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Palliative Care Requirement in Neurologic Diseases

Nörolojik Hastalıklarda Palyatif Bakım İhtiyacı

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Abstract

Objective: It has been reported that the need for palliative care (PC) increases every day in chronic critical illnesses such as neurologic disorders. We investigated the demographics and comorbidities of neurological patients followed up in a PC center (PCC), and their effect on hospitalization period and discharge status.

Materials and Methods: The medical records of 175 patients followed up in the PCC were reviewed retrospectively. Neurologic disorders were classified as stroke (ischemic and hemorrhagic), neurologic system tumors, brain hypoxia, dementia, Parkinson's disease, traumatic brain injury (TBI), and other diseases (amyotrophic lateral sclerosis, multiple sclerosis). Age, sex, PCC length of hospital stay (LOS), Glasgow Coma Scale (GCS), nutritional status [oral, percutaneous endoscopic gastrostomy (PEG)], tracheostomy, pressure ulcer, and discharge status were compared for the patients.

Results: The diagnoses of the patients whose average age was 66.58±19.97 years and LOS was 35.63±41.93 days were most often stroke and dementia (45.7% and 17%, respectively). In patients with PEG and tracheostomy, LOS in PCC was significantly longer, and patients with tracheostomy had a higher discharge rate. GCS was significantly lower in patients with TBI, whereas the home discharge rate was determined to be higher. Furthermore, age and GCS values of patients whose discharge status was exitus were found to be significantly higher.

Conclusion: Even though neurologic diseases represent the most common patient population after cancer in need of PC, there are insufficient studies for describing the characteristics of this population, meeting their needs, and increasing awareness in this area.

Keywords: Palliative care, neurological disorders, hospitalization period

Öz

Amaç: Nörolojik hastalıklar gibi kronik kritik hastalıklarda palyatif bakım ihtiyacının her geçen gün arttığı bildirilmektedir. Biz bu çalışmada palyatif bakım merkezinde palliative care center (PCC) izlediğimiz nöroloji hastalarının demografik özelliklerini, komorbiditelerini ve bunların yatış sürelerine ve çıkış durumlarına etkilerini araştırdık.

Gereç ve Yöntem: 2016-2017 yılları arasında PCC'de izlenen 175 hastanın tıbbi kayıtları retrospektif olarak tarandı. Nörolojik hastalıklar iskemik ve hemorojik inme, nörolojik sistem tümörleri, hipoksik beyin, demans, parkinson, travmatik beyin hasarı, diğer hastalıklar (amyotrofik lateral sklerosis, multipl sklerosis) olmak üzere sınıflandırıldı. Hastaların yaşları, cinsiyetleri, PCC'de yatış süreleri, Glaskow Koma Skalaları (GKS), beslenme durumları oral, perkütan endoskopik gastrostomi (PEG), trakeostomi, basınç ülseri ve çıkış durumları (ev, yoğun bakım ünitesi, eksitus) karşılaştırıldı.

Bulgular: Yaş ortalamaları 66,58±19,97 yıl, yatış süreleri 35,63±41,93 gün olan hastaların tanıları en sık inme ve demans (%45,7 and %17) idi. PEG ve trakeostomisi olan hastalarda PCC'de yatış süreleri anlamlı derecede uzun, trakeostomisi olan hastaların eve taburculuk oranlarının fazla olduğu görüldü. Travmatik beyin hasarı tanısı olan hastalarda GKS anlamlı derecede düşük iken eve taburculuk oranları yüksek bulundu. Ayrıca çıkış durumu eksitus olan hastaların yaşları ve GKS değerleri anlamlı olarak yüksek bulundu.

Sonuç: PCC de izlediğimiz nöroloji hastalarının heterojen seyirleri olmasına rağmen sosyal destek ve bakım hedeflerine odaklanan ortak bir palyatif bakım gereksinimleri vardır. Bu gereksinimleri tespit etmek ve daha iyi karşılayabilmek için prognozda yol gösterici daha geniş kitlelerle yapılan çalışmalara ihtiyaç vardır.

Anahtar Kelimeler: Palyatif bakım, nörolojik hastalıklar, yatış süresi

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Introduction

Palliative care (PC) is an extensive type of care for controlling symptoms (primarily pain), improving quality of life, and managing physical, social, psychological or moral needs of patients and their relatives in the course of advanced diseases (1). Despite some serious differences, PC has started to expand from malignant diseases to non-malignant diseases because their need for PC is identical (2,3,4).

Patients hospitalized in neurology and neurosurgery intensive care units (ICU) have high death risk, and they generally become care patients as a result of physical and cognitive impairment (5,6). PC should be started early in critical diseases in need of intensive care, especially in neurologic diseases with a rapid fatal course such as motor neuron disease (7,8). Nevertheless, it is hard to determine when the patient enters the final stage because neurologic conditions have longer and more variable time course. Symptoms are diverse and many patients have complex disabilities such as physical deficits with cognitive, behavioral, and communication problems (9).

Studies have been performed on determining the PC need of neurological patients and how to integrate PC in neurologic practices (10). In order to increase PC awareness in medical areas other than oncology, PC needs, the definition and application of procedures, and complexity and variety of symptoms should be considered, in particular chronic, incurable neurologic diseases that impair self-management (4). Patients with neurologic diseases generally have hard-to-treat and progressive diseases associated with major morbidity and mortality. The PC approach has been reported to assist in creating a treatment plan that addresses all aspects of diseases becase there are no treatment options for most of the common neurodegenerative diseases such as dementia, multiple sclerosis, Parkinson's disease, and amyotrophic lateral sclerosis (ALS) (11). As in ICUs, technologies such as enteral feeding and non-invasive ventilation extend life expectancy in various neurologic diseases including Parkinson's disease, dementia, ALS, brain tumors, and stroke (6,12). The increased life-span around the world and the fact that many neurologic diseases progress in an incurable chronic process increase the importance of PC (13).

Although early PC is considered to have a positive effect on the quality of life and survival of patients, neurologists may face a difficulty in directing patients to PC at the right time due to the heterogeneous course in acute and chronic neurologic diseases (11). We compared the frequency of neurologic diseases that were followed up in a PC center (PCC), the effect on prognosis and length of hospital stay (LOS) for chronic systemic diseases such as hypertension (HT) and diabetes, and comorbidities such as percutaneous endoscopic gastrostomy (PEG), tracheostomy, and pressure ulcers (PU). Moreover, this study is the first study in our country investigating the comorbidities and characteristics of neurologic diseases undergoing PC.

Materials and Methods

This study was approved by the local University of Health Sciences Turkey, Clinical Research Ethics Committee (date: 21.03.2018, approval no: E-18-1871). All procedures were conducted in accordance with the principles of the Declaration of Helsinki. The files of 175 patients who were followed up between January 2016 and December 2017 with a diagnosis of neurologic disease were reviewed retrospectively. Patients with incomplete patient file records, 1-day LOS, and repeat hospitalizations in PCCs were excluded from the study. Neurologic disorders were classified as stroke (ischemic and hemorrhagic), neurologic system tumors (NST), brain hypoxia, dementia, Parkinson's disease, traumatic brain injury (TBI), and other diseases [ALS + multiple sclerosis (MS)]. Age, sex, PCC LOS, Glasgow Coma Scale (GCS), nutritional status (oral, PEG) tracheostomy, PU, and discharge status (home, ICU, exitus) of patients were noted.

The GCS consists of criteria developed for the general neurologic assessment of a person. The degree of consciousness is determined. The GCS is evaluated according to the verbal response, motor response, and eye opening response of a patient. It is calculated with 15 points for the best response, and 3 points for the worst response (14). Patients were compared according to sex, nutrition, PEG, tracheostomy, presence of PU, discharge status, LOS in the PCC, and GCS.

Statistical Analysis

The MS-Excel 2003 and IBM SPSS Statistics 23.0 (IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.) programs were used for statistical analysis and calculations. In the analysis of data, number and percentage (n, %) were used for categorical variables, and mean ± standard deviation was used for numeric variables. The Kolmogorov-Smirnov normality test was used for numeric variables to undergo statistical tests, and it was observed that variables did not show normal distribution. For this reason, non-parametric statistical methods were used in this study. Accordingly, the Mann-Whitney U test was performed while examining differences between two independent groups (e.g. sex) with regard to numeric variables (e.g. GCS score). The Kruskall-Wallis test was used while examining differences among more than two independent groups (e.g. discharge status) with regard to numeric variables (e.g. LOS). The relation between two independent numeric variables was interpreted using Spearman's Rho, and the relation between two independent categorical variables was interpreted using chi-square analysis, and $p<0.05$ was assumed to indicate significant difference.

Results

A total of 175 patients, consisting of 77 (44%) females and 98 (56%) males were included in the study. The average age was 66.58±19.97 years and the average LOS was 35.63±41.93 days; the shortest LOS was 2 days and the longest was 268 days. The average GCS score was 10.45±2.89 with the lowest GCS score of 4 and the highest GCS score of 15.

The number of patients with discharge status exitus was 35 (20%) and ICU was 42 (24.0%), and the number of patients who were discharged home was 98 (56.0%). Among the patients included in the study, 80 patients (45.7%) were diagnosed as having stroke, 30 (17.1%) had dementia, 23 (13.1%) had TBI, 16 (9.1%) had NST, 13 (7.4%) had brain hypoxia, 13 (7.4%) had Parkinson's disease, and 13 patients (7.4%) were diagnosed as having other (ALS + MS) diseases. The number of patients with accompanying heart disease was 18 (10.3%), it was 65 (37.1%)

for HT, and 29 (16.6%) for diabetes mellitus. Seven patients (4%) had oral nutrition, 90 patients (51.4%) had PEG feeding, 56 patients (32%) had tracheostomy, and 35 patients (20%) had PU (Table 1).

The effect of age, LOS in PCC, and GCS on prognosis (exitus, ICU, and discharge home) was determined as statistically significant. The age of patients who experienced exitus was significantly higher than patients in ICUs and patients who were discharged home (p<0.001). Furthermore, the GCS scores of patients who died were significantly higher than in patients discharged home (p<0.017). It was observed that LOS in the PCC was shorter in patients who were transferred to the ICU compared with patients who died or discharged home (p<0.001) (Table 2).

Although diagnosis seemed to have no effect on factors affecting LOS in PCC, it was observed that having PEG (p<0.006) and tracheostomy (p<0.001) statistically extended LOS in PCC. Accordingly, LOS was significantly longer in patients with PEG and tracheostomy (Table 3).

GCS scores were significantly lower in patients with TBI, and were significantly higher in patients with NST (Table 4).

There was a statistically significant relation between discharge status and having dementia and trauma. Accordingly, death rates were significantly lower in patients with dementia and TBI. The rate of patients discharged home was significantly higher in patients with tracheostomy (Table 5).

Table 1. Demographic characteristics of the patients

Age* (Years)		**66.58±19.97**
Sex**		
	Female	77 (44)
	Male	98 (56)
	Total	175 (100)
LOS* (days)		35.63±41.93
GCS*		10.45±2.89
Outcome**		
	Exitus	35 (20.0)
	ICU	42 (24.0)
	Home	98 (56.0)
Diagnosis**		
	Stroke	80 (45.1)
	NST	16 (9.1)
	Brain hypoxia	13 (7.4)
	Dementia	30 (17.1)
	Parkinson's	13 (7.4)
	TBI	23 (13.1)
	Other	13 (7.4)
Comorbidity**		
	CD	18 (10.3)
	HT	65 (37.1)
	DM	29 (16.6)
	Oral	7 (4.0)
	PEG	90 (51.4)
	Tracheostomy	56 (32.0)
	PU	35 (20.0)

*Mean ± standard deviation, **Values are provided in n (%), LOS: Length of stay, GCS: Glasgow Coma Scale, ICU: Intensive care unit NST: Nervous system tumor, TBI: Traumatic brain injury, CD: Cardiac disease, HT: Hypertension, DM: Diabetes mellitus, PEG: Percutaneous endoscopic gastrostomy PU: Pressure ulcer

Discussion

In the application of PC in neurology, it is extremely important to consider the variability of disease prognosis. The reason is that neurologic diseases include conditions such as severe brain damage, massive stroke, and aggressive neoplasia, which are characterized by an acute onset and survival period limited to weeks or months, and diseases with longer survival periods such as dementia, neuromuscular diseases, Parkinson's, and MS, which are progressive, degenerative, and irreversible, and continue for years (4). In recent years, awareness of PC in neurologic diseases has increased and become more applicable (10). In this study, which examines the effect on prognosis and hospitalization period for diagnosis, clinical characteristics, and comorbidities of patients with neurologic diseases followed up in a PCC, we determined only seven patients who had oral nutrition among patients with the most frequent diagnoses of stroke and dementia (45.7% and 17%). Ninety patients (51.4%) had PEG feeding and 56 patients (32%) had tracheostomy. Borasio reported that the PC approach

Table 2. The relation between discharge status and age, hospitalization days and GCS

		n	Mean ± SD	Median (Min - Max)	Value*	p*
Age	Exitus	35	76.77±15.59	80.0 (35.0-99.0)	17.887	**<0.001***
	ICU	42	70.29±17.38	73.5 (29.0-92.0)		
	Home	98	61.35±20.76	62.5 (19.0-96.0)		
LOS	Exitus	35	34.06±34.37	19.0 (3.0-146.0)	21.578	**<0.001***
	ICU	42	21.31±34.83	11.5 (2.0-210.0)		
	Home	98	42.34±45.74	29.0 (2.0-268.0)		
GCS	Exitus	35	11.63±3.07	12.0 (4.0-15.0)	8.102	**0.017***
	ICU	42	10.62±2.72	10.0 (5.0-15.0)		
	Home	98	9.96±2.79	10.0 (4.0-15.0)		

*Kruskal-Wallis test p<0.05 (Statistically significant), GCS: Glasgow Coma Scale, ICU: Intensive care unit, LOS: Length of hospital stay, Min: Minimum, Max: Maximum, SD: Standard deviation

was applicable most significantly for stroke and dementia among the neurologic diseases (15). Similar to our study, Creutzfeldt et al. (16) reported that 62% of patients followed up in neuro-ICUs had a need for PC and that the most frequent diagnosis was stroke (46.2%, n=60).

The positive effects of PEG have been shown in stroke and chronic neurodegenerative diseases, particularly in dysphagia, for preventing complications due to undernutrition and decreasing mortality (17). Although nutritional problems have been reported to be associated with worsened survival in patients with advanced dementia, food and water intake may be supported with certain interventions in patients with dementia; however, it has been reported that these types of interventions were supported by almost no proof (18,19).

Cervo et al. (20) reported that there was no evidence to support PEG use in late stage dementia; however, they conceded that PEG feeding was efficient on increasing protein intake in patients,

Table 3. Examination of the relationship between diagnosis, comorbidity, and discharge state

	Death		Transfer to ICU		Home			
	n	%	n	%	n	%	Value*	p
Diagnosis								
Stroke								
Present	15	18.8	21	26.3	44	55.0	0.452	0.798
Absent	20	21.1	21	22.1	54	56.8		
NST								
Present	6	37.5	4	25.0	6	37.5	3.410	0.182
Absent	29	18.2	38	23.9	92	57.9		
Brain hypoxia								
Present	0	0,0	1	7.7	12	92.3	-	-
Absent	35	21.6	41	25.3	86	53.1		
Dementia								
Present	9	30.0	11	36.7	10	33.3	7.553	**0.023***
Absent	26	17.9	31	21.4	88	60.7		
Parkinson's								
Present	4	30.8	2	15.4	7	53.8	1.213	0.545
Absent	31	19.1	40	24.7	91	56.2		
TBI								
Present	1	4.3	3	13.0	19	82.6	7.916	**0.019***
Absent	34	22.4	39	25.7	79	52.0		
Other								
Present	2	15.4	5	38.5	6	46.2	1.468	0.480
Absent	33	20.4	37	22.8	92	56.8		
Comorbidity								
Oral								
Present	1	14.3	1	14.3	5	71.4	0.752	0.687
Absent	34	20.2	41	24.4	93	55.4		
PEG								
Present	13	37.1	23	25.6	54	60.0	3.576	0.167
Absent	22	25.9	19	22.4	44	51.8		
Tracheostomy								
Present	6	10.7	10	17.9	40	71.4	8.346	**0.015***
Absent	29	24.4	32	26.9	58	48.7		
PU								
Present	11	31.4	7	20.0	17	48.6	3.580	0.167
Absent	24	17.1	35	25.0	81	57.9		

*Chi-square p<0.05 (Statistically significant), ICU: Intensive care unit, NST: Nervous system tumor, TBI: Traumatic brain injury, PEG: Percutaneous endoscopic gastrostomy, PU: Pressure ulcer

Table 4. Examination of the difference between diseases and GCS								
Diagnosis	**Number**	**Average**	**SD**	**Med**	**Min**	**Max**	**MU**	**p**
Stroke								
Present	80	10.18	3.03	10.0	4.0	15.0	-1.092	0.275
Absent	95	10.68	2.76	11.0	5.0	15.0		
NST								
Present	16	12.06	2.67	12.0	8.0	15.0	-2.252	**0.024***
Absent	159	10.29	2.87	10.0	4.0	15.0		
Brain hypoxia								
Present	13	9.15	3.24	8.0	4.0	15.0	-1.514	0.130
Absent	162	10.56	2.85	10.0	4.0	15.0		
Dementia								
Present	30	11.10	2.37	11.0	8.0	15.0	-1.349	0.177
Absent	145	10.32	2.98	10.0	4.0	15.0		
Parkinson's								
Present	13	11.46	2.33	12.0	8.0	15.0	-1.325	0.185
Absent	162	10.37	2.92	10.0	4.0	15.0		
TBI								
Present	23	9.09	2.31	9.0	5.0	14.0	-2.442	**0.015***
Absent	152	10.66	2.92	10.0	4.0	15.0		
Other								
Present	13	11.69	2.95	12.0	6.0	15.0	-1.626	0.104
Absent	162	10.35	2.87	10.0	4.0	15.0		

*p<0.05 (Statistically significant), GCS: Glasgow Coma scale, NST: Nervous system tumor, TBI: Traumatic brain injury, MU: Mann-Whitney U test, Med: Median, Min: Minimum, Max: Maximum, SD: Standard deviation

preventing aspiration pneumonia, and improving functional status and survival in many studies (20). Moreover, it has been reported that PEG increased survival in dysphagic patients with ALS, its adverse effects were few, and that it was safe and applicable even for patients with respiratory failure (21).

Tracheostomy is indicated for patients who cannot be separated from a ventilator in neurology ICUs and require long-term mechanical ventilation (22). It has been shown that tracheostomy decreases mortality and affects disease prognosis positively in patients with ALS and stroke (23,24). In our previous study on PC after stroke, we found that patients with tracheostomy had significantly longer LOS in PC (25). It has been reported that among patients followed up in PCCs the ones with tracheostomy had lower mortality rates and better discharge home rates (26). In this study, LOS was determined to be significantly longer and the discharge rate was higher in patients with PEG and tracheostomy compared with the other patients ($p<0.015$). Our results are in compliance with literature, and we consider that LOS is longer in patients with PEG and tracheostomy because their mortality is decreased, and these patients also have longer LOS due to the training they and their relatives received on PEG and tracheostomy care and nutrition, causing a longer time to discharge.

Morbidity in patients with neurologic diseases depends on underlying disease and age (27). Unlike cancer-related diseases, which have a predictable disease course, the decrease in functional capacity has a slow course in diseases such as dementia and stroke; therefore, such patients may live longer but they gradually become more dependent. Prognosis has a poor course after a diagnosis of NST, and life-span is shorter (28,29). The death rates of patients with dementia and trauma were also significantly lower in our study. As reported by Lynn and Adamson (29), dementia has a slow course and longer life expectancy, and patients with head trauma similarly have a longer life-span than patients with cancer and chronically critical patients, but they are dependent on care, and their functional capacity is low (28,29,30). TBI is one of the major reasons of long-term disability by causing severe cognitive and physical damage in patients. The clinical picture in these patients may vary from mild brain damage to severe brain damage. GCS values are lower in severe damage and these patients need support and care in various parts of their life (30,31). In agreement with literature, GCS values were also determined to be significantly lower in patients with TBI in our results, and the discharge rates of these patients were significantly higher than in other patients. We observed that patients with identical times of death had significantly higher GCS scores, and we consider the reason for this is that patients with NST have higher GCS values and that the clinical state of patients with NST deteriorates very rapidly, and their life-span is shorter.

The limitations of this study are that in our health system, we have to discharge our patients first to home before they are admitted to rehabilitation clinics because 24 hours is needed

Table 5. Examination of the relationship between diagnosis, comorbidity and days of hospitalization

Diagnosis	Number	Average	SD	Med	Min	Max	MU	p
Stroke								
Present	80	34.56	39.94	23.5	2.0	268.0	0.010	0.920
Absent	95	36.54	43.73	21.0	2.0	234.0		
NST								
Present	16	26.69	23.01	19.0	5.0	69.0	0.386	0.534
Absent	159	36.53	43.33	23.0	2.0	268.0		
Brain hypoxia								
Present	13	51.00	47.07	33.0	4.0	165.0	2.275	0.131
Absent	162	34.40	41.41	20.0	2.0	268.0		
Dementia								
Present	30	41.27	58.04	16.0	2.0	234.0	0.332	0.564
Absent	145	34.47	37.92	23.0	2.0	268.0		
Parkinson's								
Present	13	68.92	84.73	31.0	5.0	234.0	1.662	0.197
Absent	162	32.96	35.62	21.0	2.0	268.0		
TBI								
Present	23	30.83	23.69	21.0	4.0	84.0	0.205	0.651
Absent	152	36.36	44.05	22.5	2.0	268.0		
Other								
Present	13	26.38	22.56	17.0	4.0	72.0	0.286	0.593
Absent	162	36.38	43.07	23.0	2.0	268.0		
Comorbidity								
CD								
Present	18	31.00	33.78	15.5	2.0	118.0	0.515	0.473
Absent	157	36.17	42.83	23.0	2.0	268.0		
HT								
Present	65	40.35	48.47	27.0	2.0	268.0	0.633	0.426
Absent	110	32.85	37.50	20.5	2.0	234.0		
DM								
Present	29	27.97	27.43	18.0	2.0	118.0	0.819	0.365
Absent	146	37.16	44.17	23.5	2.0	268.0		
Oral								
Present	7	46.43	35.17	40.0	10.0	118.0	2.172	0.141
Absent	168	35.18	42.22	20.5	2.0	268.0		
PEG								
Present	90	44.14	49.65	28.5	3.0	268.0	7.507	**0.006***
Absent	85	26.62	29.51	16.0	2.0	201.0		
Tracheostomy								
Present	56	45.52	45.37	31.5	4.0	268.0	11.330	**0.001***
Absent	119	30.98	39.56	17.0	2.0	234.0		
PU								
Present	35	37.40	34.56	26.0	4.0	146.0	0.557	0.456
Absent	140	35.19	43.68	21.5	2.0	268.0		

*: p<0.05 (Statistically significant), NST: Nervous system tumor, TBI: Traumatic brain injury, CD: Cardiac disease, HT: Hypertension, DM: Diabetes mellitus, PEG: Percutaneous endoscopic gastrostomy, PU: Pressure ulcer, MU: Mann-Witney U test, Med: Median, Min: Minimum, Max: Maximum, SD: Standard deviation

for the start of a new govermental health insurance period. For this reason, we could not follow the admission of our patients to reahabilitation clinics because the study is retrospective.

Conclusion

Even though patients with neurologic diseases are the second most common patient population receiving PC services after cancer, the studies performed for describing the characteristics of this population and meeting their needs, and increasing awareness in this area are not sufficient. In this retrospective study, the most common patient group we followed up was those with stroke, while observing the change in clinical course, disability, prognosis and symptoms. Although neurological patients followed up in PCCs have a heterogeneous course throughout the disease, they have a common need for PV focusing on social support and care objectives. There is a need for further studies with larger populations to meet these needs.

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Ethics

Ethics Committee Approval: University of Health Sciences Turkey, Clinical Research Ethics Committee (date: 21.03.2018, approval no: E-18-1871).

Informed Consent: Consent form was filled out by all participants.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Concept: D.A., Design: K.K., Data Collection or Processing: K.K., Analysis or Interpretation: G.S., Literature Search: D.A., Writing: G.S.

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