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Satisfaction with gastrostomy feeding in caregivers of children with home enteral nutrition; application of the SAGA-8 questionnaire and analysis of involved factors

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Abstract

Aims: To assess the degree of satisfaction of caregivers of children with gastrostomy tube (GT) feeding through the structured questionnaire SAGA-8. Secondly, to evaluate if the parental satisfaction degree was related to several independent variables.

Methods: A cross-sectional observational study was performed in 92 caregivers of children with GT feeding and chronic diseases. The following data was obtained: caregiver satisfaction with GT feeding (SAGA-8), age at GT placement, anthropometric data, length and mode of nutritional support, family demographic characteristics and caregiver psychological status.

Results: All primary caregivers were mothers. High satisfaction with GT feeding was expressed by 82.6% of families. The simplicity of the system was emphasized by 87%, and 85.9% were very satisfied with the support received from the hospital staff. 73.9% of mothers acknowledged their child's nutritional status had improved and 89.1% rated the enhancement family's overall situation. Moreover, 75% of mothers reduced feeding-time, and 68.5% reported less respiratory infections. Finally, 71.7% of mothers recognized that they would have implemented this technique earlier. Caregiver satisfaction was positively correlated with age at GT placement and length of treatment, and both variables explained the 19.4% of the satisfaction variance. No correlation with anthropometric data, nutrition support mode, family demographic characteristics or caregiver psychological status was observed.

Conclusions: The SAGA-8 questionnaire is a simple, specific, straight-forward tool to evaluate parental/caregiver degree of satisfaction with GT feeding and facilitates effective monitoring of the intervention. Lengths of

SATISFACCIÓN CON LA ALIMENTACIÓN MEDIANTE GASTROSTOMÍA EN CUIDADORES DE NIÑOS CON NUTRICIÓN ENTERAL DOMICILIARIA; APLICACIÓN DEL CUESTIONARIO SAGA-8 Y ANÁLISIS DE LOS FACTORES IMPLICADOS

Resumen

Objetivos: Valorar el grado de satisfacción de los cuidadores de niños con alimentación mediante gastrostomía aplicando el cuestionario estructurado SAGA-8. Segundo, evaluar si la satisfacción parental guarda relación con diversas variables independientes.

Métodos: Se realizó un estudio observacional, transversal en 92 cuidadores de niños con enfermedades crónicas que recibían alimentación mediante gastrostomía. Se analizaron los siguientes datos: satisfacción de los cuidadores con la alimentación por gastrostomía (SAGA-8), edad de implantación de la gastrostomía, parámetros antropométricos, tiempo de soporte nutricional, características demográficas familiares y estado psicológico del cuidador.

Resultados: Todos los cuidadores eran madres. La mayoría (82,6%) manifestaron una elevada satisfacción con la alimentación mediante gastrostomía. El 85,9% resaltó la sencillez de la técnica sintiéndose el 85,9% muy satisfecho con el apoyo ofrecido por el centro. Un 73,9% de las madres percibió mejoría nutricional en su hijo, señalando el 89,1% un mayor bienestar familiar. Además, el 75% de las madres comunicaron una disminución en el tiempo de alimentación y el 68,5% una reducción en la morbilidad respiratoria. Finalmente, el 71,7% de las madres reconoció que hubieran aceptado antes el procedimiento. La satisfacción se correlacionó significativamente con la edad de implantación de la gastrostomía y con la duración del soporte nutricional, explicando ambos factores el 19,4% de la varianza de la satisfacción. No se encontró correlación con datos antropométricos, tipo de soporte nutricional, características demográficas familiares ni con el estado psicológico del cuidador.

Conclusiones: El cuestionario SAGA-8 es sencillo, específico y fácil de aplicar para evaluar el grado de satisfacción de los padres/cuidadores con la alimentación mediante gastrostomía contribuyendo a su monitoriza-

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HEN and precocious age at GT placement are responsible for most of parental satisfaction.

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Key words: *Parental satisfaction. Caregivers. Gastrostomy. Home enteral nutrition. Nutritional support.*

Abbreviations

BMI: Body mass index.

GT: Gastrostomy tube.

HEN: Home enteral nutrition.

QoL: Quality of life.

$Z_{BMI/A}$: BMI for-age-Z score.

$Z_{H/A}$: Height for-age-Z score.

Introduction

Home enteral nutrition (HEN) is a nutritional support technique commonly used in pediatric patients suffering from chronic diseases.^{1,2} The benefits of HEN are numerous: it improves the child's nutritional status, it may restore lineal growth in some cases,³ and most importantly it improves the child's overall well-being, setting the ground for an easier adaptation to both family and school life.^{4,5} The efficiency of HEN has commonly been associated to low complication rates and childrens' longer life spans.⁶

Nevertheless, these commonly-accepted indicators prove insufficient to assess the efficiency of HEN, since other factors including the physical, psychological⁷ and social impacts of different sanitary interventions in both patient and caregivers⁸ must also be considered. Therefore, new tools that enable the measuring of nutritional intervention benefits and contribute to decision-making are needed. Assessment of these impacts will result in improved sanitary services.

The degree of satisfaction in pediatric patients with HEN is generally indirectly assessed through caregiver surveillance, since patients are usually too young to provide this information or suffer from severe neurological diseases.^{9,10,11} In a previous study, the authors designed a structured questionnaire (SAGA-8) for the assessment of the satisfaction rate among parents and/or caregivers of pediatric patients with HEN by gastrostomy.¹² The quantification of their psychometric properties revealed adequate internal consistency and appropriate sensibility.¹³ SAGA-8 also proved itself as an easily-applied tool (only 8 items) to quickly obtain essential information on the emotional and physical impacts of GT feeding to support both the patient and their parents/caregivers. In a preliminary study comprising 26 caregivers of patients with severe deficiencies, 97% of them were satisfied with their decision to put their children through gastrostomy,¹² but the specific factors that

ción. La duración del soporte nutricional y la precocidad en la implantación de la gastrostomía son los responsables principales de la satisfacción de los cuidadores.

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Palabras clave: *Satisfacción parental. Cuidadores. Gastrostomía. Nutrición enteral domiciliaria. Soporte nutricional.*

added to that satisfaction were not evaluated. Among these factors, both the characteristics of the patient (primary diagnosis, children age of GT placement, length of HEN, anthropometric data and possible complications caused by the nutritional support) and the main caregiver (family demographic characteristics, degree of stress or feeling of burden) must be considered. A deeper knowledge of the factors that influence parental satisfaction may enable improved handling of their children and the adoption of new family-support measures. Having briefly reviewed the conclusions of previous studies, the aims of this study were: 1) Assess the degree of satisfaction of caregivers of children with gastrostomy and different pathologies through the structured questionnaire SAGA-8. 2) Evaluate if the parental satisfaction degree was related to several independent variables (age of GT placement, length of HEN, anthropometric data, nutritional support mode, family demographic characteristics and caregiver psychological status).

Material and methods

The study was conducted in two public tertiary hospitals in Spain at the Gastroenterology and Nutrition Units. The sample comprised pediatric patients with HEN by GT. Written parental consent was obtained. The study protocol was approved by the Ethics Committee from each hospital in accordance with the Declaration of Helsinki of 1964, revised in Seoul in 2008.

Participants

The sample comprised 92 caregivers of children with HEN support by GT. HEN indicators were classified as neurological disorders (n = 59), cardio-respiratory disease (n = 16), metabolic disease (n = 9), and miscellaneous group (n = 8): swallowing disorders (n = 5), digestive disorders (n = 2), oncologic disease (n = 1). Age at the time of GT placement ranged from 8 months to 16.1 years (median 5.3 years). Length of GT feeding was 5.2 years (SD 3.8). Average children age was 8.4 years (SD = 5.4), 54 boys and 38 girls. Average mother age was 38.3 years (SD = 6.3).

The following data was obtained regarding family demographic characteristics: parental educational level and occupational field. These factors were introduced

in the Hollingshead Occupational Scale¹⁴ to obtain the familial socioeconomic status.

For each child, the anthropometric parameters were obtained. The weight and height were measured and recorded using a standardized technique with age-appropriate material: clinical scale or Seca[®] baby scale (models 755/334) and infant measuring table or Holtain[®] stadiometer (Harpenden models). Body mass index (BMI) was calculated as weight (kg) divided by height squared (m²). With this data, the BMI for-age-Z score ($Z_{\text{BMI/A}}$) and the height for-age-Z score ($Z_{\text{H/A}}$) were then obtained using WHO growth standards for children.¹⁵

Nutritional support mode

To describe the nutritional support mode, the type of nutrients, feeding regime and infusion systems were studied. The type of nutrients were classified into home-made meals, enteral formula or combined. Patients in which over 60% of their intake was done through either homemade meals or enteral formula were included into the first or the second group, and those with no predominant intake method were included into the “combined” group. Regarding feeding regime, this was carried out between intermittent bolus feeding and cyclic or continuous infusion. Concerning infusion systems, patients were classified depending on whether they used syringes, pumps or both. The pumps were compact and portable (Abbott Companion Clear Star[®] and Nestlé Nutrition Compat-Go[®]).

Questionnaires applied

*Satisfaction questionnaire with gastrostomy feeding (SAGA-8).*¹² The SAGA-8 is a 8-item self-report questionnaire designed to assess satisfaction with gastrostomy for caregivers of children with HEN support by GT. The following aspects are covered by the questionnaire: the caregivers’ degree of acceptance of GT feeding, difficulty in applying gastrostomy, feeling of support from their nutritional support team, time saving in completing the feeding process, frequency of respiratory infections, feeling of improved nutritional status in their children, and possible changes in their familial environment. Lastly, parents were asked if, they foreseen actual the benefits of the nutritional support, they would have accepted GT placement earlier. This assessment was done through a Likert scale, with 5 possible answers for each question ranging from 1 (minimum) to 5 (maximum) and 3 questions assessed through a dichotomous scale (yes/no). The scores obtained on each item were added up, the total sum representing the caregiver’s degree of satisfaction. SAGA total score ranged from 8 to 31; a score above 20 (upper quartile) would reflect high parental satisfaction, as they would perceive that the child is able to withstand the GT feeding and that the

treatment offers benefits to both the children and its familial entourage. Psychometric properties were satisfactory with Cronbach’s alpha of 0.76.

Caregiver psychological assessment

*Symptom Checklist 90 Revised (SCL-90-R).*¹⁶ The SCL-90-R is a 90-item self-report questionnaire designed to assess a wide range of psychological symptoms in adults on a Likert-type five-point scale ranging from 1 (total absence of symptom) to 5 (full presence of symptom). The scale provides nine groups of symptoms: somatization disorder, obsessive-compulsive disorder, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. The analysis was based on the General Severity Index, which provides a reliable and valid measurement of psychological distress combining information on the number of symptoms the person presents and the perceived intensity of psychological distress. The test-retest reliability ranged from 0.78 to 0.90. Cronbach’s alpha ranged from 0.81 to 0.90.

Caregiver Burden Inventory (Zarit).^{17,18} This scale was designed to assess the feeling of burden experienced by caregivers of patients with a high degree of dependence. The scale is a 22-item self-report to assess the negative impacts on certain everyday tasks associated with care-giving, the effects on the caregiver, the expectancy and beliefs of the caregiver’s capacity, and the relationship between caregiver and patient. The caregiver was given a Likert-type scale of five frequency values ranging from 0 (not present) to 4 (always). The scores obtained on every item were summed, being the degree of burden of the caregiver the total result. This result ranged from 0 to 88 points. Generally, it is considered that there is no burden when the score is ≤ 46 , mild burden with scores between 47-55 points, and high burden with scores ≥ 56 . The psychometric properties were satisfactory with Cronbach’s alpha of 0.91 and good test-retest reliability of 0.91.

*State Trait-Anxiety Inventory (STAI).*¹⁹ The STAI is a questionnaire designed to evaluate two independent concepts of anxiety: state anxiety as a transitory or acute emotional condition that can vary overtime and fluctuate in intensity, and trait anxiety as a relatively stable tendency to perceive situations as a threatening. The score on the items of state varies between 0 and 3, establishing operational criteria according to intensity. The scale is widely accepted and extensively used in clinical research. The test-retest reliability was above 0.86, with Cronbach’s alpha between 0.84 and 0.93.

Statistical analysis

A descriptive analysis of the intervening variables was made. Nominal variables were analyzed through

Table I
Questionnaire results of SAGA-8 items in 92 caregivers

SAGA-8 questions	Results (%)				
	1	2	3	4	5
Q1: How do you rate your satisfaction with GT feeding?	1.1	–	1.1	15.2	82.6
Q2: How do you evaluate GT management?	1.1	–	12	28.3	58.7
Q3: How do you evaluate the support offered by our centre?	2.2	–	3.3	8.7	85.9
Q4: How do you perceive your child's change in nutritional status?	–	2.2	7.6	16.3	73.9
Q5: How do you rate the change in your child and your family's overall situation?	–	1.1	9.8	32.6	56.5
			No		Yes
Q6: Has the time necessary for feeding decreased?		25			75
Q7: Has the number of respiratory infections decreased?		31.5			68.5
Q8: Would you accept earlier GT placement with your current knowledge of the procedure's benefits?		28.3			71.7

Q1: Score range from 1 (totally unsatisfied) to 5 (very satisfied).

Q2: Score range from 1 (very difficult) to 5 (very easy).

Q3: Score range from 1 (totally insufficient) to 5 (very satisfactory).

Q4 and Q5: Score range from 1 (deteriorated) to 5 (significantly improved).

Q6-Q8: Score range from 1 (no) to 2 (yes).

Note: SAGA-8 questions were originally from Martinez-Costa et al.^{11,12}

Q: Question; GT: Gastrostomy tube.

median, frequency and percentages. Continuous variables were analyzed with central-tendency methods (average and interquartile interval) and dispersion methods (typical deviation). Association between parental satisfaction and the variables of the study was made through correlation coefficients (Pearson correlation for interval data, Cramer's V for nominal data). Linear regression analysis was conducted to capture the relationship of parental satisfaction with GT feeding (dependent variable) and children age of GT placement, length of HEN, anthropometric data, nutritional support mode (type of food, feeding regime, infusion system), family demographic characteristics and caregiver psychological status (independents variables). For statistical analysis we used the *Statistical Package for the Social Sciences* (SPSS), version 16.0. For all the tests carried out, bilateral statistical significance was set at p equal to or less than 0.05.

Results

The following paragraphs focus on the results of SAGA-8 degree-of-satisfaction questionnaire, the correlation between this degree of satisfaction and the variables that characterize both children and caregivers and, finally, the analysis of the variables that best express the caregivers' satisfaction.

Caregiver satisfaction with the treatment

All primary caregivers were mothers. Results showed that 82.6% of families ($n = 76$) expressed a high degree

of satisfaction with GT feeding. The simplicity of the system and its easy handling was emphasized by 87% ($n = 80$), and 85.9% ($n = 79$) were very satisfied with the help and support received from the hospital staff. Concerning the child's nutritional status, 73.9% of mothers ($n = 68$) acknowledged their child had clearly improved, whereas 16.3% thought this improvement to be moderate. Regarding familial routine life, 32.6% of mothers ($n = 30$) noted the relationship between family members had improved significantly, while 56.5% ($n = 52$) rated this improvement as excellent. Moreover, 75% ($n = 69$) of mothers reduced feeding time, and 68.5% ($n = 63$) reported less respiratory infections. Finally, when asked about the ideal moment to start GT feeding, 71.7% of mothers ($n = 66$) agreed that they would have implemented this technique earlier, see table I.

Correlation between caregiver satisfaction and child variables

Pearson correlation proved that caregiver satisfaction was positively correlated with children age of GT placement ($r = 0.263$, $p = 0.041$) and length of HEN ($r = 0.321$, $p = 0.016$), but not with $Z_{\text{BMI/A}}$ ($r = 0.118$, $p = 0.334$), $Z_{\text{H/A}}$ ($r = -0.086$, $p = 0.482$), primary caregiver age ($r = 0.050$, $p = 0.684$), or familial socioeconomic status ($r = 0.055$, $p = 0.653$) (fig. 1). Nevertheless, the Cramer V measure of association evidenced that no significant correlation was found between caregiver satisfaction and type of nutrients ($V_{\text{cramer}} = 0.204$, $p = 0.264$), feeding regime ($V_{\text{cramer}} = 0.213$, $p = 0.242$) or infusion system ($V_{\text{cramer}} = 0.210$, $p = 0.092$), see table II for complete results.

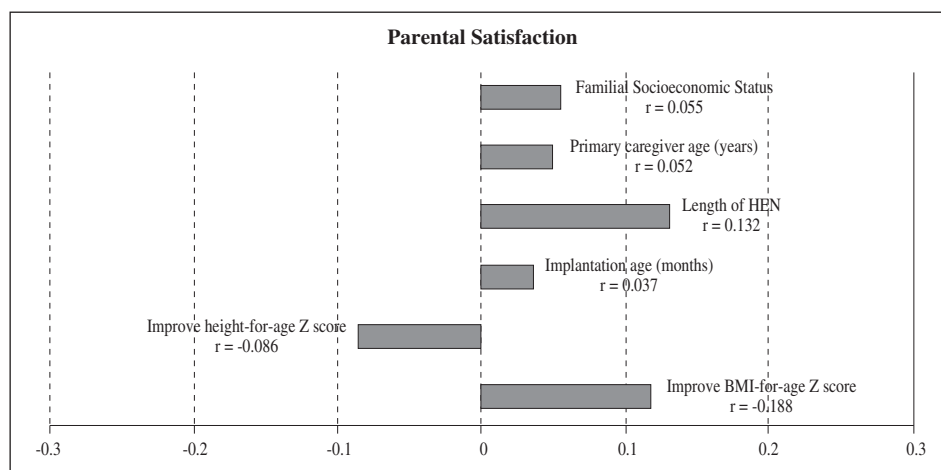


Fig. 1.—Correlation between caregivers' satisfaction with GT feeding and child variables (familial socioeconomic status, primary caregiver age, length of HEN, age of GT implantation ad anthropometric measures).

Table II
Frequency, percentage and nominal correlation between caregivers satisfaction with GT feeding and child variables (type of nutrients, regime feeding and infusion system)

Variables	N	%	Cramer's V	Sig.
<i>Type of nutrients</i>			0.204	0.264
Homemade meals	21	22.8		
Formula	43	46.7		
Combined	28	30.4		
<i>Feeding regime</i>			0.213	0.242
Intermittent bolus	55	59.8		
Continuous or cyclic	37	40.2		
<i>Infusion system</i>			0.210	0.092
Syringe	53	57.6		
Pumps	22	23.9		
Both	16	17.4		

*Miscellaneous group: swallowing disorder (n = 5), digestive disorder (n = 2), oncologic disease (n = 1).
GT: Gastrostomy tube.

Correlation between degree of satisfaction and psychological status of the caregiver

No significant correlation was found between caregiver satisfaction and psychological distress (SCL-90-R) ($r = 0.047$, $p = 0.704$), caregiver overload (Zarit) ($r = -0.125$, $p = 0.313$), anxiety state (STAI) ($r = 0.183$, $p = 0.138$) or anxiety trait (STAI) ($r = -0.105$, $p = 0.394$) in caregivers (fig. 2).

Variables expressing caregiver satisfaction with GT feeding

Linear regression results evidenced the length of HEN would be responsible for 10.3% of caregiver satisfaction ($F = 4.944$, $p = 0.031$), and that length of HEN together with the GT placement age would account for 19.4% of the variance of caregiver satisfaction ($F = 5.050$, $p = 0.011$) (table III).

Discussion

The results of SAGA-8 evidence an important degree of satisfaction in caregivers (mothers) of children suffering from different pathologies treated with HEN support by GT. Caregivers accepted the implementation of this particular treatment under the belief that it was helpful in managing their children and improved familial relationships. These findings are similar to that of other experts,^{20,21} who concluded that caregiver satisfaction with HEN in pediatric patients was mainly based in the improved well-being of their children.

In recent studies, Mahan et al.²² assessed the impact of HEN by GT in the quality of life (QoL) of children suffering from severe neurological problems by surveying their parents. These authors detected, six months after treatment start, a significant improvement in the child's overall health and motor capacity, together with a decrease in the time devoted to tasks

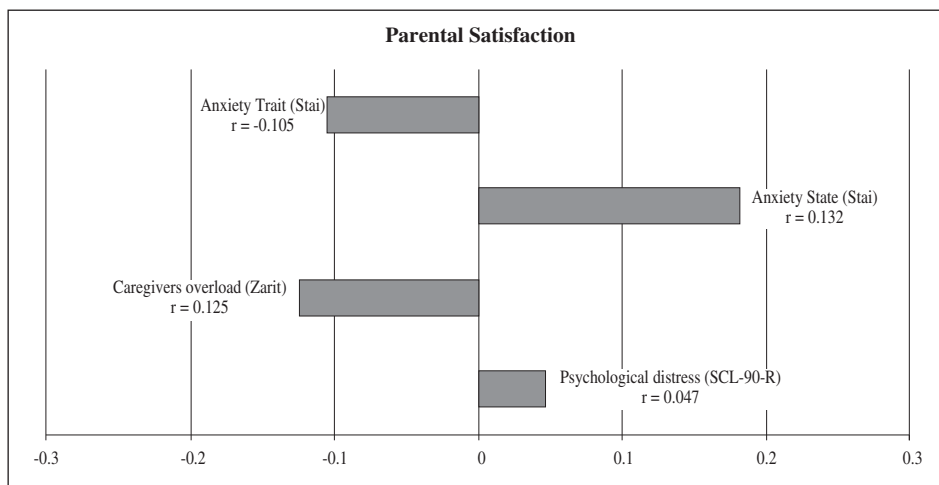


Fig. 2.—Correlation between caregivers satisfaction with GT and caregiver psychological assessment.

Table III
 Linear regression analysis to determine the relationship between caregivers satisfaction with GT feeding and the independent study variables; correlated R (R^2), non-standardized coefficient (B), and standard error, standardized beta coefficient (β); analysis of variance and significance level

Independent variables	Dependent variable	R^2	B	SE B	β	F	p
<i>Model 1</i>							
Length of HEN	Caregivers satisfaction with GT	0.103	0.017	0.008	0.321	4.944	0.031
<i>Model 2</i>							
Length of HEN	Caregivers satisfaction with GT	0.194	0.019	0.008	0.356	5.050	0.011
Age of GT placement			0.015	0.007	0.303		

Dependent variable: caregivers satisfaction with GT.

Model 1. Predictors: (Constant), length of HEN.

Model 2. Predictors: (Constant), length of HEN and age of GT placement (month).

GT: Gastrostomy tube; HEN: Home enteral nutrition.

such as feeding and drug administration. No differences, however, were found regarding factors such as pain, psychological health and the parents' emotional burden.²³ A similar investigation conducted by André et al.²⁴ found no improvement in QoL after GT feeding implementation in handicapped patients and, despite this fact, parents were satisfied with HEN. This apparent contradiction can probably be explained by the fact that QoL, defined as "multidimensional concept that compiles physical, social & psychological well-being",²⁵ is complicated to assess in children because of the already mentioned reasons, and because assessment methods are mainly generic questionnaires for children, hardly applicable to handicapped children with gastrostomy.²⁶ Probably caregiver satisfaction with GT feeding, assessed through a specific questionnaire, is a better indicator of treatment acceptance, offering at the same time valuable information about the child's physical and psychological well-being.

According to the SAGA-8 questionnaire, caregivers signaled less time was needed to feed their children, which enabled them to devote more time to other activities aimed at improving the QoL.^{27,28} Additionally, the caregiver subjectively perceived an improvement in

the child's nutritional status better than the actually anthropometrically measured one, a fact probably related to the patient's overall improvement.²⁹ Moreover, a significant percentage of the caregivers stated that respiratory infections had decreased in number, probably due to a fall in the number of aspirations. Similar results were found by Sullivan et al.,³⁰ who noticed that, although the severity of respiratory infections did not vary, less overall cases were reported after GT implementation. Improved nutritional status, in addition to preventing pulmonary aspiration, possibly favors a more effective cough, while GT ensures better hydration and drug administration.

Concerning caregiver psychological status, parental satisfaction was not significantly correlated to the caregiver's psychological characteristics, probably due to the fact that questions in SAGA-8 mainly focus on the impact of gastrostomy on the physical well-being of the child and its familial entourage. Nevertheless, some authors⁷ concluded psychological distress and parental anxiety negatively influenced in the caregiver's feeling of burden.

Length of HEN, together with age of GT placement, were found to be the two variables that accounted for a

greater percentage of the variance of caregiver satisfaction, that is, as GT feeding treatment time increased and earlier age of GT placement, the degree of satisfaction became higher. From previous experience, the correct choice of subsidiary patients of HEN (concerning both indication and age) and deciding the optimal age of GT placement, both crucial factors in treatment success, still remain a challenge for the multidisciplinary team in charge of making these decisions. Families tend to delay the time of GT placement, fearing an invasive technique accompanied of surgery and anesthesia of which they know very little, and viewed as an irreversible step in the child's evolution.^{31,32} Observation of our sample series revealed the majority of caregivers, would have implemented this technique earlier if they have foreseen its benefits.^{12,13} For this reason, GT placement is sometimes delayed over years, consequently leading to nutritional deterioration²⁷. In pediatric patients, it is crucially important that the sanitary staff takes into account the parents' perception and feelings during the process of treatment acceptance,³³ specialists and psychologists must offer their support constantly, and provide detailed information of the process.³⁴ Moreover, from our clinical experience we have concluded that putting in touch families who have gone through the same process or are currently in the same situation helps in preventing the delay in GT placement.^{12,13,27}

In conclusion, the SAGA-8 questionnaire is a simple, specific, straight-forward tool to evaluate parental/caregiver degree of satisfaction with GT feeding, helps the specialist in decision making, and facilitates effective monitoring of the intervention. Lengths of HEN and precocious age at GT placement are responsible for the most parental satisfaction.

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Conflict of interest statements: none declared.

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