

Mothers' Experiences Caring for Children With Disabilities Who Require a Gastrostomy Tube

Karen Spalding, RN, MSc, and Patricia McKeever, RN, PhD

In this qualitative study, mothers' experiences of feeding children with severe disabilities by a gastrostomy tube are described. Twelve mothers each participated in one, open-ended, home interview. Mothers gave detailed accounts of their activities and the tremendous stress involved in feeding the children. They described spending enormous time and energy seeking confirmation of the feeding problem and devising extraordinary practices to ensure the child's survival before "giving in" to the gastrostomy tube. Following gastrostomy tube insertion, they initially felt relief and disappointment, before customizing feeding and moving on. Mothers' suggestions for improving professional services are discussed along with implications for practice and research.

Although raising children who have disabling conditions involves many activities that are complex, stressful, and time consuming, there is evidence that feeding is especially problematic for parents (Cameron, Snowdon, & Orr, 1992; Cronin, 1987; Jessop, Reissman, & Stein, 1988; Leader & Lieberg, 1988; McKeever, 1992a). About 35% of children with special needs develop significant and persistent feeding problems such as anorexia, food refusal, dysphagia, vomiting, and/or aspirating (Bazyk, 1990; Howard, 1981; Luiselli, Evans, & Boyle, 1985; Morris, 1989). When necessary, gastrostomy tubes (G-tubes) are inserted through the abdominal wall to ensure that nutritional requirements are met safely (Rempel, Colwell & Nelson, 1988). Parents must learn to nourish their children partially or totally through G-tubes. Some common conditions that require a G-tube to be placed include: cerebral palsy, acquired brain injury, cystic fibrosis, and congenital heart disease (Davidson, Catto-Smith, & Beasley, 1995). Due to the dearth of research in this area, the prevalence of G-tube placement in children with disabilities is unknown.

Although G-tube feedings are necessary to provide adequate nutrition for optimum growth and development (Heine, Reddihough, & Catto-Smith,

1995; Lewis, Khoshoo, Pencharz, & Golladay, 1994; Sugarman, Georgeson, Cloud, & Woodall, 1994), they are not without complications. Studies have shown that approximately 11% to 26% of children experience complications, which include leakage at the site, tube displacement, stomal infections, and gastroesophageal reflux (Al Malki et al., 1991; Davidson, Catto-Smith, & Beasley, 1995; Gauderer, 1988; Marin, Glassman, Schoen, & Caplan, 1993). Several studies have shown that the insertion of a G-tube did not improve the children's conditions as they continued to vomit, aspirate, and experience gastroesophageal reflux (Heine et al., 1995; Kastner, Crisicone, & Walsh, 1994; Lewis et al., 1994). Kastner, Crisicone, & Walsh (1994) found that children with neurological disabilities had higher rates of complications after G-tube insertion compared with children with cystic fibrosis or congenital heart disease.

Researchers and health care professionals continue to work to improve treatment and management of feeding problems in children with disabilities. Most researchers and health professionals have focused on identifying the etiology of feeding problems and on testing interventions designed to improve oral food intake (Brizee, Sophos, & McLaughlin, 1990; Chamberlain, Henry, Roberts, Sapsford, & Courtney, 1991). However, little is known about how children's severe feeding problem impacts on their mothers. These treatment and management approaches are deficient as they fail to recognize that feeding is an interactive, social-psychological process that is deeply embedded in the mother-child relationship.

Feeding children is imbued with great symbolic

From the Child Health Network and Homecare, The Hospital for Sick Children, and University of Toronto, Toronto, Ontario.

This research was supported in part by the Easter Seal Research Institute.

Address reprint requests to Karen Spalding, RN, MSc, Clinical Nurse Specialist, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, Canada M5G 1X8.

*Copyright © 1998 by W.B. Saunders Company
0882-5963/98/1303-0004\$3.00/0*

significance and children's nutritional status and physical stature are considered cardinal reflections of their mothers' nurturing abilities (Apple, 1981; DeVault, 1991). In ideal conditions feeding and being fed are pleasurable for both the mother and the child. However, when problems arise, meal times can be the source of great frustration and distress (McKeever, 1992b). Increased understanding of mothers' experiences with children who have feeding problems could contribute to improved treatment modalities and services currently provided. To this end, this study was conducted to learn what it is like for mothers to feed children who require G-tubes.

RESEARCH DESIGN AND METHOD

Ruddick's (1989) description of the "discipline" of mothering was used as a framework to design this study and to guide the analysis of the data generated. Ruddick postulates that all mothers are subjected to the following demands: children demand that their lives are preserved and their development is fostered, and society demands that children are shaped in ways that are consistent with norms and mores. Mothers meet these demands through acts of protection or preservative love, nurturance, and behavior training. Together, these acts constitute maternal work that is skillful and based on careful thought (Ruddick, 1989, p. 17).

Feeding problems may pose especially salient threats to competence because feeding is integral to each of the three demands of maternal practice. If children do not eat, retain, and digest food, they do not survive, hence the preeminent demand—the preservation of life, is not met. Furthermore, feeding problems affect the second demand, growth, because they have the potential to impair cognitive and emotional, as well as physical development. Ruddick's conceptualization of the discipline of mothering led the researcher to question how mothers of children with disabilities, who have severe feeding problems, meet the three demands of maternal practice. It also led the researcher to wonder how mothers felt about gastrostomy tubes.

The primary focus of studies conducted on children with disabilities who have feeding problems has been the cause and treatment of such problems. Most investigators have studied the technical aspects of getting the children to eat by mouth, and on evaluating the effectiveness of interventions developed by health care professionals. The broader issues involved, such as the social and emotional aspects of eating and being fed have not been investigated. To begin to fill this gap in

knowledge, the present study was designed to explore mothers' perceptions of, and reactions to, feeding children with disabilities who have G-tubes. Specifically, the study was designed to answer the following question: What is the experience of mothers caring for children with disabilities who have severe feeding problems requiring the use of a G-tube?

Therefore, in order to elicit mothers' descriptions of their experiences, a qualitative approach was taken (Tesch, 1990, p. 51). Each of the 12 mothers in the study participated in one audiotape recorded, open-ended interview. Open-ended interviews were used to allow participants to talk freely about their experiences (Anderson, 1991). In contrast to questionnaire completion, open-ended interviews also seem to be better suited to women's communicative style and skills (Bergum, 1989; McKeever, 1992b; Rossi, 1984).

Sample and Setting

Following ethics approval, a convenience sample was recruited from the registry of an urban Canadian agency that provides home support services to children who have physical disabilities. To protect the anonymity of potential participants, letters describing the study were sent by the agency to English-speaking mothers of children who were fed by G-tube. The mothers were advised to return an enclosed reply card or to telephone the researcher if they wished to learn more about the study. Sixteen mothers did so and, of these, 12 agreed to be interviewed. Four were unable to participate because 2 of the children were in the hospital and 2 mothers were too busy during the period of the interviews.

All participants met the following criteria: they were English-speaking mothers of children who had a chronic illness or disability, were cared for at home, and were fed by a G-tube. The aim of qualitative research is to provide an in-depth description of a phenomenon from the participant's point of view, therefore the sample size was small (Guba & Lincoln, 1985). The researcher conducted one face to face interview with each of the participants ($N = 12$) in their homes. Before each interview, the purpose and voluntary nature of the study were reiterated and written consent was obtained.

Data Collection Procedures

To focus the interview, the participants were asked to first talk about the history of their child's feeding problem and then what feeding was like at present. This proved to be a good starting point

because the interviews remained focused and naturally progressed to cover the mothers' entire experience related to feeding her child. If a particular area was not covered spontaneously, prompting questions from a loosely structured interview guide were used. These questions were derived from Ruddick's (1989) formulation of the demands that constitute maternal work as they applied to feeding children through G-tubes. At the end of the interviews, data were obtained about the mothers' income and educational levels, marital and employment status, and a brief health history of the child. Field notes were recorded that included the researcher's observations, feelings, and ideas that were generated during the interview.

Data Analysis Procedures

The audiotaped interviews were transcribed verbatim onto a computer utilizing Ethnograph (1988). The overall goal of data analysis was to develop a comprehensive portrayal of the maternal experience of feeding children with disabilities. To this end, in the manner described by Tesch (1990, p. 116), transcripts were broken down into "meaning units" or comprehensible segments of text that contained one idea, episode, or piece of information. These meaning units were then grouped into preliminary categories, examined individually, and compared with one another.

Through this process of comparing and contrasting, the categories were refined and themes were developed. Categories were renamed, modified, subdivided, or replaced until each theme contained all meaning units that were considered relevant (Tesch, 1990). Random segments of transcripts were analyzed independently by one researcher and three others were involved in developing the final themes. There were few disagreements during this process, and those that arose were resolved through group discussion. Field notes were used in the development of both the preliminary categories and the final themes.

Methodological Rigor

Following the recommendations outlined by Guba and Lincoln (1981, p. 104), this research was designed to be auditable. The data collection and analytic processes have been described to allow readers to judge the quality of interpretations and conclusions made. The credibility of the findings is enhanced because data from the transcripts, field notes, and demographic questionnaires were compared and contrasted for similarities and differences. Data also were scrutinized to identify nega-

tive cases, post alternative interpretations, and to check for prevalence and universality (Guba & Lincoln, 1981, p. 107).

RESULTS

Most interviews took place in the kitchen during the early afternoon while the child slept and/or the siblings were at school. However, complete privacy was rarely achieved because the child, siblings, father, and/or health care workers were present during all or part of the interviews. Field observations were made over the course of 1 1/2 to 3 1/2 hours because the interviews, which lasted 1 or 2 hours, were interrupted frequently. After briefly engaging in "small talk," mothers were asked to describe the history of the child's feeding problem. Few probes were used because mothers spoke freely and extensively about most of the areas considered relevant. All stated that they had been eager to be interviewed because they wanted the findings to be used to improve the care children and families receive from health professionals. In presenting the findings, mothers' actual words are used whenever possible.

The Mothers and Children

All participants identified themselves as Canadian citizens; four had varying cultural backgrounds. One participant identified her family background as South American Indian, one as Italian, and two as West Indian. They ranged in age from 30 to 49 years with a mean of 35 years. Ten were married and living with their spouses and two were single after divorce. Eight husbands worked full-time and two were unemployed. Most women reported having total family incomes close to the Canadian mean (Statistics Canada, 1993) but two families depended on welfare support.

The women were relatively well educated in that ten (83%) had completed some postsecondary education, whereas only 35% of women in the general population of Canada have done so (Statistics Canada, 1990, p. 66). Nine women had been in the paid labor force before becoming mothers of children with disabilities. However, at the time of the interviews, only four were employed: one full-time and three part-time. These mothers all considered themselves fortunate to have work because they depended on the income and family health benefit plans. Of the eight unemployed women, six said they could not work because they had "full-time jobs" caring for their children with disabilities.

The children ranged in age from 3 to 12 years,

with a mean of 6 years. Seven children were girls and five were boys and all had between one and three siblings. Interestingly, with regard to birth order, seven children were the youngest and five were the eldest among their siblings. Nine had congenital chronic illnesses or disabilities and 3 had severe acquired brain injuries. One child was quadriplegic, blind, and deaf, 1 had Down syndrome, and the remaining 7 had cerebral palsy. Two of the children with acquired brain injuries remained in a vegetative state and 1 was quadriplegic with minimal communicative abilities.

None of the children could speak, however 6 mothers stated that their children could communicate through gestures and limited sounds. Seven required wheelchairs and 5 were small enough to be carried or use strollers. Eight of the children attended school or special programs for either the full day or part of the day.

All children required constant supervision during the day because of the severity of their disabilities and intensity of their needs. Eight were monitored throughout the night as they had continuous G-tube feedings and vomited, choked, or awakened frequently. Only 1 child received night nursing care provided by the provincial government home care program because he required frequent tracheotomy suctioning. In all other cases, mothers were responsible for their child's care except during the brief visits from rehabilitation therapists one to three times a week.

G-tubes had been inserted as early as 5 weeks of age and as late as 6 years. In most cases (8) they had been inserted during late infancy or toddlerhood. At the time of the interviews, the children had been fed partially (2) or completely (10) by G-tube between 1 1/2 to 8 1/2 years with a mean of 4 years. Most were tube fed 4 to 6 times a day. Each feeding took between 30 minutes to 3 hours, depending on the child's tolerance.

Substantive Findings

This study was premised on the assumption that feeding children is of utmost importance to mothers and this was born out repeatedly in mothers' eagerness to be interviewed and the poignant accounts they provided. The words of one mother epitomize how central the child's feeding problem was to them all:

This gets you at the very basic level—you can't feed your child. You're not able to feed your child. No matter what you do as a mother, you fail and that is so hard. If it was something else maybe you could understand, but not being able to feed—it's—it's the basic thing. It's like breathing.

So you are just so devastated by the fact that you can't make it work right for your child. You're just—you're emotionally wrung out all the time.

Five prominent themes were identified in mothers' accounts that substantiated this overarching sense of distress. The five themes are as follows: seeking confirmation of the feeding problem; devising extraordinary practices to ensure the child's survival; "giving in" to the G-tube; relief and disappointment; and customizing feeding and moving on. Three themes represent the period of time before the G-tubes were inserted and two represent experiences after they were inserted. The first two themes were derived from the accounts of the nine mothers whose children had congenital disabilities. The findings discussed in the remaining three themes include data from all 12 maternal accounts.

1. Seeking Confirmation of the Feeding Problem

For seven of the nine children with congenital health problems, feeding difficulties occurred in the first weeks of life and were the initial indication to mothers that something was wrong. These infants refused food, had difficulty sucking or swallowing, and/or vomited, choked, or aspirated frequently. Their mothers vividly recalled the enormous difficulty they had convincing health professionals and/or other family members that their infants had serious feeding problems. They all had received many explanations and suggestions from physicians that they could not accept. For example, one mother had had "a feeling" that something was very wrong with her infant since she was a few days old but no one would believe her. She recalled having the following conversation with her physician after several visits when the infant was 8 months old:

My family doctor at this point said to me, "I'm tired, I'm fed up with listening to you tell me that something is wrong with this baby." He said, "When are you going to get it through your thick head? You Italians are all the same. You want big fat babies. Can't you realize that she's a petite little girl?" I was crying and I said to him, "She's not eating, don't you believe me? She's not drinking anything." And he said to me, "No, she wouldn't look as healthy as she does." She had a beautiful porcelain looking type of face, like rosy. She looked healthy but her body was very weak and she looked skinny, she was really skinny.

This infant finally had a G-tube inserted when, at 10 months of age, she weighed 11 pounds. She was diagnosed with cerebral palsy when she was 1 year old.

Another mother spent over a year trying to feed

her daughter "almost constantly for 24 hours a day." This situation occurred because this particular child cried so much she only drank 5 to 10 mL of formula at a time. Although the mother reported this several times and asked for help, her doctor "did not believe the child had a feeding problem." Eventually, she took the screaming infant to a hospital emergency department and demanded that "something be done." She described the response to her desperate plea as follows:

I said to the doctor, "This kid is like this 21 hours a day. We both sleep 3 hours a day and she screams for the other 21." I said, "You either give her something for it, or give me something, but one of us is walking out of here with something for her screaming." That one day, in a matter of about 8 hours, they did every test imaginable and like she's microcephalic, she's CP (cerebral palsy), she seizures. You name it and she has it.

Although this mother described health professionals as supportive after they had diagnosed her daughter's health and feeding problems, she continued to resent the fact that her untenable situation had not been believed for almost a year. Reflecting on her experience she asked, "Why did those people torture me like this for so long? It used to be hell!"

Before confirmation of a diagnosable feeding problem, all mothers had felt responsible for the fact that their infants and toddlers were not thriving. This feeling was reinforced by their perception that others implicitly or explicitly also blamed them. Mothers described great distress related to knowing or suspecting that their feeding practices were being monitored and/or criticized by health professionals, husbands, and other family members. One mother described how her husband had frequently "dropped in unannounced" during the day to check to see if she was really trying to feed their 3-month-old infant the way she claimed she was.

Six mothers said that during this period, their distress was so great that they stopped attending family gatherings and/or answering their telephones. These strategies allowed them to avoid receiving unsolicited advice from friends and relatives about "the proper ways to feed" their children or answering questions about whether the child was "feeding yet." Three mothers stopped going out of their homes altogether to avoid criticism and stares. They described the anguish they felt when strangers approached them and "accused" them of "starving" their infants.

The anguish all mothers felt is evident in the words of the mother of a 4-year-old who had

refused to suck from a bottle as an infant. She showed the researcher a large bag full of nipples, spoons, and cups that she had purchased to get her child to drink. She described how she felt when her lack of success was confirmed repeatedly during visits to the physician:

I would be sick, just sick every time they put her on the scale, you know. She didn't gain any weight and I'd say, "What does that mean?" They'd say, "Well, you know, it's not good." Oh, I'd come out of there with this knot in my stomach that I wasn't trying hard enough and I had to keep getting more ounces into her like she had to get heavier. It was horrible!

Others recalled similar conversations and interactions with health professionals that had undermined their sense of competence over months or years before the problem was confirmed. They said they had often felt "like the dumb mom" because professionals didn't believe them and appeared to doubt their mothering abilities. Eventually, all mothers' claims were verified when the children's health status deteriorated or other symptoms arose. Formal feeding studies confirmed that the problems were due to the children's health status and had nothing to do with their mothers' nurturing abilities.

2. Devising Extraordinary Practices to Ensure Children's Survival

Mothers recalled how they struggled to nourish their children while trying to convince professionals that they and their children needed help. In most cases, the onerous task of feeding was theirs alone and mothers felt great resentment and frustration almost continuously. One mother articulated this as follows:

I would sometimes get my husband to feed her and he would say, "I can't feed her." I would get so angry. Same with my mother, she would come in and I'd say, "Feed this child," and she'd say, "I don't know if I can." I'd say, "Feed her Mom, I'm leaving—feed her." She would say, "I don't think I can." I'd get so mad. I'd say to them, "What gives you the right to say you can't do it?" "You can say that because you know I'll have to do it or else she'll die." "Why do you leave this to me?" I would think "Ugh." It was always left for me to feed her.

Mothers' lives were consumed with self-doubt and worry that the children were receiving insufficient nourishment to survive. Four mothers whose children had appeared especially small and frail described fearing that they would be accused of neglect and that the children would be taken into custody. Consequently, vast amounts of time and energy were spent devising strategies to improve

eating and weight gain. Mothers used eye droppers, syringes, or tiny spoons and some resorted to force feeding and adding high-calorie foods such as whipping cream and meat to infant formulas. In the following quote, a mother describes how she "learned how to survive" on 3 hours of sleep a night for 2 1/2 years because she fed her infant almost constantly:

It was very tiring and frustrating you know. It seemed like 24 hours a day I was feeding her because it was this slow, you know, long, drawn out process. It was really horrible, too. I was always sitting there with her, you know, like this (arms in cradling position) and she couldn't close her mouth on the bottle. She was too busy screaming to eat. My husband bought me a rocker . . . because I would be rocking her 20 hours a day. I would fall asleep. I guess I trained myself because she never fell out of my arms, you know. I'd tune the noise out to sleep in the rocker with her there, you know, I mean 20 hours—you burn out.

Despite the energy expended, strategies devised, and personal sacrifices endured, these children continued to vomit, aspirate, ingest very little, or refuse food. Eventually, their health and development were in serious jeopardy.

3. "Giving-In" to the G-tube

Despite the time, effort, and anguish associated with feeding, only one mother said she had readily consented to have a G-tube inserted when it was first presented as an option. For more than a year she had done little other than attempt to feed her infant and she saw the G-tube as "a light at the end of the tunnel." The other mothers initially resisted resorting to G-tube feeding because it meant "giving-in" to an unacceptable, unnatural solution. The G-tube signified not only that they had failed in their role as nurturers, but that their children's disabilities were severe. Hence, it is not surprising that, when G-tubes were suggested, mothers responded by intensifying their efforts to feed their children by mouth. The following rationale for refusing the G-tube initially typified that of the others:

It's very difficult to accept that your child is so badly disabled that they cannot eat. Then you start thinking, you know, what is the quality of life if you are that disabled anyway? I became really (long pause). It was a very difficult thing to face.

Mothers' resistance is even more comprehensible in light of the fact that they believed that G-tube feedings would remove one of the few pleasures and basic human abilities the children appeared to enjoy. Despite the time and distress involved, most believed that their children had

liked the taste of food and the experience of eating. Finally, the insertion of a tube through the child's abdomen was considered another invasive procedure with stigmatizing properties that they did not want the children to undergo. One mother, after being told about the need for the G-tube, spent another year trying to get her child to eat by mouth. She described her reasons as follows:

. . . I didn't really want to quit because every single day I'd get up and I'd say, "Today she'll eat!" She wouldn't eat that morning and I'd be really depressed, then I'd say "Well she'll eat at lunch," and she wouldn't eat and then supper would come and she wouldn't eat and then I'd say "But tomorrow she'll eat . . ." I'd spend a lot of time going to stores to try to find something to feed her with. It became quite a bit of an obsession to feed her.

However, after 6 to 18 months had elapsed, all mothers reluctantly agreed to the procedure, hoping the G-tube would be temporary. For most, this point was reached only when they were exhausted or the child's life was in danger. The extent of the stress endured before reaching this "breaking point" was described by the following mother who was afraid she might hurt her child:

It would have been a year and a bit and at the end, like I finally called up the doctors and said, ". . . I can't stand it any more." Because, I guess the straw that really broke the camel's back was when I spent the whole day feeding her in the presence of witnesses, . . . I thought, "I can't take this any more . . ." At the end of a 10-hour stretch I got in 4 ounces. She threw it up and some of the stuff that she threw up I recognized from 8 hours earlier. I thought, "I just cannot keep her alive this way, I just cannot, cannot, cannot."

The three mothers of previously healthy children who needed G-tubes because of sudden devastating injuries said they didn't give the decision about G-tube insertion much thought at the time. They were relieved that their children had survived and perceived the G-tube as a temporary means of sustaining their children's lives. They were devastated to learn the extent of the children's disabilities and that the G-tubes could be permanent.

4. Experiencing Relief and Disappointment

Immediately after the G-tube had been inserted, most mothers felt considerable relief because it led to positive changes in the children and in their own lives. The G-tube was described as "a Godsend" and "a blessing." One mother attributed her child's happier disposition to the fact that she was no longer "torturing her daily by trying to feed her." Many discussed the children's significant weight gains that accompanied G-tube feedings. On the

other hand, 3 mothers (25%) had been disappointed with the G-tube from the beginning. Their children didn't flourish and previous feeding problems became worse or new problems developed. One of these mothers described her reaction to the G-tube as follows:

It was the most horrific, outdated, terrible thing to put in a child. It was an awful looking thing and most awful thing to deal with that we ever, ever experienced in our lives. It changed our lives. It had such an impact, it was so permanent for her, it was a hole in her, it was like this gaping hole in her abdomen. I mean, the way I had to touch her, treat her, and position her changed. Everything changed for us. We didn't see any kind of immediate improvement in our lives because of it. It made life more stressful, definitely more stressful.

As time passed, even the mothers who initially had been pleased with the G-tube, felt growing concern. Although they had been prepared to execute the technical skills involved in G-tube feeding, they had not been prepared for the tremendous changes it would necessitate in their daily lives. G-tube feeding was very time consuming and mothers' activities continued to revolve around the children's feeding schedules. Furthermore, many children (11) continued to vomit and/or have bowel problems.

Although there were many problems associated with G-tube feeding, the main reasons for mothers' dissatisfaction were related to the abnormality of this feeding method. Although their children accompanied them almost everywhere, they were rarely fed in public to avoid unpleasant interactions. For example, during camping trips, one mother fed the child in the tent while the rest of the family ate outside. Other mothers, while shopping or attending community events, fed the children in their cars. In restaurants or during family outings mothers covered the children with a blanket and discreetly syringed the formula directly into the G-tube rather than through the pump.

In summary, relatively soon after they had been instituted, mothers realized G-tube feedings were "mixed blessings." The G-tube signified professional validation that severe feeding problems existed and led to improved nutritional status. However, mothers faced new or different technical challenges, psychological distress, and social dilemmas. In addition, many children continued to vomit frequently, have digestive disturbances and/or have bowel problems.

5. Customizing Feeding and "Moving On"

After finding prescribed G-tube feeding schedules "unrealistic," all mothers began altering them

to suit their children's needs, make them more "normal," and render them more compatible with daily family life. One mother scheduled G-tube feedings according to how she thought her son would eat if he did not have a disability. She described her thinking as follows:

Some parents would prefer to feed him according to the doctor's schedule but, if I had my child as a regular child, what would I do? Well, "What would he do?" You put yourself in his position . . . He would come home from school and may be run to the refrigerator and help himself to a cold drink. Maybe he would have five feedings a day. So consequently, I take into consideration being disabled. I calculate how many hours in a day I want to feed him. I don't want to feed him only three times a day so what I do is feed him as a (non-disabled) 6-year-old boy.

Mothers described how they had quickly become skilled at G-tube feeding and came to regard themselves as "experts." They did not readily seek advice from health professionals, preferring to devise their own strategies and solutions when problems arose. Many ($N = 10$) questioned the nutritional value of G-tube formula and some believed the children resented being fed the same thing every meal by tube. For these reasons most mothers ($N = 8$) admitted they regularly infused pureed table food through the G-tube, against the advice of physicians and manufacturers of the feeding tube. They attributed children's improved mental and physical health to this practice. One mother described the changes she observed as follows:

Once I started feeding him proper food through the tube—home cooked meals—the results were excellent. I mean I can see a child there with chubby cheeks, pink lips, happy, quiet, calm. Not irritable, not angry, sitting down like, you know, a nice happy child and I'm seeing a pleasant boy. I'm no longer seeing a child who is irritable, angry, and I'm not popping medication into him.

After G-tube insertion, most mothers continued to try to get their children to eat by mouth. Their determination seemed to be partly motivated by a desire to prove health professionals wrong in predicting the G-tube would be permanent. To this end, they sought out appropriate services and devised strategies to reach this important goal. Several had consulted the same feeding expert in the United States but they said they were unable to continue due to the expense involved. This struggle to find resources and support was very taxing. All mothers emphasized that, in addition to monitoring children's weight gain, health professionals should devote more resources to reinstating oral feeding. They also wanted their expertise to be recognized

by professionals and to be considered pivotal in the care of their children.

At the time of the interviews, most mothers were devoting somewhat less time and energy to reinstating oral feeding. Although preservation continued to be central to maternal practices and thinking, the sense of urgency had diminished because the children were physically thriving on the G-tube feedings. Four mothers, said that after 4 years they had begun to face the possibility that the G-tube would be permanent. However they still hoped that one day their children would be "off the tube."

SUMMARY AND IMPLICATIONS FOR PRACTICE

Ruddick argues that preserving the lives of children is "the constitutive, invariant aim of maternal practice" (1989, p. 19). This was certainly shown by the mothers in this study, especially before the G-tube, when the children's survival was dependent on the mothers' care. Although preservation continued to be central to maternal practices and thinking after the G-tube was inserted, there was not the same sense of urgency associated with it during this time. The pressure to feed their children had subsided for the mothers since their children were physically thriving on the G-tube feedings. Therefore, in the period after the G-tube was inserted, maternal practices and thinking included what Ruddick (1989) refers to as nurturing activities that foster their children's development (p. 19).

Feeding difficulties in children with disabilities were enormously significant to these mothers and were the source of considerable distress. Feeding had great symbolic significance and mothers clearly blamed themselves and felt blamed by others when problems arose. Mothers also emphasized that health care providers had, in many instances, failed them and that support services and resources were inadequate.

When children are diagnosed with feeding problems, mothers' feeding practices usually are scrutinized and they are taught oral feeding techniques. This approach, however inadvertently, allows the needs and distress of mothers to be minimized or overlooked. In recognition of the symbolic, psychological, and relational aspects of feeding, mothers need the opportunity to discuss what they endured in the pre-diagnostic phase. In recognition of the expertise they have developed in relation to their children's care, professionals should determine, from mothers, the approaches they would find helpful in solving the problem. Furthermore, in

recognition of the fact that many mothers blame themselves and are blamed by others for feeding problems, professionals should stress the fact that the problem is due to the child's underlying health problems. Acknowledgment that the problem usually lies with the child, not the mother, could be reflected by using the term "eating or nutrition problem" rather than "feeding problem."

Given that many mothers believe they have failed when children cannot eat by mouth, it is not surprising that consenting to G-tube insertion is very difficult. Mothers need support and understanding when they express ambivalence and their requests to keep feeding children by mouth should be respected whenever it is safe to do so. Many mothers suggested that it would be helpful to talk to another mother whose child had a G-tube before, or shortly after, the G-tube insertion. This would allow mothers to share insights and advice only mothers could have about the implications of G-tube feedings on daily life. Parents who are beginning to learn about G-tubes would also have the opportunity to observe these "expert" mothers using the G-tubes and learn about the initial difficulties they encountered, along with the emotional reactions they had experienced.

After the G-tubes were inserted, mothers became skilled in managing and customizing feedings and more assertive with health care professionals. Mothers suggested that G-tubes should be manufactured to accommodate pureed table food and health professionals should prescribe feeding schedules which are compatible with family life. Over time, dissatisfaction with the G-tube increased because new technical, psychological, and social challenges arose. All mothers remained troubled by the abnormality of the feeding method and expressed a strong desire to get their children "off the tube" eventually. They all emphasized that increased professional energy and more resources are needed to assist them in this goal.

IMPLICATIONS FOR RESEARCH

This study has contributed to the understanding of the experience of mothers caring for children fed by G-tubes. Data collected in this study reflected the experiences of a small, highly educated sample of volunteer participants, and for this reason, findings can only be generalized with caution. In addition, only one interview was conducted with each participant about a complex topic. It is possible that these volunteers represented mothers who were dissatisfied with the G-tube and saw their participation in the study as a means to voice their

concerns. Further research in this area would serve to expand this body of knowledge and validate the findings of this study.

Extending this qualitative approach to include a sample of fathers and siblings would provide an in-depth look at how families as a whole manage family life, when one child is fed by G-tube. Similarly, a follow-up study to this one, using a larger sample, would enable the researcher to compare mothers' experiences with G-tube feedings between children who were born with health problems to that of children who had sustained injuries or developed illnesses later in childhood.

Research is also required that compares fathers' and mothers' experiences of parenting children fed by a G-tube. Although mothers and fathers may share particular experiences, fathers are largely an unknown element in the research (Cronenwett, 1982; McKeever, 1981). The significance of fathering for men, their children and families, is beginning to be recognized (Hanson & Bozett, 1987).

Research could further be undertaken to examine the health professionals' perceptions of children fed

by a G-tube and to look at the difference in perceptions between mothers and health professionals. A study of this nature could shed light on the possible incongruencies in perceptions and consequently, the provision of care and services children fed by a G-tube. In particular, a study which examines the outcomes and feasibility of feeding children pureed food through the G-tube would be beneficial. Although contrary to health professional's advice, this was a common practice among mothers in this study and the mothers in McKeever's (1992b) study. The economic and social costs of caring for children with disabilities, who are fed by a G-tube at home, is finally an area for additional study.

Acknowledgments

The authors are thankful for the assistance of Dr. Heather Maclean, Director, The Centre for Research in Women's Health, University of Toronto and Women's College Hospital and Francine Wynn, Senior Tutor, Faculty of Nursing, University of Toronto.

REFERENCES

- Al Maki, T., Langer, J., Thompson, V., McQueen, M., Lau, G., Issenman, R., Winthrop, A., & Cameron, G. (1991). A prospective evaluation of the button gastrostomy in children. *Canadian Journal of Surgery, 34*, 247-250.
- Anderson, J.M. (1991). The phenomenological perspective. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 25-36). London, England: Sage Publications.
- Apple, R.D. (1981). *Mothers and medicine: A social history of infant feeding, 1890-1950*. Madison, WI: The University of Wisconsin Press.
- Bazyk, S. (1990). Factors associated with the transition to oral feeding in infants fed by nasogastric tubes. *The American Journal of Occupational Therapy, 44*, 1070-1078.
- Bergum, V. (1989). *Woman to mother: A transformation*. Granby, MA: Bergin & Garvey Publishers Inc.
- Brizee, L., Sophos, C., & McLaughlin, J. (1990). Nutrition issues in developmental disabilities. *Infants and Young Children, 2*, 10-21.
- Cameron, S., Snowdon, A., & Orr, R. (1992). Emotions experienced by mothers of children with developmental disabilities. *Children's Health Care, 21*, 96-102.
- Chamberlain, J., Henry, M., Roberts, J., Sapsford, A., & Courtney, S. (1991). An infant and toddler feeding program. *The American Journal of Occupational Therapy, 45*, 907-911.
- Cronenwett, L. (1982). Father participation in child care: A critical review. *Research in Nursing and Health, 5*, 63-72.
- Cronin, A. (1987). Incorporating social/behavioral aspects of eating dysfunction into oral-motor programs. In C. Pehoski, (Ed.), *Problems with eating* (pp. 51-64). Rockville, MD: American Occupational Therapy Association.
- Davidson, P.M., Catto-Smith, A.G., & Beasley, S.W. (1995). Techniques and complications of percutaneous endoscopic gastrostomy in children. *Australian New Zealand Journal of Surgery, 65*, 194-196.
- DeVault, M.L. (1991). *Feeding the family: The social organization of caring as gendered work*. Chicago, IL: The University of Chicago Press.
- The Ethnograph: A User's Guide* (Version 3). (1988). Littleton, CO: Qualis Research Associates.
- Gauderer, M.W. (1988). Feeding gastrostomy button: Experiences and recommendations. *Journal of Pediatric Surgery, 23*, 24-28.
- Guba, E.G., & Lincoln, Y.S. (1981). *Effective evaluation*. San Francisco, CA: Jossey-Bass.
- Hanson, S., & Bozett, F. (1987). Fatherhood and changing family roles. *Family and Community Health, 9*, 9-21.
- Heine, R.G., Reddihough, D.S., & Catto-Smith, A.G. (1995). Gastro-esophageal reflux and feeding problems after gastrostomy in children with severe neurological impairment. *Developmental Medicine and Child Neurology, 37*, 320-329.
- Howard, B. (1981). Nutritional support of the developmentally disabled child. In R. Suskink (Ed.), *Textbook of pediatric nutrition*. New York, NY: Raven Press.
- Jessop, D., Riessman, C., & Stein, R. (1988). Chronic childhood illness and maternal mental health. *Developmental and Behavioral Pediatrics, 9*, 147-156.
- Kastner, T., Crisicone, T., & Walsh, K. (1994). The role of tube feeding in the mortality of profoundly disabled people with severe mental retardation. *Archives of Pediatric/Adolescent Medicine, 148*, 537-538.
- Leader, S., & Liebig, P. (1988). High-tech home care: A re-examination. *Caring, 7*, 5-7.
- Lewis, D., Khoshoo, V., Pencharz, P.B., & Golladay, E.S. (1994). Impact of nutritional rehabilitation on gastroesophageal reflux in neurologically impaired children. *Journal of Pediatric Surgery, 29*, 167-170.
- Luiselli, J., Evans, T., & Boyce, D. (1985). Contingency management of food selectivity and oppositional eating in a multiple handicapped child. *Journal of Clinical Child Psychology, 14*, 153-156.
- Marin, O.E., Glassman, M.S., Schoen B.T., & Caplan, D.B. (1994). Safety and efficacy of percutaneous endoscopic gastrostomy in children. *American Journal of Gastroenterology, 89*, 57-61.
- McKeever, P.T. (1981). Fathering the chronically-ill child. *Maternal-Child Nursing, 6*, 124-128.
- McKeever, P.T. (1992a). Mothering children who have severe

chronic illnesses. In A.M. Ambert (Ed.), *The effect of children on parents* (pp. 170-192). New York, NY: Haworth Press.

McKeever, P.T. (1992b). *Mothering chronically-ill, technology-dependent children: An analysis using critical theory*. Unpublished doctoral dissertation, York University, North York, Ontario.

Morris, S. (1989). Development of oral-motor skills in the neurologically impaired child receiving non-oral feedings. *Dysphagia*, 3, 135-154.

Rempel, G., Colwell, S., Nelson, R. (1988). Growth in children with cerebral palsy fed via gastrostomy. *Pediatrics*, 82, 857-862.

Rossi, A. (1984). Gender and parenthood. *American Sociological Review*, 49, 1-19.

Ruddick, S. (1989). *Maternal thinking: Toward a politics of peace*. Boston, MA: Beacon Press.

Statistics Canada (1990). *Women in Canada: A statistical report (2nd ed.)*. Ottawa, Canada: Minister of Supply and Services.

Statistics Canada (1993). *Families' social and economic characteristics*. Ottawa, Canada: Minister of Supply and Services.

Sugarman, J., Georgeson, K., Cloud, H., & Woodall, N. (1994). Weight gain and triceps skinfolds fat mass after gastrostomy placement in children with developmental disabilities. *Journal of the American Dietetic Association*, 94, 849-854.

Tesch, R. (1990). *Qualitative research: Analysis types and software tools*. New York, NY: The Falmer Press.