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Home-based Palliative Care

Ev Temelli Palyatif Bakım

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ABSTRACT

Palliative care (PC) is defined as the approach that improves quality of lives of patients and their families who face up with the problems accompanied with life-threatening conditions. Provided usually in an inpatient setting, PC services are considered as an appropriate caregiving model for patients with critical illnesses. As the need for such services increases, many healthcare systems has been developing novel programs that integrate PC to their healthcare services in-hospital, outside the hospital, and home-based settings. Home-based PC is the care approach that provides meeting of physical, psychological, and moral needs of the patients with chronic and disabling health problems such as advanced cardiac, renal, respiratory, malignant, and neurological conditions in home-based setting. It is provided by a multidisciplinary team that has training in PC and that consists of physicians, nurses, public health professionals, and volunteers in line with PC programs of hospitals. Patients in need of PC have higher mortality and length of stay at intensive care units (ICU) with increased costs; in fact, they often live their terminal days in ICU. Even though it is considered as a model of care for those with life-limiting conditions in developed countries, home-based PC is still not sufficient. In our country, population gets older year by year. However, PC and home-care services are quite new and both are not yet up to the level to meet the needs. Therefore, PC services should be integrated into home-care services bearing in mind the sociocultural structure and national health policies of our country.

Keywords: Home care, palliative care, chronic critical illness

ÖZ

Palyatif Bakım (PB) yaşamı tehdit eden hastalığa bağlı sorunla karşılaşan hasta ve ailelerinin yaşam kalitesini artıran bir yaklaşım olarak tanımlanmaktadır. PB hizmetleri, çoğunlukla hastanelerde yataklı tedavi birimlerinde verilmekte olup ciddi hastalığı olan hastalar için uygun bir bakım verme modeli olarak kabul görmektedir. PB ihtiyacının artmasıyla birlikte, birçok sağlık sistemi, hastane, hastane dışında ve evde bakım hizmetlerine PB'yi entegre ederek yeni programlar geliştirmektedir. Ev temelli PB ileri dönem kalp, böbrek, solunum yolu hastalıkları, kanser ve kronik nörolojik bozukluklar gibi kronik, yaşamı sınırlayıcı sağlık sorunları olan, hastaların yaşadığı evde, fiziksel, psikolojik ve manevi ihtiyaçlarının karşılanmasını sağlayan, bakım yaklaşımıdır. Doktor, hemşire vb. sağlık çalışanları ve gönüllülerinden oluşan, PB konusunda eğitilmiş multidisipliner bir ekip tarafından hastanelerin PB programlarına bağlı olarak verilir. PB ihtiyacı olan bu hastalar genellikle yaşam sonu dönemlerini yoğun bakım ünitelerinde (YBÜ) geçirmekte olup YBÜ'de kalış süreleri ve mortalitelerinin yüksek olduğu, ayrıca maliyelerinin de fazla olduğu bilinmektedir. Ev temelli PB gelişmiş ülkelerde yaşamı sınırlayıcı hastalıkları olanlar için bir bakım modeli olarak görülse de henüz yeterli değildir. Ülkemizde de nüfusumuz her geçen gün yaşlanmaktadır. Bununla birlikte PB ve evde bakım hizmetleri oldukça yeni olup her ikisi de ihtiyacı karşılayacak düzeyde değildir. Bu nedenle ülkemizin sosyokültürel yapısı ve sağlık politikalarına göre PB hizmetlerinin evde sağlık hizmetlerine entegre edilmesi gereklidir.

Anahtar Sözcükler: Evde bakım, palyatif bakım, kronik kritik hastalık

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Introduction

The increase in the elderly population in the world leads to an increase in patients with chronic critical illnesses (CCI) in need of palliative care (PC) (1,2). The majority of CCI is comprised of patients with dementia, heart failure (HF), and diseases with high mortality and symptom burden such as cancer (3,4). CCI is the patient group that needs the services of the PC that is most focused on improving the quality of life, and these patients are known to have complex needs such as relieving symptoms and end-of-life care in the clinical management plan (3-5). The World Health Organization (WHO) defined PC as an approach that improves the quality of life of patients and their families experiencing problems related to life-threatening disease (6). PC programs mostly function as inpatient treatment units and consultation services in hospitals (1). As the need for PC services increases, many healthcare systems has been developing novel programs that integrate PC to their healthcare services in the hospital, outside the hospital, and home-based settings (7). In recent years, PC services have been suggested to be integrated into the patient's routine care along with therapeutic approaches beginning from the diagnosis of the disease (1,8,9). Today, too, PC services are provided in hospitals, polyclinics, nursing homes, or home environments, and they are considered as a basic care model especially in the end-of-life period (10,11).

What is Home-Based PC?

Home-based PC is the care approach that provides meeting of physical, psychological, and moral needs of the patients with chronic and disabling health problems such as advanced cardiac, renal, respiratory tract diseases, cancer, and chronic neurological conditions in a home-based setting (12,13). It is provided by a multidisciplinary team which has training in PC and consists of physicians, nurses, public health professionals, and volunteers in line with PC programs of hospitals (14). Home care patients with newly diagnosed serious diseases are candidates for PC. As the symptoms of these patients start affecting the quality of life, the burden of the disease increases, and thus, while the treatment for the disease continues, an advanced care planning that would increase the comfort of patients and that involves the symptoms is needed (15). PC interventions are an integral part of the care plan for these patients, and the patients have been reported to benefit more from the inclusion of the PC team in home-based healthcare institutions (12). Table 1 shows home-based PC characteristics (12). In order to provide PC at home, it is necessary to evaluate the patient's home environment. This includes assessment of living conditions such as nutrition, cleanliness, ambient temperature, access to water, electricity, and telephone, safety, and the availability of equipment (12). Most patients feel more comfortable in their homes than in hospitals or nursing homes. In addition, home-based PC enables family members to integrate into the process (13). The provision of PC services for patients with severe disease was reported to be more effective in providing care to patients, families, and health systems (16,17). Although patients with CCI have more PC requirements during the end of life period, only 1/10 of those in need of PC has access to this service according to the WHO's data (18). Patients in need of PC generally spend their end of life period at the intensive care units (ICU), and it is common that they have long ICU stays and high mortality rates in addition to their highcosts (4). Even though it is considered as a model of care for those with life-limiting conditions in developed countries, home-based PC is still insufficient (15). In our country, due to the lack of PC awareness in addition to the insufficient number of PC centers where end of life care is provided and to it being a new care model, most of the deaths occur in ICUs which cause higher spending. This situation is not peculiar to Turkey, and only a minority of patients can benefit from home-based PC services in developed countries as well (18). Studies conducted on home-based PC practice has been on an increase in recent years, and it was reported that home-based PC services increased patient satisfaction and reduced spending (17,19). It was reported in studies that outpatient or home-based PC practice at the early stages of the disease would increase the quality of life, in addition, that emergency and acute care applications were reduced thanks to training provided to patient and their families on drug use at home, crisis intervention, and patient care (16,20-22). In 2014, WHO noted that PC should be integrated into other healthcare services as the fundamental element of healthcare continuity, and it also emphasized the necessity for healthcare team and primary care physicians to have PC training in order to integrate home-based care and PC services (8). In addition to the patient and the family, home-based care team are required to receive training on symptom management and psychosocial support in order to provide PC service to patients beginning from diagnosis through a multidisciplinary team approach comprising physician, nurse,

Table 1. Home-based PC properties (12)

1. Patients with CCD who have functional disorders preventing PC polyclinic follow-ups,
2. Compliance with home-based PC is determined by need and not by prognosis,
3. Concomitant PC application with the patient's curative treatment,
4. Patient and family focused care by a multidisciplinary team consisting of a trained physician, nurse, social worker, and psychologist, physiotherapist, spiritual care specialist and home health assistant according to patient needs,
5. Home visits by all team members, including physicians to provide pain control, other symptom management, psychosocial support, and training to meet patient and family needs,
6. 24/7 phone support,
7. Informing about end-of-life care of patients and families and planning care together,
8. The PC team needs to check and control caregivers, home environment and family.

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and social service expert. The home PC team is responsible for the coordination and management of care and provides services for the evaluation of patients, planning, care delivery, follow-up monitoring and continuous reassessment of care (10,18). It has been reported that the effects of the disease and symptoms on the quality of life are less, physically and psychologically and patient satisfaction is higher in patients with home-based PC (22).

Requirements For Home-Based PC Service:

Home-based PC service can be set up quite simply. Minimum requirements for home care are given in Table 2 (23). The home environment should be a safe and accessible place for the team to store drugs and equipment, as well as to discuss patients and plan visits. In addition to transportation needs, teams need mobile phones to communicate with patients and their families 24 hours a day. A full-time nurse and part-time physician are minimum requirements for home-based PC, and the multidisciplinary team should have a psychologist, social worker and trained volunteer or community health worker. Team training should include both theoretical and practical components (23). In home-based PC, family and caregivers have duties and responsibilities that include advanced skills such as symptom and opioid management (24). Information and training should be provided to families and caregivers on the practical aspects of home-based care, such as symptom and pain management and nursing care (15). A caregiver's responsibilities include helping with housework, personal care, helping the patient's daily life activities and managing physical symptoms such as pain. Caregivers can also provide emotional and social support to the patient, as well as help in making decisions about their care (25). For many families, the diagnosis of a life-threatening disease in a family member is the first confrontation with death, leading to major psychosocial conflicts (26). At the same time, patient receiving care by their family can be exacerbated by the restrictions on time and space as well as physical, emotional, financial and social burden of care (15,26). Discussions on the clinical status, prognosis and care objectives of the patients are important, and it is very significant to inform them with family meetings, to clarify the problems, to clarify the current situation, and to set goals for care (15). Counselling and psychological support may be required to help family members and caregivers to cope with possible distress, hopelessness, unresolved relationship issues, and other emerging concerns (15,26). Standard forms should be used to document the status of patients, and patient/family must sign a consent form. For each patient, a health record should be kept and records of drugs (especially morphine) should be maintained in accordance with local laws and regulations (23). The list of equipment that may be required in the home-based PC is quite long (Table 3) (23,27).

Home-Based Palliative Care Examples

Kaiser Permanente (KP) home-based PC Program

The KP home-based PC program was first launched in 1997 as a California-based pilot project and was launched in 1998 as an official program (14,28). In order to provide better care to home care patients and their families, the PC program integrated into the home health department comprises five fundamental components (14,28,29).

- Providing pain control, symptom management and psychosocial support to the patient and family by a team of physicians, nurses and social workers,

Table 2. Things to do to set up a home-based PC service (23)

1. PC evaluation of needs and resources
Starting the PC network by evaluating existing resources including potential voluntary human resources
2. Official establishment of home-based PC
Application to the competent authorities
3. Setting up an action plan
Determining which resources are requiredand what services will be provided.
4. Home care team to start the work by providing training
If at least one doctor and nurse are not locally available for training, provide training in connection with a training center in another area.
5. Employing and training of volunteers or community health workers
Voluntary or community health workers are needed to provide supportive care.
6. Taking action to use resources
Resources can be money or non-money (transport, storage space, etc.) and can be shared with other organizations.
7. Contacting local health providers
Providing links with primary care health centers and regional hospitals for referral or inpatient support.
8. Introduction of home-based PC service
Use of networks and media to raise awareness about PC
9. Promoting wider participation
Inclusion of wider community groups (association members, students and politicians)

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- Home visits by all team members, including physicians, to provide medical care, support and training that the patient needs,
- Planning care continuity to meet patient's medical, social and emotional care needs in an uninterrupted manner,
- 24/7 telephone support for patient and family when needed,
- Improved care planning for patients and their families to make informed decisions and choices about end of life care.

Admission Criteria For KP Home-Based PC Program: (14,28)

- Patients should have a life-threatening disease (cancer, KY, and chronic obstructive pulmonary disease (COPD) etc.,
- Life expectancy of 12 months or less,
- Need for symptom management in a worsening clinical condition ,
- The patient should have an emergency service application or hospitalization 1-2 times a year,
- Patient and the family accepting home care other than aggressive treatment.

Acceptance Process (28): Admission to the program comprises four stages

- The patient and the families are interviewed by PC nurse via telephone or face to face,

Table 3. Medical equipment and medicines that should be in the home care kit for home-based PC (23,27)

1. Medical equipment and supplies	2. Supporting equipment
Stethoscope	Alternating air mattress
Sphygmomanometer	Aspirator
Thermometer	Nebulizer
Tongue depressor	Wheel chairs
Forceps	Walking aids
	Bathroom chairs
3. Tools	
Dressing materials	IV infusion sets
Cotton	Cannula and butterfly needle
Scissors	Injector and needle
Gauze	Aspirator probes
Gloves	Urinary catheters
Plaster	Bladder
Transfusion materials	Feeding tubes
4. Medicines	
Pain management	**Gastrointestinal symptom management**
Paracetamol	Metoclopramide
Ibuprofen	Domperidone
Diclofenac	Dexamethasone
Codeine	Bisacodil
Tramadol	Loperamide
Morphine	Oral rehydration salts
Gabapentin	Ranitidine
Psychological symptom management	**Antibiotics and antifungals**
Diazepam	Ciprofloxacin
Halperidol	Metronidazole
Amitriptyline	Oxacillin
	Fluconazole
Wound therapy	**Nutritional supplements**
Betadine solution and ointment	High protein and calorie food supplements
Metrogil gel	Iron, vitamin and mineral supplements
Hydrogen peroxic	
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- The PC nurse makes the first assessment of the patient in the patient's home. Physical evaluation, medications used, patient preferences and care planning related to DNR, home security, evaluation of needed medical equipment, education and training needs,
- Based on this assessment, patient admission and a necessary care plan are established,
- All other physicians and assistants to provide patient care will be included in the program.

Care Plan: The care plan developed after admission is updated at regular intervals. The PC nurse prepares a self-care plan and helps patients to create personal goals. During the evaluation, the patient and family members will learn more about their disease and prognosis. They are trained on managing the patient's home care and advanced care directives (17,28). What are the patient's treatment and care preferences? What additional services are needed to support the family? Is there a need for education and training? A maintenance plan is prepared considering all this information. It is updated by reviewing the maintenance plan every 60 days or more frequently when necessary (28). PC physician conducts home follow-up visits once a week or when required. The PC physician makes an assessment of the patient's medical condition and sets advanced care plans and treatment goals (28). The PC nurse makes a home visit according to the care plan and as often as the patient wants. A nurse visits 2-3 times a week to establish a strong relationship with the patient and to help manage home care can then visit less frequently. However, a few weeks before death, patients and families may need to be visited more frequently due to their increased psychosocial support (28,30). Among the nursing services are the assessment of the patient's medical needs as well as the effectiveness of the care management and the prescribed medical treatment in addition to the provision of emotional support to the patient and the family (28,30). Social workers provide advice and support to help patients and their families meet their economic, psychosocial and emotional needs. The social worker completes the initial assessment of the patient and their family within one week. They then conduct a telephone consultation or home visit at least once a month or more often if necessary (28,29).

Additional Services

Home Health Assistance Services: Certified personnel provide personal hygiene and personal care services to help patients stay comfortable at home. They also assist in creating a safe and healthy environment for patients. Under the observation and supervision of the nurse, such services as bathing, food preparation, shopping, etc. are provided (28,30).

Spiritual Care Services: These services are offered by an emotional care professional to help patients and families maintain their hopes and deal with changes. At the same time, they help the dying patient and their family to reach the meaning and goal of the spiritual values associated with the belief system. Spiritual care services can also be used for bereavement counselling and funerals or memorial services (28).

Rehabilitation Services: Such therapies as physiotherapy, occupational therapy and speech therapy help the patient to maintain basic functional skills and symptom control that support the daily life activities and physical and psychosocial independence of the patient (28,31).

Pharmacist Consultation: Since patients often have multiple co-morbid conditions that require multiple drugs, they provide guidance in preventing adverse effects of complex drug regimens, and in managing pain and other symptoms (28).

Diet/Dietician Services: Many patients have a negatively affected nutrition due to side effects and symptoms. With the support of a dietician, team members can be supported by educating the patient and their family about practical diet interventions that increase comfort and nutrition satisfaction (28).

Social Workers: For the evaluation and fulfillment of the needs of the family, it is necessary to develop a care plan both before and after the patient's death and these services are provided to the surviving family members for at least one year after the death of the patient (28,29).

Voluntary Services: The volunteers who are supervised by the KP home-based PC team provide support to patients and their families and accompanythem. They also provide care for the patient during their stay with the patient to reduce the burden of caregivers. They offer support to family members after the patient's death. All volunteers receive training before serving (28,29).

Patient Care in Inpatient Wards: In case of inability to home care or to manage terminal care, patient care is also provided in inpatient wards. It is at the lowest possible level in accordance with the patient's care plan and, if possible, given in a nursing home or hospital. If the patient needs acute care, the patient is transferred to an inpatient institution as soon as possible, if consistent with his/her preference and therapeutic goals (28,29).

Medical Supplies: The equipment, oxygen and drugs needed can be provided 24 hours a day and 7 days a week (28).

Sutter Health Care Program

Sutter Health is an integrated care system that is participated by 24 hospitals and 5.000 physicians, oriented towards increasing the terminal patient care and decreasing the use of acute care facilities, and that provides PC in between hospital and home transitions (32). In 2000, it began as a service to provide symptom management and care planning for home care patients with advanced stage diseases, and in time, a chair management model was established that would cover patient/care participation, and bounced care planning, and care transitions (33). For home care, service is provided to patients with a life expectancy of 1 year or less that meet the criteria for medicare compliance, and patients' care plans and current situation of their drugs are coordinated on real-time information exchange upon assigning the caregivers of the patients to the established program network (33). With this care model, it was reported that patient's requests and goals were better adapted, and that a decrease in hospital stays

and an increase in patient/caregiver satisfaction were ensured (9,33). First of all, this model is not a PC program consists of a multidisciplinary team comprising a home care team, hospital doctors and caregivers. Close cooperation with inpatient care teams is provided to ensure smooth transition of patients from hospital to home. The multidisciplinary team identifies care goals with patients and their families and improves care plan (33). Sutter patients that are eligible for advanced disease management have more than one hospitalization, emergency room service, and clinical, functional or nutritional problems in the last 12 months. The care plan created after the patient is registered to the care system is shared with the whole team supporting the patient through the common network and the patient is followed up regularly .

Home-based Primary Care Model

The home-based primary care program was initiated in 1983, and in 1998, the program was expanded and a new program titled "care of veterans with life-limiting disease" was initiated in order to provide end-of-life care for the veterans and to meet the needs of these patients (34,35). A comprehensive home-based care service has been created by including PC and hospice care in the home care program. Patients can be reached 24 hours a day and 7 days a week through a call program managed by nurses, and nurses are provided medical support from the geriatrics clinic if needed and then nurses observe patients at home (34). Services such as telephone support to patients, infusion therapy, ventilator, patient monitoring, wound care and counselling are given (36). In the home-based primary care program, patients often have cerebrovascular diseases, HF and COPD, and in 30% of the patients, diabetes is the secondary diagnosis and 26% had dementia. Home care is provided for patients requiring ventilator and oxygen-dependent infusion therapy and total parenteral nutrition and enteral nutrition (34,37). In addition, there are nurses and dieticians certified in terms of chemotherapy and diabetes. Patients and caregivers have access to home-based primary care program for 7 days/24 hours. Data on patients in the program that reach office during working hours, and that reach nurses out of working hours, weekends, and at night via a phone are accessed via a computer, and their anxieties are relieved, in addition to medical issue resolutions; and if needed, a home visit is made to solve any problems. Nurses can access the geriatrics department academia when they see it necessary. Medications of patients may be prescribed by doctors (34). Physical therapist apply physiotherapy to patients at first at home two days a week, and then, at the hospital in groups if the patient is mobilized (34). For home-based primary care program services, patients get in touch with program staff and receive intensive health training after admission to the program. The purpose of this program is to improve the ability of patients to manage their diseases on their own, to reduce hospitalization and admission to the emergency department (36). Patients and families are monitored by the supervisor or physician and the information is recorded and the scope of service and clinical privileges and protocols are determined. Treatment plans are regularly reviewed by the program team, and necessary procedures are established, including admission and discharge criteria (34,38). Patients are evaluated with a functional assessment form called the Katz Functional Daily Living Activities, and the functional status of the patient is evaluated at the beginning and at least every 90 days, and the treatment plan is reviewed and documented (34).

In our country, PC has not been put into practice in home care services, despite the rapid spread and necessary in-service trainings while especially taking part in the health services group due to the health policies in recent years. PC services are provided in hospitals, and PC services are not offered in consultation and home health services. Home health services such as PC have also gained momentum in the last 10 years, and the Regulation on the Presentation of Home Care Services dated 10 March 2005 and No. 25751 entered into force after being published in the Official Gazette (39). The Regulation on the Implementation Procedures and Principles of Home Health Care Services came into force on 01.02.2010 for the delivery of home health services by health institutions and organizations affiliated to the Ministry of Health (40). Home health services are presented in family and home settings especially to bedridden patients, patients with respiratory diseases, advanced muscle diseases, terminal cancer, and to newborns. Home health services are provided in coordination with Turkish Public Health Association through family physicians community health centers, and Turkish Public Hospitals Authority within the health institutions (training and research hospitals, general hospitals or branch hospitals) and are also offered through units established oral and dental health centers (40,41). Inspection and consultation within the scope of home health services, renewal of health board reports, prescription of medicines, examination and treatment (dressing, wound care, probe applications), rehabilitation, oral and dental health services, home to hospital or hospital to home transportation, training and support are the services that are provided. Medical devices that patients need, that may be of help for the treatment, and that are routinely used are provided for the use of the patients as entrusted to them. Necessary coordination with relevant institutions and organizations is provided by determining the patients' needs for social services (42).

Conclusion

Considering the benefits of home-based PC, together with the ageing population, the increase in CCD, and limited inadequate health resources, the integration of home-based PC into health systems becomes important. It is necessary to develop and implement PC policies and to ensure integration of PC with primary care, community and home based health services. Patients with CCD and PC need to be evaluated by a multidisciplinary team and referred to a hospital or home-based PC. Hospital-based PC is a more appropriate choice for patients who need more intensive symptom management or are unable to cope with the family's burden of care. In order to implement home-based PC; the health care team, the patient and the family must agree that the patient can be adequately managed at home, and the treatment plan should be approved by all parties. Depending on the patient's medical condition in home-based PC, it is necessary

to evaluate patients with home visits at intervals determined by a specialized PC team, to take samples for the necessary tests and to arrange the treatment protocol. However, the necessary actions should be directed to the PC centers if they cannot be performed adequately in the home environment. Consequently, it is necessary to create and implement national health policies that integrate PC services into home health services.

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