

A retrospective study examining the properties and characteristics of dementia patients in a palliative care center

Metin DİNÇER*

Department of Health Management, Faculty of Health Sciences, Ankara Yıldırım Beyazıt University, Ankara, Turkey

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Background/aim: The aim of this study is to evaluate why dementia patients (DPs) are admitted to a palliative care center (PCC) and which factors affect the length of stay (LOS) of DPs in the PCC, and to predict the course of the disease.

Materials and methods: The files of DPs were scanned retrospectively in the PCC between 2013 and 2016. Data related to age, sex, LOS, symptoms, clinical conditions, comorbidities, and prognosis were recorded.

Results: The study included 85 DPs with a mean age of 84.1 ± 6.7 years. LOS was determined as a median of 15.0 days. While LOS decreased due to age and cancer, it increased due to pressure injury. Although mortality was increased by LOS, it was decreased by hypertension, mobilization, and percutaneous endoscopic gastrostomy. Among the DPs who were admitted to the PCC, the death rate was 54.1% and the discharge rate was 45.9%.

Conclusion: It is concluded that adopting a palliative care approach eases symptom management. While this approach decreases the burden of symptoms, it at the same time increases the quality of life of DPs and their families.

Key words: Dementia, palliative care, length of stay, hospital mortality

1. Introduction

Increased life expectancy causes an increase in the prevalence of chronic diseases such as dementia. There is an ongoing increase in the number of dementia patients (DPs) worldwide. It is predicted that the number of DPs will double every 20 years (1), increasing from 46.8 million in 2015 to 74.7 million in 2030 and reaching 131.5 million in 2050 (2).

At present, dementia remains as an incurable disease, which restricts the quality of lives (3). Dementia, which affects memory, thinking, behavior, and the ability to perform everyday activities, is a chronic or progressive syndrome caused by various brain diseases (1). The advanced stage of dementia, which causes loss of cognitive function, may be accompanied by complex clinical findings and severe symptoms (4,5). These symptoms have a negative effect on the patients, their families, and those around them (4). Palliative care (PC) focuses on improving the quality of life of patients with life-restricting diseases such as dementia, but unfortunately, many advanced-stage DPs are unable to access PC services (6).

In the past, dementia care attracted little interest, but now it has become a global agenda in the scopes of healthcare,

education, social care, economics, politics, and research (7). Together with an increase in the number of patients, the care and problems associated with the treatment of DPs have created a greater interest in PC for these patients (8).

In Turkey, the necessity of PC and the PC approach for advanced-stage DPs with life-threatening conditions are unknown. The aim of this study is to determine the characteristics of DPs who were admitted to a palliative care center (PCC) for PC and to find out factors affecting the length of stay (LOS) and prognosis of DPs. This study, the importance of which is to define PC requirements for DPs, is an unprecedented research in this scope in Turkey.

2. Materials and methods

2.1. Ethics statement

The files of DPs who were admitted to the PCC for PC of Ankara Ulus State Hospital between 1 January 2013 and 31 December 2016 were scanned retrospectively. The study was approved by the Ankara Numune Training and Research Hospital Ethics Committee (22.02.2017, Approval No: E-17-1281). All these procedures were performed in accordance with the principles of the Declaration of Helsinki.

* Correspondence: drmetindincer@yahoo.com

2.2. Measurements

The data of DPs admitted to the PCC included the following: age, sex, location prior to admission to the PCC (home/hospital), dependence scale, symptoms (shortness of breath, pain, nausea/vomiting, agitation), comorbidities (hypertension (HT), diabetes mellitus (DM), cerebrovascular event (CVE), chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD), cancer), clinical conditions (mobilization, oral intake, percutaneous endoscopic gastrostomy (PEG), pressure injury (PI), pneumonia, fall history), and discharge (dead or alive). The dependency scale is a scale that measures the degree of support that the DP is in need of; the patients are graded between 0 and 5 according to the scale. Level 0 includes patients who are independent and who have normal life activities, while Level 5 includes patients who have the highest level of dependency (9). According to this dependency scale, patients who use diapers, who have a urinary catheter, who have feeding tubes, or who cannot move by themselves are fully dependent (9). In other words, they are Level 5 dependent patients. The dependency levels used in this study were established according to the information obtained from patient files. The data used in the study were gathered from electronic patient records by using Hospital Information Management System (HIMS) software (Alpdata Co. Inc., Ankara, Turkey).

2.3 Statistical analysis

MS Excel 2007 and IBM SPSS Statistics 21.0 software (IBM Corp., Armonk, NY, USA) were used for statistical analyses, calculations, and graphs.

Necessary controls and corrections were made in the data gathered from HIMS. Whether the continuous variables (age and LOS) were in conformity with normal distribution was examined graphically and with the Shapiro–Wilk test. Normal distribution was observed for

the age variable but not LOS in the PCC. While descriptive statistics for age were shown as the mean \pm standard deviation (SD), LOS in the PCC was demonstrated with the median [interquartile range (IQR)]. Categorical variables (sex, symptoms, clinical conditions, and comorbidities) were shown as the number (n) and percentage (%).

The Mann–Whitney U test was used to examine differences between LOS and the following variables: symptoms, clinic conditions, and comorbidities. The independent-samples t-test (Student's t-test) was used to compare age with the following variables: symptoms, clinic conditions, and comorbidities. To determine the factors that could affect mortality, the confidence interval (CI) was calculated using the odds ratio (OR). Chi-square test (χ^2) was used to determine to distribution of clinical conditions and comorbidities according to gender.

A multivariable linear regression model was established to evaluate the factors affecting LOS. A binary logit model was used to evaluate the factors on mortality. A dummy dependent variable was used in this model: value 1 was given to the dummy dependent variable for those who passed away and value 0 was given to the dummy dependent variable for those who survived. $P < 0.05$ was considered to be statistically significant. In this study, those who were discharged were either alive or dead.

3. Results

Of 103 DPs admitted to the PCC of the Ankara Ulus State Hospital between 1 January 2013 and 31 December 2016, 18 patients were excluded from the study: one had incomplete records, nine had LOS of ≤ 2 days, and eight had repeated admissions. Thus, a total of 85 patients were included in the study.

Of 85 patients, there were 47 females (55.3%) and 38 males (44.7%), with a mean age of 84.1 ± 6.7 years: 39

Table 1. Demographic information and length of stay of patients.

	Variables	Min–max	Mean \pm SD Median (IQR)	Statistical test	
				t/Z	P
Age* (years)	Female (n = 47)	64–100	85.15 \pm 7.38	t = 1.600	0.113
	Male (n = 38)	74–93	82.84 \pm 5.51		
	Admitted from home (n = 39)	64–95	83.31 \pm 6.81	t = 1.031	0.306
	Admitted from other clinics (n = 46)	73–100	84.80 \pm 6.55		
LOS** (days)	Female (n = 47)	3–116	17.0 (18.0)	Z = 0.933	0.351
	Male (n = 38)	3–148	14.5 (25.0)		
	Admitted from home (n = 39)	3–148	17.0 (18.0)	Z = 0.079	0.937
	Admitted from other clinics (n = 46)	3–116	15.0 (25.0)		

*Mean \pm standard deviation (SD). **Interquartile range (IQR). LOS: Length of stay.

(45.9%) patients admitted to the PCC were from home and 46 (54.1%) were transferred from another healthcare institution. LOS in the PCC ranged from 3 to 148 days, with a median of 15.0 days (IQR = 24.0) (Table 1). Neither sex nor the origin of the patient (home or another healthcare institution) was found to be effective on the age of the DP or LOS ($P > 0.05$).

3.1. Comorbidities and clinical conditions

The most common symptoms of DPs admitted to the PCC were shortness of breath ($n = 46$; 54.1%), pain ($n = 14$; 16.5%), nausea/vomiting ($n = 13$; 15.3%), and agitation ($n = 11$; 12.9%). The most frequently observed comorbidities in these patients were HT ($n = 35$; 41.2%), DM ($n = 19$; 22.4%), CVE ($n = 29$; 34.1%), CHF ($n = 10$; 11.8%), COPD ($n = 8$; 9.4%), and cancer ($n = 7$; 8.2%). The most common clinical conditions of DPs admitted to the PCC were immobilization ($n = 69$; 81.28%), oral intake and PEG ($n = 25$; 29.4%), PI ($n = 42$; 49.4%), pneumonia ($n = 14$; 16.5%), and falls ($n = 10$; 11.8%). The number of male patients with complaints of falling was four times more than that of females and a significant difference was observed between the sexes with respect to falling ($\chi^2 = 5.711$; $P = 0.017$). When all the other factors (age and clinical conditions) were assumed to be fixed, male sex showed a higher risk of hospital admittance with complaints of falling, with odds ratio (OR) = 6.0 (95% CI = 1.19–30.22), when compared with that of females. The rates of other clinical conditions and comorbidities showed no differences according to sex ($P > 0.05$) (Table 2).

3.2. LOS

According to the multivariable linear regression analysis results, LOS as a variable had a statistically meaningful association with age ($z = -2.47$; $P = 0.016$), cancer ($z = -2.10$; $P = 0.039$), and PI ($z = 2.98$; $P = 0.004$). When the P-value is accepted to be below 10% ($P < 0.10$), DM can be accepted to be effective in the established model. As variables such as age and cancer reduced LOS, PI prolonged LOS. On the condition that the other variables were constant, the period of hospitalization decreased by 1.07 days when the age of patient increased by 1 year. The average LOS in patients with PI increased by 16.32 days. On the contrary, the average LOS in patients with cancer decreased by 21.1 days (Table 3).

3.3. Discharge and mortality status

It was determined that 39 (45.9%) of the DP admitted to the PCC were discharged and 46 (54.1%) of them died in the hospital. According to binary logit model results, independent variables HT ($z = -2.85$; $P = 0.004$), mobilization ($z = -3.14$; $P = 0.002$), and PEG ($z = -2.13$; $P = 0.033$) were found to be statistically meaningful in mortality. When the P-value is accepted to be below 10% ($P < 0.10$), LOS and DM can be accepted to be effective in the established model. The possibility of mortality risk in

DPs with HT decreased by 41.54% when compared with DP without HT (marginal effect = -0.4154 ; OR = 0.1720). Similarly, the possibility of mortality risk in DPs who were mobile decreased by 30.43% compared with DPs who were immobile (marginal effect = -0.3043 ; OR = 0.0596). In addition, the results indicated that the possibility of mortality risk of DPs with PEG decreased by 21.36% in the PCC (marginal effect = -0.2136 ; OR = 0.2816) (Table 4).

4. Discussion

The reality that DPs are highly in need of PC was neglected worldwide until 2000 and it has been on the agenda more frequently in healthcare policies and in the literature due to the fact that chronic diseases and dependencies of elderly have increased in recent years (7,8). During the advanced stage of dementia, the symptoms that reduce the quality of life are studied in the literature (10–12). The most frequent symptoms of DPs in the literature were pain (52%), agitation (35%), and shortness of breath (35%) and the same results have been found in this study (5). In a study carried out in a nursing home on the clinical course of DPs, among distressing symptoms, dyspnea at 46% was the most frequent symptom, and the second was pain at 39% (13). Similar to the findings in the literature, in this study comorbidities such as CHF and CVE were observed in 24.6% and 15.7% of DPs, respectively (14). In DPs the incidence of chronic and systematic diseases is increasing (1,15). Since DPs gradually lose control of managing systematic and chronic diseases such as HT and DM, the burden of these diseases is becoming more and more obvious (1,16).

It has been observed that the number of male patients who complained about falling was four times more than that of the female patients. The reason why male patients fall more often than female patients is that male patients lose both visual perception and walking ability much more than female patients (17).

In this study it has also been observed that old age and diagnosis of cancer in DPs reduced LOS while PI increased LOS. In other studies, it was observed that old age and cancer reduced LOS and increased mortality (7,18,19). If a DP has PI, it shows that there is poor quality of care (4,20), and consequently this patient is admitted to the PCC (21).

It is concluded that PI has no association with mortality, but since a long time to cure it, PI prolongs the LOS (21).

It has also been observed that the rate of death was lower in DPs with HT. The relationship between HT and dementia is very complicated and HT is a risk factor for dementia (22,23). Furthermore, HT is one of the diseases that has been observed most frequently in DPs (15,23). Since regulating blood pressure can diminish brain function disorders it is thought that this can contribute to prolongation of the lifespan (22,23).

Table 2. Distribution of clinical conditions and comorbidities according to sex.

Variables	Conditions	Female		Male		Statistical test	
		n	%	N	%	χ^2	P
Dependence scale							
	3 moderate	4	57.1	3	42.9	0.105	0.949
	4 severe	4	50.0	4	50.0		
	5 severe	39	55.7	31	44.3		
Symptoms on admission							
Shortness of breath	Absent	21	53.8	18	46.2	0.061	0.805
	Present	26	56.5	20	43.5		
Pain	Absent	39	54.9	32	45.1	0.023	0.879
	Present	8	57.1	6	42.9		
Nausea/vomiting	Absent	37	51.4	35	48.6	2.904	0.088
	Present	10	76.9	3	23.1		
Agitation	Absent	39	52.7	35	47.3	1.553	0.213
	Present	8	72.7	3	27.3		
Comorbidities							
HT	Absent	26	52.0	24	48.0	0.533	0.465
	Present	21	60.0	14	40.0		
DM	Absent	35	53.0	31	47.0	0.612	0.434
	Present	12	63.2	7	36.8		
CVE	Absent	29	51.8	27	48.2	0.817	0.366
	Present	18	62.1	11	37.9		
CHF	Absent	42	56.0	33	44.0	0.128	0.720
	Present	5	50.0	5	50.0		
COPD	Absent	41	53.2	36	46.8	1.463	0.226
	Present	6	75.0	2	25.0		
Cancer	Absent	43	55.1	35	44.9	0.011	0.918
	Present	4	57.1	3	42.9		
Clinical conditions							
Mobilization	Absent	38	55.1	31	44.9	0.007	0.932
	Present	9	56.3	7	43.8		
Oral nutrition	Absent	33	55.0	27	45.0	0.007	0.933
	Present	14	56.0	11	44.0		
PEG	Absent	36	60.0	24	40.0	1.828	0.176
	Present	11	44.0	14	56.0		
Pressure injury	Absent	23	53.5	20	46.5	0.115	0.735
	Present	24	57.1	18	42.9		
Pneumonia	Absent	40	56.3	31	43.7	0.190	0.663
	Present	7	50.0	7	50.0		
Fall	Absent	45	60.0	30	40.0	5.711	0.017
	Present	2	20.0	8	80.0		

HT: Hypertension, DM: diabetes mellitus, CVE: cerebrovascular event, CHF: chronic heart failure, COPD: chronic obstructive pulmonary disease, PEG: percutaneous endoscopic gastrostomy.
 Values are given as number of cases (%).

Table 3. Multivariate linear regression model results for length of stay.

Variables	Coefficient	Std. error	z	P	95% Confidence interval	
Age	-1.0738	0.4346	-2.47	0.016	-1.9387	-0.2087
Diabetes mellitus	12.6479	6.8002	1.86	0.067	-0.8848	26.1806
Cancer	-21.1035	10.0691	-2.10	0.039	-41.1415	-1.0653
Pressure injury	16.3276	5.4781	2.98	0.004	5.4257	27.2293

$R^2 = 0.1740$; F-test: test statistics value: 5.42; P: 0.0006.

Table 4. Binary logit model result for mortality.

Variables	Coefficient	Std. error	Odds ratio	Marginal effects	z	P	95% confidence interval	
Length of stay	0.0194	0.0112	1.0196	0.2880	1.76	0.078	0.9978	1.0418
Hypertension	-1.7600	0.1062	0.1720	-0.4154	-2.85	0.004	0.0513	0.5767
Diabetes mellitus	1.2896	2.5777	3.6315	0.1652	1.82	0.069	0.9034	14.5978
Mobilization	-2.8199	0.0535	0.0596	-0.3043	-3.14	0.002	0.0103	0.3460
PEG	-1.2671	0.1672	0.2816	-0.2136	-2.13	0.033	0.0880	0.9019

Pseudo $R^2 = 0.2334$; LR test: test statistics value: 27.36; degrees of freedom: 5; P: 0.0000.

PEG: Percutaneous endoscopic gastrostomy.

Campbell et al. (18) reported that functional status affected mortality; in this study, the fact that patients were mobile reduced the rate of mortality. DPs who took part in this study were those who were in need of help from other people, most of whom were fully dependent (n = 69, 81.2%).

Hendriks et al. (5) reported that dehydration/cachexia at 38% was the most frequent reason for mortality in DPs. In the present study, it was observed that 70.6% of DPs did not have oral intake and 29.4% were nourished with PEG. Suzuki et al. (24) reported that feeding with PEG decreased mortality and it was also observed that feeding with PEG decreased mortality in this study, although some studies said that there was no evidence for the fact that DPs who are fed with PEG survive longer than those who are not (19,25).

In conclusion, as the human lifespan is steadily increasing, there is a significant increase not only in chronic diseases such as dementia but also in the necessity of PC. The burden of DPs also increases in Turkey as observed throughout the world. For better symptom management in DPs, a PC approach should be used. The PC approach not

only decreases the burden of dementia but also increases the quality of life of the patients and their families. Family members are willing to hospitalize their DPs in Turkey because the care of the majority of DPs is given by family members. Also, family members are not in the position to decide on the health condition of their patients.

The PCC where this study was carried out is a pioneer of its kind in Turkey because it serves not only patients with cancer but also those who have other ailments, whereas the other PCCs deal only with a few types of disease. Patients' families and caregivers are trained in how to give care and how to live together with those patients in the PCC.

Although PC is beneficial for DPs, the importance of PC can hardly be understood and the number of PCCs all over the country is not adequate. Therefore, it is necessary to conduct more studies to emphasize the need of PC for DPs in Turkey.

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