Original Article

ANATOLIAN CURRENT MEDICAL

DOI: 10.38053/acmj.1423588

Anatolian Curr Med J. 2024;6(2):155-160

Clinical characteristics of patients discharged from a palliative care center to home care: a retrospective cross-sectional study

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Cite this article as: Parpucu ÜM, Kahveci K, Döger C, Aydemir S, Küçük O. Clinical characteristics of patients discharged from a palliative care center to home care: a retrospective cross-sectional study. *Anatolian Curr Med J.* 2024;6(2):155-160.

Received: 22.01.2024 ◆ **Accepted**: 18.02.2024 ◆ **Published**: 08.03.2024

ABSTRACT

Aims: The aim of this study was to establish the clinical characteristics and their impact on the length of stay (LOS) of patients discharged from a palliative care center (PCC) to home care (HC).

Methods: Our cross-sectional study retrospectively analysed 314 patients who were discharged from PCC to HC between 1 January 2015 and 30 September 2018. The patients were divided into two groups based on their LOS in the PCC. Prolonged hospitalisation was defined as hospitalisation for more than 30 days. Clinical characteristics associated with prolonged hospitalization were analyzed.

Results: The study included 314 patients, with 129 (41.08%) female and 185 (58.92%) male. The mean age was 68.41±18.91 years and the LOS in PCC was 36.27±40.34 days. Of the patients, 186 were hospitalized for 30 days or less, while 128 were hospitalized for more than 30 days. The most frequent diagnosis was cerebrovascular event (CVE) (37.57%). The most common accompanying chronic systemic diseases were hypertension (20.70%), followed by diabetes mellitus and heart failure (9.87%; 6.68%, respectively). Out of the total number of patients, 9.87% (n=31) were mobilized. Among them, 55.09% (n=173) were able to receive oral nutrition, 42.03% (n=132) had percutaneous endoscopic gastrostomy (PEG), 23.88% (n=75) had pressure ulcer (PU), and 27.07% (n=85) had tracheostomy. Additionally, 6.68% (n=24) of the patients were receiving respiratory support with a home ventilator. It was observed that the LOS of patients who were mobile, able to feed orally, and diagnosed with cancer was shorter. The presence of CVE (p=0.001), head trauma (p=0.013), hypoxic brain diagnosis (p=0.001), PEG (p<0.001), tracheostomy (p<0.001), PU (p=0.011), and home ventilator (p=0.024) were identified as predictors of long LOS. Hypoxic brain diagnosis was found to be the clinical feature most strongly associated with long-term hospitalization (OR:6.8), followed by PEG feeding (OR:6.6) and the presence of tracheostomy (OR:5.2).

Conclusion: In our study we observed that time to discharge is extended due to training on care and nutrition for patients undergoing tracheostomy, PEG and PU.

Keywords: Palliative care, home care, length of stay, discharge, prolonged hospitalisation

INTRODUCTION

The increase in the number of chronic diseases (CD) requiring care, together with the growing elderly population in the world, is causing a serious increase in the demand for post-hospital care services and healthcare expenditure.[1,2] Patients with CD are known to have the greatest need for palliative care (PC) aimed at improving quality of life, and these patients have complex needs such as symptom relief and end-of-life care.[3,4] The majority of CD are patients with dementia, heart failure (HF) and diseases with high mortality and symptom burden such as cancer.[5,6] Many health systems are developing novel programs by integrating nursing homes and home care (HC) with PC for sustainable health care due to a lack of resources as the need for PC increases.[7]

In our country, the Ministry of Health's Pallia-Turk project recognised PC as a medical discipline in 2010, and community-based PC services were planned to be provided at home and by family practitioners.[8,9] As a result of these plans, the first Palliative Care Center (PCC) was opened for adult patients, and PC services previously provided in oncology clinics are now planned independently of oncology clinics and for all other critically chronic patients in addition to cancer. The number of PCCs are increasing day by day, and HC

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services, such as PC, have gained momentum in the last 10 years and started in 2005 and are offered mainly to bedridden patients, together with respiratory patients, advanced muscle disease patients, terminal cancer patients and newborns in family and home settings.[10,11] HC is provided by family practitioners, hospital-based units and mobile teams formed by community health centers.[10] Despite the rapid expansion of PC and HC in Turkiye and the necessary in-service training, PC services are not provided as part of HC, although they are present in hospitals.

Most people prefer to remain in their familiar home environment for the rest of their lives, even if they are seriously ill.[12] Integrating PC services with HC and providing PC in the home can improve patient satisfaction and reduce the length and cost of hospital stays.[6,13] By better adapting to patients' wishes and goals, hospital stays can be reduced and patient and carer satisfaction increased.[14,15] Effective symptom control can be achieved through a coordinated effort between PC and HC teams. A multidisciplinary approach and a seamless transition from PCC to HC can further improve patient care.[16] In this context, it is important to integrate PC services into HC and to encourage patients to be cared for at home so that they can live comfortably and in line with their values.

This study was designed to provide guidance for the implementation of home-based PC in terms of the clinical characteristics of patients and their transition from PC to HC. Our basic aim was to determine the clinical characteristics and their impact on the length of stay (LOS) of patients discharged from PC to HC.

METHODS

Study Design and Ethics

This retrospective cross-sectional descriptive study was started after obtaining the approval of the Health Sciences University Ankara Numune SUAM Clinical Researches Ethics Committee (Date: 28.03.2019, Decision No: 2625/2019). All procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national) and with the Declaration of Helsinki as revised in 2013.

Participants

A retrospective analysis was conducted on the data of all patients aged 18 years or older who were discharged from the PCC between 1 January 2015 and 30 September 2018. The study excluded 22 patients, including 4 with missing records, 12 with a LOS of one day or less in the PCC, and 6 with recurrent hospitalisation. **Figure** shows the patient flow chart.

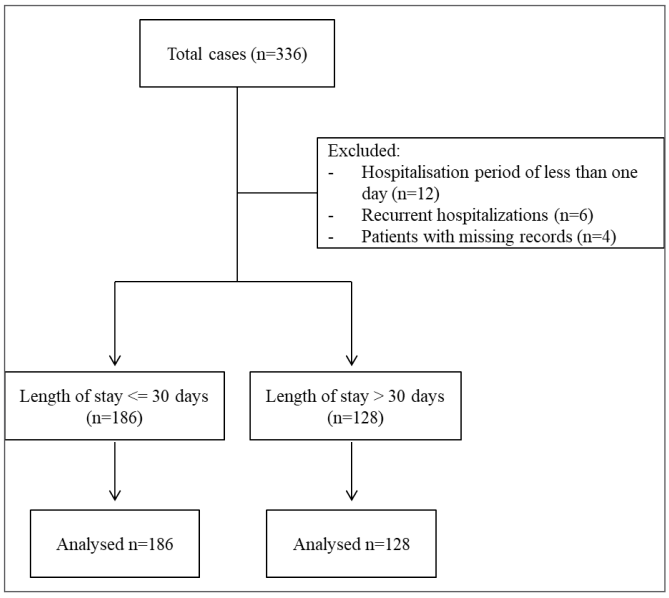

Figure. Flow charts of the patients

Interventions and Clinical Definitions

Age, sex, LOS in PCC, Glasgow Coma Scales (GCS), diagnoses, and chronic systemic diseases such as HF, hypertension (HT) and diabetes mellitus (DM) were recorded. In addition, patients with comorbidities such as mobilization status, oral feeding, percutaneous endoscopic gastrostomy (PEG), tracheostomy, home ventilator, and pressure ulcer (PU) were identified.

A 30-day limit was accepted to determine the clinical characteristics that were effective in long-term hospitalization. The patients were divided into two groups according to the LOS in PCC as LOS of 30 days or less and LOS more than 30 days.

Outcomes

The study's primary outcome measure is the clinical characteristics of PC patients who are discharged home. The secondary outcome measure is the clinical characteristics associated with prolonged LOS (more than 30 days) in patients who are discharged home from PCC.

Statistical Analysis

Statistical analysis and calculations were carried out using 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.) software. Tables were formed for the analysis of demographic data. The data in the tables were shown as number (n), percentage (%), and numerical variables were demonstrated by mean±standard deviation (SD). Cross tables were created for each clinical feature between the two groups for LOS. Chi-square test was used in the evaluation of the cross tables. The odds-ratio (OR) was calculated to evaluate the effect of each factor on hospitalization. $P<0.05$ was considered significant for all calculations.

RESULTS

The study included 314 patients, with 129 (41.08%) female and 185 (58.92%) male. The mean age was 68.41±18.91 years and the LOS in PCC was 36.27±40.34 days. Of the patients, 186 were hospitalized for 30 days or less, while 128 were hospitalized for more than 30 days. The mean GCS was established as 11.6±3.2. Of the 314 patients included in the study, diagnoses were 21.68% (n=68) cancer, 8.28% (n=26) chronic obstructive pulmonary disease (COPD), 37.57% (n=118) cerebrovascular event (CVE), 3.50% (n=11) Parkinson's, 13.37% (n=42) dementia, 5.09% (n=16) hypoxic brain, 2.58% (n=8) motor neuron disease, 7.32% (n=23) trauma, and 6.05% (n=19) infection. CVE (37.57%) was observed as the highest, while the lowest rate was motor neuron disease (2.54%). The most common concomitant chronic systemic diseases were HT (20.70%), followed by DM and HF (9.87%; 6.68%, respectively). While 9.87% (n=31) of patients were mobilized, 55.09% (n=173) of them were able to receive oral nutrition, 42.03% (n=132) patients had PEG, 23.88% (n=75) had PU, and 27.07% (n=85) had tracheostomy and 6.68% (n=24) of the patients were receiving respiratory support with a home ventilator (**Table 1**).

Table 1. Demographic characteristics of patients

Variable	Value
Age (Years)*	68.11±18.91
Gender**	
Female	129 (41.08)
Male	185 (58.92)
Length of stay (days)*	36.27±40.34
GCS*	11.6±3.2
Diagnosis**	
Cancer	68 (21.68)
CVE	118 (37.57)
Parkinson's disease	11(3.50)
Dementia	42 (13.37)
COPD	26 (8.28)
Hypoxic brain	16 (5.09)
MND	8 (2.54)
Trauma	23 (7.32)
Infection	19 (6.05)
Heart failure	21 (6.68)
Hypertension	65 (20.70)
Diabetes mellitus	31 (9.87)
Comorbidity**	
Mobilization	31 (9.87)
Oral nutrition	173 (55.09)
PEG	132 (42.03)
Tracheostomy	85 (27.07)
Home ventilator	24(6.68)
Pressure ulcer	75 (23.88)

*Values are presented as mean±standard deviation; **Values are presented as n (%)
GCS: Glasgow coma scales; CVE: Cerebrovascular event; MND: Motor neuron disease; COPD: Chronic obstructive pulmonary disease; PEG: Percutaneous endoscopic gastrostomy

When the effect of clinical characteristics on the LOS was evaluated, it was found that patients diagnosed with cancer, mobilized patients, and patients with oral nutrition were hospitalized for less than 30 days (p values respectively; 0.003, 0.001, 0.049). However, it was established that patients with CVE (p=0.001), head trauma (P=0.013), hypoxic brain (p=0.001) diagnoses, along with PEG (p<0.001) and tracheostomy (p<0.001), patients that were followed up with home ventilator (p=0.024), patients with PU (p=0.011) spent more than 30 days in the hospital (**Table 2**). Hypoxic brain diagnosis was the clinical feature most associated with long-term hospitalization (OR: 6.8). This was followed by PEG feeding (OR: 6.6) and the presence of a tracheostomy (OR: 5.2). LOS was prolonged 2.9-fold by the diagnosis of head trauma, 2.6-fold by the use of a home ventilator, 2.3-fold by the diagnosis of CVE, and 1.9-fold by the presence of PU.

DISCUSSION

Along with a coordinated work by PC and HC teams, a better quality of life can be ensured for patients through an uninterrupted transition from PC to HC and a multidisciplinary team approach. This study is the first of its kind that investigates the clinical characteristics and LOS of patients that were discharged home from PC and transferred to HC. Similar to international studies,[4,17,18] most patients were male and over 65 years old. The rate of non-cancer patients was higher (78.32%). The patients who were difficult to care for by their relatives, had poor self-care and communication skills, and required training for care had a longer LOS in the PCC. This patient group required more services and hospitalisation time.

In a study by Brian Cassel et al.[19] which investigated the effects of healthcare service use and costs of a home-based PC program, it was found that cancer patients had shorter hospital stays compared to patients with COPD, HF, and dementia. Additionally, the study reported that home-based PC practice during the end-of-life period reduced hospital stays and costs. Additionally, several studies have shown that factors such as diagnosis, tracheostomy, home ventilator, and nutritional status can influence the discharge of PC patients to their homes.[20-22] In our study, it was found that cancer patients had a shorter hospital stay compared to other patient groups. Patients who underwent PEG, tracheostomy, and PU, and required home ventilator support, as well as those who could not be mobilized, had a significantly longer hospital stay compared to patients who could be mobilized and fed orally (P<0.001).

Table 2. Variables related to length of stay in palliative care center

		<=30 days	>30	Total	OR	P
Gender	Male	106 (57%)	79 (61.7%)	185 (58.9%)	0.822 (0.519-1.301)	0.403
	Female	80 (43%)	49 (38.3%)	129 (41.1%)		
Cancer	None	135 (72.6%)	111 (86.7%)	246 (78.3%)	0.405 (0.221-7.741)	0.003
	Yes	51 (27.4%)	17 (13.3%)	68 (21.7%)		
CVE	None	131 (70.4)	65 (50.8%)	196 (62.4%)	2.309 (1.445-3.687)	0.001
	Yes	55 (29.6%)	63 (49.2%)	118 (37.6%)		
Head trauma	None	178 (95.7%)	113 (88.3%)	291 (92.7%)	2.954 (1.213-7.191)	0.013
	Yes	8 (4.3%)	15 (11.7%)	23 (7.3%)		
Hypoxic brain	None	183 (98.4%)	115 (89.8%)	298 (94.9%)	6.896 (1.923-4.723)	0.001
	Yes	3 (1.6%)	13 (10.2%)	16 (5.1%)		
Alzheimer	None	161 (86.6%)	111 (86.7%)	272 (86.6%)	0.986 (0.509-1.912)	0.967
	Yes	25 (13.4%)	17 (13.3%)	42 (13.4%)		
Parkinson's disease	None	181 (97.3%)	122 (95.3%)	303 (96.5%)	1.780 (0.532-5.963)	0.344
	Yes	5 (2.7%)	6 (4.7%)	11 (3.5%)		
MND	None	183 (98.4%)	123 (96.1%)	306 (97.5%)	2.480 (0.582-0.566)	0.205
	Yes	3 (1.6%)	5 (3.9%)	8 (2.5%)		
COPD	None	169 (90.9%)	119 (93%)	288 (91.7%)	0.752 (0.324-1.744)	0.505
	Yes	17 (9.1%)	9 (7%)	26 (8.3%)		
Hypertension	None	145 (78%)	104 (81.3%)	249 (79.3%)	0.816 (0.465-1.433)	0.479
	Yes	41 (22%)	24 (18.8%)	65 (20.7%)		
Heart failure	None	169 (90.9%)	124 (96.9%)	293 (93.3%)	0.321 (0.105-3.977)	0.036
	Yes	17 (9.1%)	4 (3.1%)	21 (6.7%)		
Diabetes mellitus	None	168 (90.3%)	115 (89.8%)	283 (90.1%)	1.055 (0.497-2.238)	0.889
	Yes	18 (9.7%)	13 (10.2%)	31 (9.9%)		
Infection	None	176 (94.6%)	119 (93%)	295 (93.9%)	1.331 (0.525-3.374)	0.546
	Yes	10 (5.4%)	9 (7%)	19 (6.1%)		
Oral nutrition	None	75 (40.3%)	66 (51.6%)	141 (44.9%)	0.635 (0.403-2.999)	0.049
	Yes	111 (59.7%)	62 (48.4%)	173 (55.1%)		
PEG	None	141 (75.8%)	41 (32%)	182 (58%)	6.649 (4.030-8.967)	<0.001
	Yes	45 (24.2%)	87 (68%)	132 (42%)		
Tracheostomy	None	160 (86%)	69 (53.9%)	229 (72.9%)	5.262 (3.063-9.737)	<0.001
	Yes	26 (14%)	59 (46.1%)	85 (27.1%)		
Home ventilator	None	177 (95.2%)	113 (88.3%)	290 (92.4%)	2.611 (1.105-6.166)	0.024
	Yes	9 (4.8%)	15 (11.7%)	24 (7.6%)		
Pressure ulcer	None	151 (81.2%)	88 (68.8%)	239 (76.1%)	1.961 (1.161-3.313)	0.011
	Yes	35 (18.8%)	40 (31.3%)	75 (23.9%)		
Mobilisation	None	156 (85.2%)	120 (96.8%)	276 (89.9%)	0.193 (0.065-6.565)	0.001
	Yes	27 (14.8%)	4 (3.2%)	31 (10.1%)		

Values are presented as n (%); OR: Odds ratio; p<0.05 is significant; CVE: Cerebrovascular Event; MND: Motor Neuron Disease; COPD: Chronic Obstructive Pulmonary Disease; PEG: Percutaneous Endoscopic Gastrostomy

Palliative medicine is a medical speciality that aims to enhance the quality of life of patients with serious or advanced medical conditions.[23] It is appropriate at all stages of illness, including at the time of diagnosis. Neurological conditions often have high symptom burdens, variable disease courses, and poor prognoses, which affect not only patients but also their families and carers. Major contributing factors to the difficulty of care include inadequate communication with patients. Ideally, a comprehensive care approach should manage the complex needs of these patients by addressing their physical, psychological, social, and spiritual aspects of care to reduce suffering.[24] Taylor et al.[25] reported that patients with neurological diseases require more PC than those with cancer. They also found that patients admitted to a PCC with neurological disease had more severe symptoms than those admitted for cancer and had lower Palliative Performance Scale scores. Additionally, the group with neurological disease had longer hospital stays. In our study, the patient group with neurological disease had the highest percentage of diagnosis. The clinical feature most associated with prolonged hospitalisation was the diagnosis of hypoxic brain. We believe that this patient group requires the longest duration of service both in terms of disease treatment and care requirements.

Tracheotomy is recommended for patients with airway obstruction or requiring long-term mechanical ventilation support. The growing number of patients undergoing tracheotomy has resulted in an increase in referrals to hospices and PC.[26] Tracheostomies are often

performed to wean patients off the ventilator. However, in most cases, tracheostomies are placed in patients who are at the end of their life with little hope of meaningful recovery. The use of tracheostomy in PC offers a convenient option for airway control.[27] Tracheostomy care is a complex process that requires knowledge and skills for elderly patients and their caregivers. Caregivers of tracheostomy patients have reported feeling burdened due to the intensive and complex nature of their role. They require guidance and training to carry out this process effectively.[28-30] A study conducted by Nagi et al.[31] in 2014 found that training was necessary for caregivers of elderly patients with tracheostomy, and that the provided training made a significant difference. In previous descriptive studies conducted with caregivers of elderly tracheostomy patients, it was reported that they experienced a heavy burden due to the intensive and complex tracheostomy care required.[29,30] They expressed a need for training to carry out this process and highlighted the time-consuming nature of the care. In our study, we observed that patients with tracheostomy had a longer hospitalisation period. Tracheostomy care and education provided to elderly patients and their caregivers can extend the LOS.

Approximately 40-300 million patients worldwide receive PC, with PU being particularly prevalent due to limited mobility and changes in tissue perfusion caused by antalgic posture, dyspnoea, oedema, anorexia-cachexia syndrome, and impaired sensory perception due to analgesia.[32,33] Studies have shown that the likelihood of PU development is greater in CD such as stroke and in patients over 65 years of age, and that it prolongs hospital stay.[34,35] In our study, we found that patients with PUs had longer hospital stays. Furthermore, a retrospective review that investigates PU prevalence, incidence, and related factors in home PC patients reported that terminal patients were at risk of PU that adversely affected quality of life, and that effective PU prevention and care management was important, and that caregivers should be supported by PC nurses.[18] Hudson[36] emphasized that PC providers should provide caregivers with coping strategies and train them to provide care, and reported that end of life care of patients in the home environment can increase the quality of life and reduce the burden on the health system. In a study evaluating the applicability of a training program on acute symptom management for caregivers of cancer patients receiving home care, they observed that hospital admissions of patients for acute symptoms decreased by 80%.[37] Our study population consisted of patients requiring special care: PEG (42.03%), tracheostomy (27.07%), home ventilator (6.68%), and PU (23.88%). It is challenging to provide HC for this patient group, and therefore, training for carers and HC services provided by healthcare providers are crucial. This approach can reduce the burden on the health system and ensure cost-effective service management.

In our clinic, care planning of the patients is made with a multidisciplinary team approach, and their caregivers are provided with more difficult and specific feeding, PEG, tracheostomy, and wound care trainings as well as routine care of the patient. Thus, it is easier for patients that are discharged home to continue receiving care in the home environment, and for carers to cope with the difficulties while providing care. In our study, the presence of PEG and tracheostomy was found to be the most effective factor on hospital stays for more than 30 days. We believe that the reason for providing caregivers with nutrition, tracheostomy, and wound care trainings is for the possibility of prolonged stays, and in addition, their quality of life may increase by conducting HC in an uninterrupted and more effective fashion.

Limitations

There were several limitations to the present study. Due to PCC patients not being a homogenous patient group, and patients to have a variety of age groups, diagnoses, and clinical characteristics, a standardization could not be fully ensured. Furthermore, it is important to note that our study was conducted retrospectively at a single center and therefore cannot be extrapolated to the wider population. However, our study put forth certain fundamental data on the clinical characteristics of patients discharged from PCC in order to clarify their care needs. Further research is required on this topic, particularly larger multicenter prospective studies.

CONCLUSION

Our study identified the clinical characteristics of patients that were discharged home from PC and some of the main factors affecting hospitalization for more than 30 days.

Clinical features such as PEG feeding, tracheostomy, pressure ulcers, and home ventilator use can significantly prolong hospitalisation and these features can be integrated into HC. In order to provide more effective HC for patients scheduled for discharge, we believe that adequate training in PEG, tracheostomy and wound care is necessary, and that a home-based PC is necessary by integrating PC into HC services.

ETHICAL DECLARATIONS

Ethics Committee Approval

Approval was obtained from the Health Sciences University Ankara Numune SUAM Clinical Researches Ethics Committee (Date: 28.03.2019, Decision No: 2625/2019).

Informed Consent
Ankara Numune SUAM Clinical Researches Ethics Committee did not require informed consent because the study was retrospective.

Referee Evaluation Process
Externally peer-reviewed.

Conflict of Interest Statement
The authors have no conflicts of interest to declare.

Financial Disclosure
The authors declared that this study has received no financial support.

Author Contributions
All of the authors declare that they have all participated in the design, execution, and analysis of the paper and that they have approved the final version.

REFERENCES

1. Christensen K, Doblhammer G, Rau R, Vaupel JW. Ageing populations: the challenges ahead. *Lancet.* 2009;374(9696):1196-208.
2. Radbruch L, Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 1. *Eur J Palliat Care.* 2009;16(6):278-289.
3. Nelson JE, Cox CE, Hope AA, Carson SS. Chronic critical illness. *Am J Respir Crit Care Med.* 2010;182(4):446-454.
4. Parpucu ÜM, Küçük O, Sağ F, et al. Pre-assessment criteria for the needs of patients in palliative care: the role of palliative care by age groups. *Turkish J Geriatr.* 2023;26(3):334-346.
5. Ibrahim JE, Anderson LJ, MacPhail A, Lovell JJ, Davis MC, Winbolt M. Chronic disease self-management support for persons with dementia, in a clinical setting. *J Multidiscip Healthc.* 2017;10:49-58.
6. Wiencek C, Coyne P. Palliative care delivery models. *Semin Oncol Nurs.* 2014;30(4):227-233.
7. Reymond L, Parker G, Gilles L, Cooper K. Home-based palliative care. *Aust J Gen Pract.* 2018;47(11):747-752.
8. Ozgul N, Koc O, Gultekin M, et al. Opioids for cancer pain: availability, accessibility, and regulatory barriers in Turkiye and Pallia-Turk Project. *J Pediatr Hematol Oncol.* 2011;33:S29-S32.
9. Ozgul N, Gultekin M, Koc O, et al. Turkish community-based palliative care model: a unique design. *Ann Oncol.* 2012;23(Supplement 3):iii76-iii78.
10. Mergen H, Unluoglu I, Elcioglu O. Contemporary home care service and family medicine in Turkiye. *Home Health Care Manag Pract.* 2013;25(3):104-109.
11. Emuk Y, Naz I. The current situation of palliative care in Turkiye. *J Cancer Policy.* 2017;13:33-37.
12. Radbruch L, Maier BO, Bausewein C. Palliative home care: which type for whom and when? *Schmerz.* 2019;33(4):285-286.
13. Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc.* 2007;55(7):993-1000.
14. Ciemins EL, Stuart B, Gerber R, Newman J, Bauman M. An evaluation of the advanced illness management (AIM) program: increasing hospice utilization in the San Francisco Bay area. *J Palliat Med.* 2006;9(6):1401-1411.
15. Hughes MT, Smith TJ. The growth of palliative care in the United States. *Annu Rev Public Health.* 2014;35(1):459-475.
16. Labson MC, Sacco MM, Weissman DE, Gornet B, Stuart B. Innovative models of home-based palliative care. *Cleve Clin J Med.* 2013;80(E-Supplement 1):30-35.
17. Maida V, Ennis M, Kuziemsky C, Corban J. Wounds and survival in cancer patients. *Eur J Cancer.* 2009;45(18):3237-3244.
18. Artico M, Dante A, D'Angelo D, et al. Prevalence, incidence and associated factors of pressure ulcers in home palliative care patients: a retrospective chart review. *Palliat Med.* 2018;32(1):299-307.
19. Brian Cassel J, Kerr KM, McClish DK, et al. Effect of a home-based palliative care program on healthcare use and costs. *J Am Geriatr Soc.* 2016;64(11):2288-2295.
20. Bosel J, Schiller P, Hook Y, et al. Stroke-related early tracheostomy versus prolonged orotracheal intubation in neurocritical care trial (SETPOINT): a randomized pilot trial. *Stroke.* 2013;44(1):21-28.
21. Spataro R, Bono V, Marchese S, La Bella V. Tracheostomy mechanical ventilation in patients with amyotrophic lateral sclerosis: clinical features and survival analysis. *J Neurol Sci.* 2012;323(1-2):66-70.
22. Pan CX, Gutierrez C, Maw MM, et al. Impact of a palliative care program on tracheostomy utilization in a community hospital. *J Palliat Med.* 2015;18(12):1070-1073.
23. Glover TL, Kluger BM. Palliative medicine and end-of-life care. *Handb Clin Neurol.* 2019;167:545-561.
24. Robinson MT, Holloway RG. Palliative care in neurology. *Mayo Clin Proc.* 2017;92(10):1592-1601.
25. Taylor BL, O'Riordan DL, Pantilat SZ, Creutzfeldt CJ. Inpatients with neurologic disease referred for palliative care consultation. *Neurol.* 2019;92(17):e1975-e1981.
26. Newman III AJ, Kvale EA, Williams BR, Bailey FA. What about the trach? Tracheotomy removal as a palliative care maneuver. *Am J Hosp Palliat Care.* 2007;24(5):371-375.
27. Chan T, Devaiah AK. Tracheostomy in palliative care. *Otolaryngol Clin North Am.* 2009;42(1):133-141.
28. Sherlock ZV, Wilson JA, Exley C. Tracheostomy in the acute setting: patient experience and information needs. *J Crit Care.* 2009;24(4):501-507.
29. Cameron JI, Chu LM, Matte A, et al. One-year outcomes in caregivers of critically ill patients. *N Engl J Med.* 2016;374(19):1831-1841.
30. Nakarada-Kordic I, Patterson N, Wrapson J, Reay SD. A Systematic review of patient and caregiver experiences with a tracheostomy. *Patient.* 2018;11(2):175-191.
31. Nagi M, Kapoor S, Kaur S, Gupta S. Effect of an intervention on performance regarding change of tracheostomy tube among the caregivers of the patient. *Indian J Neurosurg.* 2014;3(1):31-35.
32. World Health Organization. Strengthening of palliative care as a component of integrated treatment throughout the life course. *J Pain Palliat Care Pharmacother.* 2014;28(2):130-134.
33. Langemo DK, Black J. Pressure ulcers in individuals receiving palliative care: a National Pressure Ulcer Advisory Panel white paper. *Adv Skin Wound Care.* 2010;23(2):59-72.
34. Lyder CH, Wang Y, Metersky M, et al. Hospital-acquired pressure ulcers: results from the national Medicare Patient Safety Monitoring System study. *J Am Geriatr Soc.* 2012;60(9):1603-1608.
35. Allman RM. The impact of pressure ulcers on health care costs and mortality. *Adv Wound Care.* 1998;11:2.
36. Hudson P. Improving support for family carers: key implications for research, policy and practice. *Palliat Med.* 2013;27(7):581-582.
37. Chellappan S, Ezhilarasu P, Gnanadurai A, George R, Christopher S. Can symptom relief be provided in the home to palliative care cancer patients by the primary caregivers? An Indian study. *Cancer Nurs.* 2014;37(5):E40-E47.