



Original article

Evaluation of burden and depression among caregivers of stroke patients: The role of percutaneous endoscopic gastrostomy feeding tube

Devrimsel Harika Ertem^a, Faik Ilik^{b,*}^a University of Health Sciences, Şişli Hamidiye Etfal Training and Research Hospital, Department of Neurology, Istanbul, Turkey^b KTO Karatay University, Medical Faculty Affiliated Konya Medica Hospital, Department of Neurology, Konya, Turkey

ARTICLE INFO

Article history:

Received 9 November 2018

Accepted 3 June 2019

Keywords:

Burden

Caregiver

Depression

Stroke

Percutaneous endoscopic gastrostomy

SUMMARY

Background & aims: Malnutrition problems are very common after a stroke. Several clinical studies have shown the contribution of percutaneous endoscopic gastrostomy (PEG) feeding after stroke in terms of improving nutritional status and reducing mortality. The aim of this study is to compare the burden and depression among caregivers of ischemic stroke patients fed with PEG and orally.

Methods: A total of 63 caregivers of patients with acute ischemic stroke who were followed up in the neurointensive care unit with modified Rankin Scale 4 or 5 were recruited in this cross-sectional survey. Clinical data of patients and demographical profile as age, gender, kinship to patient, income, and level of education of caregivers were recorded. On their 3rd-month follow-up visit, Beck Depression Inventory and The Zarit Burden Interview (ZBI) were administered to caregivers to evaluate depressive symptoms and caregiver burden. A semi-structured questionnaire was developed and conducted by the researchers with the caregivers to assess their thoughts of nutrition.

Results: Thirty-two caregivers of stroke patients on PEG and 31 caregivers of stroke patients who were fed orally were evaluated. The groups did not differ statistically in terms of demographic variables and depression scores ($p > 0.05$). However, the mean score of ZBI was significantly higher in the group of caregivers of stroke patients who were fed orally ($p = 0.00$). Caregivers of stroke patients on PEG had higher scores of caregivers' thoughts of nutrition support therapy questionnaire ($p = 0.00$).

Conclusions: Our findings demonstrate that caregivers of stroke patients report lower burden and higher level of positive thinking with PEG feeding than oral feeding. This suggests that nutritional care could include convenient and practicable methods for caregivers of patients with stroke in order to meet patients' nutritional requirements.

© 2019 European Society for Clinical Nutrition and Metabolism. Published by Elsevier Ltd. All rights reserved.

1. Introduction

People with stroke may suffer from difficulties associated with eating and drinking due to impaired consciousness, swallowing deficits, reduced mobility, and arm or facial weakness, fatigue, and visual-perceptual impairment. These patients are therefore at risk of disease-related malnutrition [1]. Dysphagia, difficulty with swallowing, is common after acute stroke, occurring in 20%–65% of patients. The great variation in prevalence can depend on the

heterogeneity of the patient population, timing of nutritional assessment and the diagnostic method used. Nutritional impairment can lead to serious complications outcomes (e.g., prolonged hospital stay, developing infections, decreased quality of life, higher mortality rates), in patients with both ischemic and hemorrhagic stroke [2–7]. For this reason, nutrition should be considered as part of stroke treatment [8]. Nutrition support is recommended for malnourished patients with stroke who are unable to obtain enough protein and calorie. If the patient with stroke is able to consume food or fluid orally and consume sufficient quantities, oral nutritional intake should be provided; however, PEG tube placement should be considered if neurological deficit cause impairment in ability to obtain sufficient oral intake [4,8]. Although major the stroke survivors are able to continue oral feeding, some cannot be

* Corresponding author.

E-mail addresses: hkazo@kto.ku.tr (D.H. Ertem), faikilik@hotmail.com (F. Ilik).

fed orally due to impaired consciousness, severe neurological deficits or dysphagia. In patients with acute stroke and dysphagia, to prevent complications resulting from the energy-protein deficit, enteral nutrition with a nasogastric tube or through percutaneous endoscopic gastrostomy (PEG) should be provided until swallowing difficulties improve or the patient is able to consume orally [9,10].

A high number of stroke patients with PEG tend to be older and dependent. Therefore, these group of patients require a caregiver to support them. Family caregivers of stroke patients have been reported to have stress, anxiety, exhaustion, isolation, and lower quality of life because of heavy responsibility [11–13]. Due to the unpredictable nature of stroke recovery, caregiving generally leads to being burden on family members or relatives of patients with stroke. It is evident that there is a higher risk of psychiatric symptoms among the caregivers of chronic illnesses as compared to the general population [14]. Using PEG to feed patients with stroke may be considered as a stressor factor for caregivers in their daily lives. However, no recent study has been conducted on the role of nutrition in the burden of caregivers of patients with stroke. The present study aimed to provide new data on the nutritional burden on caregivers comparing the burden and depression levels among caregivers of ischemic stroke patients fed by PEG and orally.

2. Methods

2.1. Participants

The prospective and cross-sectional study was approved by the Ethics Committee of the University of KTO Karatay where the study was performed (approval number: 41901325–050.99) and carried out in accordance with the Declaration of Helsinki. All participants signed an informed consent form. This study was conducted in caregivers of stroke patients who had been followed in our neurology department from January 2017 to January 2018. Ischemic stroke patients were selected to obtain a homogeneous patient group. The reason for an insertion of a PEG tube in these stroke patients was a clinical manifestation of swallowing difficulties. The patients were stratified into 2 groups: patients who were fed by PEG and patients who were fed orally. The study inclusion criteria were: 1) Caregivers of ischemic stroke patients with Modified Rankin Score (mRS) 4 or 5; 2) patients who were fed by PEG or orally; 3) caregiving at least 3 months by the same person. Subjects were excluded if: 1) the patients had hemorrhagic stroke; 2) the patient had PEG tubes used for other conditions; 3) other neurological or psychiatric diseases were present; 4) the caregiver had been assigned by professional health care companies; 6) the caregiver was earlier diagnosed mental illness and used psychiatric medications. Patients with similar stroke severity and dependency according to mRS were enrolled. All of the patients were fed by their caregivers. The patients who were fed orally did not have a nasogastric catheter or intravenous route and patients using PEG were not fed orally. All of the caregivers of the patients using PEG had been trained regarding PEG tube use and care.

One hundred thirty-seven ischemic stroke patients were evaluated during the study period. Six patients who had developed intracerebral haemorrhage, 5 patients whose caregivers had changed, 63 patients with mRS score 1 to 3 were excluded. A total of 63 patients and their caregivers were finally enrolled in the study.

2.2. Procedures

2.2.1. Sociodemographic data form

The data of the caregivers on sociodemographic variables such as age, gender, income, level of education and kinship to patient were recorded.

2.2.2. Evaluation of caregivers' thoughts of nutrition support therapy

A semi-structured questionnaire consisting of 5 questions was developed by the authors relating to the aim of this study based on relevant literature and the authors' experience. The questionnaire was conducted by the researchers to evaluate caregivers' experience of feeding. The items on the questionnaire are answered in a 5-point Likert format of 1–5 corresponding to strongly disagree, disagree, neither agree nor disagree, agree and strongly agree. A higher score indicates higher positive thinking.

The questions are listed below:

1. Do you think that feeding your patient is easy?
2. Do you think that feeding method of your patient is safe?
3. Do you think that your patient receives adequate nutrition?
4. Does feeding method of patient influence the workload of the caregiver?
5. Does feeding method of patient reduce caregiver's social disability?

2.2.3. The Beck Depression Inventory

The Beck Depression Inventory (BDI) is a 21-question, multiple-choice, self-report inventory for measuring the severity of depression [15]. Each question has 4 alternative options and the participants are asked to select the option that best describes their feelings for the last seven days among the options scored between 0 and 4. The total score ranges from 0 to 63 and higher scores indicate more severe depressive symptoms. Turkish validity and reliability of the BDI were made by Hisli et al. [16].

2.2.4. The Zarit Burden Interview

The Zarit Burden Interview (ZBI) evaluates the subjective experience of caregiver burden quantitatively [17]. ZBI consists of 22 questions with 5 possible answers (never, rarely, sometimes, quite frequently or nearly always). These questions assess the impact of caregiving on the physical and emotional health, social activities and financial status of the caregiver. The total score ranges between 0 and 88 points. Higher scores on the inventory indicate higher levels of burden. The application of the scale in Turkish has been tested for validity and reliability [18].

2.3. Statistical analysis

SPSS 23.0 was used as the statistical analysis program. Descriptive statistics (mean, standard deviation, frequency, and percentage) were used for demographic and clinical characteristics. The Mann–Whitney U test is used to compare differences between two independent groups. Pearson's Chi-square test was used for the comparison of categorical variables. The Spearman rank correlation was used for correlation analyses. $P < 0.05$ was considered significant in all statistical analyses.

3. Results

Sixty-three stroke patients and their caregivers were assessed. Thirty-two stroke patients on PEG (age 76.59 ± 7.99 ; range: 62–84; 12 male) and 31 stroke patients feeding orally (age 79.83 ± 7.09 ; range: 66–89; 14 male) did not have a statistically significant difference on mean age, gender, and mRS scores ($p > 0.05$). Demographic characteristics of the caregivers of stroke patients on PEG and feeding orally are shown in Table 1. In addition, there was no significant difference in terms of income of the relatives of the patients ($p > 0.05$). No statistically significant differences were

Table 1
Demographic characteristics of caregivers.

	Caregivers of stroke patients on PEG	Caregivers of orally fed stroke patients	P values
Number	32	31	0.98
Age (years)	49.56 ± 9.50	50.19 ± 8.87	0.80
Gender			
Male	9	12	0.37
Female	23	19	
Marital status			
Single	10	10	0.93
Married	22	21	
Level of Education			
Uneducated	11	10	0.97
Primary school	15	16	
High school	4	3	
University	2	2	
Kinship to patient			
Spouse	8	10	0.48
Daughters/sons	16	12	
Daughter-in-law	6	7	
Others	2	2	

found for socio-demographic characteristics of both caregiver groups.

The mean depression and burden scores of caregiver groups are presented in Table 2. No differences in depression levels were detected according to the BDI ($p = 0.42$). The mean burden score on the ZBI for caregivers of stroke patients on PEG was 41.68 ± 5.72 , representing a moderate burden and 49 ± 5.63 for caregivers of orally fed stroke patients which also indicates a moderate burden. However, the type of nutritional feeding affected the results. Thus, the mean burden score of caregivers was higher in oral feeding over PEG ($p = 0.00$). Table 3 shows the survey results of caregiver's opinions about patient's nutritional care. Caregivers of stroke patients on PEG had a higher scores of caregivers' satisfaction of nutrition support therapy questionnaire indicating higher level of positive thinking on their patient's feeding. In the correlation analyses, there were no correlation between BDI and ZBI ($p = 0.722$ $\rho = -0.046$).

4. Discussion

The aim of this study is to examine the effects of type of feeding on depression and caregiver burden in the caregivers of ischemic stroke patients population. The findings of this study demonstrated that even though both caregivers of stroke patients on PEG and who were fed orally had moderate caregiver burden, caregivers with PEG feeding reported lower burden and higher satisfaction than caregivers with oral feeding. Patient's nutritional status did not affect

depressive symptoms of caregivers. In addition, according to the results of questionnaire we developed, caregivers of stroke patients on PEG stated that they found feeding with PEG easy and safe and applicable to reduce their workload. It can be concluded that lower scores of ZBI in stroke patients with PEG might be considered as the patient was adequately fed and this caused a decrease in the workload and better functioning in caregiver's social life.

Recent studies reported that half of the patients with severe stroke were malnourished at some point during their hospital stay if longer than three weeks and in poststroke patients and the prevalence of malnutrition was found nearly 60% [19,20]. Malnutrition, dehydration, weight loss, fatigue, aspiration pneumonia and even higher mortality risk may arise in stroke over the course of the disease with the decreased ability to swallow [10]. It is well established that PEG tubes provide an actual benefit to the patient and his caregiver on long-term quality of life. Nonetheless, there is a lack of studies investigating the relationship between feeding type in patients with stroke and the caregiver burden.

In the study by Caro et al., they evaluated the burden and quality of life of family caregivers of patients with stroke [12]. They found that moderate burden was associated with an increased risk of depression and had effects on emotional health. The authors explained the reduction in burden by patients' cognitive decline, restricted physical mobility, old age, demand for intimate care, and carer being married. Our work differs from this study in terms of some features. First, in their study, they did not explore the effects of the type of feeding on caregiver's burden. Secondly, their sample

Table 2
Mean depression and burden scores of caregivers.

	Caregivers of stroke patients on PEG	Caregivers of orally fed stroke patients	P values
Mean BDI scores	15.37 ± 5.92	16.32 ± 5.28	0.42
Mean ZBI scores	41.68 ± 5.72	49 ± 5.63	0.00

Table 3
Survey results of caregiver's opinions about patient's nutritional support.

	Caregivers of stroke patients on PEG	Caregivers of orally fed stroke patients	P values
1. Do you think that feeding your patient is easy?	3.031 ± 0.860	2.354 ± 0.109	0.001
2. Do you think that feeding method of your patient is safe?	2.968 ± 0.860	2.387 ± 0.667	0.004
3. Do you think that your patient receive adequate nutrition?	3.125 ± 0.870	2.225 ± 0.668	0.000
4. Does feeding method of patient influence your workload?	2.875 ± 0.906	2.354 ± 0.550	0.008
5. Does feeding method of patient reduce caregiver's social disability?	3.062 ± 0.800	2.225 ± 0.668	0.000

of participants were predominantly caregivers of male stroke patients without associated comorbidities. In our two caregiver samples, the distribution of gender was very similar. The authors did not find a correlation between the level of burden and the psychological health and suggested that coping strategies and controlling emotions might be responsible for this.

PEG is a minimally invasive and convenient procedure with low complication rates [21]. PEG may provide reducing malnutrition and sequelae and improving survival for patients with impaired oral intake. However, feeding via PEG takes time and impacts daily routine of caregivers. The study by Jukic et al. is unique for assessing the difficulties and satisfactions of caregivers assisting older patients with home enteral nutrition therapy [22]. The authors examined the experiences of caregivers who were not healthcare professionals, who assisted old patients treated with enteral nutrition, and identified caregivers' level of preparation, their concerns and needs. They reported that all participants testified the initial fear and refusal to manage the nutrition therapy and informal caregivers suffered from the limitation in their leisure time. By contrast, according to the results of research by Villar-Taibo et al., the intense burden was more frequent in oral over enteral nutrition [23]. The researchers stated that the type of home artificial nutrition may be a reason for caregiver's burden. In our study, we observed that caregivers of stroke patients on PEG found feeding with PEG secure and easy to use. Our findings support the results of Villar-Taibo et al.

In spite of the importance of the impact of nutrition type in the burden of caregivers of patients with stroke, there are currently no published studies regarding the assessment of levels of burden and the psychological distress toward caregivers of ischemic stroke patients fed by PEG and orally. The strength of our study includes that we compared our results with two caregiver samples who provide different types of feeding for their patients. Besides this, we evaluated the depressive symptoms among caregivers of stroke patients and demonstrated that the type of feeding did not have direct effects on depression. The study was conducted in caregivers' of ischemic stroke patients which led to identify characteristics of burden and depression in a homogeneous group of participants. The questionnaire we developed helped us to explore family caregivers' experiences from their own perspectives. However, the lack of validation of the questionnaire for the assessment of caregivers' satisfaction of nutritional support therapy is one potential limitation of the current study.

In conclusion, our findings support a beneficial effect of feeding with PEG on caregiver's burden. To provide sufficient nutritional care, PEG tube feeding offers a considerable medical benefit in comparison with feeding orally. Further studies are needed to develop guidelines for a home-based long-term care plan to help caregivers of patients with stroke.

Funding

We don't have any financial disclosures. No funding to declare.

Authorship

Faik Ilik; design study, practical performance. Devrimsel Harika Ertem; data analysis, preparation manuscript, critical review manuscript.

Conflict of interest

The authors declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.clnesp.2019.06.002>.

References

- [1] Nishioka S, Okamoto T, Takayama M, Urushihara M, Watanabe M, Kiriya Y, et al. Malnutrition risk predicts recovery of full oral intake among older adult stroke patients undergoing enteral nutrition: secondary analysis of a multicentre survey (the APPLE study). *Clin Nutr* 2016;36(4):1089–96.
- [2] Gomes F, Emery PW, Weekes CR. Risk of malnutrition is an independent predictor of mortality, length of hospital stay, and hospitalization costs in stroke patients. *J Stroke Cerebr Dis* 2016;25(4):799–806.
- [3] Mourao AM, Lemos SMA, Almeida EO, Vicente LC, Teixeira AL. Frequency and factors associated with dysphagia in stroke. *CoDAS* 2016;28(1):66–70.
- [4] Martineau J, Bauer J, Isenring E, Cohen S. Malnutrition determined by the patient-generated subjective global assessment is associated with poor outcomes in acute stroke patients. *Clin Nutr* 2005;24:1073–7.
- [5] Davalos A, Ricart W, Gonzalez-Huix F, Soler S, Marrugat J, Molins A, et al. Effect of malnutrition after acute stroke on clinical outcome. *Stroke* 1996;27:1028–32.
- [6] Mosselman MJ, Kruitwagen CL, Schuurmans MJ, Hafsteinsdottir TB. Malnutrition and risk of malnutrition in patients with stroke: prevalence during hospital stay. *J Neurosci Nurs* 2013;45(4):194–204.
- [7] Foley NC, Salter KL, Robertson J, Teasell RW, Woodbury MG. Which reported estimate of the prevalence of malnutrition after stroke is valid? *Stroke* 2009;40:66–74.
- [8] Ojo O, Brooke J. The use of enteral nutrition in the management of stroke. *Nutrients* 2016;8.
- [9] Finestone HM, Greene-Finestone LS, Wilson ES, Teasell RW. Malnutrition in stroke patients on the rehabilitation service and at follow-up: prevalence and predictors. *Arch Phys Med Rehabil* 1995;76:310–6.
- [10] Teismann IK, Suntrup S, Warnecke T, Steinstrater O, Fischer M, Floel A, et al. Cortical swallowing processing in early subacute stroke. *BMC Neurol* 2011;11:34.
- [11] Wagachchige MM, Samarasinghe K, Elgán C. Caring for stroke survivors: experiences of family caregivers in Sri Lanka—a qualitative study. *Top Stroke Rehabil* 2018;20:1–6.
- [12] Caro CC, Costa JD, Da Cruz DMC. Burden and quality of life of family caregivers of stroke patients. *Occup Ther Health Care* 2018;32(2):154–71.
- [13] Perry L, Middleton S. An investigation of family carers' needs following stroke survivors' discharge from acute hospital care in Australia. *Disabil Rehabil* 2011;33(19–20):1890–900.
- [14] Abdollahpour I, Noroozian M, Nedjat S, Majdzadeh R. Caregiver burden and its determinants among the family members of patients with dementia in Iran. *Int J Prev Med* 2012;3(8):544–51.
- [15] Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatr* 1961;4:561–8.
- [16] Hisli N. Reliability and validity of the Beck depression inventory for university students. *J Psychol* 1989;7(23):3–13 (in Turkish).
- [17] Zarit S, Zarit J. Instructions for the burden Interview. University Park: Pennsylvania State University; 1987.
- [18] Inci F, Erdem M. Validity and reliability of the burden Interview and its adaptation to Turkish. *J Anat Nurs Health Sci* 2010;11:85–95.
- [19] Corrigan ML, Escuro AA, Celestin J, Kirby DF. Nutrition in the stroke patient. *Nutr Clin Pract* 2011;26(3):242–52.
- [20] Chai J, Chu FC, Chow TW, Shum NC. Prevalence of malnutrition and its risk factors in stroke patients residing in an infirmary. *Singap Med J* 2008;49(4):290–6.
- [21] Vanis N, Saray A, Gornjakovic S, Mesihovic R. Percutaneous endoscopic gastrostomy (PEG): Retrospective analysis of a 7-year clinical experience. *Acta Inf Med* 2012;20(4):235–7.
- [22] Jukic PN, Gagliardi C, Fagnani D, Venturini C, Orlandoni P. Home Enteral Nutrition therapy: difficulties, satisfactions and support needs of caregivers assisting older patients. *Clin Nutr* 2017;36(4):1062–7.
- [23] Villar-Taibo R, Martínez-Olmos MA, Bellido-Guerrero D, Calleja-Fernandez A, Peino-García R, Martis-Sueiro A, et al. Burden assessment in caregivers of patients with home artificial nutrition: a need and a challenge. *Eur J Clin Nutr* 2017;71(2):192–7.