

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

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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

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.

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.

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