

RESEARCH PAPER

Psychometric properties of the structured Satisfaction Questionnaire with Gastrostomy Feeding (SAGA-8) for caregivers of children with gastrostomy tube nutritional support

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Abstract

Aim: To analyse the psychometric properties of the structured Satisfaction Questionnaire with Gastrostomy Feeding (SAGA-8) in parents/caregivers of children with home enteral nutrition (HEN) by gastrostomy tube (GT).

Methods: Eighty-six caregivers (mothers) of paediatric patients with HEN by GT were recruited. Patients suffered from neurological disease (61.6%) and other chronic diseases. The SAGA-8 scale, a structured questionnaire to explore satisfaction with HEN by GT, and the Caregiver Burden Inventory (Zarit) were completed. The discriminating power of each of the SAGA-8 items, internal consistency and external validity were evaluated. An exploratory factor analysis and Kaiser–Meyer–Olkin (KMO) was performed as well.

Results: Eighty-four percent of the families expressed high satisfaction with GT feeding. All eight items of SAGA-8 gave additional information. The exploratory factor analysis revealed that a significant part of the items' variability could be explained by two independent factors: Factor 1 (direct benefit), which compiled the variables related to the perception of children's overall improvement by GT feeding; Factor 2 (indirect benefit), which grouped the variables related to a decrease in respiratory infections, feeding time and institutional support. Results from KMO (0.628) indicated the high adequacy of the items assessed in the factorial analysis. Moreover, the questionnaire presented high internal consistency (0.76), and the external validation analysis confirmed the correlation between SAGA-8 and Zarit, thereby emphasising the appropriate use of the SAGA-8 to detect carers' satisfaction.

Conclusions: The SAGA-8 questionnaire has a high discriminatory power to assess the degree of satisfaction experienced by parents/caregivers of children with HEN by GT and, subsequently, the patients' wellbeing.

3 Introduction

Home enteral nutrition (HEN), particularly by gastrostomy tube (GT), is a safe nutritional support mode in

paediatric patients. It is becoming increasingly used as a result of its advantages for both children and caregivers (Gómez-López *et al.*, 2010). Among these benefits, GT feeding facilitates the correction of nutritional deficits,

helps maintain an adequate growth (Craig *et al.*, 2006) and favours the patients' global improvement (Sleigh & Brocklehurst, 2004). Moreover, HEN by GT reduces the duration of hospital admission (Scott *et al.*, 2005) and enables a comfortable reintegration to the familiar and scholar environment. These factors contribute to improve the quality of life (QoL) of patients and their parents/caregivers (Sullivan *et al.*, 2004).

However, the accomplishment of all these goals entails the family's unconditional cooperation. Parents and caregivers must firstly accept GT insertion and subsequently receive adequate training in the child's particular disease and the necessary devices for a safe and efficient nutritional support (Townsend *et al.*, 2008). Together with the decision-making process required, such efforts often lead to a feeling of burden in patients and caregivers. This feeling is related to psychological distress and anxiety, which may lead to the disruption of family comfort. Early identification of this situation is essential to plan for specific support (Calderón *et al.*, 2011). It requires adequate tools for assessing the physical, social and emotional impact of GT feeding on both children and caregivers.

Many caregivers are initially reluctant to GT placement. However, after the initiation of this nutritional support, they acknowledge that it improves their child's nutritional status and thereby patients' QoL (Wang & Barnard, 2004). Assessing the satisfaction of both parents and caregivers is a practical method for adequately conducting therapy and preventing a lack of compliance (Petersen *et al.*, 2006). Similarly, the satisfaction of patients and caregivers is an accurate indicator of the quality of care provided and the QoL of both patients and their families (Wilson *et al.*, 2010).

The degree of satisfaction with HEN, in particular GT feeding, has been rarely analysed in the paediatric literature. This assessment is not always easy because patients are often too young and/or suffer from serious neurological diseases that prevent them from adequately responding to questionnaires. Hence, satisfaction must be indirectly assessed by evaluating care providers (Calderón *et al.*, 2011). In a previous study, our group assessed the degree of satisfaction reached by the caregivers of paediatric patients with HEN by GT through a structured questionnaire (Martínez-Costa *et al.*, 2011). The present study aimed to analyse the psychometric properties of the Structured Satisfaction Questionnaire with Gastrostomy Feeding among parents and caregivers of children with GT feeding to assess the multidimensionality, degree of reliability and validity of this tool.

Materials and methods

The study was carried out between September 2008 and September 2009 at the Paediatric Gastroenterology and

Nutrition Units of two public tertiary hospitals in Spain. The sample comprised voluntary parents or caregivers of paediatric patients with HEN by GT. The study protocol was approved by the Ethics Committee of each hospital in accordance with the Declaration of Helsinki of 1964, revised in Edinburgh in 2000. Written parental informed consent was obtained.

Participants

Eighty-six caregivers of children with HEN support by GT were recruited. All primary caregivers were mothers. The sample of patients comprised 49 boys and 37 girls with an mean (SD) age of 8.7 (5.3) years. Patients' diagnoses are provided on Table 1. Neurological pathology was the most common diagnosis (53 cases; 61.6%). This specific group was distributed as: quadriplegic spasticity (i.e. the severe form of cerebral palsy) was present in 33 cases; degenerative neuromuscular disorders such as muscular dystrophies were found in five cases; epileptic encephalopathy was found in four; dysmorphic syndromes were found in three; and, finally, the underlying disease was undetermined in eight cases. Age at the time of GT placement ranged from 8 months to 16.1 years (median 3.58 years). The mean (SD) duration of GT feeding was 5.5 (3.9) years. Mean (SD) maternal age was 38.1 (6.42) years. Regarding maternal education, 41.2% had completed basic studies, 25% had completed secondary studies and 33.8% had attained a higher educational level. With respect to occupation, 30.9% of mothers worked full-time, 25% worked part-time and 44.1% had no job at the time of the study.

Questionnaires applied

Structured Satisfaction Questionnaire with Gastrostomy Feeding (SAGA-8)

The structured Satisfaction Questionnaire with Gastrostomy Feeding (SAGA-8), which is specifically intended for parents and caregivers of children with HEN support through GT (Martínez-Costa *et al.*, 2011), was implemented to assess the degree of satisfaction with GT feeding (Table 2). The

Table 1 Main diagnoses

Main diagnosis	n (%)
Neurological illness	53 (61.6)
Cardiorespiratory disease	16 (18.6)
Inborn metabolic disease	9 (10.5)
Oncologic disease	4 (4.7)
Digestive disorder	2 (2.3)
Swallowing disorder	2 (2.3)

Table 2 Questionnaire results in 86 parents/caregivers

Question (Q)	Frequency (n) Values				
	1	2	3	4	5
Q1: How do you rate your satisfaction with GT feeding?	0	0	1	13	72
Q2: How do you evaluate GT management?	0	0	11	23	52
Q3: How do you evaluate the support offered by our centre?	0	2	2	6	76
Q4: How do you perceive your child's change in nutritional status?	0	2	7	13	64
Q5: How do you rate the change in your child and your family's overall situation?	0	1	7	29	49
	No			Yes	
Q6: Has the time necessary for feeding decreased?	22			64	
Q7: Has the number of respiratory infections decreased?	27			59	
Q8: Would you accept earlier GT placement with your current knowledge of the procedure's benefits?	22			64	

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

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

Q8, Q9, Q10: Score range from 1 (no) to 2 (yes).

questionnaire comprised eight questions: the first three surveyed the caregiver regarding parents' degree of acceptance towards gastrostomy, ease in implementation and assistance provided by their nutritional support unit. The other five surveyed the patient about the decrease in time needed for feeding, frequency of respiratory infections, and parental perception of their child's nutritional status improvement, together with possible changes in their family life. Lastly, parents were asked whether they would have agreed to gastrostomy implementation at an earlier stage had they foreseen its actual results. The assessment was performed with a Likert-type scale of five frequency values ranging from 1 (not present) to 5 (always present), or with a dichotomous scale (yes/no). In the latter case, a score of 1 corresponded to 'no' and a score of 2 corresponded to 'yes'. Accordingly, the total score of SAGA-8 ranged from 8 to 31 points. The questionnaire was conducted by telephone by a single paediatrician with no previous relationship to any of the patients or caregivers to avoid involuntary biasing.

Caregiver Burden Inventory (Zarit)

The Zarit (Hanzawa *et al.*, 2008) was designed to assess the potential negative impact of caregiving on certain daily tasks, effect on the caregiver's expectations, and caregiver-patient relationship. The scale comprises 22 items that are evaluated with a Likert-type scale. The individual scores on each item are added up, and the degree of burden of the caregiver is given by the total sum. This result ranges from 0 to 88 points: 'no burden' corresponds to a score ≤ 46 , 'mild burden' corresponds to the range between 47 and 55 points, and 'high burden' corresponds to a sum ≥ 56 . This scale was chosen on

the basis of its widespread use as a tool to evaluate the intensity of the caregiver's feeling of burden (Black *et al.*, 2009). Psychometric properties were satisfactory with Cronbach's α of 0.91 and test-retest reliability of 0.91.

Statistical analysis

The discriminatory power of each of the items of the SAGA-8 was analysed by calculating the item total correlation between each question score and overall assessment score. Values above 0.30 were considered acceptable. The Cronbach α of the instrument excluding each of the items was evaluated. For empirical evidence of the internal structure of the scale, an exploratory factor analysis using principal axes method and varimax rotation was conducted. Kaiser-Meyer-Olkin (KMO) index was used to measure sampling adequacy to investigate whether the application was relevant for factor analysis. Reliability analysis was conducted based on the analysis of internal consistency by calculating Cronbach's α . The minimum acceptable value for Cronbach's α coefficient was 0.60 and the expected maximum value was 0.90; beyond this value, it was considered that no redundancy or item duplication exists. Finally, external validity was assessed by applying Pearson's chi-squared test to compare SAGA-8 and the Zarit. To this effect, both variables were dichotomised. SAGA-8 categorised 25% of respondents as 'very satisfied' (highest total score) and 25% of respondents as 'somewhat unsatisfied' (lowest total score). Zarit classified participants with scores ≤ 46 as with 'no burden' and those with scores ≥ 56 as with 'high burden'. SPSS, version 16.0 (SPSS Inc., Chicago, IL, USA) was used for data

processing. For all the tests carried out, bilateral statistical significance was set at $P < 0.05$.

Results

SAGA-8

The results of the application of the SAGA-8 are shown in Table 2. A high satisfaction rate was manifested by 84% of the families ($n = 72$). Most parents/caregivers agreed moderate and strongly with the feasibility of the procedure (87%, $n = 75$). The majority emphasised the high-quality support provided by the hospital staff (88%, $n = 76$) and confirmed that time necessary for feeding and frequency of respiratory infections had decreased. As many as 74% ($n = 64$) of the families recognised they would have accepted earlier GT placement should they have foreseen its benefits. The remaining parents/caregivers (26%, $n = 22$) felt that GT placement was implemented at the appropriate time.

By contrast, total score analysis revealed 'somewhat unsatisfied' caregivers, who corresponded to the first quartile of total score distribution, scored ≤ 15 points. 'Very satisfied' caregivers, who corresponded to the fourth quartile, scored ≥ 20 points.

Statistical analysis of items in SAGA-8

The independent analysis of the discriminatory power of each of the items in SAGA-8 found that all eight items had correlation values ranging from 0.30 to 0.60. Additionally, internal consistency analysis revealed that exclud-

Table 3 Analysis of the discriminatory power of each of the eight items of the SAGA-8 and analysis of the Cronbach's α on standardised items

	α	r_{i-t}
Q1: How do you rate your satisfaction with GT feeding?	0.404	0.517
Q2: How do you evaluate GT management?	0.443	0.384
Q3: How do you evaluate the support offered by our centre?	0.522	0.318
Q4: How do you perceive the change in nutritional status?	0.343	0.570
Q5: How do you rate the change in your child and your family's overall situation?	0.330	0.600
Q6: Has the time necessary for feeding decreased?	0.453	0.341
Q7: Has the number of respiratory infections decreased?	0.474	0.277
Q8: Would you have agreed to earlier GT placement with your current knowledge of the procedure's benefits?	0.433	0.408

α = Cronbach's α if item deleted; r_{i-t} = Corrected item-total correlation; Cronbach's α based on standardised items = 0.764. GT, gastrostomy tube.

ing one of the items would not result in an increase in internal consistency, thereby confirming that all items provided complementary data (Table 3).

Analysis of SAGA-8 factors

Factorial analysis proved to be a practical means to condense the information collected with the questionnaire, in that it served to identify the minimum number of factors needed to explain the information compiled through the patients' answers. Results from KMO indicated high adequacy of the items assessed in the factorial analysis (KMO = 0.628) (Table 4). Results of the exploratory factorial analysis evidenced that the variability of the majority of the items (64%) could be explained by two factors: Factor 1 (direct benefit), which compiled the variables related to the perception of overall improvement through GT by the children and their families (items Q1, Q4, Q5 and Q8); Factor 2 (indirect benefit), which grouped the variables related to a decrease in respiratory infections, feeding time and institutional support (items Q2, Q3, Q6 and Q7). Item Q1 (degree of satisfaction with GT feeding) was the one which best represented factor 1 (72.8% of its variance). On the other hand, item Q7 (number of respiratory infections) was the one that best represented factor 2 (67.9% of its variance).

Table 4 Exploratory factorial analysis of the Satisfaction Questionnaire with Gastrostomy Feeding (SAGA-8) using varimax rotation and Kaiser–Meyer–Olkin (KMO) as a measure of sampling adequacy

	Factor 1	Factor 2
Q1: How do you rate your satisfaction with GT feeding?	0.728	
Q5: How do you rate the change in your child and your family's overall situation?	0.726	
Q4: How do you perceive the change in nutritional status?	0.711	
Q8: Would you have agreed to earlier GT placement with your current knowledge of the procedure's benefits?	0.518	
Q7: Has the number of respiratory infections decreased?		0.679
Q2: How do you evaluate GT management?		0.606
Q3: How do you evaluate the support offered by our centre?		0.577
Q6: Has the time necessary for feeding decreased?		0.568
Variance explained by each factor (%)	24.22	17.55
Cronbach's α based on standardised items	0.717	0.643

Extraction method: principal component analysis. rotation method: varimax with Kaiser normalisation.

KMO measure of sampling adequacy = 0.628.

Bartlett's test of sphericity (χ^2) = 79.208, $P = 0.0001$.

GT, gastrostomy tube.

Reliability analysis of SAGA-8

In the present study, Cronbach's α analysis found SAGA-8 has high inner consistency in samples of caregivers of children treated with gastrostomy (Cronbach's α based on standardised items; $\alpha = 0.764$). Inner consistency (Cronbach's α values) were 0.717 for factor 1 and 0.643 for factor 2, thereby confirming that SAGA-8 was a reliable tool.

External validity analysis of SAGA-8

Comparison of SAGA-8 and Zarit through Pearson's chi-squared test found a statistically significant association ($\chi^2 = 69.21$; $P = 0.001$) between degree of satisfaction according to SAGA-8 and feeling of burden according to Zarit. Sixty-two percent of the mothers who ranked high in Zarit also declared themselves unsatisfied with the results of HEN treatment in SAGA-8.

Discussion

The success of HEN support has been traditionally represented by the patients' reduced complication rate and prolonged survival. However, the degree of satisfaction of patients and caregivers is becoming a widely acknowledged indicator of HEN performance (McGrath *et al.*, 1992; Wang & Barnard, 2004). In addition, healthcare professionals are becoming increasingly aware that the attitude of parents/caregivers towards GT acceptance and subsequent HEN implementation is a key factor for the quality of care in patients with HEN (Brotherton *et al.*, 2007).

A significant number of children with this support mode are unable to express their satisfaction or disapproval with HEN treatment as a result of their youth or an underlying neurological disorder. Consequently, the opinion of parents/caregivers becomes an essential indicator. Gastrostomy feeding tends to be a stressful condition for children and families (Tawfik *et al.*, 1997) and professionals must be aware of this to enable the development of effective, family-focused and patient-specific interventions that facilitate GT acceptance and HEN implementation (Pedersen *et al.*, 2004).

Over the last decade, parental satisfaction towards certain medical or surgical paediatric procedures has been evaluated in different settings. Although some studies have performed their studies at the hospital (Sitzia & Wood, 1997), others have conducted their investigations at the family home (Chesney *et al.*, 2005; Mah *et al.*, 2006). At any rate, a close association has been found between the disease suffered by the patient and its impact on everyday life issues (Wogelius *et al.*, 2011; Varni *et al.*, 2012). Other studies have suggested that the satisfaction

of the patient's family is linked to a significant improvement in their capacity to adapt to the patient's situation (Pasquarella *et al.*, 2007; Edge *et al.*, 2011).

Focusing on HEN by GT, to our knowledge, there were no previous structured questionnaires capable of assessing the degree of satisfaction of parents/caregivers with this means of nutritional support. The results obtained in the present study indicate that SAGA-8 is a practical tool for this aim. In addition, it is simple, easily applied and fast. The analysis of items in SAGA-8 revealed that results can be explained by two factors: Factor 1 (direct benefit), which compiled the variables related to the perception of overall improvement through GT by the children and their families; Factor 2 (indirect benefit), which grouped all variables related to the overall decrease in respiratory infections, feeding time and necessary institutional support. In particular, the findings related to factor 1 are in agreement with those by Sleight & Brocklehurst (2004), who concluded that satisfaction with HEN in patients suffering from cerebral palsy was associated with an overall improvement in the child's condition. This improvement perception is also the result of a significant decrease in necessary feeding time, simplified drug administration and reduced concern about the child's nutritional status (Wang & Barnard, 2004). In a previous study by our group, parental perception of the patient's overall improvement was higher than the objective improvement in nutritional parameters, decrease in respiratory infections and shorter feeding times (Martínez-Costa *et al.*, 2011).

Patients with HEN are highly dependent on their caregivers, who must make an extensive effort, both physically and psychologically, to make up for all of the patient's needs. This burden tends to be bared most often by the mother (Gómez-López *et al.*, 2010). The present study assessed the relationship between this burden and the caregiver's degree of satisfaction with HEN. A positive correlation between SAGA-8 and Zarit (i.e. caregivers' feeling of burden) was found, in that caregivers who appeared to be more satisfied with GT were also those who ranked lower in the questionnaire that assessed the feeling of burden. This finding emphasises the ability of SAGA-8 to detect possible unsatisfied carers of children with GT feeding. In clinical practice, nurses could implement the questionnaire such that the clinical and emotional consequences of GT feeding could be assessed in an objective, fast, straightforward way. Similarly, this method would provide a sensitive means of evaluating whether the quality of the assistance offered by the Nutritional Support Unit is optimal or not. Because the scoring system ranges from 8 to 31 points, a score above 20 (upper quartile) would reflect high patient satisfaction.

Regarding the limitations of the present study, it must be noted that the information provided by SAGA-8 is not obtained directly from the patient but rather indirectly from its caregivers. Therefore, the extrapolation of results to other samples is limited. In future studies, it would be convenient to validate SAGA-8 in larger samples of children with GT feeding, which will permit us to obtain data related to sensibility, precision and discrimination capacity of this structured questionnaire.

Conclusions

In conclusion, SAGA-8 has a high discriminatory power to assess the degree of satisfaction experienced by caregivers of children with HEN by GT and, subsequently, the patient's wellbeing. The integration of this tool into the diagnostic process may provide key information to properly guide the patient's treatment and facilitate its family's adaptation to the situation.

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Conflict of interests, source of funding and authorship

- 4 The study has ethical adherence in all aspects. The authors declare that there are no conflicts of interest. All authors meet the appropriate authorship criteria and no author has been omitted from the list.

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CM-C, CC and CP-G were responsible for study design, data-collection, data analysis and preparation of manuscript. SB advised on patient recruitment and data interpretation, and revised the manuscript. LG-L was involved in study design, data interpretation and manuscript revision. All authors contributed to the concept and design of the manuscript, and critically reviewed and approved the final version.

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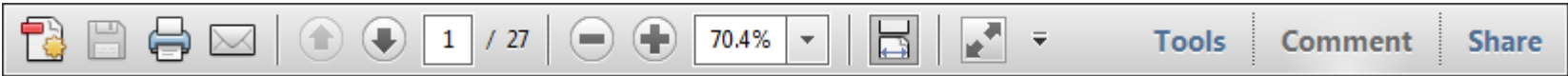


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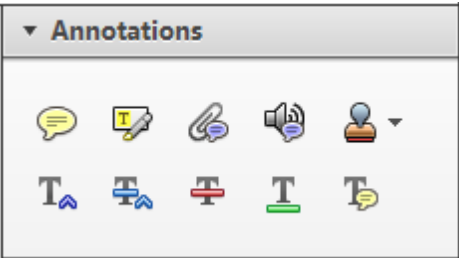
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This will open up a panel down the right side of the document. The majority of tools you will use for annotating your proof will be in the [Annotations](#) section, pictured opposite. We've picked out some of these tools below:



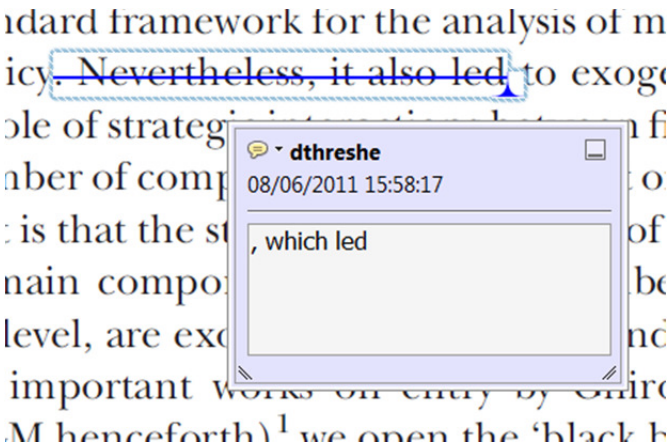
1. [Replace \(Ins\)](#) Tool – for replacing text.



Strikes a line through text and opens up a text box where replacement text can be entered.

How to use it

- Highlight a word or sentence.
- Click on the [Replace \(Ins\)](#) icon in the Annotations section.
- Type the replacement text into the blue box that appears.



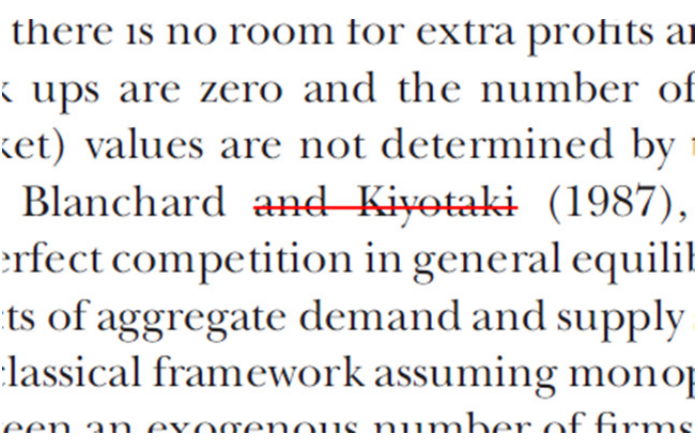
2. [Strikethrough \(Del\)](#) Tool – for deleting text.



Strikes a red line through text that is to be deleted.

How to use it

- Highlight a word or sentence.
- Click on the [Strikethrough \(Del\)](#) icon in the Annotations section.



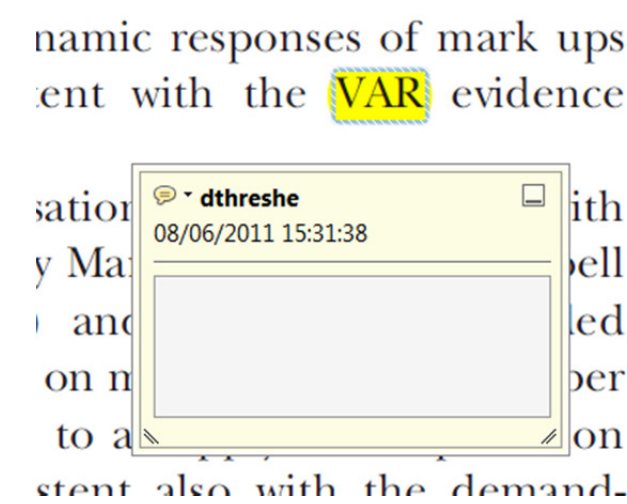
3. [Add note to text](#) Tool – for highlighting a section to be changed to bold or italic.



Highlights text in yellow and opens up a text box where comments can be entered.

How to use it

- Highlight the relevant section of text.
- Click on the [Add note to text](#) icon in the Annotations section.
- Type instruction on what should be changed regarding the text into the yellow box that appears.



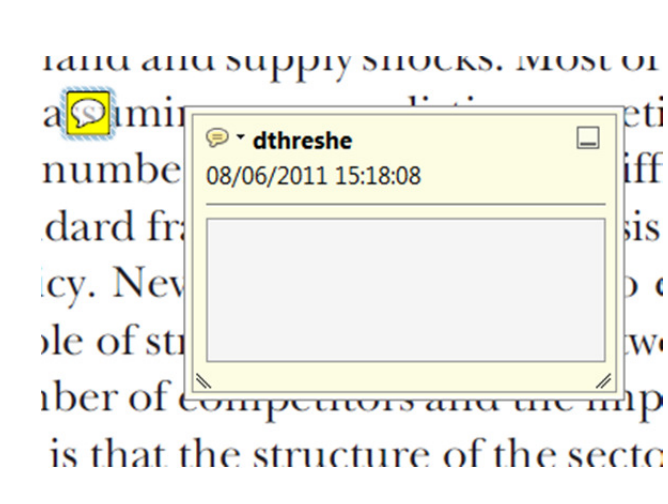
4. [Add sticky note](#) Tool – for making notes at specific points in the text.



Marks a point in the proof where a comment needs to be highlighted.


How to use it

- Click on the [Add sticky note](#) icon in the Annotations section.
- Click at the point in the proof where the comment should be inserted.
- Type the comment into the yellow box that appears.



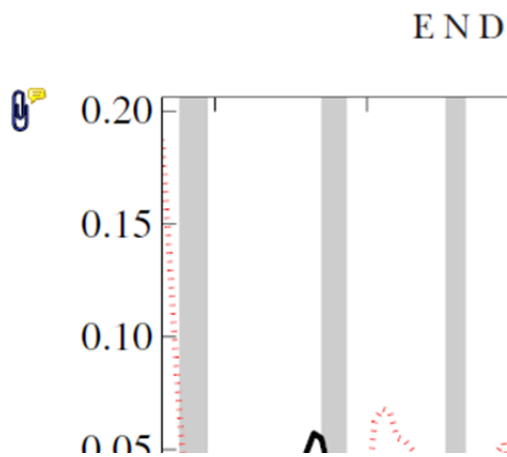
USING e-ANNOTATION TOOLS FOR ELECTRONIC PROOF CORRECTION

5. **Attach File** Tool – for inserting large amounts of text or replacement figures.


 Inserts an icon linking to the attached file in the appropriate place in the text.

How to use it

- Click on the **Attach File** icon in the Annotations section.
- Click on the proof to where you'd like the attached file to be linked.
- Select the file to be attached from your computer or network.
- Select the colour and type of icon that will appear in the proof. Click OK.



6. **Add stamp** Tool – for approving a proof if no corrections are required.

 Inserts a selected stamp onto an appropriate place in the proof.

How to use it

- Click on the **Add stamp** icon in the Annotations section.
- Select the stamp you want to use. (The **Approved** stamp is usually available directly in the menu that appears).
- Click on the proof where you'd like the stamp to appear. (Where a proof is to be approved as it is, this would normally be on the first page).

of the business cycle, starting with the
on perfect competition, constant returns
production. In this environment goods
extra profits and the structure of market
he model. The New-Keynesian model is
determined by the model. The New-Keynesian
otaki (1987), has introduced product
general equilibrium models with nominal
and supply shocks. Most of this literature

APPROVED

Drawing Markups

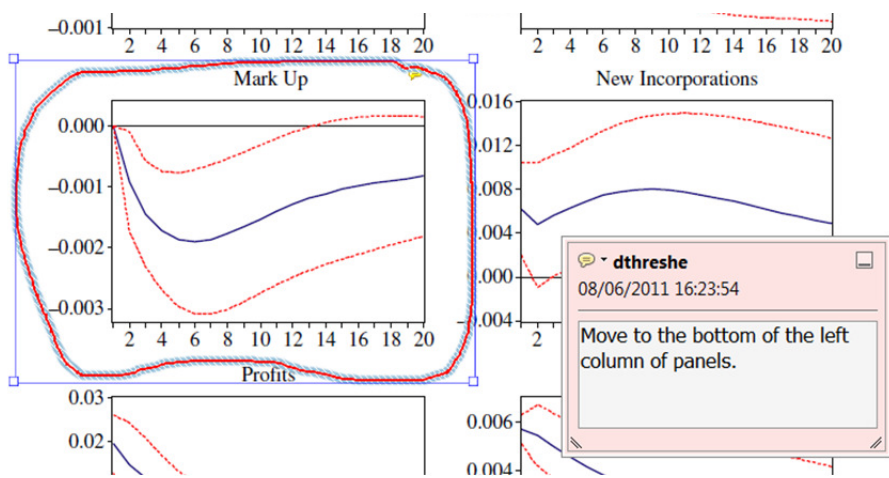


How to use it

- Click on one of the shapes in the **Drawing Markups** section.
- Click on the proof at the relevant point and draw the selected shape with the cursor.
- To add a comment to the drawn shape, move the cursor over the shape until an arrowhead appears.
- Double click on the shape and type any text in the red box that appears.

7. **Drawing Markups** Tools – for drawing shapes, lines and freeform annotations on proofs and commenting on these marks.

Allows shapes, lines and freeform annotations to be drawn on proofs and for comment to be made on these marks..



For further information on how to annotate proofs, click on the **Help** menu to reveal a list of further options:

