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Original Article

Quality of life evaluation study for caregivers of patients undergoing enteral tube feeding at home

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Abstract

Aim: Care burden in patients undergoing enteral tube feeding at home reduces the quality of life their caregivers. Quality of life for caregiver, an integral part of a good homecare, has not been adequate researched with regard to quantity and attribution.

Material and Methods: A quantitative sample was created totally 95 primary caregivers of patients undergoing more than one year enteral tube feeding. Quality of life measurement was done with Rolls Royce Quality of Life Scale. The data was evaluated Kruskal-Wallis test and t-test.

Results: In this study was determined that demographic data have 81% were female, 22% illiterate. 96% caregivers lived together in the same home with the patient, 64% have children. The data significant lowness all the quality of life dimensions; also mean ± standard deviation was defined as 102.05±23.49(min 42, max 170).

Conclusion: It was obtained evidence relating to caregivers of patients undergoing enteral tube feeding at home have low quality of life.

Keywords: Caregivers; Enteral Nutrition; Enteral Tube Feeding; Quality of Life.

INTRODUCTION

Home enteral nutrition (HEN) support is a method of providing the daily oral intake requirements of a patient at home by using enteral nutrition products administered with a feeding tube via the enteral canal (1,2). Patients with mastication and deglutition dysfunctions, multimorbidities, irreversible intestinal failure, tissue and organ loss, burns, trauma, and some neurological and psychiatric conditions, are all potential candidates for HEN support, once their hospital treatment is complete (3-5). Patients undergoing enteral tube feeding at home (ETFH), even young patients, lack any capacity for self–care and need support, healthcare, and periodic or unscheduled hospital visits (4-6).

Providing this level of care leads to significant physical and emotional demands on caregivers (7). It is important for the caregivers to be careful, diligent, and devoted, as well as possess some technical knowledge of correct usage and care of enteral tube, gastritis residue control, and correct positioning of the patient (4,5). Supporting caregivers by identifying any gaps in their knowledge, acknowledging problems encountered during periods of care, and attempting to meet their personal needs, can increase the quality of life (QoL) of both the patient and the caregiver (3,5). Care of patients requiring ETFH is often the result of an unexpected situation beyond the control of the caregiver. Taking responsibility for a dependent patient is stressful, and psychologically, socially, and physically exhausting. It is has a negative impact on a caregiver's QoL; emotional, social, and financial status; and can involve high levels of risk (6-9).

However, it is likely that the number of enteral nutrition patients and home caregivers in our country will increase, given that palliative care practices are continually improving. The current study aimed to evaluate the QoL of individuals caring for ETFH patients for more than a year, by systematically assessing their requirements. It is hoped that by increasing understanding of the issues caregivers face in caring for ETFH patients, it will be possible to help them adjust to changing patient/caregiver dynamics, and to increase their QoL while fulfilling their role as a caregiver.

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MATERIAL and METHODS

Study design

A quantitative design was used, with participants completing the Rolls Royce Quality of Life (RRQoL) Scale. The study protocol was approved with 2013/300-16 code by the Clinical Research Ethics Committee of IU

Participants

Volunteers for this study and caregivers of the patients feeding with enteral tube more than one year at home (N = 95; 77 female and 18 male). The sample comprised family members, aged above 18 years, and unpaid person.

The sample was not selected; consequently, all caregivers who agreed to participate in the study were included in the study. 8 caregivers separated from the study the confession voluntarily.

Data collected

The study universe was two university hospitals in East Anatolia Region between November and December 2012. The data including caregiver socio-demographics (age, sex, intimacy, educational and economic status), and duration of the disease (more than one year) for that time of evaluation were obtained from face to face interview and entered in the data system for the study. The quality of life of caregivers was evaluated using a RRQoL survey designed and validated (10) with a reliability of Cronbach alpha of 0.93 and Split-half reliability of 0.80 (Alpha factor and Guttman Split-half reliability method were used). Thus the Turkish version of the RRQoL scale used comprised 42 questions. Table 1 shows the mentioned data along with minimum and maximum scores (Table 1).

Table 1. Caregiver's Dispersion According to Identifier Features

Identifier Features	N	Percentage (%)
Age		
18 to28	13	13.7
29 to39	41	43.2
40 to50	24	25.3
51 and over	17	17.9
Gender		
Female	77	81.1
Male	18	18.9
Educational Status		
Illiterate	21	22.1
Literate	19	20.0
Elementary	28	29.5
High school and over	27	28.4
Economic Status		
Good	34	35.8
Middle	38	40
Poor	23	24.2
The Intimacy between the Patient and Caregiver		
Parents (Mother or father)	20	20
Child(Daughter, son or bride)	37	37
Sibling (Sister or brother)	7	7
Relative	2	2
Wife (Or husband)	29	29

Availablity of data and materials

In this study was used to the original RRQoL scale includes 10 factors (11,12). Factor 1 evaluated the psychological well-being of the study population. Factor 2 of the QOL survey assessed the self-competence of caregivers. Factor 3 included of the physical well-being of caregivers. Factor 4 assessed the confidence in the self-talent of the study sample. Factor 5 evaluated the environmental support reached by the caregiver. Factor 6 assessed the dimension of pain experienced by the study sample. Factor 7 evaluated the activity of the caregivers. Factor 8 assessed the optimal and relax of the study sample. Factor 9 and factor 10 evaluated the interpersonal interaction and self-adequacy and independence of the study sample, relatively. Internal structure validity have defined as r=0,996, p<0,001 by Özyılkan et. al. It agreed that individual characteristics were considered as independent variables, questions of RRQoL scale dependent on evaluation of the data. It was determined 5 choices for every question in RRQoL scale. These choices were pointed as 5, 4, 3, 2, 1 for positive questions, 1, 2, 3, 4, 5 negative. Obtained the high points indicate to superior quality of life (10).

The distribution of RRQoL Scale according to 8 factors and 42 questions

1. General well-being 1, 5, 14, 22, 24, 26, 42
2. Physical symptom and activity 2, 3, 4, 8, 11, 23, 27, 29
3. Sleep disorders 9, 17, 28
4. Appetite 10, 30
5. Sexual function 16, 21, 25, 34
6. Perception function 15, 32, 35, 37, 39, 41
7. Medical interaction 7, 12, 18, 33
8. Medical interaction 6, 13, 19, 20, 31, 36, 38, 40

Data analysis: Data were worked prospectively in a database and required analysis was accessed with SPSS statistical software (17.0 version). The data were expressed with using percentage, number, and mean±standard deviation. Kruskal-Wallis test was realized to evaluate the effect of gender, their intimacy to the patient depends on their personal responsibilities, health conditions, age, and financial conditions on the QoL of the caregivers and P<0.05 was regarded significant. Also; t-test was done to evaluate the parameters of the survey that had generally obsessed the QoL.

RESULTS

The QoL of the caregivers are shown in Table 3. Demographic characteristics showed an age range of 29-39 years, 81% were female, 22% illiterate. 23% were facing substantial economic problems, 37% caregivers were sons, 96% caregivers lived together in the same home with the patient, 64% have children, and 44% have poor housing situation (Table 1-2). QoL for caregivers was found low in all measured dimensions and total scores, the average score being 102.05±23.49 (min 42, max 170; Table 3). Females showed lower QoL scores than males, and caregivers aged 18 to 23 scored lower than other age groups (p<0.005; Table 4).

Table 2. Caregiver's Dispersion According to Identifier Features

Identifier Features	N	Percentage (%)
At the same home with patient		
Yes	92	96.8
No	3	3.2
Obliged to look after individuals		
There	61	64.2
No-there	34	35.8
Supporting persons in patient care		
There	74	77.9
No-there	21	22.1
The Degree of dependence of the patient on the bed		
Addicted	74	77.9
Semi-addicted	21	22.1
Chronic disease state in caregivers		
There	24	25.3
No-there	71	74.7
Total	95	100

Table 3. The Scores from the Quality of Life Subtitles by Caregivers

Subtitles	Minimum Score	Maximum Score	Mean±Standard Deviation
General well-being	7	32	17.97±4.57
Physical symptom and activity	8	58	19.67±6.93
Sleep disorders	3	15	6.97±2.37
Appetite	2	10	5.26±1.75
Sexual function	4	18	9.01±3.97
Perception function	6	27	13.13±4.50
Medical interaction	4	17	9.81±2.42
Social relations and em-ployee performance	8	32	20.20±4.66
Grand total	42	170	102.05±23.49

Table 4. Caregiver's the Mean±Standard Deviation Dispersion in Quality of Life Subtitles According to Age and Gender (N=95)

	Quality of Life Subtitles								
Age	General well-being	Physical symptom and activity	Sleep	Appetite	Sexual function	Perception function	Medical interaction	Social relations and employee performance	Grand total
18-23 n=13	20.61±5.66	23.76±9.50	7.69±1.93	5.61±2.21	11.69±4.28	15.53±5.48	10.69±2.81	21.30±5.39	116.92±29.44
29-39 n=41	18.09±4.63	20.21±7.63	20.21±7.63	5.34±2	8.85±4.07	12.63±4.45	9.75±2.79	19.36±65.08	101.02±24.36
40-50 n=24	17±3.51	17.66±3.33	17.66±3.33	5±1.38	8.04±3.34	12±3.84	9.5±1.47	21.08±3.91	97.20±15.83
51 and over n=17	17.05±4.39	18.05±5.49	18.05±5.49	5.17±1.18	8.70±3.73	14.11±4.21	9.70±2.28	20.11±3.93	100±22.96
KW P	1.16 P>.005	1.82 P>.005	1.58 P>.005	2.31 P>.005	.78 P>.005	2.1 P>.005	2.28 P>.005	.02 P>.005	.3 P<.005
Gender									
Female n=77	17.61±4.27	18.55±4.79	6.90±2.45	5.33±1.73	8.62±.89	12.70±4.35	9.61±2.41	19.87±4.63	99.22±22.88
Male n=18	19.55±5.52	24.44±11.55	7.27±2.02	4.94±1.86	10.66±3.98	15±4.78	10.66±2.35	21.61±4.66	114.16±22.82
P	P>.005	P<.05	P>.005	P>.005	P>.005	P>.005	P>.005	P>.005	P<.005

DISCUSSION

HEN is, particularly for older patients with neurological issues who lack capacity for self-care, one of the most common methods of therapy. Generally, non-professional caregivers, who are relatives, are responsible for the patient's safety. The quality of this care is highly related to the labor force of the caregivers. Caregivers encounter various problems during the adaptation period for their new role, their possibility of making a mistake is very high, and these mistakes can jeopardize the patient's health (5,13). Identifying the requirements and problems of caregivers, finding solutions and supporting them when they have difficulties can all contribute to the homecare.

Caregivers have a limited ability to provide homecare management and can provide support at home only if they are practically encouraged to do so (13). Conflicting aims of taking care of the HEN patient, and also trying to fulfill their own personal roles, lead to a decrease in QoL for caregivers. Caregivers intimacy to the patient, their personal responsibilities, health conditions, age, gender, financial conditions and relationships with another people have affected the quality of care.

In this study was found that women caregivers have a lower QoL than men in every aspect except for appetite; therefore, it is suggested that gender differences are important in terms of physical status. Because it is more important for women to take responsibility of sick people because of their traditional social roles. Women tried to continue their lives with the responsibility of caregiving, without giving up their personal roles.

Similar studies have shown that increased complexity of healthcare makes caregiving harder, and caregivers have to change their habits in order to fulfil the needs of their patients. Most of the patients live with their families (6), and caregivers give up social activities owing to their new caring duties and responsibilities, and experience social isolation (14). Accordingly, recent studies have shown that caregiving responsibility ranges from mild to medium levels and female caregivers have more responsibility than their male counterparts (15). Another study shows that caregivers spend 4-7 hours on patients and try to perform the job along with their daily errands, increasing the workload of women (16). This information suggests that emphasis is at present given to the instruction of caregivers, and home care services are formed by health care practices, which cannot compete with evidence-based interventions and multidisciplinary approaches. This study found that 96% of caregivers lived with their patients. In this study; QoL for caregivers was measured with RRQoL scale. The caregivers of patients suffering from a chronic illness give care during the 24 hours; therefore, all dimensions of QoL are deeply affected. Also, well-educated caregivers become familiar with process of percutaneous endoscopic gastrostomy (PEG) feeding faster (17). In the current study, it is pointed out that differences between the educational backgrounds of the caregivers did not increase the quality of life statistically. The results presented here are consistent with the existing literature. Descriptive studies on this issue are important in order to identify caregivers' problems and attempt to find solutions. However, it is more important that these attempts are discovered, and caregivers are supported in every aspect.

The fact that this research is not experimental is accepted as a limitation. Also, the healthcare problems of the caregivers were not detailed in their work performance.

CONCLUSION

The study showed that the homecare support given by the caregivers had burden a great influence in their quality of life-threatening. It will be useful that development the health care foundation at home to the supporting QoL for caregivers, providing psychological and social relief, is done family-oriented, enabling caregivers to realize their social roles.

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