

# **Abant Tip Dergisi**

Araştırma Makalesi / Cilt 10 Sayı 2 Yıl 2021

## **Abant Medical Journal**

Research Article / Volume 10 Issue 2 Year 2021

# Palyatif Bakım Merkezinde Yatan Hastaların Bakım Bağımlılık Düzeyleri ve Etkileyen Faktörler

The Care Dependency Levels of the Inpatients in The Palliative Care Center and Influencing Factors

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### Öz

**GİRİŞ ve AMAÇ**: Bu araştırma, palyatif bakım merkezinde yatan hastaların bakım bağımlılık düzeylerini ve bunu etkileyen faktörlerin incelenmesi amacıyla yapılmıştır.

YÖNTEM ve GEREÇLER: Araştırmanın evrenini Elazığ şehir

hastanesinin palyatif bakım kliniğinde yatan hastalar oluşturmaktadır. Örneklemini, güç analizi yapılarak belirlenen 102 hasta oluşturmuştur. Örneklemin evrenden seçilmesinde, rastgele örnekleme yöntemi kullanılmıştır. Çalışma Ocak 2019- Şubat 2020 tarihleri arasında yürütülmüştür. Araştırmanın verileri sosyo-demografik bilgileri içeren form ve "Bakım Bağımlılık Ölçeği" kullanılarak toplanmıştır. İstatistiksel değerlendirmede SPSS 21.0 paket programı kullanılmıştır. Veriler; tanımlayıcı analizler (frekans ve yüzde dağılımı), Mann Whitney U ve Kruskal-Wallis H kullanılarak analiz edilmiştir. Arastırmada istatistiksel anlamlılık düzeyi p<0.05 olarak kabul edilmiştir. BULGULAR: Araştırmaya katılan hastaların bakım bağımlılığı ölçeği puan ortalamasının 40.1±6.0 olduğu belirlenmiştir. Yaş ile bakım bağımlılığı ölçeği arasında negatif yönde orta seviyede ilişki olduğu tespit edilmiştir (r=-.402\*\*, p=.000). Cinsiyet, medeni durum, eğitim seviyesi, tanı süresi ve bakımda yardım alma değişkenleri ile bakım bağımlılığı arasındaki farkın istatistiksel olarak anlamlı olduğu bulunmuştur (p<0.05). Hastaların en çok hijyen, giyinmesoyunma ve hareketlilik aktivitelerinde bağımlı oldukları saptanmıstır.

TARTIŞMA ve SONUÇ: Bu sonuçlar doğrultusunda; palyatif bakım merkezinde yatan hastaların bağımlılık düzeylerinin yüksek olduğu belirlenmiştir. Palyatif bakım merkezinde yatan hastaların özellikle bağımlı oldukları gereksinimlere göre hemşirelik bakımının planlanması ve daha sonraki araştırmalarda daha geniş hasta sayıları ile çalışmaların yapılması önerilmektedir.

Anahtar Kelimeler: bakım bağımlılığı, hemşirelik, palyatif babım

#### **Abstract**

**INTRODUCTION**: This study has been conducted with the purpose of determining care dependency levels of inpatients in palliative care center and factors affecting those levels.

**METHODS**: The universe of the research consists of inpatients in an Elazig city hospital palliative care clinic in Eastern Turkey. The sample size was determined to be 102 patients by conducting power analysis. A random sampling method was used. The study has been conducted between January 2019 and February 2020. The data of the research were collected by using the questionnaire form containing socio-demographic information and the "Care Dependency Scale". SPSS 21.0 package program was used for statistical evaluations. Descriptive statistics (frequency and percentage), Mann Whitney U and Kruskal-Wallis H tests were used in the analysis of data. The statistical significance level was accepted as p <0.05 in the study.

**RESULTS**: The mean score of the care dependency scale was 40.1±6.0. There was significant, moderate negative correlation between age and care dependence scale scores (r=-.432\*\*, p=.000). The difference between the variables of gender, marital status, education level, duration of diagnosis, and getting help in care and care dependency was found to be statistically significant (p<0.05). Patients were most dependent on caregivers while performing hygiene, dressing and undressing and mobility, respectively.

**DISCUSSION** and **CONCLUSION**: Patients in palliative care center were found to have high levels of care dependency. It is recommended to plan nursing care according to the needs of patients hospitalized in palliative care centers, and to conduct studies with larger numbers of patients in subsequent studies.

Keywords: palliative care, nursing, care dependency

## **INTRODUCTION**

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The World Health Organization (WHO) has redefined palliative care as: An approach that

improves the quality of life of patients and their families with problems-associated with life threatening illnesses, through the prevention and

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relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (1). It is a person- and family-centred approach, providing relief from the symptoms and stress of a disease to people living with serious diseases. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family (2). 78% of people in need of palliative care live in low- and middle-income countries, and 40 million people need palliative care each year (3). The primary goal of palliative care is to ensure that the individual spends his last days at ease in situations where medical treatment insufficient for the individual and the healing process stops. Therefore, what is important in palliative care is the quality of life, not the life span of the individual (4). The content of palliative care can vary according to the needs of the individual and the course of the disease (5). The basic principles of palliative care are summarized as; addressing the physical, psychosocial and spiritual aspects of patient care together, providing relief of other symptoms alongside the most common symptom of pain, treating death as a normal process like life, helping the patient live as actively as possible until the last moments of life, identifying and addressing the needs of patients and their relatives, supporting the relatives of patients during the loss and mourning process (6, 7).

World Health Organization (WHO)- Worldwide Palliative Care Alliance (WPCA) has identified diseases requiring palliative care in adults as follows: cancer, Alzheimer's disease and other dementias, cardiovascular disease, cirrhosis, chronic obstructive pulmonary disease, diabetes, Acquired Immune Deficiency Syndrome (AIDS), kidney failure, multiple sclerosis, Parkinson's disease and rheumatoid arthritis. Most of the individuals in this disease group are dependent or semi-dependent, especially if they are in palliative care (8).

Dependency can be in many ways physical, mental, emotional, cognitive, social, economic and environmental. Dependency has been defined as a person receiving aid for one or more of six daily life activities (ADL) or using auxiliary devices (walking stick, wheel chair, tubes etc.) to realize one or more of eight instrumental daily life activities (I-ADL) (9). Care dependency has been defined as the patient's need for professional support, a decrease in the level of meeting self-care needs and demanding a certain level of care according to the dependency status (10). The purpose of nursing care is to ensure the patient's independence in performing self-care. For nurses, it is very important to plan and implement individualized nursing care in patients with different care dependency (11). In recent years, it has been observed that with the increase in the number of chronic diseases, the need for care and the time spent in hospitals have increased. Chronic diseases, old age, sensory losses, changes in physical and psychological conditions may increase the dependency of the individual in meeting their needs (12, 13, 14, 15). In order to determine the care needs of hospitalized patients, it is necessary to determine the dependence-independence levels in their daily activities. There are studies in the literature evaluating the levels of care dependency of patients hospitalized in different clinics (12, 16, 17, 18).

Elderly patients and patients with chronic lifethreatening diseases are frequently hospitalized in palliative care centers. As in the rest of the world, the elderly population is increasing in our country. This causes an increase in the number of patients with life-threatening chronic diseases. Due to chronic diseases and old age, the ability of these patients to fulfill their care needs gradually decreases. The burden of care of individuals who become addicted in many life activities also affects family members (19, 20, 21). Nurses can encounter patients with life-limiting illnesses in a wide range of health care settings. All nurses must develop competences in palliative care to improve patient comfort and quality of life. However, the competence of nurses in many countries in the field of palliative care and in providing care to patients with life-limiting diseases is not sufficient (22). Poor palliative care adequacy can affect the quality of care and quality of life for these patients (23). In the palliative care clinic, which is a special unit, it is thought that determining the level of care dependence of patients will be a guide in nurses care practices and will increase the quality of nursing care.

Purpose: This study has been conducted with the purpose of determining care dependency levels of inpatients in palliative care center and factors affecting those levels.

Research questions;

What is the care dependency level of inpatients in palliative care center?

What are the factors affecting care dependency?

#### **METHODS**

This is a descriptive-cross sectional type of study.

## Sampling

The universe of the research consists of inpatients in the Palliative Care Clinic of an Elazig city hospital located east of Turkey. The sample size was determined to be 102 patients by conducting power analysis. The power analysis was based on an alpha of 0.05 error level, power of 0.99, and assumed effect size of 0.5 for the sample size estimation. A random sampling method was used. The Elazig city hospital is an institution where wide-ranging and special branch health services are provided and located in east of Turkey. In the palliative care clinic, patients with diagnoses such as neurological diseases, stroke, dementia, alzheimer disease, end-stage organ failure and cancer have been treated in general.

#### **Data Collection:**

The data were collected by face-to-face interview technique with the inpatients in the palliative care clinic. The patients in the service were visited in the patient rooms and informed about the research and received informed consent from the patients who agreed to participate in the research. Questionnaire forms were distributed to patients who were conscious, literate and did not have communication problems, and they were given time to answer. The questions were read for the patients who are illiterate and who have no physical power to fill questionnaire forms, and answers were marked questionnaire forms. Evaluation dependency levels of patients was done by the researcher. Answering forms took approximately 15-20 minutes. Data of the research was collected by using "The questionnaire form" consisting sociodemographic information and "Care Dependency Scale (CDS).

## The questionnaire form:

This form was consisted of demographic information of patients and prepared by the researcher. The questionnaire form consists of 7 questions related with variations of patients' age, gender, marital status, education level, income level, diagnosis period and taking aid status in care.

## Care Dependency Scale (CDS):

CDS was based on human requirements of Virginia Henderson and is a scale developed in 1998 in Netherlands by Dijkstra with the purpose of assessing care dependency statuses of patients (10). CDS consists of various physical and psychological aspects and it provides assessment of patients care dependency in wide ranging. Validity and reliability of CDS were made by Yont et al., in Turkey. The result of validity and reliability study in Turkish, memory and worshipping articles were added to the scale and the scale became one consisting 17 items in total.

In the scale in 5-likert type; it is pointed as 1= completely dependent up to 5= not independent. The lowest score that can be obtained from the scale is 17 and the highest score is 85. High scale score indicates that the patient is independent in meeting self-care needs, while low scale score indicates that patients are dependent on others in meeting care needs. Cronbach alpha value of the scale was found to be 0.91 (24). In this study, Cronbach alpha value has been determined as 0.89.

## **Data Analysis:**

The data in the study were evaluated in SPSS (Statistical Package for the Social Sciences) 23.0 software program. Descriptive characteristics of the patients are expressed in numbers, percentages, mean, and standard deviation. In addition, data were analyzed in independent groups with t-test, Mann-Whitney U test, ANOVA, Kruskal-Wallis H and correlation tests.

#### **Ethics:**

Ethical approval was obtained from a university Non-Interventional Research Ethics Committee (2019/13-16) and written permission from the city hospital chief physician for conducting the research. Patients were informed about the research, it is explained that the information obtained will be kept confidential, and written or verbal consent was obtained from those who volunteered to participate in the study.

#### **FINDINGS**

Mean age of the patients who participated in the study, was 67.7±9.6 years. 43.1% of the patients were female, 67.6 % of them were married, 40.2 % of them had primary school education level, 83.3 % of them had medium level financial status, 82.4 % of them had aid in care and 70.6 % of them were affected in daily life activities due to their diseases (Table 1).

In the research, it was determined that there was negative relationship between age and CDS (r=-

.432\*\*, p=.000). It was determined that the score obtained from the CDS decreases as the age increases, that is, the level of care dependence increases. When gender and CDS point averages were compared, it was determined that the difference between these was significant (p<0.05) and females have higher dependence levels than males. It was determined that the difference between marital status and CDS mean scores was statistically significant (p<0.05), and dependency levels of divorced ones are higher than married or single ones. It was determined that the difference between education level and CDS mean scores was statistically significant (p<0.05). It was seen that CDS mean scores of the patients in illiterate group, is lower than CDS point averages of the patients in high school and university graduated group. It was determined that the difference between economic level and CDS mean scores was not statistically significant (p>0.05), dependence level of the patients with bad financial status, is higher. It was detected that the difference between diagnosis time period and CDS mean scores was statistically significant (p<0.05). According to that result, it was seen that dependence levels of the patients with more than 11 years of diagnosis time period, are higher. It was determined that the difference between getting help during care and CDS mean scores was statistically significant (p<0.05) (Table 2).

Table 3. Care Addiction Scale Score Average

Care Dependency Scale (CDS)	Min-Max	X±SD
Total CDS	25.0-53.0	40.1±6.04

X: Mean, SD: Standard Deviation

It has been determined that CDS point average of patients hospitalized in palliative care center, is 40.1±6.0 and that they are dependent in high level (Table 3).

The mean scores of the CDS sub-items of the patients participating in the study are given in

Table 4. The most dependent activities of patients in palliative care center are given in order. These activities are: hygiene (1.78), getting dressed and undressed (1.92), mobility (1.98), body posture (2.07), eating and drinking (2.10), recreational activities (2.17), learning activities

(2.22), daily activities (2.23), continence (2.24), memory (2.27), avoidance of danger (2.31), performing worship (2.37), body temperature (2.66), day/night pattern (2.67), sense of rules and values (2.82), communication (3.13), contact with others (3.17) (Table 4).

**Table 1.**The socio-demographic features of patients

Sociodemographic features	Number	Percentage
<b>Age</b> 67.7±9.6		
Gender		
Female	44	43.1
Male	58	56.9
Marital Status		
Married	69	67.6
Single	13	12.7
Divorced	20	19.6
<b>Educational Level</b>		
Illiterate	30	29.4
Primary school	41	40.2
High school	17	16.7
University	14	13,7
Economic Level		
Good	6	5.9
Medium	85	83.3
Bad	11	10.8
Diagnosis Time Period		
< 1 year	12	11.8
1-5 years	41	40.2
6-10 years	40	39.2
11 years and above	9	8.8
Status of getting help during care		
Yes	84	82.4
No	18	17.6

 Table 2. Comparison of the Socio-demographic variables of patients and the mean scores of the Care Dependence Scale (CDS)

Sociodemographic features	Number	X±SD	Test and
			Significance
Gender			
Female	44	40.1±5.9	t=.529
Male	58	42.0±6.1	p=.038*
Marital Status			
Married	69	41.0±5.3	KW=5.761
Single	13	42.0±3.4	p=.002*
Divorced	20	$36.0\pm7.9$	
Educational Level			
Illiterate	30	36.2±7.1	
Primary school	41	$40.0 \pm 5.7$	KW=7.641
High school	17	41.4±4.3	p=. <b>003</b> *
University	14	43.0±6.0	
Economic Level			
Good	6	41.0±3.8	KW=5.727
Medium	85	40.8±5.3	p=.021
Bad	11	$39.9 \pm 9.2$	
Diagnosis Time Period			
< 1 year	12	44.1±7.9	
1-5 years	41	40.5±5.0	KW=15.01
6-10 years	40	39.6±4.8	p=.005*
11 years and above	9	37.0±4.2	
Status of getting help during care			
Yes			
No	84	$39.8 \pm 6.2$	MWU=637.5
	18	44.7±4.5	p=.000*
Care Dependency Scale	Age		
	r=432		
	p=.000**		

 Table 4. Distribution of Care Dependency Scale Item Score Averages

		All, n=102
Characteristics	Min-Max	Mean ± SD
Eating and drinking	1,00-4.00	$2.10 \pm 0.8$
Continence	1,00-5.00	$2.24 \pm 0.9$
<b>Body Posture</b>	1,00-5.00	$2.07 \pm 0.9$
Mobility	1,00-4.00	$1.98 \pm 0.8$
Day/night pattern	1,00-5.00	$2.67 \pm 1.1$
Getting dressed and undressed	1,00-4.00	$1.92 \pm 0.8$
Body temperature	1,00-5.00	$2.66 \pm 1.1$
Hygiene	1,00-5.00	$1.78 \pm 0.8$
Avoidance of danger	1,00-5.00	$2.31 \pm 0.9$
Communications	1,00-5.00	$3.13 \pm 1.0$
Contact with others	1,00-5.00	$3.17 \pm 1.0$
Performing worship	1,00-4.00	$2.37 \pm 0.9$
Sense of rules and values	1,00-5.00	$2.82 \pm 0.8$
Daily activities	1,00-4.00	$2.23 \pm 0.8$
Recreational activities	1,00-5.00	$2.17 \pm 1.0$
Memory	1,00-5.00	$2.27 \pm 1.0$
Learning ability	1.00-5.00	$2.22 \pm 0.9$

### **DISCUSSION**

It is thought that assessing care dependence levels of the inpatients in palliative care center in today, will take an important place in increasing nursing care quality. The results of the study we performed with the purpose of determining care dependence levels of the patient hospitalized in palliative care center and factors affecting them, were discussed with current research results.

In this research, it was determined that the patients hospitalized in palliative care service had 40.1±6.0 point from the CDS and their dependence level is high. In the study conducted by Korhan et al., It was determined that the patients hospitalized in the internal medicine clinics got 68.4 ± 22.7 points from the CDS and the patients hospitalized in the surgical clinics got  $73.7 \pm 18.1$  points (12). In another study that was conducted in Turkey, it was determined that the patients hospitalized in internal diseases clinics had 83.5 point from CDS and the patients hospitalized in surgical clinic had 59.5 point (25). It was seen the dependence levels of the patients hospitalized in palliative care center is very higher than the ones in another clinic. In the research conducted by Lohrmann et al., it was determined that the patients hospitalized in Nursing Home had 38.1±15.2 point from CDS, and the ones hospitalized in Geriatric ward, had 39.3±19.8 point (26). It was seen that they had similar results with ours. In addition to that, it is thought that too high age for the patients hospitalized in nursing homes and geriatric ward, increased dependence levels (26). In the research of Doroszkiewicz et al; it was found that elderly patients staying in the geriatric unit got 55.3 ± 15.1 points from CDS (27). It is an expected result that the patients hospitalized in palliative care service, are more dependent to meet their basic needs. Having that the patients hospitalized in palliative care services are in the last stage of their diseases, the situation that their diseases are chronic and progressive, the changes in their conscious together with aging, the symptoms those take long periods dues to treatments those applied to them and side effects of their diseases, might make those patients more dependent.

It was detected that the inpatients in palliative care services are dependent on high level as follows; hygiene (1.78), getting dressed and undressed (1.92), mobility (1.98) respectively. Lohrmann et al.in their research, it was determined that the individuals staying in nursing homes were dependent on daily activities (1.7), recreational activities (1.8) and hygiene activities (1.9), respectively. Patients in the geriatric ward were found to be highly dependent on daily activities (2.0), recreational activities (2.1), mobility, hygiene and getting dressed and undressed (2.3) activities (26). In our study, the presence of patients with advanced age, stroke and neurological disease is thought to cause an increase in addiction levels in daily activities. Doroszkiewicz et al., in their study with elderly patients were determined to be dependent on activities such as recreational activities (1.14), daily activities (1.59), learning activities (1.78), mobility (1.85), getting dressed and undressed (1.93), avoidance of danger (1.95), continence (2.14), contact with others (2.36), eating and drinking (2.36), body temperature (2.59), body posture (2.59), and day/night pattern (2.68) respectively (27). Another study carried out in Poland elderly patients of clinic of geriatrics showed that; the main problems associated with the fulfillment of needs were difficulties with the adoption of appropriate body posture, movement restrictions, and problems connected with participating in leisure activities, unassisted, outside the home (28). In these researches conducted with older individuals, it is thought that older age may have affected all activities negatively.

In this study, it was determined that there was a significant relationship between age and CDS. It was found that as the age of the patients increased, their addiction levels also increased. It was also determined that age was an important

factor in predicting care dependency. In the study conducted by Korhan et al., it was found that the difference between the age groups of the patients and the mean score of the CDS was statistically significant (12). Various studies are encountered in literature demonstrating that there is a relation between age and dependency level (26, 29-32). In the study evaluating the care dependency levels of patients after laparoscopic abdominal surgery in China, a strong relationship was determined between age and care dependence (33).

In this research, it was determined that dependence levels of females are higher than dependence levels of males. However, it was determined that gender was not an important factor in predicting care dependency. In the research that was conducted by Korhan et al., it was found that dependence levels of females is higher than males, however the difference between them is not significant (12). In the research of Turk and Ustun that they assessed care dependence level of the patients with COPD, dependence level of males is higher and the difference between them is statistically significant. It was thought that older age of males caused to obtain higher dependence level (34). In the literature, there are studies showing that there is a significant difference between gender and care dependence (33-36), as well as studies showing that there is no significant difference between them (12, 25, 37). In this research, it is thought that due to the fact that females have higher age average and due to their emotional structure, their dependence levels might increase.

It was determined that the difference between marital status and CDS scale mean score was significant and the dependency levels of widowed people were highest. Also, in the research that was conducted by Kavuran and Turkoglu, a significant difference was found between marital status and CDS. However, in the research, it was determined that married ones

have higher dependence levels (32). It is thought that due to the fact that the patients who lost their spouses, are at late ages and there is few supports during their care, their dependence level could increase.

It was determined that the difference between the educational level and the CDS mean score was significant, and that the illiterate had high levels of care dependency. In the study conducted by Li et al., educational level was associated with care dependency (33). In research that was conducted by Turk and Ustun, it was detected that average point from CDS taken by the ones graduated from high school and university, were higher than points of the ones graduated from primary school and illiterate (34). However, it has been determined in a study conducted by Koberich et al., (2015) that there was no change in the level of care dependence of patients after the self-care training program provided to the patients (17). Due to the fact that it was thought that increasing education level will increase financial level, it is thought that increasing awareness about the disease will be effective on dependency level.

The difference between getting help during care and CDS mean scores was statistically significant. In the study of Doroszkiewicz et al., it has been determined that there was a statistically significant differences between patients' activities of daily living (ADL) and instrumental activities of daily living (I-ADL) and the levels of care dependency (27). The results of previous studies using CDS, published in many countries, shows that there is a relation between age, functional capabilities, and the level of care dependency (26, 38, 39). The functional capacities of people who can meet their care independently are sufficient.

Care addiction always occurs when the patient's ability to meet human needs is less than necessary. Therefore, avoiding dependence on care has become, and will be, the increasingly

core tasks of nursing (40). The human being is a and any insufficiency/shortcoming occurring in a field, affect another field naturally. Most of the patients hospitalized in hospitals, can be dependent partly to meet their basic care needs or can completely be dependent on others (12). In order to increase care qualities of nurses, they are required to assess patients as a whole with a holistic aspect. In this assessment stage, it is very important to assess dependence level of patients and status of them to meet their daily activities. After vital activities those the patients are dependent, are determined, nurses can identify care planning and priorities in application stage easier. Thus, nursing care quality being presented can be increased.

### Conclusion and recommendations

It was found that the total score average of the CDS of the inpatients in the palliative care center was low. It was determined that the patients were very dependent in various care activities. It was determined that age, marital status, educational level, and getting help during care have effect on care dependence. Patients in palliative care clinics who are determined to be dependent on many care activities are advised by nurses to provide training and counselling on care practices to patients and their relatives in order to reduce their level of dependence on care. In order to reduce the level of dependence of patients who are determined to be highly dependent on the hygienic practices, it is recommended that patients and their relatives actively participate in hygienic care practices and support their independence. In order to protect patients with high levels of addiction in dressing and mobility activities from accidents and injuries, it is recommended to take the necessary precautions against the risk of falls and to be closely monitored and to inform the patient's relatives about this issue. In addition, it is recommended to use a reliable measuring tool that measures the risk of falling in services, identify risk areas and take the necessary safety measures. It is recommended to train healthcare professionals to use the fall symbol and stickers for patients at risk of falling, to wear the armband, to ensure the safety of patient beds and to prevent falls caused by patient transfer.

## Limitations of the study

Collecting data only from the patients hospitalized in palliative care clinic in this research, formed limitation of this research. Inability to collect data from infected patients is another limitation of the study. Also, dependency may be evaluated with structured observations and from different sources (i.e. patients, families, caring staff etc).

**Informed Consent:** Written consent was obtained from the participants.

**Conflict of Interest:** Authors declared no conflict of interest.

**Financial Disclosure:** Authors declared no financial support.

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