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EVALUATION OF THE QUALITY OF LIFE OF CAREGIVERS OF PATIENTS WITH A GASTROSTOMY FEEDING TUBE

Gastroenterology

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ABSTRACT

The life quality of patient's caregivers who have a gastrostomy feeding tube at home has not been adequately researched, although it consists of an integral part of good home care. The aim of this study was to investigate the quality of life (QoL) of caregivers and identify the effective factors. A quantitative sample was created by 120 caregivers of patients with a gastrostomy feeding tube. The participants answered the following collection of questions: a sociodemographic characterization form, the SF-36 Health Research Questionnaire, the Greek Multidimensional Fatigue Questionnaire (MFI), and the Caring Behaviors Inventory-24 (24-item CBI or CBI-24). Regarding the SF-36 questionnaire, the lowest scores were recorded for the summary mental health scale (average value 43.8), the summary physical health scale (average value 49.8), as well as for the physical role dimension (average value 57.1). The data showed a positive correlation between married caregivers and cohabitants and physical functioning scores ($P = 0.001$) and that increasing year of care was associated with lower physical functioning scores ($P = 0.001$). In addition, an increase in the overall fatigue score (MFI-20) was associated with a decrease in the overall health score ($P <0.001$), vitality, emotional role, mental health ($P <0.001$), physical pain. ($P <0.001$) and social functionality ($P <0.001$). Moreover, informal caregivers had a higher score of physical pain than standard caregivers ($P = 0.010$). The results of this analysis suggest that the QoL of caregivers is affected across various domains and underscore the importance of QoL research particularly in the target populations.

KEYWORDS

Caregivers; Gastrostomy Tube Feeding; Quality of Life; SF-36; CBI24; MFI20

INTRODUCTION

Home enteral nutrition support is a method used to provide artificial administration of food to the gastrointestinal tract of patients who are unable or refuse to consume adequate oral intake requirements [1]. Tube feeding is effective in preventing or reversing malnutrition when digestive and absorption functions are adequate, but the nutritional requirements cannot be met by the oral route [2, 3]. Patients with dysphagia, anorexia, or small intestinal malabsorption [4], patients with stroke, dementia, cancer, neurodegenerative diseases [5], with multimorbidity, burns, neurological and psychiatric conditions, are potential candidates for home enteral nutrition support [6,7,8]. Intestinal feeding methods include the application of a nasogastric tube, nasolacrimal tube, gastrostomy, and jejunostomy [9].

The benefits of enteral feeding include improving the outcome of patients' health, reduced septic complications (compared to parenteral feeding), the fact that it is a more normal method of feeding (compared to parenteral), reduced costs [10], maintaining the immune system, stimulating intestinal adaptation and preventing bacterial displacement [11].

Intestinal feeding at home has become a widespread practice. The increase in its prevalence is expected to increase the burden on patient's families. Patients undergoing enteral feeding need support as they cannot self-care, thus the individual care required is provided by the caregivers leading to significant physical and emotional demands [12]. Taking responsibility for an enteral nutrition patient is stressful and has a negative impact on caregivers' quality of life [13].

The are several approaches to the term quality of life in social research. According to the World Health Organization, quality of life is defined as the 'perception of people of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations, and concerns' [14]. Quality of life is a multidimensional concept including domains related to mental, emotional, physical, and social functioning [15].

In the context of enteral feeding, providing therapy at home means transferring responsibilities and risks from the hospital to the home, with the physical and emotional demands placed on patient caregivers affecting their quality of life. Concurrently, the risks of care can turn caregivers into occult patients and affect both the quality of care provided and the outcome of treatment [8]. To balance the commitment of health professionals, resources, and quality of life of the family involved, monitoring the caregivers' situation is particularly important, especially in cases where caregivers are first-degree relatives, as is the case in approximately 80% of cases [16].

The psychological consequences for caregivers of patients undergoing enteral feeding depend on three main factors, namely a) external factors, such as home care, family social support, and financial resources, as well as cooperation with medical services and related factors including the doctor-patient relationship, knowledge of the disease, feeding route and ease of obtaining equipment and materials, b) by patient-related factors such as the severity of the disease, poor short-term prognosis, the patient-caregiver relationship, psychological condition, the ability to communicate with the family, any difficulty in handling the patient due to weight or deformities, etc.; c) by factors related to the caregiver, such as basic lifestyle, stress, fear of leaving the patient with another caregiver, prepare for technical work, work, etc. [17].

Some studies have revealed that family caregivers of patients receiving enteral feeding at home are more likely to suffer from weakness, limited social life, and social relationships as well as anxiety, depression, and psychosomatic symptoms, especially when the patient is a child. Other studies conducted on oncology caregivers reported a direct correlation between caregivers' quality of life and caregivers' quality, and others showed that caregivers' quality of life depended on the patient's type of disease [16].

Mauri et al. [18], conducted a study involving 84 caregivers of patients in a permanent vegetative state receiving enteral nutrition at home in order to investigate the health-related quality of life and psychological well-being of these caregivers and to identify the factors that affect their physical and psychological burden. The study found no differences in the health-related quality of life of caregivers compared to the general population, and caregivers reported satisfaction with the home-based bowel feeding method and the ongoing support they received to manage it. The most frequently mentioned advantages of enteral feeding at home were its friendly use but also its unique role in the health and well-being of the patient. On the other hand, it was found that depression, anxiety, and various psychosomatic symptoms were common in caregivers. The researchers concluded that it is important to provide psychological support to address the psychological burden of caregivers caused by providing assistance to their disabled relatives [18].

The findings of Pedrón‐Giner et al. were similar. The study investigated the predictors of discomfort among parents/caregivers of children with neurological diseases who received enteral feeding at home. The researchers found a high prevalence of anxiety-depressive symptoms, as well as a perception of psychological distress among caregivers [19].

The current study aimed to evaluate the quality of life of individuals caring for patients with a gastrostomy feeding tube and highlight the characteristics that affect the burden of care.

MATERIAL AND METHODS

The study included 120 caregivers in patients with a gastrostomy feeding tube. The study was carried out from December 2019 to May 2020. A permit was requested and received from the medical supplies manufacturing and marketing company "ORAMA SA", before the study. The company "ORAMA SA" was the carrier conducting the study. The principles of anonymity, the confidentiality of data, and voluntary participation of the study population were observed throughout the study. Each participant was assigned a serial number to ensure anonymity. The participants were informed about the study and the distribution and completion of the questionnaires took place after their written consent. Participation was voluntary and each caregiver reserved the right to terminate their participation and withdraw from the study at any time.

In the present study, the second version of the SF-36 (SF-36 version 2) was used to assess the health-related quality of life. The questionnaire consists of 36 items and explores eight dimensions of quality of life namely physical functioning (PF), physical role (PR) limitations due to health problems, bodily pain (BP), general health perceptions (GH), vitality (VT) tapping energy levels and fatigue, social functioning (SF), role limitations due to emotional problems (ER), and mental health (MH). The survey's validity and screening ability have been documented in various studies [20, 21].

MFI-20 was used as a complementary self-report scale. The questionnaire was designed to measure fatigue. It covers the following dimensions: general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue [22].

Additionally, the Caring Behaviors Inventory-24 (24-item CBI or CBI-24) was used in order to measure care. The instrument consisted of 75 questions, which later through a psychometric process were reduced to 42 and then to 24 questions. The questionnaire evaluates four factors, which include knowledge and skill, respect for others, human dignity as well as positive cohesion [23].

In the present study, permission was obtained for the use of all three questionnaires.

Statistical analysis

For the analysis of the results and the extraction of the relevant conclusions in the present study, the standardized scores (Norm-based Scoring - Mean = 50, SD = 10) were used for the easier comparison of the results with the corresponding results of similar studies. Standardized scores were simply referred to as scores in the present analysis.

The categorical variables are presented as absolute (n) and relative (%) frequencies, while the quantitative variables are presented as mean (standard deviation), or as median (intra-quadratic range). Kolmogorov-Smirnov test and regularity diagrams were used to control the normal distribution of quantitative variables.

The student's t-test was used to investigate the relationship between a quantitative variable and a bisector variable when the quantitative variable followed the normal distribution. Pearson's correlation coefficient was used to investigate the relationship between two quantitative variables that followed the normal distribution. Spearman's correlation coefficient was used to investigate the relationship between a quantitative variable and an orderly variable.

In the case where more than 2 independent variables were statistically significant at the level of 0.2 (P <0.2) in the bivariate analysis, multivariate linear regression was applied and scores were the dependent variable. In this case, the method of multiple linear regression with the backward stepwise line regression was applied. With respect to multiple linear regression, coefficients b (beta coefficients), the corresponding 95% confidence intervals, and P-values are presented.

The bilateral level of statistical significance was set equal to 0.05. Data analysis was performed with the IBM SPSS Social Science Statistical Package (Version 21.0. Armonk, NY: IBM Corp)

RESULTS

Internal consistency

Cronbach's alpha factor for the "assurance" score was 0.91, for the "knowledge and skills" dimension it was 0.86, for the "respectful" dimension it was 0.93, and for the "connectedness" dimension it was 0.91. In addition, for the data concerning the overall score of caring behaviors (CBI-24) the value was 0.97, which indicates an excellent internal consistency of the questionnaire.

Cronbach's alpha factor for the data concerning the "general fatigue" and "physical fatigue" dimensions was 0.95, for each, for the "reduced activity" dimension it was 0.85, for the "reduced mobilization" dimension it was 0.95, and for the "mental fatigue" dimension it was 0.98. Furthermore, for the data concerning the overall score of the fatigue (MFI-20) dimension the value was 0.98, which indicates excellent internal consistency of the questionnaire.

The internal consistency ratios for both summary scales were > 0.7 which indicates an acceptable internal consistency of the SF-36v2.

Participants/Demographic characteristics

The samples consisted of 26 males and 94 females, most of them informal caregivers of patients with gastrostomy catheter. Table 1 presents the demographic characteristics of the study participants.

Table 1: Demographic characteristics of the study participants.

Feature	N (%)
Sex	
Male	26 (21,7)
Female	94 (78,3)
Age (in years)[a]	52 (14,6)
Marital status	
Married	74 (61,7)
In cohabitation	2 (1,7)
Unmarried	22 (18,3)
Divorced	12 (10,0)
Widow	10 (8,3)
Type of caregiver	
Formal	45 (37,5)
Informal	75 (62,5)
Years of care[b]	5,0 (4,0)
Values are expressed as absolute frequency N and relative frequency (%), unless otherwise stated. [a] Mean (standard deviation) [b] Intermediate (intra-quadratic range)	

Scale of caring behaviors (CBI-24)

Caregivers' responses to the Four Dimensions of the Care Behavior Scale (CBI-24) (assurance, knowledge and skills, respectful, connectedness) are as follows:

Table 2: Descriptive measures of the CBI-24 Scale.

Dimensions	Mean value	Standard deviation	Medium	Minimum	Maximum
Assurance	5.2	0.8	5.4	2.8	6
Knowledge & Skills	5.2	0.8	5.3	2.8	6
Respectful	5.3	0.8	5.7	3.2	6
Overall	5.2	0.7	5.3	2.9	6

Short Form Health Survey Version 2.0 (SF-36v2)

Caregivers' answers regarding a questionnaire consisting of 36 items and exploring eight dimensions of quality of life including physical functioning (PF), physical role (PR) functioning, bodily pain (BP), general health perceptions (GH), vitality (VT), social functioning (SF), emotional role functioning (RE), and mental health (MH) are as follows (Table 3):

Table 3: Descriptive measures of the SF-36v2 quality of life ratings.

Dimensions	Mean value	Standard deviation	Medium	Minimum	Maximum
Physical functioning (PF)	88.1	20.8	95.0	10.0	100.0
Physical role functioning (PR)	57.1	47.8	100.0	0.0	100.0

Bodily pain (BP)	77.4	27.6	92.0	12.0	100.0
General Health (GH)	65.2	30.3	72.0	0.0	100.0
Vitality (VT)	63.0	31.3	70.0	0.0	100.0
Social role functioning (SF)	65.8	34.0	68.8	0.0	100.0
Emotional role functioning (ER)	60.0	47.7	100.0	0.0	100.0
Mental health (MH)	67.6	29.2	70.0	12.0	100.0

Greek Multidimensional Fatigue Questionnaire (MFI-20)

Caregivers' answers regarding the five dimensions of the Greek Multidimensional Fatigue Questionnaire (MFI-20) (general fatigue, physical fatigue, reduced activity, reduced mobilization, mental fatigue) are as follows (Table 4):

Table 4: Descriptive measures of the MFI-20 Questionnaire.

Dimensions	Mean value	Standard deviation	Medium	Minimum	Maximum
General fatigue	11.3	5.5	10.5	4	20
Physical fatigue	10.5	5.6	8.5	4	20
Reduced activity	9.1	4.3	9.5	4	20
Reduced Motivation	9.6	5.3	8.5	4	18
Mental Fatigue	11	5.8	11	4	20

Score correlations of variables

According to the results of the multivariate linear regression, for the correlation of the "physical function" score with 23 independent variables, it was revealed that married caregivers, or cohabiting caregivers, had a higher score of physical function than unmarried/divorced/widows ($P < 0.001$). Most years of care were associated with a lower score of physical function ($P = 0.003$). The highest overall score of caring behaviors (CBI-24) was associated with the highest score of physical function ($P = 0.001$) and the highest overall fatigue score (MFI-20) was associated with the lowest score of physical function ($P = 0.003$).

The correlation of the "physical role" score with 25 independent variables showed that the highest overall score of caring behaviors (CBI-24) was associated with a lower score of physical role ($P = 0.011$), while the highest overall fatigue score (MFI-20) was associated with the lowest physical role score ($P < 0.001$).

The correlation of the "physical pain" score with 24 independent variables showed that single, divorced and widowed caregivers had a lower rate of physical pain than married, or cohabiting caregivers ($P < 0.001$). The highest overall score of caring behaviors (CBI-24) was associated with the highest score of physical pain ($P < 0.001$), whereas the highest overall fatigue score (MFI-20) was associated with the lowest physical pain score ($P < 0.001$).

The correlation of the "general health" score with 25 independent variables showed that most years of care were associated with a lower general health score ($P = 0.001$). In addition, the highest overall score of caring behaviors (CBI-24) was associated with the highest overall health score ($P = 0.009$) while the highest overall fatigue score (MFI-20) was associated with the lowest overall health score ($P < 0.001$). Informal caregivers had a higher score of physical pain than standard caregivers ($P = 0.010$).

The correlation of the "vitality" score with 24 independent variables showed that that the highest overall score of caring behaviors (CBI-24) was associated with a higher score of vitality ($P = 0.030$), whereas, the highest overall fatigue score (MFI-20) was associated with the lowest vitality score ($P < 0.001$).

The correlation of the "social role functioning" score with 24 independent variables showed that the highest overall score of caring behaviors (CBI-24) was associated with the highest score of social functioning ($P = 0.015$), while, the highest overall fatigue score (MFI-20) was associated with the lowest social functioning score ($P < 0.001$).
The correlation of the "emotional role functioning" score with 23 independent variables showed that older age was associated with a lower emotional role score ($P = 0.025$). In addition, the highest overall fatigue score (MFI-20) was associated with the lowest emotional role score ($P < 0.001$).

The correlation of the "mental health" score with 24 independent variables showed that the highest overall fatigue score (MFI-20) was associated with the lowest mental health score ($P < 0.001$).

The correlation of "summary physical health" score with 2 independent variables showed that single, divorced and widowed caregivers had a lower score compared to married, or cohabiting caregivers ($P = 0.002$). In addition, most years of care were associated with a lower score ($P = 0.029$). The highest overall score of caring behaviors (CBI-24) was associated with the highest score ($P = 0.004$), while the highest overall fatigue score (MFI-20) was associated with the lowest summary physical health score ($P < 0.001$).

The correlation of the "summary mental health" score with 24 independent variables showed that the highest overall fatigue score (MFI-20) was associated with the lowest summary mental health score ($P < 0.001$).

The correlation of the score of "assurance" dimension with 22 independent variables showed that informal caregivers had a higher score (CBI-24) compared to formal caregivers ($P = 0.003$) and most years of care were associated with a higher score ($P = 0.010$). In addition, the highest score of the "summary physical health" was related to the highest score of the "assurance" dimension ($P = 0.003$), whereas, the highest of the total fatigue score (MFI-20) was associated with the lowest score of the "assurance" dimension ($P = 0.003$).

The correlation of the score of "knowledge and skills" dimension with 24 independent variables revealed that the highest overall fatigue score (MFI-20) was associated with the lowest score of the "knowledge and skills" dimension ($P < 0.001$).

The correlation of the score of "respectful" dimension with 21 independent variables showed that the highest score of the dimension was associated with the highest score of the summary mental health scale ($P = 0.007$). Furthermore, informal caregivers had a higher score of the "respectful" dimension compared to formal caregivers ($P = 0.005$).
The correlation of the score of the "connectedness" dimension with 21 independent variables showed that the highest score of the "summary physical health" was related to the highest score of the "positive connectedness" ($P = 0.004$). Respectively, the highest score of the "summary mental health" was related to the highest score of the "positive connectedness" dimension ($P = 0.038$). In addition, informal caregivers had a higher score of "positive connectedness" compared to informal caregivers ($P = 0.004$).

Finally, the correlation of the score of the "total care behavior" with 21 independent variables showed that the highest score of the "summary physical health" was associated with the highest overall score of care behavior (CBI-24) ($P = 0.039$), while the highest overall fatigue score (MFI-20) was associated with the lowest overall care behavior score (CBI-24) ($P < 0.001$). Furthermore, informal caregivers had a higher score of the total care behavior score (CBI-24), compared to formal caregivers ($P < 0.001$).

DISCUSSION

The analysis of the socio-demographic characteristics of the participants showed that the majority of caregivers were informal (62.5%) and mainly women (78.3%). The average age of caregivers was 52 years and almost 2/3 of them were married (61.7%). These findings are similar to those of the European project Eurofamcare, which showed that informal caregivers are mainly women (76%), with an average age of 55 years, married (22%), with children of their own or adopted (60%), living in the same household or in the same building as their patients (56%). In this study, the average duration of care was 5 years [24].

The average value of the scores of the SF-36 questionnaire for the "physical functioning" and "vitality" dimensions was 88.1 and 63.0, respectively. According to a survey, the average score for the "physical function" dimension of the SF-36 questionnaire in developed countries is between 80 and 90, while the average score for the "vitality" dimension is below 60, on a scale of 100 points, in the general population. [14]. Based on this finding, the health status of the caregivers participating in our study was close to the average. In addition, for the SF-36 questionnaire the lowest scores were recorded for the "summary mental health scale" (average value 43.8), for the

"summary physical health scale" (average value 49.8) as well as for the "physical role" dimension (average value 57.1).

The multivariate linear regression with the "physical functioning" score as a dependent variable, showed that marital status and years of care are factors that affect the physical functionality of caregivers. In particular, it was found that married caregivers and cohabitants had a higher score of "physical functioning" than unmarried, divorced and widowed (P = 0.001) and that most years of care were associated with a decrease in the score of "physical function" (P = 0.003). In terms of years of care, our findings contradict those of another study which found that a shorter duration of care was associated with a higher burden on caregivers, suggesting that new caregivers may take time to adjust to the stress of taking on additional care [25]. Regarding the marital status of caregivers, contrary to the findings of our research are those of Tulek et al. [26], whose study concerned the assessment of burden and quality of life in caregivers of patients with dementia. The authors found that the marital status affected the overall burden on caregivers, but contrary to our findings they found that married caregivers had significantly worse outcomes in terms of physical, social and overall burden compared to single/divorced or widowed caregivers and that marital status was associated with a lower quality of life [26].

In the present study, a statistically significant positive correlation was found between the score of caring behaviors (CBI-24) and physical function (P = 0.001), as well as a statistically significant negative correlation found between the total fatigue score (MFI-20) and the physical functioning score (P = 0.003).

We also found that the highest overall fatigue score (MFI-20) was associated with the lowest "mental health" score (P <0.001). This finding is consistent with the findings of other international studies, according to which the increased burden on caregivers has been associated with the deterioration of their health-related quality of life (HRQoL) and especially mental health. Caring for a person with a disability immediately leads to a lack of personal time and as a result, caregivers may find it difficult to relax or engage in social activities. This puts a lot of pressure on caregivers. The research of Du et al. showed that caregivers who reported high levels of stress also had poorer physical function, fewer social contacts, and more emotional distress than other caregivers [27].

Regarding the "physical role" dimension, it was found that the highest total score of care behavior (CBI-24) and the highest overall fatigue score (MFI-20) were associated with the lowest physical role score (P = 0.011 and P < 0.001, respectively).

From the multivariate linear regression with the score of "physical pain" dimension as a dependent variable, we found that unmarried, divorced and widowed caregivers had a lower score of "physical pain" than married, or cohabiting caregivers (P = 0.001). We also found that the total score of caring behaviors (CBI-24) was associated with a higher score of "physical pain" (P<0.001), while the highest total score of fatigue (MFI-20) was associated with a lower score of "physical pain" (P <0.001). We also found that informal caregivers had a higher score of "physical pain" than formal caregivers (P = 0.010). The latter finding of our study is contrary to that of Diniz et al. [28] who conducted a study comparing the health conditions and burden of formal and informal caregivers of the elderly. The study showed that caregivers had health problems and injuries directly related to their work and that formal caregivers had a higher prevalence of back pain compared to informal caregivers, suggesting that it was not just age that was associated with physical symptoms, but also the performance of the caregiver [28]. This difference may be due to the different population of caregivers studied by the researchers.

In addition, the highest total fatigue score (MFI-20) was associated with a lower score of general health (P <0.001), vitality, emotional role (P <0.001), and social functioning (P <0.001) of the SF-36 questionnaire. Our findings are consistent with the literature, according to which the care of patients with chronic diseases for long periods of time is accompanied by many consequences for informal caregivers, such as mental, physical and material burden but also with an increased risk of death [24]. According to the literature, caregivers' risk factors include depression and social isolation [29], while subjective burden for caregivers has also been associated with anxiety, depression and adverse effects on their physical health [30]. Other prognostic sociodemographic and psychological risk factors for caregivers include low monthly income, female gender, low educational attainment, cohabitation with the patient, poor mental health, poor well-being, high levels of stress, increased patient care burden and inadequate family functioning [31].

Another finding of the present study is that the highest total fatigue score (MFI-20) was associated with the lowest score of the "Knowledge and skills" dimension (P <0.001) of the CBI-24 questionnaire. It has been shown in the literature that family caregivers often feel unprepared for care, have insufficient knowledge to provide adequate care, and receive little guidance from official health care providers. These insufficient knowledge and skills result in family caregivers not being familiar with the type of care they need to provide or the amount of care required [32] and therefore may have low self-esteem and feel unprepared. These feelings of uncertainty that they experience contribute to feelings of discomfort [33]. In addition, these caregivers may not know when they need community resources, or how to better access and use available resources. As a result, caregivers often neglect their own health care needs in order to help their family member, thereby worsening their own health and well-being [32].

Finally, in the present study we found that the highest score on the summary mental health scale was associated with a higher score of the "Respectful" dimension (P = 0.007), with informal caregivers having a higher score of this dimension, compared to the formal ones (P = 0.005). Smith et al, who investigated long-term correlations between caregiver stressors, caregiver depression, and quality of care, found that caregivers who were more depressed, provided care with less respect for the patient and were more likely to engage in potentially harmful behaviors, such as shouting, threatening, or even physically abusing the patient [34, 35].

Limitations

Limitations of the study include the small sample size, the fact that the results do not reflect the quality of life of caregivers over time but only at the time of completing and submitting the questionnaires. Furthermore, because the study is cross-sectional, the observed correlations cannot be interpreted as causal.

As for the external validity of the study, it concerns a sample from a specific company and cannot be generalized to the entire population of Greek caregivers. In addition, no analyses were presented depending on the underlying disease of the patients, or technical characteristics of the feeding (tube types, etc.) or further characteristics of the patients (e.g., body mass index, patient age, same or different sex with caregiver and patient's family environment).

CONCLUSION

Patients undergoing enteral feeding at home are highly dependent on their caregivers, who must make significant efforts, both physical and psychological, to compensate for all of the patient's needs [36] and for this reason caregivers are at increased risk of physical and mental health problems [37]. The literature provides essential evidence that informal caregivers are individuals who need protection from the physical and emotional consequences of the care they provide [24].

Only a few questionnaires specifically designed and validated for patient caregivers are available, while valid and reliable questionnaires specifically assessing the quality of life of patient caregivers are available for chronic diseases such as Alzheimer's disease and cancer, but not for caregivers of patients undergoing home enteral feeding. The development of such tools is an important step in examining the quality of life of caregivers.

This study underscores the importance of quality of life research particularly for this population group. More studies are required on the caregivers of these patients, as well as the factors that affect their quality of life, in order to design appropriate interventions to meet their needs. Supporting caregivers, identifying the gaps in their knowledge, pointing out the problems that may arise in the course of care and meeting their personal needs, can increase the quality of life of both the patient and the caregiver.

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