets all tangled in		
it so she does sleep in a co-sleeper next to my bed; my son does not		
sleep well because of the churning of the pump and when it occludes, i	t	
wakes A. and the rest of us up; having to wake up in the middle of the		
night to deal with it		
Mechanical Problems	4	10
His stoma site always leaks; once a month we have to change the		
tube; the machine beeping all the time		
Financial Burden	1	2.5
My son cannot live without the support of machines and very		
expensive, specially ordered formula;	-	2.5
Cleanliness	l	2.5
Making sure everything is clean	1	2.5
Limited Caretakers	1	2.5
Family, babysitters, even close intends are alraid to do anything with		
Nothing	2	F
At this time in life. I don't have an hard issue about N's feeding	4	5
tube: I don't think any of it is hard		

Easiest Aspects of HEN	n	%
Nutrition/Hydration	20	50
Knowing he is going to get calories and I don't have to struggle; I		
never have to worry about how much she is taking in; just knowing		
she's getting the nutrients she needs to survive; I know if she doesn't		
eat as well as she should orally, I can get calories into her; this is the		
way we can guarantee that he gets adequate calories; she "eats"		
everything I give her; he never gets dehydrated or underfed; calculating		
and controlling what he is getting; I know she is getting what she needs		
Mechanics of using the tube	17	42.5
Hooking the tube up; M. has so many GI issues that using the tube		
allows us to manage those issues with little problem; unhooking her an		
d letting her be off the feed; it's something we can do anywhere; if		
she's sick, we can back the feed out of her stomach and we can also		
vent her if she gets gas		
Time Factors	11	27.5
It's quick; the length of time it takes and how easy it is to be able to		
feed her while she sleeps; don't have to wake up child; with her pump,		
I can hook her up and if I need to go do something else, like in the		
kitchen, I can; I don't have to take any timeout except to hook him up; I		
get to sleep through the night		
Medication Administration	7	17.5
Giving her medications without a fight; you can give meds via the		
tube and not fight with the child; medicine is so much easier to give to		
a child with a tube; you can give all of their medications through the		
tube		
Decreased Worries	5	12.5
We don't have to worry about what she was allergic to; I don't have		
to worry about infections; I don't have to worry about cooking a special		
diet for her		
It's All I Know	2	5
We've been doing this for so long that it's all I know; it has become		
a part of our lives		
Nothing	3	7.5

Table D.8: The Easiest Aspects of HEN (Home Enteral Nutrition)

Significant Burdens	n	%
Limited Caretakers	14	35
The burden mostly is that there is a small number of people that can		
take care of K. for any length of time; I just can't go out and find a		
babysitter for her; the inability to take a break from the constant care;		
she can't be with people who can't feed her; no sitters or family will		
watch him while he's hooked up; our social life in some areas is		
compromised; not being able to take him to my sister's or a babysitter;		
it does make it really hard to find a babysitter, because I have to have		
someone specially trained; it's difficult to leaved a child who is tube		
fed with others	14	25
Scheduling	14	35
It's time-consuming; time constraints; I have to plan things around has facility as he dulay the mayor and inc. doily routing and recognity of ity		
ner feeding schedule; the never-ending daily foutine and necessity of it;		
iny husband and I work opposite sinits so we rarely spend time together		
as a family, I always am on can, the feedings take a fong time, making a schedule and arranging everyone's schedule around when she		
needs fed: scheduling, we do everything we have to do before 5:00 so		
that we are stationary when he is on the feeding nump: the time		
consumption we have to plan our day around getting home to book		
him un		
Problem for Extended Family	10	25
Getting the whole family to understand why she has the tube: we	10	20
can't eat together as a family: her older sister doesn't get as much		
attention as she should: she gets more one-on-one time and the older 2		
feel left out; my ex-husband couldn't handle it; every aspect of our		
family has been affected; having to train my mom and deal with her		
anxiety; I think they are all intimidated by it all		
Emotional Feelings	9	22.5
It's the emotional and psychological trauma of it; I worry about		
doing things wrong; stress level is very high dealing with chronic		
illness; extreme worries about her health; I have depression, which has		
been worse; worrying about his mickey falling out when I am not there		
with him; feedings are stressful; it can be kind of frustrating; everyone		
is scared to take care of her		

Table D.9: Significant Burdens Placed on the Family as a Result of Child's Feeding Difficulties

Table D.9, continued

Significant Burdens	n	%
Financial Burden	9	22.5
The expenses of taking her to the hospital; paying for his formula;		
financial burdens; expenses can be an issue at times; insurance does not		
cover formula if it is supplemental feedings and only covers a		
percentage of the supplies and equipment rental; I have had to quit		
work to care for her; financial as far as his food, it is expensive so we		
order it on eBay because we shopped around and we can get a deal; it		
costs quite a bit of money for the bags and supplies; money is the		
biggest burden		
Psychological Problems for Child	8	20
Having to hold her down to hook her up; he gets excluded from a lot		
of stuff because of his feeding issues; her childhood has been		
drastically altered by her dependency on enteral feeding; I don't want		
her to feel so different from others; she can't have the normal things a		
2-year-old has;		
Teaching others/self	7	17.5
You are always in education mode; explaining it to everyone and		
answering questions from people; having to learn something new that,		
if you mess up, could be a big thing; I have to train other caregivers and		
school personnel; having to train my mom; we have to explain what we		
are doing and why		
Difficulty	4	10
It makes everything more difficult; the issues can kind of cascade;		
school is difficult; it's really cumbersome to go out on the feeding		
pump		
Medical Issues	3	7.5
All the trips to the hospital; hard to get compassion form the doctors;		
all the doctors visits and hospital stays and now we have home therapy		
that comes, and I have to let strangers come into my home		
Lack of Family Support	3	7.5
The hardest part is the lack of family support; my mom won't keep		
her overnight because she is terrified of the pump; the other kids will		
go and spend the night at Grandma's and he can't because he is on the		
tube feeding all night		

Continued

Significant Burdens	n	%
Sleep Difficulties	3	7.5
It has upset our sleeping patterns; at night the pump beeps, so I don't		
sleep well at night; you never really get a peaceful night's sleep		
Dealing with Insurance	2	5
In the early years, when he had home nursing, the insurance decided		
he didn't need tube feedings; endless battles with insurance companies		
Equipment	2	5
Making sure you have all the equipment that she's going to need for		
feeding; we can't just go to a restaurant, we have all this stuff we have		
to take with us		
Mechanical/Physical Problems	2	5
Keeping the tube in; before anti-reflux medications, she vomited		
every day		
Travel	1	2.5
It's difficult when we travel or go camping, we have to make sure		
that there are electrical hookups and take cases of formula with us		
Cleanliness	1	2.5
Feedings can be messy so we have a system for feeding and cleaning		
that works well		
Mobility	1	2.5
Limitations of movement affect her independence		
None	1	2.5

Negative Aspects	%	Positive Aspects	%
Social Stigma	37.5	Nutrition/Hydration	70.0
Equipment	27.5	Kept Child Alive	22.5
Mechanical Problems	22.5	Weight Gain	17.5
Physical Problems	22.5	Medication Administration	15.0
Emotional Feelings	20.0	Ease of Using the Tube	15.0
Scheduling	20.0	Quality Time with Child	10.0
Inability to Enjoy Food	12.5	Increase Child Development	7.5
Location Problems	10.0	Decreased Worries	7.5
Problems for the Child	10.0	Allowed Child to be Home	2.5
Traveling	7.5	Helps Others Understand	2.5
Financial Burden	7.5	Meeting New People	2.5
Limited Caretakers	5.0	Helped Career	2.5
Mobility	5.0	_	
Sleep Difficulties	2.5		
Cleanliness	2.5		
Nothing	2.5		

Table D.10: Comparison of Negative Aspects of HEN with Positive Aspects of HEN

Negative Aspects	%	Significant Burdens	%
Social Stigma	37.5	Limited Caretakers	35.0
Equipment	27.5	Scheduling	35.0
Mechanical Problems	22.5	Problem for Extended Family	25.0
Physical Problems	22.5	Emotional Feelings	22.5
Emotional Feelings	20.0	Financial Burden	22.5
Scheduling	20.0	Psychological Problems for	20.0
Inability to Enjoy Food	12.5	Child	17.5
Location Problems	10.0	Teaching others/self	10.0
Problems for the Child	10.0	Difficulty	7.5
Traveling	7.5	Medical Issues	7.5
Financial Burden	7.5	Lack of Family Support	7.5
Limited Caretakers	5.0	Sleep Difficulties	5.0
Mobility	5.0	Dealing with Insurance	5.0
Sleep Difficulties	2.5	Equipment	5.0
Cleanliness	2.5	Mechanical/Physical Problems	2.5
Nothing	2.5	Travel	2.5
_		Cleanliness	2.5
		Mobility	2.5
		None	

 Table D.11: Comparison of Negative Aspects of HEN with Significant Burdens

Placed on Family

	D.11./		0/
Kesponse	Problem/	n	%0
	Emotion-		
	focused*		
Just deal with it	Р	11	27.5
We're working on it; I don't have an answer for how			
we deal with all this, we just do; you just get use dot it;			
when you go through it, you just do it; we just day-by-day			
deal with it; it just becomes a way of life; I just have to			
take time out at times			
Social support	Ε	8	20
I have a very good support system and many family			
members who know how to feed her; my husband deals			
with the doctors when I just can't any more; my husband			
tries to devote more time to my older daughter;			
grandparents take her one weekend a month so we can do			
stuff with the other children; we have found a friend who			
is a nurse and our older kids how to hook him up and			
unhook him; I have a lot of help from family members and			
friends:			
Help from professionals	Ε	7	17.5
I've had some really wonderful nurses who try to listen			
and be on my side: I have a nurse who stays with her:			
respite care providers: we started therapy at Vanderbilt:			
we have a lot of help from here (hospital):			
Schedule	Р	6	15
I plan to do stuff when she is not going to need to eat:		-	
we keep ourselves organized: we try to schedule outings			
so it doesn't fall during a feeding: we feed him before they			
(grandparents) come and shut his feed off for a few hours:			
we try to schedule everything during the day. you just			
have to plan			
have to plan			
			1

Table D.12: Ways Mothers Cope with Significant Burdens Placed on Their Family (* P = Problem-focused coping, E = Emotion-focused coping)

Table D.12, continued

Response	Problem/	n	%
Response	Emotion-		70
	focused*		
Special times	P	5	12.5
It also helps if I go places with my little girl to help			
us have a mother-daughter relationship rather than a			
caretaker-patient relationship; on weekends we try to			
do things geared towards her (older daughter) like			
going to the petting zoo or arcade or something; we try			
to take time to spend special time with them (siblings);			
sometimes we just shut off the pump for a while			
Financial assistance	Р	3	7.5
The IO waiver an d BCMH help pay for his formula			
and stuff; MRDD Early Intervention and BCMH help,			
and I recently applied for Social Security, which they			
think we'll be approved for; our friends had a			
fundraiser to help pay our bills and we fight with the			
insurance company			
Teach others	Р	3	7.5
We try to educate my friends and family; we			
explain what we are doing and why; we just keep			
teaching them and having them practice			
Be prepared	Р	3	7.5
We have to make sure that everything is packed;			
you have to be prepared for everything; we stick with			
a strict program			
Cry/vent	E	3	7.5
I cry a lot and vent to anybody who will listen; I'm			
a big crier, I definitely cry a lot; reaching out by phone			
to any ear I could talk to and finding other parents who			
had tube fed kids and finding that listening ear			_
Special equipment	Р	2	5
We purchased a bag with wheels to enable her some			
independence; we have a carryall bag, a portable bag			
that the pump goes in	D	1	2.5
Steep arrangements	ľ	1	2.5
She s in a co-sleeper and I keep my nand on it	р	1	25
Antiroflay modications have halped	ľ	I	2.3
Anurenex medications have helped	1	1	

	Problem/	n	%
Response	Emotion-		
-	focused*		
Social support	Ε	18	45
Support form my husband and family, support			
groups; I have some good friends that I talk to and my			
husband has been a wonderful support; my husband is			
real good about watching the kids; church and friends;			
just moved to a new city, so trying to develop a			
network of special-needs childcare;			
Special time	Ε	14	35
We enjoy doing things as a family; my husband and			
I try to go out as much as we can on weekends and			
have couple time; I need to get away for myself at			
times, so I just do it; we play and go visit family; I			
take every vacation day, sick day and FMLA day that I			
have, I even take days off with no pay; we go out on			
date nights; go to my room to get away; take a day or			
two where E. and I jus tstay in bed and hang out all			
day and watch TV; spend quality time with my			
husband			
Exercise	Ε	11	27.5
I do yoga; I take the dogs to the park and I ride			
horses; go to the gym; I lift weights, do tai chi and			
aerobics; I get, not enough, but some exercise;			
Hobbies	Р	10	25
I try to get together with a friend and we scrapbook;			
I do write poetry; read; artwork, writing; read and			
garden; read a book or watch TV;			
Work/school	Ε	8	20
I go to school; I went back to work; I'm in nursing			
school right now; I work and I go to school;			

Table D.13: What Mothers do to Take Care of Themselves (* P = Problem-focused coping; E = Emotion-focused coping)

Table D.13, continued

Response	Problem/	n	%
L	Emotion-		
	focused*		
Pamper self	Е	7	17.5
I actually go and get good haircuts, I go to a nice			
place and get it done regularly; I take time to do my			
hair and makeup to feel good; occasionally I will get a			
massage; last year I went on a cruise; I go to the			
beauty salon;			
Babysitter/extra help	Р	7	17.5
Occasionally we will get a baby sitter, we are			
willing to accept help; grandparents baby-sit;			
Food/drink	Ε	6	15
I eat cookies late at night; I drink on the weekends;			
eating as healthy as I can; I self-medicate with			
caffeine; I try to eat well;			
Find a way	Р	3	7.5
I try to find ways to do the things I like to do; I			
maintain; what any mother does to take care of herself;			
Counseling/Medications	Ε	2	5
I have an autoimmune disorder, so taking care of me			
now consists of taking my medications regularly; I'm			
in counseling;			
Emotional outbursts	Ε	2	5
I shut down and cry; laughter			
Helping others	Р	2	5
I'm involved with advocating for children; being			
able to help someone else;			
Nothing		12	30
Not a whole lot; not much, not as much as I should;			
my child comes first; I really haven't done that yet; not			
a lot of stuff, there just isn't enough time in the day;			
not near enough;			

Response	n	%
Able to taste foods	26	65
We put some chocolate on her finger and let her taste it; I'll mash up		
her cake and soften it with milk so she can eat it; we are like any other		
family, we always offer it; we allow her limited oral intake so she		
doesn't lost the taste of food and the concept of eating; we just let her		
try it; we gave him things to taste; she can eat for pleasure; we take his		
pacifier and dip it in stuff; he sits at the table with us and we give him		
suckers and we do tastes; we let her cheat and eat;		
Play with food	7	17.5
We put the cake in front of him, but he just plays with it; she got the		
little cake, but she just played with it and made a huge mess; we		
encourage her to play with her food; he gets a cake and plays with it;		
we just do more tactile things;	_	
Special toys/play time	5	12.5
With special play time and trips to her favorite places; our child		
would get little party gifts for all, stickers, whistles, whatever; books or		
stickers	-	
Bolus during celebration	4	10
She sits at the regular table with the family and we bolus her; she		
sits with us and socializes and we try to arrange for things to happen		
while she is on her tube feeding so she associates things with food;	•	
Not a big deal	3	7.5
She is still so little, she doesn't seem to notice a difference yet, so		
that hasn't been a problem for us yet; he still sits at the table with us,		
not any differently than if he was eating by mouth, he's just not; it's		
hard to know how much she understands, so it's not much of an issue		a -
Changed way eat	I	2.5
I have changed the way I eat, and the way I serve food so that		
everything we eat is something she could eat too	4	25
Avoided celebrations	I	2.5
when M. was no longer an infant, we avoided a lot of family		
gatherings that centered around food	1	25
Pool not a part of celebrations	1	2.5
Because sne has been tube red almost her entire life, food has never		
been a part of these celebrations		

Table D.14: How Mothers Deal with Celebrations

Response	n	%
Family	33	82.5
Mother, father, in-laws, sister, siblings, other extended family		
members	27	67.5
Husband/spouse		
Husband, fiancé, child's father	21	52.5
Professionals		
Nurses, doctors, care providers, respite providers, teachers	4	10
Friends		
Self	4	10
I turn to myself; we do a lot of it ourselves;		
Support groups	2	5
Support groups, other parents of disabled children		

 Table D.15: People Mothers Turn to for Help with Caring for Their Child

Response	n	%
Professionals	33	82.5
Clinic/hospital, nurses, doctors, therapists, dieticians, school		
personnel, psychologists, home care staff	15	37.5
Family		
Husband, mother, father		
Friends	15	37.5
Support groups		37.5
Support groups, other parents, church, Oley Foundation		
Self	6	15
Own research, internet		

Table D.16: People Mothers Turn to When They Need to Talk about Caring for Their Child

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