Living with cerebral palsy and tube feeding: A population-based follow-up study

Stephanie W. Smith, BSc, Carol Camfield, MD, FRCP (C), and Peter Camfield, MD, FRCP (C)

Objectives: To assess the impact of surgically placed feeding tubes on children with severe cerebral palsy (CP) and their families and to determine the survival of these children after initiation of tube feeding (TF).

Methods: Virtually all children from Nova Scotia who had gastrostomy or jejunostomy procedures between the years 1980 and 1998 and who had been diagnosed with CP were identified. Caretakers of those children who had TF initiated in the last 8 years were evaluated by using a semi-structured interview. Names of children who had not had recent follow-up visits were submitted to the provincial Vital Statistics office to determine whether they had died. Data from patients who were tube-fed between 1980 and 1989 were then used in combination with data from the more recent cases to create a survival curve.

Results: A total of 61 children were identified; 16 had died. Forty of 45 eligible families were interviewed; 90% were pleased with the effect of TF on their child and family life. Negative reports were associated with increased stress related to feeding. Survival rates after gastrostomy and/or jejunostomy were 83% after 2 years and 75% after 7 years.

Conclusions: In children with severe CF, initiation of TF improved the quality of life for both the child and family in 90% despite frequent minor complications. (J Pediatr 1999;135:307-10)

Cerebral palsy is a common cause of severe neurologic disability in children,[1] with an incidence of 2 to 3 per 1000 live births in Canada.[2] This nonprogressive encephalopathy usually arises in the prenatal period, interferes with normal development of the brain, and presents as a disorder of motor function. Those with severe CP are non-mobile and depend on caregivers for their daily needs. Despite gains in perinatal care, the incidence of CP does not appear to be declining.[3]

Feeding difficulties are common in severely neurologically impaired children and have been found in 90% of children with CP.[4] Oral-motor dysfunction places children at high risk for malnutrition, aspiration, infection, and gastroesophageal reflux.[5]

See editorial, p. 272.

Feeding tubes have been used as adjuncts in the care of children with feeding difficulties to correct malnutrition and failure to thrive.[6] Tawfik et al[7] found that introduction of a gastrostomy tube was related to decreased irritability in the child and more time for the parents to spend with their other children. Rempel et al[8] found that gastrostomy feeding in children severely affected by CP could improve nutritional status. Shapiro et al[9] reported an improvement in quality of life with the introduction of tube feeding.

CP	Cerebral palsy
TF	Tube feeding

Rice et al[10] found that Nissen fundoplication reduces hospital visits and improves weight gain in neurologically impaired children with gastroesophageal reflux. Studies have also found parents to be satisfied with the Nissen procedure.[11]

Few studies have addressed both the physical consequences of tube placement and the psychologic and social implications for the child and family. We hypothesized that gastrostomy or jejunostomy TF would successfully resolve physical problems relating to feeding and possibly increase survival. Because the act of eating has both social and nutritional aspects, we also hypothesized that TF would have a significant impact on the family, creating higher levels of psychologic stress for the caregivers.

From Dalhousie University Medical School and IWK-Grace Health Centre, Department of Pediatrics, Dalhousie University, Halifax, Nova Scotia, Canada

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Reprint requests: Carol S. Camfield, MD, Division of Child Neurology, IWK–Grace Health Centre, 5850 University Ave, PO Box 3070, Halifax, NS B3J 3G9, Canada.

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Table I. Precipitating factors leading to initiation of TF and their resolution

Symptom	No. of children affected who responded with a decrease in symptoms	No. of children without initial symptom who responded	*P* value
Failure to thrive	33/37	0/3	.003
Difficult to feed	34/37	0/3	.002
Long time spent feeding child	33/37	0/3	.003
Stress associated with feeding	34/37	0/3	.002
Aspiration	8/22	1/17	.02

Table II. Associations between psychosocial problems and overall impact of TF

Reported problem with TF	No. of respondents who rated the tube as positive overall	No. of respondents who rated the tube as negative overall	*P* value
Restricted mobility	5/35	4/5	.006
Difficulty getting respite care	5/35	4/5	.006
Stress related to feeding not reduced	1/35	5/5	.0001
Time to feed not reduced	3/35	4/5	.002

METHODS

The IWK Grace Health Centre is the only tertiary pediatric care center for the province of Nova Scotia, and virtually all gastrostomy and jejunostomy procedures for residents of Nova Scotia are performed here. The medical records department identified patients living in Nova Scotia who had a gastrostomy or jejunostomy procedure performed between 1980 and 1998 by using the International Classification of Diseases. Patient charts were then reviewed, and those with an additional diagnosis of CP were selected. Each of the 4 pediatric neurologists in Nova Scotia work at the IWK-Grace and have provided follow-up care to these patients on an outpatient basis or in traveling clinics that cover all areas of Nova Scotia. The only other hospital in the province that might perform such procedures was contacted. Their medical records department confirmed that during the study period only 2 children with CP had gastrostomy tube placement. Because details of their clinical course were not available to us, these cases were excluded from analysis.

The following information was obtained through chart review: name, date of birth, address, telephone number, diagnosis, date of gastrostomy or jejunostomy, any complications related to the procedure, date of death, and cause of death (if included in the chart). The names of children without recent follow-up visits were submitted to the Nova Scotia Division of Vital Statistics, which was then able to establish whether any of these patients had died. Cross-referencing lists from medical records with those from the operating room database verified those patients who had gastrostomy or jejunostomy procedures between 1990 and 1998. The resulting patient population comprises all children in Nova Scotia who have been diagnosed with CP and who received a surgically placed feeding tube.

The cohort was divided into those who had a gastrostomy or jejunostomy before or after 1990. Letters were sent to the family doctors of the patients who had a gastrostomy or jejunostomy after 1990 asking them to contact the neurology division if they believed that speaking to the family would be unwise (none responded). Subsequently, letters explaining the study were sent to the caregivers of these same children. They were informed that one of the authors would be contacting them to participate in a semi-structured telephone interview of approximately 30 minutes in length. Verbal consent was obtained over the telephone at the time of the interview. A number of open-ended questions were asked to assess the problems and positive aspects associated with TF. Those who had gastrostomy or jejunostomy procedures between the years 1980 and 1989 were not included in the interview group because of the remoteness of the experience and the relative infrequency of feeding tube procedures before the introduction of percutaneous endoscopic gastrostomy. The mortality data obtained from the earlier group was combined with data from those who had feeding tubes placed after 1989 to create a survival curve.

Statistical Methods

Data analysis was performed by using the Epi Info 6.0 statistics package.[12] Baseline variables were examined and compared with outcome variables by using the Fisher exact test for dichotomous data. In all analyses *P* values of <.05 were regarded as statistically significant. To provide survival rates, a Kaplan-Meier survival function plot was used.[13] Children lost to follow-up were analyzed in the survival calculations for the period during which they were known to be alive after initial surgery. Survivors at follow-up were compared with non-survivors for age at surgery, seizure disorders, and gender. The study was approved by the IWK-Grace Health Centre Ethics Review Board.

RESULTS

Caregiver Interviews

Forty of 45 patients identified with feeding tubes inserted between 1990

and 1998 participated in the study. Four families refused to participate, and one was lost to follow-up. Twenty-seven primary caregivers were mothers of the children, and one was a father. One child had an alternate primary caregiver. Eleven children lived in a group home. Twenty patients lived in rural areas. Thirty-five children had spastic CP, 3 had athetoid CP, and 2 had mixed CP. Related diagnoses included severe mental handicap (40, 100%), seizure disorder (27, 67%), contractures requiring surgery (25, 62%), cortical blindness (16, 39%), and congenital abnormalities (7, 17%). Thirty-seven patients (93%) were non-verbal.

The mean age of children at follow-up was 8.5 years (range, 1 to 20 years). The mean age for initiation of TF was 5 years (range, 2 months to 18 years). Forty-two percent of the patients received their feeding tubes in the first 2 years of life. There was no difference in the responses of parents of children older or younger than 5 years of age at the time of initiation of TF.

The type of feeding tubes were: 6 gastrostomy tubes, 3 jejunostomy tubes, 6 gastrostomy plus jejunostomy tubes, 23 gastrostomy buttons, and 2 jejunostomy buttons.

The precipitating factors and symptom resolution are outlined in Table I.

Overall, the caregivers felt satisfied with the TF. Thirty-two (86%) caregivers believed it had had a positive impact on the lives of their child and the rest of their family. Additionally, 22% of caregivers reported an improvement in their child's mood with the introduction of TF, and 86% indicated that they would have started TF earlier if they had known that it would have been so successful.

The problems the caregivers encountered are divided into 3 groups. Eight children (20%) had serious medical complications including volvulus, prolapse, bowel obstruction, ulceration, gastrointestinal bleeds, and peritonitis. Thirty-eight (95%) had minor medical complications and tube-related problems such as diarrhea and constipation, tube obstruction, infections around the tube site, accidental dislodgment, leakage around the tube, and problems with the valve (for button tubes only). Finally, 11 families (28%) had problems related to family functioning and stress that they attributed to TF. This category includes: (1) difficulty getting respite care because of lack of adequately trained caregivers; (2) restriction of mobility, especially if a pump was needed; (3) changed relationship with child; and (4) missing the taste of food.

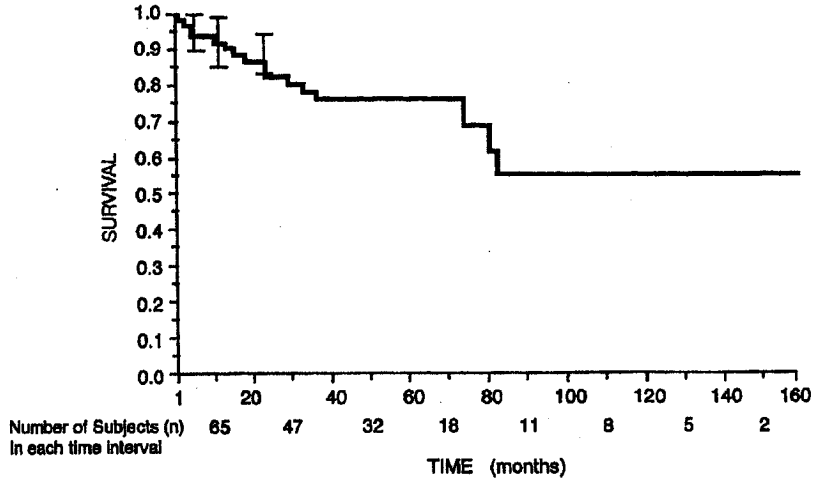

Figure. Survival of cohort after feeding tube placement (Kaplan-Meier survival function). *Vertical bars* indicate 95% CIs.

There was a positive association between the precipitating factors that led to the placement of a feeding tube and the problems relieved by the gastrostomy or jejunostomy tubes. Caregivers who reported their child had failure to thrive also reported weight gain more frequently than those who did not initially report failure to thrive. A significant number of caregivers who reported problems feeding their child before TF reported that their child was easier to feed after tube placement. Preoperatively identified aspiration was associated with a decrease in aspiration after surgery, although one parent who did not initially report aspiration as a problem reported that it decreased with surgery. All children with gastroesophageal reflux before tube placement had a fundoplication (n = 27), and in 50% the reflux resolved.

Only one problem was significantly associated with the type of TF the child received; 84% of children who received a gastrostomy button had mechanical problems with the button valve. This led to leakage of stomach contents with resultant chemical burn of the skin around the button site.

The only problems negatively associated with caregivers' overall satisfaction with TF were in the psychosocial category (Table II).

Survival Analysis

The total number of deaths recorded was 16, and none of the children died of causes directly related to surgical placement of the tube or complications of TF. The children died of causes such as respiratory failure or sepsis. The mean age of death was 9 years for the entire sample. The Kaplan-Meier survival function plot is shown in the Figure. Survivors at follow-up were compared with non-survivors for age at surgery, seizure disorders, and gender. There were no statistically significant differences. Therefore the Cox proportional hazards model was not required.

DISCUSSION

In this population based study we found that initiation of TF in children

with CP appears to improve the quality of life of both the child and the family. We noted a significant subsequent mortality rate, but it was lower than previously reported.[8,14-8]

In Nova Scotia a greater number of children with CP are receiving feeding tubes since the introduction of percutaneous endoscopic gastrostomy. Yet the impact of these feeding tubes has not been extensively studied. In our study 88% of all caregivers interviewed believed that TF had a positive impact on the lives of their child and the rest of the family. Our telephone interviews may have allowed a less structured but broader range of information than a mailed questionnaire. The TF procedures were highly endorsed, with 82% of caregivers reporting fewer feeding problems, less stress related to feeding, and less time required to ensure adequate nutrition. Eighty-six percent of caregivers reported they would have started the TF earlier had they known the beneficial effects.

All the caregivers reported at least one minor complication of TF. This is much higher than the complication rate reported by Gauderer and Stellato (13%).[19] These differences may be explained by the large number of factors included in our definition of complications. However, complications were not associated with a negative attitude to the TF, probably because many of these complications were minor and were dealt with at home.

Psychosocial problems such as restricted mobility, inadequate respite care, or stress related to TF itself were associated with an overall negative rating of the TF. It was our unquantified impression that the children of unsatisfied caregivers were at a higher functional level with fewer reasons for TF.

The Kaplan-Meier 1-year survival rate for our patients was 91%, similar to that for institutionalized or community-based children with CP.[4,14] We found a 2-year survival rate of 83% and a 4-year survival rate of 76%. These results are similar to those found by Strauss et al,[18] who reported a 75% survival rate after 2 years. These are higher than those reported by Eyman et al,[16,17] who reported a life expectancy of 4.1 to 4.8 years for severely mentally retarded individuals requiring TF (n = 985). They reported that only 20% were still alive after 11 years. Our sample is much smaller, but we found a 55% 10-year survival rate after an initial gastrostomy or jejunostomy procedure. We emphasize that the cause of death is related to the problems associated with CP, and not complications of TF.

Several limitations of our study should be noted. The data were based on self-report, primarily by mothers. The length of follow-up varied widely, which may have influenced caregivers' reports. The number of children with severe CP who currently have gastrostomy or jejunostomy tubes in Nova Scotia is relatively small, although the population basis of our study adds some validity. It is difficult to truly assess how much stress TF causes, because the reason for starting TF was probably stressful in itself. Relief of the cause as perceived by parents was more important than stress intrinsic to TF.

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