

A Comparative Longitudinal Study of Gastrostomy Devices in Children

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Long-term gastrostomy is a predictable intervention to ameliorate the effects of feeding and swallowing difficulties among children with severe spastic cerebral palsy. The evidence evaluating the efficacy and implications of the available gastrostomy devices in common use has focused primarily on the operative phase, ignoring the long-term effects that may be critical from a nurse's or family caregiver's point of view. In this study, the authors describe a sample of children with gastrostomy, comparing skin-level and tube devices on measures of nutritional outcome, complications, and caregiver satisfaction. In contrast to manufacturer's claims about the superiority of skin-level devices, the results presented here reveal few differences between the devices. The authors conclude, therefore, that device selection should be determined by individualized comprehensive assessment of the child and family circumstances.

Gastrostomy feedings assume a key role in the nutritional management of children with swallowing and feeding difficulties (Gauderer, Olsen, Stellato, & Dokler, 1988; Nutrition Committee, 1994). Children who require this type of prolonged nutritional support include those with gastrointestinal anomalies, severe neurological disorders, and developmental disabilities (Huth & O'Brien, 1987; Nelson & Hallgren, 1989; Paarlberg & Balint, 1985; Rempel, Colwell, & Nelson, 1988). There are numerous problems or complications associated with long-term use of the conventional tubes or catheters (i.e., dePezzer, Malecot, Foley) used for gastrostomy feedings, particularly in children (Cohen, Donner, & Berlatzky, 1981; Gauderer, Picha, & Izant, 1984;

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Huddleston & Palmer, 1990; Huddleston, Vitarelli, Goodmundson, & Kok, 1989; Paarlberg & Balint, 1985). These complications include site leakage, skin breakdown, granulation tissue, discomfort, tube deterioration, inadvertent removal, gastroesophageal reflux, tube blockage, internal migration, bowel obstruction, esophageal rupture, and psychological problems (Eisenberg, 1989; Gauderer & Stellato, 1986; Malki et al., 1991; Nelson & Hallgren, 1989).

In an attempt to circumvent these problems, a skin-level gastrostomy device was commercially developed for use in 1982 (Gauderer et al., 1988). The skin-level gastrostomy has received a great deal of attention in the literature and is generally viewed as an improvement over traditional gastrostomy tubes (Gauderer et al., 1988; Huth & O'Brien, 1987; Malki et al. 1991; Reynolds & Kirkland, 1989). Much of the research in support of this claim, however, has been done with small samples (Gauderer et al., 1984; Malki et al., 1991), has investigated recently placed skin-level devices (Gauderer et al., 1988; Gauderer et al., 1984; Malki et al., 1991), and has involved only a brief follow-up period (Malki et al., 1991). There is little research about the skin-level device regarding the long-term use specifically related to maintenance, complications, nutritional outcomes, and caregiver satisfaction.

Nurses and others involved in the daily care of children with gastrostomies are not only concerned with the short-term postsurgical recovery period but are also highly attuned to issues and concerns arising from the ongoing implications of the intervention on all aspects of the child's health and well-being. At a tertiary rehabilitation facility from which care for most children with developmental disabilities in a Western Canadian province is planned and coordinated, the Foley catheter, the Bard Percutaneous Endoscopic Gastrostomy tube (PEG), Medical Innovations Corporation gastrostomy tube (MIC), and the Bard Button gastrostomy are all routinely used for long-term gastrostomy feedings. On the basis of their anecdotal experience with various devices, nurses at this facility wondered if the enthusiastic claims about the advantages of the skin-level (button) devices would be substantiated over the long term. They witnessed no fewer complications from skin-level gastrostomies than from gastrostomy tubes. This opinion reflected a departure from findings that have emerged within the research literature; however, occasional anecdotal reports within the nursing literature reflect similar perceptions (Coldicutt, 1994; Hagelgans & Janusz, 1994).

PREVIOUS RESEARCH

Complications

Although there is an extensive body of literature relating to gastrostomy feeding in general, few studies have investigated the long-term use of gastrostomy feeding devices, especially in children. The majority of studies have focused on operative techniques and immediate postoperative complications rather than the quality of life that children and their parents experience with these devices. Although frequently considered a simple operative procedure, any gastrostomy has considerable potential for mortality and morbidity (Gauderer et al., 1984; Gauderer & Stellato, 1986; Stellato, Gauderer, & Ponsky, 1984). The literature suggests that infants and children are at significant risk for postoperative complications following gastrostomy placement (Haws, Sieber, & Kiesewetter, 1966; Stellato et al., 1984), although some studies refute this (Holder, Leape, & Ashcraft, 1972; Shellito & Malt, 1985).

Researchers have identified several major complications, including separation of the stomach from the abdominal wall on reinsertion of a displaced tube, spontaneous intraperitoneal leak, and uncontrollable external stomal leakage when gastrostomies have been evaluated beyond the postoperative period. Less dramatic complications that have been reported include stomal leaks, tube prolapse into the duodenum, and wound infection. Researchers surveying gastrostomy patient samples have reached varied conclusions about the nature and rate of complications (Haws et al., 1966; Holder et al., 1972; McGrath, Splaingard, Alba, Kaufman, & Glicklick, 1992; Shellito & Malt, 1985; Stellato et al., 1984). For example, late complication rates range from 2.5% (Holder et al., 1972) to more than 40% (McGrath et al., 1992). Shellito and Malt (1985) noted that these puzzling variations cannot be explained by differences in the indications for gastrostomy, the technique, or patients' ages. Furthermore, few of these studies reveal information about the quality of life experience of the children with gastrostomy or their family caregivers.

The literature suggests that complications directly related to the long-term use of gastrostomies can be divided into three categories: those related to care of the stoma and skin, those related to nutritional intake and the gastrointestinal tract, and those related to caregiver satisfaction. Skin irritation, usually related to leakage of stomach contents, is probably the most frequent complication encountered (Gauderer et al., 1988; Gauderer & Stellato, 1986; Huddleston & Palmer, 1990; Malki et al., 1991). According to Gauderer and

Stellato (1986), the main cause of leakage in most patients, particularly children, is the enlargement of the stoma by the pivoting motion of a gastrostomy tube that is too large or too stiff. Internal tube migration and inadvertent tube removal are two other common gastrostomy complications that are believed to be particularly problematic in children (Bernard & Forlaw, 1984; Gauderer & Stellato, 1986; Huddleston & Palmer, 1990). Gauderer and Stellato (1986) reported that Foley catheters are especially prone to internal migration and accidental dislodgment and that accidental removal is less likely with PEG tubes because of the presence of the inner crossbar. Several authors have suggested that the skin-level gastrostomy has several advantages over conventional gastrostomy tubes in this regard as it is less likely to trigger skin breakdown at the site (Huth & O'Brien, 1987), children are less likely to pull at it (Huddleston & Palmer, 1990), and it is more aesthetically acceptable to parents (Malki et al., 1991).

The most common gastrointestinal complications related to gastrostomies are nausea, vomiting, diarrhea, and constipation (Bernard & Forlaw, 1984; Farley, 1988; Gauderer & Stellato, 1986). These complications are reported to occur in as many as 10% to 20% of patients who are tube fed (Bernard & Forlaw, 1984). The etiology of these complications appears to be multifactorial and may include lactose intolerance, high formula osmolality, too rapid infusions of formula, cold feedings, and insufficient water in the diet (Bernard & Forlaw, 1984; Kagawa-Busby, Heitkemper, Hansen, Hanson, & Vanderburg, 1980).

Nutritional Outcomes

A review of the nutritional outcomes literature reveals that height and weight measurements, traditionally used to document nutritional outcomes for children following gastrostomy, yield unclear conclusions for children with developmental and physical disabilities (Rempel et al., 1988; Shapiro, Green, Krick, Allen, & Capute, 1986; Sanders et al., 1990). Although many authors have reported growth and development advantages that can be obtained from gastrostomy feeding, several note that there are also some serious risk factors, such as linear growth deceleration, over- or underweight, and major complications including gastrointestinal bleeding or peritonitis with bowel obstruction (Rempel et al., 1988). The latter authors concluded, therefore, that gastrostomy feeding is not a panacea for nutritional disorders and growth retardation and that the risks must be weighed against the benefits when deciding whether to institute gastrostomy feeding in children.

Caregiver Satisfaction

Although caregiver satisfaction has not been routinely addressed in the studies of long-term gastrostomy, the general consensus is that parents and caregivers tend to be satisfied with gastrostomy devices (Gauderer et al., 1988; McGrath et al., 1992; Rempel et al., 1988; Sanders et al., 1990; Shapiro et al., 1986). Specifically, many authors believe that reduction in feeding time and noticeable nutritional and physical health benefits tend to outweigh any disadvantages for caregivers. The available literature on nutritional outcomes and caregiver satisfaction does not distinguish between skin-level and tube gastrostomy devices.

Issues Arising From the Available Research

As can be seen from review of the available literature, there are discrepancies regarding the nature and extensiveness of serious complications from long-term gastrostomy. Much of what is used to make treatment decisions derives from studies of the immediate postoperative period rather than a more comprehensive and long-term evaluation of the complex effects on the child's physiological status, nutritional status, and general well-being. Therefore, the present study was designed to gather and analyze a wide range of objective measures that would describe various implications of long-term gastrostomy use in children and answer the following questions: Is gastrostomy type related to the child's ability to meet intake requirements for calories, nutrients, and fluids? Are there differences in the type and frequency of long-term complications between tube and skin-level gastrostomies? Is gastrostomy type related to caregiver satisfaction level? Beyond creating a foundation for descriptive analysis of the nature and extent of complications of long-term gastrostomy for this pediatric population, it was anticipated that answering these questions would assist in clarifying the conflicting claims regarding various types of gastrostomy devices.

METHODS

Sample

A sample of children with severe spastic quadriplegia who had one of four types of gastrostomy devices for a minimum of 6 months was recruited

through the inpatient and outpatient rosters of the tertiary provincial rehabilitation facility. Because this facility coordinates and tracks service to this population throughout the province, the sample represented the available population of children with cerebral palsy requiring long-term gastrostomies in the province during the study period (Turner-Henson, Holaday, & O'Sullivan, 1992). It therefore included children who were resident in care facilities as well as those living in family settings and group homes throughout the province. Although we initially proposed to recruit 15 children, each with one of the four devices, the increasing popularity of the skin-level device (often replacing a tube device) reduced the total tube sample sufficiently that all three (PEG, MIC, and Foley) were collapsed into a single category; additional skin-level cases were eventually recruited to permit equal numbers in the tube and skin-level groupings.

The final sample consisted of 62 children between the ages of 13 months and 19 years ($Mdn = 8.25$ years). The sample was generally balanced for gender (52.5% male, 47.5% female) and the majority had primary (75%) rather than acquired (25%) disabilities. Most (69%) resided in a community setting, either with the family of origin or a foster family, with the remainder living in a hospital or residential facility (31%). Parents were the primary caregiver for one third of the sample (35%); parent substitutes for another third (33.3%); and nurses or, in a few cases, paraprofessional caregivers (31.7%) in the final third. The children with gastrostomies typically had some mobility (64.4%), although 6.8% were not mobile at all and 28.8% had excessive mobility, such as spastic quadriplegia. The sample reflected a range in length of time since gastrostomy was first introduced from 6 months to 9 1/2 years ($Mdn = 35$ months).

Instruments

Nutritional Outcomes

Height and weight are difficult to obtain, and existing measures tend to be unreliable for children with physical and developmental disabilities due to the presence of contractures, muscle spasms, scoliosis, and mobility aids (Spender, Cronk, Charney, & Stallings, 1989). For this reason, nutritional outcomes were assessed using anthropometric and nutritional intake measures. The Sunny Hill Anthropometric Pediatric Evaluation (S.H.A.P.E.) for the pediatric population with disabilities is a system of measurement that consists of 10 anthropometric measures indicative of growth and body composition (weight, recumbent length, upper arm and lower leg segment

lengths measure with modified segometer, head, relaxed arm and calf girths, triceps, and abdominal and medial calf skinfolds) that can be compared against matched population norms (Schlenker & Ward, 1994; Schlenker, Ward, & O'Donnell, 1996). Inter- and intrarater reliability estimates on a sample of more than 500 typical children exceeded 0.95, and technical errors of measurement were also found to be acceptable in comparison to published standards (Schlenker et al., 1996). Second, a 3-day food intake record, completed by caregivers and analyzed for nutritional variables using Quilchena Nutrient Computer Software (NUTS) yielded the percentage of Recommended Nutrient Intakes (RNI) for 15 selected nutrients (such as calcium, folate, iron and total protein) as well as fluid intake. Because energy needs are typically lower for children with cerebral palsy than are the rates calculated for population RNI, normative comparisons took into account estimated basal metabolic rate (BMR) and lower activity factors as recommended in the Krick method (Krick, Murphy, Markham, & Shapiro, 1992).

Complications

Because no appropriate instrument has been reported in the literature for measurement of skin and gastrointestinal complications, the authors developed a checklist with which to record the presence or absence of the 18 most common and predictable complications reported in the literature. The checklist was pretested with a small sample of children with gastrostomies prior to the study and found to have a satisfactory interrater reliability.

Caregiver Satisfaction

Caregiver satisfaction was measured using a Vertical Visual Analogue Scale similar to those used in the measurement of symptom intensity and subjective experiences (Gift, 1989). Because validity for a satisfaction score is known to be problematic in complex clinical situations, numeric scores were contextualized using qualitative data to interpret patterns over time and to link satisfaction measures with the subjective variables that explained them. The subjective caregiver satisfaction data was generated using the qualitative, interpretive tradition of Naturalistic Inquiry (Lincoln & Guba, 1985). Semistructured interviews loosely guided by a set of initial trigger questions permitted an ongoing construction of themes related to the experience of caring for a child with gastrostomy, and the detailed results of analysis of this data are reported elsewhere (Thorne, Radford, & Armstrong, 1997; Thorne, Radford, & McCormick, 1997).

Procedures

Ethical approval for this study was obtained from the University Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects and from the research review panel at the provincial tertiary pediatric rehabilitation facility. An information letter sent out to parents or caregivers of children who met the criteria invited them to participate in the study. Those volunteering received detailed information about the study and signed an informed consent prior to their participation. In the few instances in which children were cognitively capable of participating in the consent process, their assent was also obtained.

Bimonthly data gathering for each patient was conducted by a registered nurse research assistant trained in the application of the instruments. Home visits were conducted upon recruitment into the project and at 4-month intervals thereafter. In addition to baseline demographic data and gastrostomy history data collected at the initial interview, each of the home visits (months 4, 8, and 12) involved anthropometric measures, food intake records, the complications inventory, and the caregiver satisfaction scale. Telephone interviews were conducted in the intervals between home visits (months 2, 6, and 10) to obtain additional measures of complications and food intake. Caregiver interviews were conducted by a second research assistant at a convenient time during the year in which a family was enrolled in the study. As might be anticipated for this population, some of those recruited were unable to complete the full year of data collection due to such factors as the child's death (which occurred in 3 families) or a geographic move. In some instances, children enrolled with one type of gastrostomy device changed devices during the year. In other cases, despite our efforts to obtain measures at each of the seven interval points throughout a 12-month period, some data collection periods were missed due to the child's hospitalization, family holiday, respite, or, in several instances, parent/caregiver exhaustion that created reluctance to schedule any additional appointments. Where complete data sets were not possible, the subjects were retained in the study for the purpose of descriptive findings regarding the population and comparisons between devices in general but were excluded from the analyses relating to changes over time.

Outcome data for each of the seven data collection intervals were plotted for each client. Because of missing data for the reasons mentioned above, longitudinal analysis on the variables of complication rates, nutritional outcomes, and caregiver satisfaction could only be estimated for two thirds of the overall sample. Because the cases in which there was a complete data

set revealed no significant changes over time, descriptive data across all cases was aggregated and comparisons between tube and skin-level devices were conducted in addition to a comprehensive description of the overall sample.

RESULTS

Preliminary analysis was conducted to ascertain whether the comparison groups differed in relation to demographic or clinical variables of interest. Chi-square was used to assess relationships between the gastrostomy devices and age, gender, diagnostic category, reason for gastrostomy, and family configuration. *T* test was used to assess the two groups for length of time since gastrostomy. No significant differences were found between the tube and skin-level subgroups.

Nutritional Intake

Nutritional intake scores revealed that all children were receiving adequate nourishment for their body size with their gastrostomy device. Although there were four cases in which a child's intake fell below the 90th percentile (adjusted RNI) for total caloric intake at one or more measurement points, all other measurements revealed nutrition at the 90th percentile or better, and weight was maintained or gained by all children throughout the 12-month testing period.

Complications

Overall complication rates generally reflected what has been reported in the literature in that although major complications were relatively infrequent, minor complications were common. Disconnection was the most common complication, with 83.9% of caregivers reporting its presence on at least one occasion over the 12-month period. During the year, at least one reported episode of 14 additional complications was documented (see Table 1). There were no reported instances of migration, bowel obstruction, or fistula.

Comparisons of the frequency with which various complications occurred were made using chi-square procedures, and significant relationships were found between complication rates and type of gastrostomy device (see Table 2). Blockages, granulation, and site infections occurred more frequently among children with tube gastrostomies than among those with skin-level devices.

TABLE 1: Frequency of Gastrostomy Complications Over a 12-Month Period (In percentages)

Disconnection	83.9
Constipation	79.0
Vomiting	72.6
Leakage around device	74.2
Retching	72.6
Cramping	71.0
Leakage through device	62.9
Respiratory tract infection	61.3
Diarrhea	56.0
Granulation	50.0
Skin irritation	48.4
Blockage	38.7
Distention	35.5
Dislodgement	32.3
Site infection	27.4
Migration	0
Bowel obstruction	0
Fistula	0

All caregivers of children with PEG devices reported some granulation during the year. Disconnection (on two or more occasions during the year), leakage around the device (three or more times during the year), and leakage through the device (overall) occurred more frequently among the children with skin-level gastrostomy devices than those with tubes. No significant complication rate differences between skin-level and tube gastrostomy devices were found for all other complications.

Anthropometric Measures

Although sophisticated anthropometric measures were used to estimate the effects of nutritional outcome, excessive variations within many of our measures over time led us to conclude that these measures proved more imprecise than was predicted. In particular, because children with severe spasticity are generally incapable of lying flat, recumbent length proved extremely unreliable, even with a trained professional using standardized instrumentation and procedures. The most stable measures for this population, and therefore those that we believed most reliable measures of nutritional outcome, were arm muscle and arm fat stores. Arm muscularity was measured by arm circumference at the measured midpoint between the

TABLE 2: Associations Between Type of Device and Gastrostomy Complication Rates

	<i>Skin-Level Devices</i> (n = 31)	<i>Tube Devices</i> (n = 31)	χ^2 (df = 1)	p Value
Blockage	33.0%	67.0%	4.6	.04
Granulation	35.5%	64.5%	5.23	.02
Site infections	16.1%	38.7%	3.97	.05
Disconnection (2 or more times)	80.6%	41.9%	9.79	.01
Leakage around (3 or more times)	67.7%	41.9%	4.2	.04
Leakage through	61.3%	19.4%	11.3	.001

acromial process of the shoulder and the tip of the elbow with the arm flexed. Arm fat stores were calculated from triceps skinfold fat mass. Together, these measures provide reliable information about total body composition (Nutrition Committee, 1994; Spender, Cronk, Stallings, & Hediger, 1988; Tomezsko, Scanlin, & Stallings, 1994). In typical children, such measures would normally reveal more muscle than fat stores. In contrast, the majority of these children (57%) scored equivalent arm fat and muscle stores, whereas 24.5% had more arm fat than muscle and only 18.4% had more arm muscle than fat stores.

Although arm muscle stores measures revealed no differences between the tube and skin-level subgroups, there was a small difference between the groups in the percentage whose arm fat stores fell below the level of the 10th population percentile (27% of the tubes versus 57% of the skin-level devices, $\chi^2 = 4.43$; $p < .04$). Because this difference was most apparent at the first data collection period and disappeared throughout the course of the year, this difference may have been an artifact of the increasing popularity of the skin-level devices. Overall, both subgroups reflected the established trend of general growth retardation (typically understood as the effect of long-standing undernutrition during the developmental process) for the population of children with cerebral palsy (Stallings, Cronk, Zemel, & Charney, 1995).

Caregiver Satisfaction

Caregiver satisfaction ratings were generally high ($M > 80\%$) at all testing times. No significant correlations were found between satisfaction scores and frequencies of any of the complications documented. Despite the consistently high ratings of the device itself, caregiver interviews revealed that gastro-

tomy management was a major challenge to families and that successful coping required complex adaptive strategies developed over time and experience. A detailed description of caregiver coping with long-term gastrostomy in children is presented elsewhere (Thorne, Radford, & Armstrong, 1997). Of particular note was the finding that the technical aspects of managing the device itself were rather more easily addressed than were issues associated with managing ongoing feeding schedules, health routines, and normal family life when a child with gastrostomy was being cared for in the home.

DISCUSSION

The results of this study confirmed that nutritional outcomes for this population are difficult to estimate. Anthropometric measures reveal different body compositions from those of typical children, and thus the value of comparison against population norms is questionable. Children with severe spastic quadriplegia tend to have considerably decreased muscularity in comparison to fat stores, probably related to limited mobility and other factors. Because nutritional intake has generally been estimated on the basis of these measures and population nutritional norms, there is considerable work to be done in refining nutritional guidelines for these children. Nurses and others involved in supporting families with such children or providing direct care require sophisticated assessment skills to monitor the adequacy (and potential excess) of gastrostomy nutrition.

Because the caregiver interviews we conducted in the context of this study permitted us a rich exposure to what family life with a child with gastrostomy entailed, we became sensitive to how difficult it could be for these families to schedule even one more activity and considered ourselves fortunate to have as many complete data sets as we did. Despite careful planning and follow-up, we were unable to obtain exhaustive measures for all children at all data collection points. Although we remain convinced that longitudinal studies are important for documenting the repercussions of this intervention on child health and family life, we would recommend that future studies take the extreme demands of family context into consideration in their design.

Despite the claims of manufacturers and advocates, the advantage of skin-level over traditional tube devices was not supported in this sample. Although skin-level gastrostomy devices were associated with fewer instances of blockage, granulation, and site infection, tube devices fared better in the rates of disconnection and leakage. There were not any nutritional intake, nutritional outcome, or caregiver satisfaction score differences be-

tween tube and skin-level devices. Although both types of gastrostomy successfully nourished the children, they both presented caregivers with a range of challenging complications.

This study confirms that both tube and skin-level gastrostomy devices contribute positively to amelioration of the undernutrition that tends to accompany severe spastic cerebral palsy. For many of the children in this study, nutrition was a serious and even life-threatening problem prior to the insertion of the gastrostomy. The technological intervention clearly accomplishes its primary goal of providing adequate nourishment safely. The findings of this study also reveal, however, that both types of devices present caregivers with a range of frustrating adverse effects. Although the skin-level device may present an aesthetic appeal in that it is more easily concealed than are most tube devices, there is little evidence to suggest an improvement over conventional tube devices in nourishing the child or in preventing untoward complications. Because skin-level devices force a higher level of dependence on professional health providers than do tube devices, especially when reinserting is required, they may not be the device of choice in all contexts. The relative prevalence of different complications may make one or the other device more suitable in individual instances. Thus, instead of relying on general manufacturers' claims when making decisions about gastrostomy device selection, expert assessments of each individual child's posture, motor activity, social awareness, and skin condition should continue to be afforded considerable authority. Such comprehensive and holistic assessment remains a critical component of nursing's contribution to the health care team making decisions on behalf of such children and families.

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Commentaries

Commentary by Onyskiw

In their practice, nurses observed no fewer complications in children with skin-level gastrostomy devices than in children with traditional tube gastrostomy devices, and they wondered whether manufacturers' claims of the superiority of skin-level devices would really be justified with long-term use. This study is an excellent example of how clinical practice provides an important source for research questions. The topic has received little attention in the nursing literature. Past research has mainly examined the effects of gastrostomies during the operative and/or immediate postoperative period. Because most children with cerebral palsy have gastrostomies for long periods of time, health care professionals and family caregivers need information about the long-term effects to aid in their decision making about the optimal care for these children.

Findings showed that both types of gastrostomy devices helped children obtain adequate nutrition for their body size measured using anthropometric and nutritional intake scores. Comparisons of the frequency of the various complications experienced were appropriately tested using chi-square tests, and significant associations were

found between complication rates and the type of gastrostomy device. Blockages, granulation, and site infections occurred more frequently in children with tube devices, whereas disconnection and leakage around the device occurred more frequently in children with skin-level devices. Other than identifying the associations, however, there was minimal attempt to explain them. This information would be helpful to clinicians making choices between gastrostomy devices.

The authors ascertained that both groups were comparable on several demographic and other variables of interest. There are a number of other variables that may have varied between the groups. Were any of the complications associated with the specific formula used or the amount of fluid in the diet? Were the effects of continuous versus intermittent feedings, purees versus formula, or formula osmolarity considered? Is it possible that individual practices in caring for the gastrostomy varied? What about the effects of having one versus multiple people caring for the gastrostomy? Although it is understandable that there were insufficient numbers of tube devices to permit comparison, it was somewhat unfortunate that all the traditional devices had to be collapsed into one group because this approach obscured any differences that may have existed between the traditional devices.

The study highlighted the importance of assessing reliability and validity of all instruments for each particular sample. Despite the fact that the instrument chosen to measure nutritional outcomes, the S.H.A.P.E. (Schlenker & Ward, 1994) was specifically developed for disabled children and reported to have high reliability in a study using a sample of disabled children as well as in a study using a sample of nondisabled children (Schlenker, Ward, & O'Donnell, 1996), the instrument proved unreliable in this study. Excessive variations within many of the anthropometric measures were found. In particular, measuring recumbent length in children with contractures and spasticity was difficult. A small pilot using a sample of children with cerebral palsy may have alerted the researchers to the problem sooner.

As an alternative to using the S.H.A.P.E., the authors used arm muscle and arm fat stores, believing these provided the most reliable measures of nutritional outcome. There should have been evidence provided, other than a statement from the researchers, to support the reliability and validity of this alternative. This information is important to help readers judge the validity of the study results and to assist others planning similar studies.

The authors appropriately raised their concerns about the value of comparing the anthropometric measures of disabled children against population norms estimated using samples of nondisabled children. This is one of the measurement challenges faced by investigators working with chronically ill or disabled populations—instruments and normative scores based on typical populations are often not clinically meaningful with the target population.

Clinical research always presents researchers with many challenges. This study is a good example of efforts to address clinically relevant questions and of the methodological challenges faced when target populations are small and there are numerous influencing variables. Discussion and dialogue among researchers about these chal-

lenges through avenues such as this provide a means to benefit from each other's experiences.

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Commentary by Day

There are five main features about this research study that are of particular interest: the source of the research idea; the longitudinal nature of the study; and the focus on outcomes, measurement issues, and decision making. The first point is that nurses are questioning their practice and the anecdotal evidence they have collected. Rather than accepting the claims of manufacturers of the new skin-level gastrostomy devices and the research literature, a research project emerged. The decision to look longitudinally throughout the course of a year provided enough time to see whether complications, nutritional status, and caregiver satisfaction changed over time.

The focus of the research is on outcomes of an intervention: in this case, the long-term effects of two different types of gastrostomy devices. According to Carroll (1996), "we have little knowledge about how different treatments compare in terms of overall effectiveness and safety. Treatment regimens are often based on prescriber preference, or on traditional, ritualistic, non-evidence-based practice, rather than on scientific fact" (p. 59).

There are numerous examples of measurement issues within this study. It is interesting to look at the list of complications to gastrostomy devices and to note that common problems such as constipation (second most frequent complication) and diarrhea (ninth most frequent complication) appear. Some are probably surprised that constipation is so common. However, when the four main causes of constipation are considered (lack of fluids, lack of fiber, lack of exercise, weak abdominal muscles) (Exton-Smith, 1972) and are applied to the children in this study, the result is not so surprising. As the authors point out, not giving enough water through the gastrostomy may be one of the problems. This may be due to a lack of knowledge on the part of

the caregiver and/or the extra time required to be added to the feeding times. Children with cerebral palsy may have difficulty communicating the need to defecate and may hold the stool longer in the bowel, resulting in the reabsorption of fluid from the stool (Day & Monsma, 1995).

A second measurement issue is related to nutritional status. Even though the authors avoided the use of traditional height and weight measures, they were still faced with the problems of measuring recumbent length. The authors identified the most useful measurements to be the arm muscle and arm fat stores. Keller (1997) studied the problem of undernutrition in institutionalized older men. She employed two ways to measure height: the use of a stadiometer attached to an institutional wheelchair balance scale using standardized techniques (Gibson, 1990) and the estimation through knee height for nonambulatory patients (Cockram & Baumgartner, 1990). Midarm circumferences were measured three times and then averaged, and the scores were used to determine midarm muscle circumference, midarm muscle area, and percentages of body fat (Heymsfield, McManus, Smith, Stevens, & Nixon, 1982). Keller (1997) found that the midarm circumference, midarm muscle circumference, midarm muscle area, and the percentage of body fat all were significantly lower for the malnourished subjects. Keller also examined the relationship between nutritional status and functional ability and found that the undernourished men had lower functional ability and strength. Although this relationship was not statistically significant, it may be clinically significant. A group of researchers in Sweden measured nutritional status with body mass index, triceps skinfold thickness, arm muscular circumference, plasma albumin, serum transferrin, and plasma prealbumin. If two or more results were subnormal, then the diagnosis of undernourished was made (Jacobsson, Axelsson, Norberg, Asplund, and Wenngren, 1997).

An additional issue connected to measurement concerns norms. The authors of this current study lament the lack of norms for children with severe spastic cerebral palsy. Keller (1997) also experienced difficulties in locating norms for older men. More studies are needed to provide norms for people of all ages with a variety of disabilities.

The final issue in this article is about decision making. Because both types of gastrostomy devices are effective in improving nutritional status, what other factors must be considered in making a choice? According to O'Connor (1993), problems in making a decision relate to the risks involved, the significant gains or losses that may occur, the need to make value trade-offs, and anticipated regrets about aspects of the rejected choices. Other factors include a lack of information about risks, benefits and alternatives, emotional upheaval, pressure from others, lack of skill in decision making, and unclear values (O'Connor, 1993). Nurses want clients to "make choices and act on choices that are informed and consistent with personal values" (Bunn & O'Connor, 1996, p. 16). This fits with Bandura's (1977) concept of self-efficacy or the feeling of being adequate and efficient in dealing with life situations.

The authors clearly state the need for nurses to accurately assess both the client and the caregivers as being essential for making decisions about which gastrostomy device will be most suitable. The personal values and concerns of the child and the

caregivers, the physical condition of the child, and proximity to medical services can all be considered in relation to the risks of complications for the two types of gastrostomy devices. When all aspects of the situation are considered, the outcome should be the best match of type of device to a particular child and his or her caregivers.

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Response by the Authors

As the commentaries have so effectively highlighted, the complexities involved in measurement for this type of study can be daunting. The best measurement devices available will be variously reliable depending on the specific features of an individual

subject's physical challenges (such as spasticity), and the utility of measurement norms for studying populations inherently distinct from those on whom the norms have been established will always be problematic (Albrecht, 1992). In the final analysis, whatever body parts and dimensions come to be accepted as baseline measures, outcomes such as undernourishment or malnourishment will inevitably represent relative determinations and clinical judgments. Thus, one could argue that improving the measures will have a limited value at best and that developing a consensus around alternative outcome claims might be equally important.

This study was designed to investigate a problem arising from frontline nursing practice, specifically, the basis for decision making around gastrostomy devices. We believe that nurses ought to be skeptical about scientific claims as to the implications of various technological devices intended to support bodily functions, particularly when the claims originate exclusively from research supported by the corporations promoting the product. To responsibly argue for intelligent nursing involvement in advocating for one or another device, however, it seems important to test the implications of the available technological options as far as is possible. In a situation as complex as long-term gastrostomy, such testing does require trade-offs with regard to which variables will be controlled, which will be measured, and which will be accepted as inherently problematic. For example, the concern that the device might be differently manipulated depending on whether multiple or single caregivers are involved is an entirely legitimate one. There is an intuitive truth value to the notion that no two caregivers will interact with a technological appliance in quite the same manner and that these differences might well influence the ultimate success of a nutritional program as well as the presence or absence of untoward complications. Collateral findings from the family caregivers of such children confirm that confidence with experimentation and manipulation of scheduling, dosage, and adherence to routines is highly variable and shifts over time as families gain experience and work out their own responses to the challenge of caring for these medically complex children in the home (Thorne, Radford, & Armstrong, 1997).

Examination of the problem from a clinical perspective thus serves to heighten our awareness of its complexity. Further, using the methods of traditional science, each new variable could itself become the focus of study. We believe, however, that some of these complex clinical problems can appropriately be addressed by using a combination of formal research inquiries and clinical problem-solving activities, what Johnson and Ratner (1997) might consider the rational aspect of nursing knowledge development combined with the speculative knowledge of human experience. In this study, we established that there were not many important differences between the devices and that both served the purpose of nourishing the child quite effectively. Rather than extending research into the business of additional variables, our inclination is to take that finding back to the clinical context and set practicing nurses to the task of developing the next set of reasonable questions within the logic of clinical problem solving. The issue of which device will be best for which child may therefore derive more from theoretical developments on the issues of posture, mobility, social

acceptability, geographic location, and aesthetic preference than from correlations with various nutritional and health outcomes.

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