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SCIENTIFIC LETTERS

Gastrostomy in pediatric palliative care: How well does it work?

Gastrostomía en cuidados paliativos pediátricos: ¿funciona bien?

Dear Editor:

Currently, there is a greater number of children with chronic diseases who sometimes have lifelong disability, are more fragile and are considered medically complex. Many of them require paediatric palliative care (PPC).[1] These patients are at risk of malnutrition[2] and often experience severe feeding problems, although their prevalence has not been reported. There is widespread consensus that nutritional support via gastrostomy tube (GT) can be an appropriate approach to treat malnutrition in children.[3] However, there is little evidence on the performance of GT feeding in PPC.[4] The aim of our study was to address this knowledge gap, assess the satisfaction of caregivers and report the complications associated with GT feeding in PPC.

We conducted a cross-sectional study in paediatric patients aged 1 month to 20 years who received PPC and had a GT in place for at least 3 months. The Association for Children with Life Threatening or Terminal Conditions and their Families (ACT) Classification[5] was used to categorise the different groups of PPC. To assess the degree of satisfaction of the caregivers of children managed with GT feeding and the wellbeing of patients, we used the standardized questionnaire on the satisfaction with gastrostomy feeding (SAGA-8),[6] administered via telephone or email (Table 2). The SAGA-8 is an 8-item self-report instrument, of which 5 questions (Q1–Q5) are rated on a Likert scale (1: minimum satisfaction, 5: maximum satisfaction) and 3 have yes/no dichotomous answers (Q6–Q8). A total score greater than 20 indicates a high level of satisfaction in the respondent. We also added questions regarding prior knowledge of GT feeding and potential complications based on the previous literature on GT feeding in children.[7] We summarised the demographic characteristics of the participants with descriptive statistics. Participation in the survey implied informed consent.

Table 1 presents the demographic and clinical characteristics of participants, the prior knowledge about GT and the complications of GT in a sample of 19 children receiving PPC and primarily fed through a GT. The sample amounted

Table 1 Demographic and clinical characteristics and gastrostomy complications in a sample of paediatric palliative patients.

Sex	Male: 9 (47.4%)
	Female: 10 (52.6%)
Median age at the time of the survey	8.2 years (range, 0.6—20)
Ethnicity	Caucasian: 13 (68.4%)
	Romani: 3 (15.8%)
	Other: 3 (15.8%)
ACT group	I: 1 (5.3%)
	II: 3 (15.8%)
	III: 4 (21%)
	IV: 11 (57.9%)
GT placement at admission to PPC unit	Before: 7 (36.8%)
	After: 12 (63.2%)
Age of GT placement	2.5 years (range, 0.5–16.4)
GT placement procedure	Endoscopic: 16 (84.2%)
	Surgery: 3 (15.8%)
GT access	Button: 15 (79.0%)
	Tube: 4 (21%)
Questionnaire respondent	Mother: 16 (84.2%)
	Father: 2 (10.5%)
	Others: 1 (5.3%)
Caregiver employed	Yes: 8 (42.1%)
	No: 11 (57.9 %)
Caregiver educational attainment	Primary: 6 (31.6%)
	Secondary: 6 (31.6%)
	Higher: 5 (26.3%)
	Not answered: 2 (10.6%)
GT tube replaced by caregivers	Yes: 13 (68.4%)
	No: 6 (31.6%)
Oral feeding	Yes: 9 (47.4%)
	No: 10 (52.6%)
Type of nutrition	Standard enteral formula: 11 (57.9%)
	Blended diet: 8 (42.1%)

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Table 1 (*Continued*)

Prior knowledge about GT	Yes: 12 (63.2%) No: 7 (36.8%)
GT complications	Hypergranulation tissue: 13 (68.4%) External reflux: 12 (63.2%) Stoma infection: 7 (36.8%) Accidental decannulation: 7 (36.8%) Obstruction: 5 (26.3%) Aspiration pneumonia: 2 (10.5%) Catheter displacement: 1 (5.3%) Fistulisation: 1 (5.3%) Gastrointestinal haemorrhage: 1 (5.3%)

ACT, Association for Children with Life Threatening or Terminal Conditions and their Families; GT, gastrostomy; PPC, paediatric palliative care.

to 48.7% of the total patients in PCC. During the follow-up, 1 patient classified as ACT group III died 4 months after placement of the GT. Most caregivers (78.9%) reported an improvement in self-confidence after GT placement.

Table 2 summarises the results of the SAGA-8 questionnaire. The mean total SAGA-8 score was 24.9 (standard deviation, 4.9). A high level of satisfaction with GT feeding (SAGA-8 > 20) was reported by 89.5% of caregivers (Table 2). Severe complications (aspiration, fistulisation or haemorrhage) were infrequent, although 10.5% of respondents reported the patient had aspiration pneumonia at least once.

PPC is a dynamic process that involves the management of many symptoms (respiratory failure, malnutrition, pain etc.) in which various techniques (non-invasive ventilation, gastrostomy, etc.) can be used to improve the quality of life of terminally ill patients, even if they have a reduced life expectancy.[1] Our study is the first to use the standardized SAGA-8 questionnaire to assess the satisfaction of caregivers of PPC patients. Our results showed a lower level of satisfaction with the support offered by professionals in the centre (Q3), in agreement with studies in children without palliative care needs.[2] Our findings suggest that the exchange of information between health care professionals and caregivers needs to be better to improve the care of patients before and after GT placement. This exchange would not only improve the overall acceptance of GT feeding by caregivers, but also the prevention of potential complications of this technique.[6]

Table 2 Responses to the items of the SAGA-8 questionnaire by the caregivers of 19 patients receiving paediatric palliative care.

Question	Results % (n)				
	1	2	3	4	5
Q1.- How do you rate your satisfaction with GT feeding?	5.3% (1)	–	10.5% (2)	10.5% (2)	73.7% (14)
Q2.- How do you evaluate GT management?	5.3% (1)	5.3% (1)	21.0% (4)	21.0% (4)	47.4% (9)
Q3.- How do you evaluate the support offered by our centre?	10.5% (2)	21.0% (4)	10.5% (2)	21.0% (4)	37% (7)
Q4.- How do you perceive your child's change in nutritional status?	–	5.3% (1)	10.5% (2)	21.0% (4)	63.2% (12)
Q5.- How do you rate the change in your child and your family's overall situation?	10.5% (2)	–	10.5% (2)	26.3% (5)	52.7% (10)
	No		Yes		
Q6.- Has the time required for feeding decreased?	31.6% (6)		68.4% (13)		
Q7.- Has the number of respiratory infections decreased?	31.6% (6)		68.4% (13)		
Q8.- Would you accept earlier GT placement with your current knowledge of the benefits of the procedure?	42.1% (8)		57.9% (11)		

GT, gastrostomy; Q, question.
The scores for each item are added, and the total sum represents the level of satisfaction of the caregiver. The total score of the SAGA-8 ranges from 8 to 31.
Q1: Score ranges from 1 (totally unsatisfied) to 5 (very satisfied). Q2: Score ranges from 1 (very difficult) to 5 (very easy). Q3: Score ranges from 1 (totally insufficient) to 5 (very satisfactory). Q4 and Q5: Score ranges from 1 (deteriorated) to 5 (significantly improved). Q6-Q8: Score ranges from 1 (no) to 2 (yes).

On the other hand, we found a high level of satisfaction (84.2%) when caregivers were asked about the effect of GT on the nutritional status of the child (Q4). This goes against the widespread belief that, given the aggressiveness of the intervention and the limited lifespan of PPC patients, the potential benefits of GT do not compensate its risks. This result suggests that GT can also be contemplated as a means to improve feeding in PPC.[6] In our study, the most frequently reported complication associated with GT feeding was hypergranulation tissue, but other studies have reported infection at the GT site.[6] Furthermore, our study has identified an important challenge in care quality in the use of GT in PCC patients: adequate communication and support from health care providers. One limitation of the SAGA-8 questionnaire is that it is administered after GT placement and does not reflect the needs or difficulties that caregivers had during this process, for instance during mealtimes. As for our study, one of its limitations was the lack of assessment of anxiety levels. Future studies should include an evaluation of emotional factors before, during, and following any interventions. Also, a larger sample size would be advisable to explain a greater part of the variance in the responses and to document all possible complications in patients accurately. In conclusion, GT placement appeared to improve feeding in PPC and was associated with a high level of satisfaction in caregivers, but the exchange of knowledge between health care professionals and caregivers needs to improve.

Ethical considerations

This study was reviewed and approved by the Ethics Committee of the Hospital Universitario Río Hortega (Valladolid, Spain).

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Pablo del Villar Guerra*, Ana Martínez Flórez, Clara Domínguez Martín, Alfredo Cano Garcinuño

Department of Paediatrics, Hospital Universitario Río Hortega, Valladolid, Spain

* Corresponding author.
E-mail address: pdelvillarguerra@gmail.com
(P. del Villar Guerra).

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