

## **Critical Review: An Exploration of the Perceptions of Gastrostomy Tube-feeding in Caregivers of Children who have Cerebral Palsy**

Backx, R., MCIsc. Candidate, S-LP

School of Communication Sciences and Disorders, U.W.O.

This critical review examined caregiver perceptions of gastrostomy tube-feeding in children with cerebral palsy. A literature search was completed, and interpretive descriptive studies based on interviews were reviewed. Overall, the articles identified multiple and variable themes that were positive, negative and neutral in nature from the individuals' experiences. Such themes included: attempts to maintain normalcy, dealing with stigma and attitudinal barriers, relief, loss and lessened feelings of maternal competence.

### ***Introduction***

Cerebral palsy is a defect of motor strength and coordination found to be related to brain damage occurring prenatally, perinatally or in the first three years of life (*Stedman's Medical Dictionary*, 2005). The term can be used to describe a number of disabling conditions, of which motor impairment is a main challenge, showing large variability in its presentation (Panteliadis & Strassburg, 2004).

Cerebral palsy is the most common physical disability in children, and is present in about 0.1-0.24% of all live births (Panteliadis & Strassburg, 2004). A study conducted between 1993 and 2002 found that, as rates of infant mortality declined due to advances in medical technology, increases in the prevalence of cerebral palsy were observed (Vincer, et al., 2006).

In a study of preschool children with cerebral palsy (Reilly, Skuse, & Poblete, 1996), more than 90% of the sample had oral motor difficulties that were deemed clinically significant. Such a high prevalence of feeding and swallowing difficulties in this relatively large disability population poses obvious challenges for nutrition, hydration and growth. Risk of undernourishment was found among 1/3 of the subjects in the abovementioned study. A leading cause of death for individuals with cerebral palsy is pneumonia, in many cases caused by aspiration of food into the lungs as a result of dysphagia (Strauss, Cable, & Shavelle, 1999). Additionally, one of the largest difficulties often cited by parents of children with special needs are challenges arising from feeding, underscoring the essential nature of feeding issues in child care (Hunt, 2007).

When oral feeding is not deemed safe or appropriate, gastrostomy tube-feeding is often recommended. It is currently being used as a long-term mode of nutritional intake, and increasingly, families are being required to manage the technology in the home (Thorne, Radford, & McCormick, 1997b). Since perceptions of gastrostomy tube-feeding have been found to impact on nutritional intake decision-making as

well as adherence to NPO recommendations (Petersen, Kedia, Davis, Newman, & Temple, 2006), there is a great need for an understanding of such subjective experiences. Gaining a glimpse into the experiences of such families can help the clinician with counseling and joint decision-making regarding nutritional intake modes.

There are an increasing number of individuals with cerebral palsy surviving, and gastrostomy tube-feeding in the home is becoming a common recommendation for the management of resulting dysphagia. As such, this review examines the perceptions of caregivers in order to better understand the critical issues surrounding optimal feeding modes. Health and well-being outcomes can be assumed to, at least in part, depend on such perceptions.

### **Objectives:**

The primary purpose of this review is to examine caregiver perceptions of gastrostomy tube-feeding in children with cerebral palsy. A cursory review of the issues faced by families in making nutritional intake mode decisions for their children will be examined in order to inform practice.

### ***Methods***

#### **Search Strategy:**

Computerized databases including SCOPUS, Cumulative Index to Nursing & Allied Health Literature (CINAHL) and MedLine were searched using the following search strategy:

((caregiver perception) OR (caregiver satisfaction) AND (tube-feeding) OR (gastrostomy) OR (PEG))

#### **Selection Criteria:**

Studies were excluded if they involved the use of structured questionnaires, because the tools used in such studies tend to focus on very specific aspects of caregiver satisfaction. This review instead focused on studies that were theme-based, consisting of exploratory investigations into the subjective perceptions of caregivers. Surveys have

been found to result in a high degree of satisfaction with gastrostomy tubes, whereas qualitative, theme-based studies tend to allow for an exposition of more ambiguity (Sleigh, 2005). As such, a systematic review was excluded because it included studies that used structured questionnaires. Studies were also excluded if they did not include children with cerebral palsy, or if they looked at the impact of tracheostomy and gastrostomy care together in order to narrow the focus to the chosen topic.

## **Data Collection:**

### *Results*

#### Study 1:

A longitudinal, interpretive, descriptive study was completed by Thorne, Radford, and Armstrong (1997a), involving face-to-face interviews over a 12 month period. The participants were caregivers of children with birth or prenatal disabilities (n=36) and secondary illnesses (n=10) who had received gastrostomy feeding for at least three months prior to the study. The interviews were transcribed verbatim, and analyzed by the authors.

As part of a larger, longitudinal study examining the effects of gastrostomy on children with cerebral palsy, caregiver perspectives of coping were examined. Nine categories were found, and grouped into three broad themes: feeding tube management, dealing with people, and maintaining normalcy. Challenges included difficulties in equipment management, problems with professionals, as well as the greater social world, and an inability to maintain normalcy.

Thirty of the children lived in a family home; fifteen were in a hospital, and one lived in a group home. Failing to control for the environment likely contributed to variability in themes identified, as it can be assumed that the setting would have an impact on coping and the perceptions of caregivers, as the amount of responsibility will vary depending on the setting. Analyzing the themes separately would have allowed for improved understanding of the particular issues as related to the setting. Additionally, a large variability in age (21 months – 19 years) and time since tube insertion also were not accounted for in the analysis.

The caregiver's relationship to the child could also be assumed to impact on perceptions of the tube and coping abilities, but the data from the 14 birth parents, 16 parent substitutes, 14 nurses and 2 other healthcare workers were not analyzed separately. It can be assumed that such perceptions would differ in important ways that were not gleaned from this study.

It was stated that the qualitative study principles and methods for establishing credibility by Lincoln

& Guba (1985) were followed. However, it was not explicitly explained how particular aspects of this protocol were implemented.

An interview guide was used for all participants to prompt for discussion of previously designated topics. Such topics were listed, making the study more replicable.

Data analysis and collection occurred concurrently, in keeping with the naturalistic methods of the study. Periods of immersion into the data as well as distancing from the data, were stated to have occurred, but it was not reported how this was accomplished. Member checking was not completed to verify thematic results, nor were controls for experimenter bias mentioned in the study. Inter-rater reliability methods could have improved the strength of the results. Despite participant demographic variability in the study, due to relatively rigorous reliability and validity checks, this study was found to have a high level of evidence.

#### Study 2:

A cross-sectional, qualitative research study by Brotherton, Abbott and Aggett (2007) was conducted through the use of semi-structured interviews to examine parental perceptions of the impact of enteral feeding on daily life. The parameters examined in the study included: impact on daily life, quality of life, community supports, problems encountered, feed administration and social interactions. Interviews were transcribed and analyzed manually, and relevant phrases were extracted and coded.

Key issues identified by the study were: delayed and disturbed sleep; restricted mobility; difficulties in finding places to feed; and problems with finding childcare. Other themes included attitudinal barriers; divisions within the family; missing out on familial bonding at mealtimes; and relief of pressure to feed and give medications orally.

Purposive sampling was used in order to include children with a wide range of disabilities. As such, results cannot be assumed to be representative of all families with children who have cerebral palsy. Some difficulties unrelated to cerebral palsy may have played a role in the different perceptions of gastrostomy feeding discovered.

Methods of oral feeds used (pump, bolus or a combination), and NPO recommendations given, varied among the participants. The sample children included 21 females and 3 males. Gender, a possible confound, was not stratified. However, all parents were caring for the child at home, controlling for setting variability.

Inter-rater reliability was addressed through an independent analysis of one-third of the transcripts by the second author. When minor discrepancies presented in allocating phrases to categories, they were discussed until agreement was reached. It was stated that interviewer bias was minimized through maintenance of a nonjudgmental approach, yet the protocol used to this end was not outlined. Member checking was not employed to verify results, nor was there blind analysis or transcription of the data, weakening the results. The setting was controlled for, but since the only measure described to strengthen the results of the study was an inter-rater reliability check, this study was found to have a moderately strong level of evidence.

### Study 3:

A study by Craig and Scambler (2006) was conducted to explore the way mothers constructed their experiences with gastrostomy tube-feeding. A sub-sample of 22 mothers participating in a large, quantitative study on gastrostomy feeding was recruited for 45-90 minute interviews, before and 3-7 months after gastrostomy surgery.

Ten of the twenty-two children had cerebral palsy. Interviews before surgery consisted of questions about feeding history, the referral process, perception of health services and support needs. Interviews after surgery elicited descriptions of the experiences of tube-feeding; the impact on familial quality of life; whether the right decision was made and support needs. Interviews were transcribed and analyzed, and text was selected based on its relevance to mothering and feeding.

Results showed anxiety about transformation of the child into an 'other', and changes in the mother-child relationship. The tubes were viewed as 'stigma symbols', and perceived negative reactions resulted, through hostile staring or unwelcome questioning, which caused barriers for leaving the house. Fear of judgments by others and the logistical impracticality of feeding in public also were found to limit outings. Force feeding was seen as a limit to the child's autonomy, yet resulting thin body morphology lead to a self-perception of being a neglectful mother.

The study concluded that decisions made about tubes were related to the mother's perceptions of the ideal child and the ideal mother. It was suggested that gastrostomy tube-feeding can be perceived as further proof of failure of the mother to establish oral feeding. Powerlessness and uncertainty in making the decisions were noted, and overall, tubes were found to challenge cultural narratives about good mothering.

Ten of the mothers asked to take part in the study refused, leading to a response rate of 69%. It is possible that the refusal group could have differed in some significant way from the participant group. They may not have agreed with the theoretical underpinnings of the study, which could have impacted upon the degree of agreement with the theory that was observed.

The use of a feminist, theory-driven framework in data collection and analysis was conducive to obtaining only certain types of information. As such, perceptions that did not conform to the norms were discounted, leading to potential bias, and an incomplete understanding of the mother's experiences.

There was a fair degree of subjective interpretation within the study as related to the theoretical model used, that was not stated to have been verified through member checking. However, direct quotations were used to support statements made by the researchers, helping to validate the interpretations.

The relationship between the researcher, the data and participants was not identified. It did not state how bias was reduced in the interviews, or analysis of the transcripts. Making use of inter-rater reliability, analyzing data that did not fit into the theory separately and identifying interview questions a priori, could have improved the strength of the results. Results of this study should be viewed with caution, as bias from a pre-existing theoretical model could potentially have skewed results, and reliability as well as validity checks were not utilized, leading to a low level of evidence.

### Study 4:

A study by Sleight (2005) used loosely-structured interviews to examine mother's experiences of feeding children with cerebral palsy. Four parents of children being fed by mouth and six being fed through gastrostomy participated in 1.5-2 hour interviews that were transcribed and manually analyzed using a phenomenological approach. Resultant themes found in the study included: struggling to maintain normalcy; reduced pressure for oral feeding; improvements in management of illnesses; mourning the loss of the nurturing experience of joint food intake; lack of privacy and guilt in forcing the child to eat. Overall, most were happy with gastrostomy placement, but perceptions ranged from complete satisfaction to absolute dissatisfaction. Although most were generally pleased, there was a fair degree of ambivalence revealed through the discourse analysis.

Only 4 out of the 16 of those contacted through a tertiary feeding clinic decided to participate in the study; a low response rate. The study was limited to those who had a gastrostomy inserted 6 months to 3 years prior to the study, which made the results relatively cohesive, and improved the potential for an understanding of the experiences of individuals at a certain stage of acceptance. It also helped to make distant memory of events less of a confounding variable. All children of the mothers interviewed had cerebral palsy, improving cohesion, but severity of disability and age varied between participants.

Interview questions and the coding method used were not identified in the study, which would make the study difficult to replicate. Extracting and coding of phrases with meaning was completed, and sequential stages of ordering and restructuring were used to increase rigor in placing the data into themes. Meaning units were written down and numbered & grouped and labeled as a theme. Reflection on the data, experimenting with alternative explanations, and frequent readings of the transcripts improved the reliability and validity of the study.

The two groups, those fed by mouth and those through gastrostomy, were analyzed independently. All transcripts were analyzed by the author, and four were re-evaluated by a sociology research colleague. Discussion resulted in some theme changes. Respondent validation was completed through contacting four participants, and no changes in themes were suggested. Inter-rater reliability and stratification of the groups improved the strength of the results. This study has a high level of evidence, due to a relatively homogeneous sample and a high level of rigor applied to the results.

#### Study 5:

In a study done by Spalding and McKeever (1998), 1.5-3 hour long open-ended interviews were conducted with twelve mothers of children with gastrostomy tubes. The purpose was to determine how such mothers met the demands of motherhood, and how they felt about the tubes. The history of feeding difficulties was first addressed, and a loosely structured interview guide based on the theoretical discipline of motherhood framework was used. The five themes identified were: seeking confirmation of the feeding problem; devising extraordinary practices to ensure the child's survival; 'giving in' to the tube; relief and disappointment; customizing feeding; and moving on.

A relatively good response rate of 75% was established. Children ranged from 3-12 years in age, and 7/12 had cerebral palsy. The environment of the child was controlled for, as all families had the child living at home, and all individuals interviewed were primarily responsible for the gastrostomy tube-feedings.

Using the 'discipline of motherhood' framework in design and analysis may have limited what was gleaned from the study. If data collection and analysis came from the data itself, as opposed to making the data fit into a pre-existing model, it is possible that more information may have been gained.

Transcripts were broken down into meaning units, which were then grouped into preliminary categories that were examined individually, and compared. Comparing and contrasting of categories led to theme revisions. Identifying negative cases was also stated to have occurred in the data analysis process. Inter-rater reliability was established through having one researcher analyze the transcripts, and three others help in theme development. Disagreements were resolved through group discussions. Such measures improved the strength of the study. This study has a moderate level of evidence, as the use of a theoretical model may have lead to polarization of results in one direction, but adequate methodological rigor was used.

#### ***Conclusions:***

##### **Clinical Implications:**

The diversity in findings and the descriptive nature of the studies reviewed do not allow for specific particular generalizations to be made. Instead, clinical decisions should be made on a case-by-case basis. However, such studies illuminate some of the many issues faced by such families that may be addressed through appropriate investigation of individual needs and a willingness to provide adequate support systems.

The serious social issues identified, such as normalization, stigma, feelings of incompetence and loss underscore the fact that enteral feeding can have large social and emotional ramifications for caregivers.

It has been found that parents have a need for some understanding of how tube-feeding would potentially fit into family life before a decision is made. They felt that nurses and doctors did not adequately understand the social repercussions of this decision (Hunt, 2007). As such, an interdisciplinary approach, with adequate health and social support professionals is important to provide for this population. Beyond clinical and

technical support, the social-emotional issues identified in this review may need to be addressed to improve quality of life for children and caregivers.

#### **Future Directions:**

Through controlling a number of variables, a more thorough understanding of the issues related to various circumstances could be better understood. Such variables include: time since gastrostomy placement, setting of the child, type/severity of disability and type of tube-feeding.

Further studies could examine the economic and social costs of tube-feeding for families. Others could study the degree to which the identified issues pose challenges by quantifying the qualitative findings. For example, further analysis of outliers, looking at dissatisfaction in depth from surveys could bring about an improved understanding of difficulties.

Populations in future studies could include those in which there is medical instability, or those in which gastrostomy tube-feeding has failed. Such individuals were excluded from the above studies, and including them may give a more complete picture of the population of caregivers of children who use a gastrostomy tube.

Overall, the studies illuminate the need for social supports to be put in place, and decisions to be made on a case-by case basis, due to results indicating that there was much variability in individual experiences. The emotional nature, and life-changing aspects of tube-feeding should not be underestimated, with the understanding that adequate care for this population necessitates an interdisciplinary approach.

#### **References**

- Brotherton, A. M., Abbott, J., & Aggett, P. J. (2007). The impact of percutaneous endoscopic gastrostomy feeding in children: the parental perspective. *Child: Care, Health and Development*, 33, 539-546.
- Craig, G. M., & Scambler, G. (2006). Negotiating mothering against the odds: Gastrostomy tube-feeding, stigma, governmentality and disabled children. *Social Science & Medicine*, 62, 1115-1125.
- Hunt, F. (2007). Changing from oral to enteral feeding: Impact on families of children with disabilities. *Paediatric Nursing*, 19(7), 30-32.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Beverly Hills CA: SAGE Publications.
- Panteliadis, C. P., & Strassburg, H. (2004). *Cerebral palsy: Principles and management*. Thessaloniki, Greece: Giapoulis Publications.
- Petersen, M. C., Kedia, S., Davis, P., Newman, L., & Temple, C. (2006). Eating and feeding are not the same: Caregiver's perceptions of gastrostomy feeding for children with cerebral palsy. *Developmental Medicine and Child Neurology*, 48, 713- 717.
- Reilly, S., Skuse, D., & Poblete, X. (1996). Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: A community survey. *Journal of Pediatrics*, 129, 877-882.
- Sleigh, G. (2005). Mother's voice: Feeding and cerebral palsy. *Child: Care, Health & Development*, 31(4), 373-383
- Spalding, & McKeever, (1998). Mother's experiences caring for children with disabilities who require a gastrostomy tube. *Journal of Pediatric Nursing*, 13(4), 234-243.
- Stedman's Medical Dictionary for the Health Professions and Nursing 5<sup>th</sup> Edition. (2005). Baltimore: Lippincott Williams & Wilkins
- Strauss, Cable, & Shavelle (1999). Causes of excess mortality in cerebral palsy. *Developmental Medicine and Child Neurology*, 41, 580-585.
- Thorne, S. E., Radford, M. J., & McCormack, J. (1997a). Long-term gastrostomy in children: Caregiver coping. *Gastroenterology Nursing*, 20(2), 46-53.
- Thorne, S. E., Radford, M. J., & McCormick, J. M. (1997b). The multiple meanings of long-term gastrostomy in children with severe disability. *Journal of Pediatric Nursing*, 12(2), 89-99.
- Vincer, M. J., Allen, A. C., Joseph, K. S., Stinson, D. A., Scott, H., & Wood, E. (2006). Increasing prevalence of cerebral palsy among very preterm infants: A population-based study. *Pediatrics*, 118(6), 1621-1626.