



Tube-feeding Training, Caregiver Burden, and Quality of Life in Home Enteral Nutrition: A Comparison of PEG and Nasogastric Feeding

Evde Enteral Beslenmede Tüpü Besleme Eğitimi, Bakım Veren Yükü ve Yaşam Kalitesi: PEG ve Nazogastrik Beslenmenin Karşılaştırılması

^{ID} Aybüke Bacanlı, ^{ID} Seçil Arica

University of Health Sciences Turkey, Prof. Dr. Cemil Taşcıoğlu City Hospital, Department of Family Medicine, İstanbul, Turkey

Abstract

Objective: This study aimed to evaluate caregiver burden, complications, knowledge level, and quality of life (QoL) in caregivers of patients receiving home enteral nutrition (HEN) via percutaneous endoscopic gastrostomy (PEG) or nasogastric (NG) tube; to compare PEG and NG caregiver groups; and to identify independent predictors of physical QoL and caregiver burden.

Method: This cross-sectional, descriptive study enrolled 156 caregivers consecutively selected from 338 registered HEN patients at a home health unit. Data were collected face-to-face using the Zarit burden interview (ZBI), the SF-12 health survey, a researcher-developed knowledge level form, and a complication assessment form. Mann-Whitney U test, Kruskal-Wallis test with Bonferroni post-hoc correction, Spearman's correlation, chi-square/Fisher's exact tests, and multiple regression analyses [ordinary least squares (OLS) for SF-12 physical component summary; Huber-T robust regression for ZBI] were performed. Effect sizes were reported as r ($z/\sqrt{N}$) and η^2 .

Results: Of 156 caregivers, 81.4% were female with a mean age of 47.1 ± 13.1 years. Mean ZBI score was 41.08 ± 8.21 ; 62.2% had high caregiver burden. Short form-12 PCS was 37.77 ± 6.68 , markedly below the population norm of 50; 96.8% scored below this normative mean. The most frequent complications were diarrhea (58.3%), weight loss (49.4%), and feeding frequency problems (39.7%). PEG caregivers had significantly higher training rates (55.2% vs. 7.5%, $p < 0.001$), higher knowledge scores (median: 2.0 vs. 1.0; $r = 0.26$, $p = 0.001$), and fewer complications ($r = 0.19$, $p = 0.016$) than NG caregivers. Caregivers who had received tube-feeding training had higher knowledge

Öz

Amaç: Bu çalışma; evde perkütan endoskopik gastrostomi (PEG) veya nazogastrik (NG) tüpü ile beslenen hastaların bakım verenlerinde bakım yükü, komplikasyon profili, bilgi düzeyi ve yaşam kalitesini (YK) değerlendirmeyi; PEG ve NG grupları arasındaki farklılıkları ortaya koymayı ve fiziksel YK ile bakım yükünün bağımsız yordayıcılarını belirlemeyi amaçlamaktadır.

Yöntem: Kesitsel tanımlayıcı tasarımı bu çalışmaya, bir evde sağlık birimine kayıtlı 338 enteral beslenme [evde enteral beslenme (EEB)] hastasının bakım verenlerinden ardışık örnekleme yöntemiyle seçilen 156 kişi dahil edilmiştir. Veriler; Zarit bakıcı yük ölçeği (ZBY), SF-12 YK ölçeği [fiziksel bileşen özeti (FBO)], araştırmacı geliştirmesi bilgi düzeyi formu ve bakım komplikasyonları formu (BKF) ile yüz yüze toplanmıştır. Analizlerde Mann-Whitney U testi, Bonferroni düzeltmeli Kruskal-Wallis testi, Spearman korelasyonu, ki-kare/Fisher'in kesin testi ve çoklu regresyon [SF-12 FBO için sıradan en küçük kareler (SEK); ZBY için Huber-T robust regresyon] kullanılmış; etki büyüklükleri r ve η^2 olarak raporlanmıştır.

Bulgular: Bakım verenlerin %81,4'ü kadın olup yaş ortalaması $47,1 \pm 13,1$ yıldır. ZBY ortalaması $41,08 \pm 8,21$; %62,2'si yüksek bakım yükü kategorisindedir. SF-12 FBO $37,77 \pm 6,68$ ile popülasyon normunun (50) belirgin altında; bakım verenlerin %96,8'i norm ortalamasının altında kalmıştır. En sık komplikasyonlar ishal (%58,3), kilo kaybı (%49,4) ve sıklık sorunudur (%39,7). PEG bakım verenlerinde eğitim oranı (%55,2 vs. %7,5, $p < 0,001$), bilgi puanı ($r = 0,26$, $p = 0,001$) ve komplikasyon yükü ($r = 0,19$, $p = 0,016$) NG grubundan anlamlı biçimde farklıdır. Tüpü besleme eğitimi aldığını bildiren bakım verenlerin

Address for Correspondence: Aybüke Bacanlı, University of Health Sciences Turkey, Prof. Dr. Cemil Taşcıoğlu City Hospital, Department of Family Medicine, İstanbul, Turkey

E-mail: aybuke.bacanlı@gmail.com **ORCID:** orcid.org/0000-0003-1836-194X

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Abstract

scores ($p<0.001$); however, training status was not associated with lower complication burden, caregiver burden, or better QoL. Age was the sole independent predictor of PCS ($\beta=-0.240$, $p<0.001$). Daily caregiving hours ($\beta=0.184$, $p=0.009$), complication count ($\beta=0.627$, $p=0.027$), age ($\beta=0.102$, $p=0.020$), and caregiving duration ($\beta=-0.051$, $p=0.001$) independently predicted ZBI burden.

Conclusion: Physical health of HEN caregivers is substantially below population norms. Although previous tube-feeding training was associated with higher caregiver knowledge, it was not associated with better clinical or caregiver-related outcomes. Sustainable caregiver support, regular monitoring, and multidisciplinary interventions are needed beyond one-time education.

Keywords: Caregiver burden, caregivers, enteral nutrition, gastrostomy, home care services, quality of life

Öz

bilgi puanları daha yüksek olmakla birlikte ($p<0,001$), eğitim durumu komplikasyon yükü, bakım yükü veya YK'de anlamlı bir farklılıkla ilişkili bulunmamıştır. SF-12 FBO'nun tek bağımsız yordayıcısı yaştır ($\beta=-0,240$, $p<0,001$); ZBY'yi günlük bakım saati ($\beta=0,184$, $p=0,009$), komplikasyon sayısı ($\beta=0,627$, $p=0,027$), yaş ($\beta=0,102$, $p=0,020$) ve bakım verme süresi ($\beta=-0,051$, $p=0,001$) bağımsız olarak yordamıştır.

Sonuç: EEB hastalarının bakım verenlerinin fiziksel sağlık düzeyi popülasyon normlarının belirgin biçimde altındadır. Eğitim almış olmak daha yüksek bilgi düzeyiyle ilişkili bulunmakla birlikte, daha iyi klinik veya bakım verene özgü sonuçlarla ilişkili bulunmamıştır. Evde sağlık hizmetlerinde sürdürülebilir bakım veren desteği, düzenli izlem ve multidisipliner müdahaleler, tek seferlik eğitimin ötesinde gereklidir.

Anahtar kelimeler: Bakım verenler, bakım veren yükü, enteral beslenme, evde sağlık hizmetleri, gastrostomi, yaşam kalitesi

Introduction

Enteral nutrition is the standard nutritional support for patients with a functional gastrointestinal tract who cannot achieve adequate oral intake. Percutaneous endoscopic gastrostomy (PEG) and nasogastric (NG) tube feeding are the two most frequently used home enteral nutrition (HEN) modalities for long-term care (1). Advances in technology and shorter hospital stays have increasingly transferred enteral feeding management to informal caregivers at home.

HEN requires technical knowledge, continuous monitoring, and sustained physical effort—a multidimensional burden falling predominantly on family members without formal medical training. Folwarski et al. (2) reported poor quality of life (QoL) in 19% and depressive symptoms in 57% of HEN caregivers. Villar-Taibo et al. (3) identified intense burden in 32% of home artificial nutrition caregivers. A systematic review by Mou et al. (4) found that most HEN caregivers lack adequate information and support, developing coping strategies largely on their own.

Caregiver burden is multidimensional, encompassing temporal demands, physical effort, emotional exhaustion, and social isolation. Qualitative studies have documented a four-stage psycho-emotional transition in NG tube caregivers: Disruption, despondency, adjustment, and integration (5). Despite this, comparative analyses of PEG versus NG caregiver outcomes remain scarce, particularly in developing healthcare system contexts.

This study aimed to: (i) evaluate caregiver burden, complication profile, knowledge level, and QoL in PEG-

and NG-fed patients' caregivers; (ii) compare PEG and NG groups; (iii) examine the association between previous tube-feeding training and caregiver-related outcomes; and (iv) identify independent predictors of physical QoL and caregiver burden.

Materials and Methods

Study Design and Ethical Approval

This cross-sectional, descriptive study was conducted in accordance with the Declaration of Helsinki. Ethical approval was obtained from the local Non-Interventional Clinical Research Ethics Committee of University of Health Sciences Turkey, Prof. Dr. Cemil Taşcıoğlu City Hospital (decision no: 288, date: 16.12.2024). Written informed consent was obtained from all participants prior to data collection. Data were collected during routine home health visits using face-to-face structured interviews.

Study Population and Sampling

The target population comprised primary caregivers of patients registered with a home health service unit. Of 13,000 registered patients, 338 received enteral nutrition (PEG: $n=256$; NG: $n=82$). Sample size was calculated using the 19% poor-QoL rate reported by Folwarski et al. (2), with finite population correction ($n=338$), 95% confidence level, and 5% margin of error, yielding a minimum of 140 participants. A 10% increase was applied for potential data loss, setting the target at ≥ 155 . Consecutive sampling was performed during routine home visits over three months. Inclusion criteria: (i) Patient receiving enteral nutrition ≥ 2 months; (ii) caregiver aged ≥ 18 years; (iii) written informed

consent. A total of 156 caregivers were enrolled (PEG: n=116, 74.4%; NG: n=40, 25.6%).

Data Collection Instruments

A socio-demographic information form assessed caregiver age, sex, education, relationship to patient, employment, chronic/psychiatric illness history, caregiving duration, daily caregiving hours, feeding route, and use of an enteral feeding pump.

The knowledge level form (KLF) is a 5-item true/false instrument developed by the researchers, drawing on the ESPEN guideline on HEN (6) and the A.S.P.E.N. Enteral Nutrition Practice Recommendations (7), combined with clinical experience regarding the knowledge gaps most frequently encountered among caregivers of HEN patients. The items assessed: (i) Knowledge of the clinical indications for PEG/NG tube feeding; (ii) knowledge of the expected duration of tube use before scheduled replacement; (iii) knowledge of the importance of maintaining sterile/hygienic technique during feeding and tube care; (iv) knowledge of the recommended cleaning frequency for the tube and feeding equipment; and (v) knowledge of correct patient positioning and tube-position verification before feeding. Each item was coded 0 (incorrect/false) or 1 (correct/true); total scores range 0-5, with ≥ 3 indicating adequate knowledge. Cronbach's alpha was 0.600.

The complication assessment form (CAF) is a 13-item researcher-developed tool evaluating tube-related complications and care practices, generated by cross-referencing complication categories described in the ESPEN (6) and A.S.P.E.N. (7) enteral nutrition guidelines with the complication types most frequently observed in clinical experience within the unit's home health caseload. The items assessed: Correct water administration practice around feeds; equipment/material-related problems; correct dressing/stoma-site care practice; feeding temperature-related problems; feeding quantity/volume-related problems; difficulty checking gastric residual; feeding frequency/scheduling problems; tube obstruction; tube leakage; diarrhea; constipation; nausea/vomiting; and weight loss. Items CAF-1 (water administration) and CAF-3 (dressing/stoma-site care) assess correct care practices and are positively coded (reverse-scored: "Yes" =0, correct practice; "No" =1); the remaining 11 items assess complication occurrence directly ("Yes" =1; "No" =0). Higher scores indicate greater complication burden (range: 0-13). Item-total correlations ranged 0.064–0.273; Cronbach's alpha was 0.351. Because each item addresses

a physiologically independent complication, the CAF was treated as a numerical sum of clinical events rather than a psychometric scale; content validity was prioritized over internal consistency.

The Zarit burden interview (ZBI) is a validated 22-item, 5-point Likert scale (0-4; range: 0-88) developed by Zarit et al. (8) and validated in Turkish by İnci and Erdem (9). Scores ≥ 41 indicate high caregiver burden (10). Cronbach's alpha in this study was 0.741.

The SF-12v2 health survey (11) generates physical component summary (PCS) and mental component summary (MCS) scores (range: 0-100). The US normative mean is 50 (standard deviation: 10); higher scores indicate better health. Because 96.8% of caregivers scored below PCS<50, PCS was retained as a continuous variable in regression analyses.

Statistical Analysis

Data were analyzed using IBM SPSS Statistics 26.0 (IBM Corp., Armonk, NY, USA). Normality was assessed by Shapiro-Wilk test; all continuous variables violated normality ($p<0.05$). Two-group comparisons used Mann-Whitney U test; three-group comparisons used Kruskal-Wallis test with Bonferroni-corrected post-hoc pairwise comparisons. Categorical associations were assessed by chi-square or Fisher's exact test (when expected cell counts <5). Spearman's rank correlation coefficient quantified relationships between continuous variables. Effect sizes: r ($z/\sqrt{N}$) for Mann-Whitney U [small <0.30 ; medium 0.30-0.50; large >0.50] and η^2 for Kruskal-Wallis.

Residual normality for SF-12 PCS was confirmed (Shapiro-Wilk $W=0.989$, $p=0.257$); OLS regression was applied. ZBI residuals were non-normally distributed ($W=0.962$, $p=0.003$); Huber-T robust regression (iteratively reweighted least squares) was applied to reduce outlier influence. Multicollinearity was assessed by variance inflation factors (VIF); all predictors yielded $VIF<5$. Statistical significance: $p<0.05$.

Results

Socio-demographic Characteristics

Mean caregiver age was 47.1 ± 13.1 years (median: 45; range: 21-76); 81.4% were female. Educational attainment was predominantly low: 49.4% primary school, 40.4% secondary, 10.3% university. Most caregivers (80.8%) were unemployed. Regarding relationship to patient: 48.7% children, 25.6% spouses, 25.6% other relatives. Chronic

illness was reported by 45.5%; psychiatric illness by 21.2%. Mean caregiving duration was 38.5±38.5 months (median: 24); daily caregiving time was 19.5±7.4 hours (median: 24). Only 42.9% (n=67) had previously received tube-feeding training (Table 1).

Scale Scores and Classifications

Mean ZBI score was 41.08±8.21 (median: 42.0; range: 20-78); 62.2% (n=97) had high burden. SF-12 PCS was 37.77±6.68 and MCS was 40.49±8.89, both markedly below the normative mean of 50. Critically, 96.8% (n=151) scored below PCS<50—indicating near-universal physical health impairment, suggestive of widespread and underrecognized physical morbidity among HEN caregivers. Adequate knowledge was found in 60.9%; high complication burden in 26.3% (Table 2).

Complication and Burden Profiles

The most frequent complication was diarrhea (58.3%), followed by weight loss (49.4%), feeding frequency problems (39.7%), constipation (34.0%), and nausea/vomiting (31.4%). Gastric residual checking difficulties were reported by 30.1%. Water administration (98.1%) and dressing changes (87.2%) were performed correctly by most

caregivers. The highest ZBI item scores were for “feeling that the patient is dependent” (item 8: mean=2.90/4), “effect on relationships” (item 6: mean=2.60), and “fear about the future” (item 7: mean=2.50).

Comparison of PEG and NG Caregivers

PEG caregivers provided care for significantly longer durations (median: 36 vs. 12 months; $r=0.27$, $p<0.001$). Training uptake was substantially higher in the PEG group (55.2% vs. 7.5%, $\chi^2=25.68$, $p<0.001$), resulting in higher knowledge scores (median: 2.0 vs. 1.0; $r=0.26$, $p=0.001$) and lower complication burden (median: 3.0 vs. 4.0; $r=0.19$, $p=0.016$). Caregiver burden and physical QoL did not differ significantly between groups. NG caregivers achieving MCS ≥ 50 (37.5%) was significantly higher than PEG caregivers (18.1%; $\chi^2=5.26$, $p=0.022$) (Table 3).

Factors Associated with QoL and Caregiver Burden

Spearman’s analysis revealed a large-effect negative correlation between age and SF-12 PCS ($r=-0.538$, $p<0.001$). Caregiving duration showed medium ($r=-0.328$, $p<0.001$) and daily hours small effect ($r=-0.260$, $p=0.001$) on PCS. Positive correlations with ZBI were found for daily hours ($r=0.166$, $p=0.039$) and CAF score ($r=0.165$, $p=0.040$).

Table 1. Socio-demographic and clinical characteristics of caregivers (n=156)

Variable	n	%
Sex—female/male	127/29	81.4/18.6
Education—primary/secondary/university+	77/63/16	49.4/40.4/10.3
Relationship—child/spouse/other	76/40/40	48.7/25.6/25.6
Employment—unemployed/employed	126/30	80.8/19.2
Feeding route—PEG/NG	116/40	74.4/25.6
Enteral pump—yes/no	78/78	50.0/50.0
Chronic illness—yes/no	71/85	45.5/54.5
Psychiatric illness—yes/no	33/123	21.2/78.8
Tube-feeding training—yes/no	67/89	42.9/57.1
Age (years): Mean $\pm$ SD/median/range	47.1 $\pm$ 13.1/45/21-76	—
Caregiving duration (months): Mean $\pm$ SD/median	38.5 $\pm$ 38.5/24	—
Daily caregiving hours: Mean $\pm$ SD/median	19.5 $\pm$ 7.4/24	—

PEG: Percutaneous endoscopic gastrostomy, NG: Nasogastric, SD: Standard deviation

Table 2. Descriptive statistics of scale scores (n=156)

Scale	Mean $\pm$ SD	Median	Min-max	Class 1 n (%)	Class 2 n (%)
ZBI (0-88)	41.08 $\pm$ 8.21	42.0	20-78	59 (37.8%) low	97 (62.2%) high
SF-12 PCS (0-100)	37.77 $\pm$ 6.68	37.3	16.7-53.7	151 (96.8%) <50	5 (3.2%) ≥ 50
SF-12 MCS (0-100)	40.49 $\pm$ 8.89	38.3	28.0-59.9	120 (76.9%) <50	36 (23.1%) ≥ 50
KLF (0-5)	2.08 $\pm$ 1.31	2.0	0-5	61 (39.1%) inadequate	95 (60.9%) adequate
CAF (0-13)	3.19 $\pm$ 1.80	3.0	0-9	115 (73.7%) low	41 (26.3%) high

ZBI: Zarit burden interview, PCS: Physical component summary, MCS: Mental component summary, KLF: Knowledge level form, SF: Short form, CAF: Complication assessment form, SD: Standard deviation. PCS class 2 n=5; PCS used as continuous variable in regression analyses

Caregivers with chronic illness had lower PCS (median: 35.6 vs. 39.3; $p<0.001$, $r=0.43$). Employed caregivers had higher PCS (median: 42.7 vs. 37.3; $p<0.001$, $r=0.30$). Kruskal-Wallis showed significant PCS differences by education ($H=20.42$, $p<0.001$, $\eta^2=0.120$) and relationship to patient ($H=17.41$, $p<0.001$, $\eta^2=0.101$). Post-hoc: University graduates had higher PCS (median: 45.0) than primary ($p<0.001$) and secondary school graduates ($p=0.001$); spouse caregivers had lower PCS (median: 33.3) than caregiver children (median: 38.1; $p<0.001$) (Table 4).

Multiple Regression Analysis

The OLS model for SF-12 PCS was significant ($F=14.46$, $p<0.001$; adjusted $R^2=0.342$). Age was the sole independent predictor ($\beta=-0.240$, $p<0.001$): each additional year was associated with a 0.24-point PCS decrease. Other variables lost significance in the multivariable model. The Huber-T robust regression for ZBI showed daily caregiving hours ($\beta=0.184$, $p=0.009$) and CAF score ($\beta=0.627$, $p=0.027$) were

independent burden predictors. Age ($\beta=0.102$, $p=0.020$) and caregiving duration ($\beta=-0.051$, $p=0.001$) also contributed significantly (Table 5).

Clinical Outcomes According to Tube-feeding Training Status

Trained caregivers ($n=67$) had significantly higher knowledge than untrained caregivers ($n=89$; median: 3.0 vs. 1.0; $p<0.001$). However, no significant differences were observed in complication burden ($p=0.518$), ZBI score ($p=0.446$), SF-12 PCS ($p=0.345$), or SF-12 MCS ($p=0.091$). Caregivers with prior training had higher knowledge scores, but training status was not associated with measurable differences in complication burden, caregiver burden, or QoL.

Discussion

This study demonstrated that nearly all HEN caregivers (96.8%) had physical health scores below population

Table 3. Comparison of PEG and NG caregiver groups

Variable	PEG (n=116) median (mean $\pm$ SD)	NG (n=40) median (mean $\pm$ SD)	p	Effect size
Age (years)	48.0 (48.8 $\pm$ 13.2)	42.5 (42.3 $\pm$ 11.7)	0.010*	$r=0.21$
Caregiving duration (months)	36.0 (45.4 $\pm$ 40.8)	12.0 (18.5 $\pm$ 20.8)	<0.001***	$r=0.27$
KLF score	2.0 (2.3 $\pm$ 1.3)	1.0 (1.5 $\pm$ 1.3)	0.001**	$r=0.26$
CAF score	3.0 (3.0 $\pm$ 1.7)	4.0 (3.8 $\pm$ 1.9)	0.016*	$r=0.19$
ZBI score	41.5 (41.0 $\pm$ 8.8)	42.5 (41.3 $\pm$ 6.2)	0.583	—
SF-12 PCS	37.3 (37.8 $\pm$ 7.4)	37.3 (37.6 $\pm$ 4.2)	0.580	—
SF-12 MCS	36.2 (39.5 $\pm$ 8.3)	41.7 (43.3 $\pm$ 10.0)	0.072	—
Training received—n (%)	64 (55.2%)	3 (7.5%)	<0.001***	$\chi^2=25.68$
MCS ≥ 50 —n (%)	21 (18.1%)	15 (37.5%)	0.022*	$\chi^2=5.26$

Mann-Whitney U (continuous); chi-square (categorical). *: $p<0.05$, **: $p<0.01$, ***: $p<0.001$, PEG: Percutaneous endoscopic gastrostomy, NG: Nasogastric, KLF: Knowledge level form, CAF: Complication assessment form, ZBI: Zarit burden interview, PCS: Physical component summary, MCS: Mental component summary, SD: Standard deviation, SF: Short form

Table 4. Group comparisons of SF-12 PCS scores

Variable	Groups	PCS median (mean $\pm$ SD)	p	Effect size
Sex	Male/female	40.6/37.3	0.005**	$r=0.23$
Chronic illness	Yes/no	35.6/39.3	<0.001***	$r=0.43$
Employment	Employed/unemployed	42.7/37.3	<0.001***	$r=0.30$
Relationship (Kruskal-Wallis)	Spouse/child/other	33.3/38.1/37.7	<0.001***	$\eta^2=0.101$
Post-hoc: Spouse vs. child	—	—	<0.001***	—
Education (Kruskal-Wallis)	Primary/secondary/university+	37.3/37.3/45.0	<0.001***	$\eta^2=0.120$
Post-hoc: Primary vs. university+	—	—	<0.001***	—
Post-hoc: Secondary vs. university+	—	—	0.001**	—

Mann-Whitney U (two groups); Kruskal-Wallis + Bonferroni post-hoc (three groups). **: $p<0.01$, ***: $p<0.001$, PCS: Physical component summary, SD: Standard deviation, SF: Short form

Table 5. Multiple regression results for SF-12 PCS (OLS) and ZBI total (Robust regression)

Predictor	β	SE	t/z	p	95% CI
SF-12 PCS — OLS $R^2=0.368$; Adj. $R^2=0.342$ $F=14.46$, $p<0.001$ Residual normality: $W=0.989$, $p=0.257$ VIF max=2.12					
Age*	-0.240	0.048	-4.97	<0.001	[-0.34; -0.14]
Caregiving duration	-0.007	0.013	-0.53	0.595	[-0.03; 0.02]
Daily caregiving hours	-0.099	0.082	-1.21	0.227	[-0.26; 0.06]
Chronic illness	-0.602	1.204	-0.50	0.618	[-2.98; 1.78]
Sex (female)	-2.343	1.336	-1.75	0.082	[-4.98; 0.30]
Unemployed	-1.500	1.497	-1.00	0.318	[-4.46; 1.46]
ZBI—Huber-T Robust IRLS Residuals non-normal ($W=0.962$, $p=0.003$) VIF max=1.32					
Daily caregiving hours*	0.184	0.070	2.63	0.009	[0.047; 0.321]
CAF score*	0.627	0.283	2.21	0.027	[0.072; 1.182]
Age*	0.102	0.044	2.32	0.020	[0.016; 0.188]
Caregiving duration*	-0.051	0.015	-3.38	0.001	[-0.080; -0.021]
*: $p<0.05$, β : Regression coefficient, SE: Standard error, CI: Confidence interval, OLS: Ordinary least squares, IRLS: Iteratively reweighted least squares, VIF: Variance inflation factor, PCS: Physical component summary, ZBI: Zarit burden interview, CAF: Complication assessment form					

normative means and 62.2% experienced high caregiver burden. These figures substantially exceed those of Folwarski et al. (2) (poor QoL: 19%; WHOQOL-BREF) and Villar-Taibo et al. (3) (intense burden: 32%). The higher rates reflect the vulnerable sociodemographic profile of our sample: 80.8% unemployed and 45.5% with chronic illness. ZBI burden rates also exceeded the 22% moderate-to-severe rate among home parenteral nutrition caregivers (12).

At the ZBI item level, dependency, disruption of relationships, and existential fear were the primary burden sources, extending well beyond physical demands to encompass identity and autonomy. These findings align with qualitative reports of NG tube caregivers (5), underscoring that burden measurement tools capturing only practical load may underestimate the full caregiving experience.

The absence of significant differences in ZBI and PCS between PEG and NG groups suggests caregiver burden and physical health are shaped more by caregiving intensity and duration than by feeding modality. Nonetheless, PEG caregivers showed fewer complications, attributable to the structural advantage of longer caregiving experience combined with higher training uptake. The significantly higher rate of NG caregivers achieving MCS ≥ 50 (37.5% vs. 18.1%) may reflect the perception of NG feeding as a transient intervention—consistent with findings by Bentur et al. (13) on dependency-related outcomes in advanced dementia care.

The most clinically relevant finding is that prior tube-feeding training was associated with higher caregiver knowledge but was not associated with measurable differences in complication reduction, caregiver burden, or QoL. A video-enhanced training program by Kwok et al. (14) improved caregiver performance by 40%; however, Mou et al. (4) found that most HEN caregivers lacked adequate support and developed coping strategies independently. Our findings suggest that available training was theoretically oriented, without sufficient focus on practical complication management, adaptive problem-solving, or emotional resilience. Burnout-related reduction in implementation capacity and absence of ongoing reinforcement are plausible explanations. Recent evidence supports sustained, systematic training over single-session instruction to achieve meaningful HEN complication reductions (15). These results underscore that training caregivers alone is insufficient; sustainable support systems, regular professional monitoring, and multidisciplinary interventions are essential.

Age was the sole independent predictor of PCS, absorbing the effects of chronic illness, caregiving duration, and employment—highlighting the particular vulnerability of older caregivers. For ZBI, daily caregiving hours and complication count were independent predictors: directly actionable targets for intervention.

Study Limitations

The cross-sectional design precludes causal inference. Single-center sampling limits generalizability. The KLF and

CAF are researcher-developed instruments without full psychometric validation; in particular, the limited internal consistency of these forms, particularly the CAF (Cronbach's alpha: 0.351; KLF: 0.600), reflects the heterogeneous, single-domain nature of individual items rather than an underlying latent construct, and results based on these forms should be interpreted with this measurement limitation in mind. Self-reported data are subject to social desirability and recall bias. The NG group (n=40) was smaller than the PEG group (n=116), potentially limiting statistical power in some subgroup comparisons. Consecutive rather than random sampling may have introduced selection bias. The content and delivery format of tube-feeding training were not standardized or independently verified, so the null effect of training on clinical outcomes may partly reflect variability in training quality rather than an inherent limitation of caregiver education itself. Finally, this single-center study was conducted in one home health unit in Istanbul, and cultural, organizational, and healthcare-system factors specific to this setting may limit generalizability to other regions or countries.

Conclusion

Caregivers of home-fed PEG and NG patients face high burden, near-universal physical health impairment below population norms, and significant complication prevalence. Prior tube-feeding training was associated with higher knowledge but not with reduced complications, lower burden, or improved QoL. A paradigm shift is needed: from one-time caregiver education to sustainable support, regular physical health monitoring, and multidisciplinary intervention. Systematic health assessment of caregivers—particularly older and spouse caregivers—should be integrated into home health visit protocols.

Ethics

Ethics Committee Approval: Ethical approval was obtained from the local Non-Interventional Clinical Research Ethics Committee of University of Health Sciences Turkey, Prof. Dr. Cemil Taşcıoğlu City Hospital (decision no: 288, date: 16.12.2024).

Informed Consent: Written informed consent was obtained from all participants prior to data collection.

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Footnotes

Authorship Contributions

Surgical and Medical Practices: A.B., Concept: A.B., S.A., Design: A.B., S.A., Data Collection or Processing: A.B., Analysis or Interpretation: A.B., S.A., Literature Search: A.B., S.A., Writing: A.B., S.A.

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