

Mental Health Status of Caregivers of Patients in Home Health Unit and Palliative Care Services

Evde Sağlık Birimi ve Palyatif Bakım Servislerindeki Hastaların Bakım Verenlerinin Ruh Sağlığı Durumu

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Summary

Objective: This research was performed with the aim of revealing the mental health state of caregivers of patients in home health unit and palliative care service.

Material and Method: In line with the aim; the “Personal Information Form” and “Brief Symptom Inventory (BSI)” were applied. The sample comprised 140 patients and relatives monitored and treated by Home Health Unit and Palliative Care Unit linked to a university hospital in Ordu province from January-November 2017. All statistical calculations were completed with SPSS 21.0 statistical program. Findings are given as n, mean and standard deviation. Additionally; student t test, one-way analysis of variance and Pearson correlation coefficient tests were performed with the Tukey multiple comparison test used for advanced analyses.

Results: According to the results; as the care duration increases, the BSI subscale points increased ($p<0.01$). Depending on the carer’s educational level, there were significant differences identified in terms of BSI subscale points for smatization (S), obsessive compulsive disorder (OCD), anxiety (A), hostility (H), paranoid thoughts (PT), psychotism (P) and additional items (AI) ($p<0.05$). The S, interpersonal sensitivity (IS), H and P mean points for male carers were identified to be higher than female carers. According to the income-expenditure situation of carers, there were significant differences between mean points obtained for depression (D), A, phobic anxiety (PA), and PT BSI subscales ($p<0.05$).

Conclusion: Society-based studies continue about treatment of chronic diseases in Turkey. Experts need to be informed about problems experienced by patients and caregivers, who will struggle with these diseases for the rest of their lives. Coping strategies for these situations should be recommended.

Key words: Brief symptom inventory, caregiver, mental health, palliative care

Özet

Amaç: Bu araştırma, evde sağlık birimi ve palyatif bakım servisindeki hastaların bakım verenlerinin ruh sağlığı durumunu ortaya koymak amacıyla yapılmıştır.

Gereç ve Yöntem: Amaç doğrultusunda, “Kişisel Bilgi Formu” ve “Kısa Semptom Envanteri (KSE)” uygulanmıştır. Örneklem, Ordu ilinde bir üniversite hastanesine bağlı Evde Sağlık Birimi ve Palyatif Bakım Ünitesinde, Ocak-Kasım 2017 tarihleri arasında takip ve tedavi altındaki 140 hasta ve hasta yakınından oluşmaktadır. İstatistiksel hesaplamalar SPSS 21.0 istatistik paket programında yapılmıştır. Araştırma bulguları; n, ortalama ve standart sapma ile ifade edilmiştir. Ayrıca student t test, tek yönlü varyans analizi ve Pearson korelasyon katsayısı yapılmış, ileri analizlerde Tukey çoklu karşılaştırma kullanılmıştır.

Bulgular: Bulgularımıza göre; bakım verme süresi arttıkça KSE alt grup puanlarının da arttığı görülmektedir ($p<0,01$). Bakım verenin eğitim durumuna göre KSE alt grup puanları arasında somatizasyon (S), obsesif konvulzif bozukluk (OKB), anksiyete (A), saldırganlık (H), paranoid düşünceler (PD), psikoz (P) ve ek maruziyet (EM) açısından anlamlı bir farklılık tespit edilmiştir ($p<0,05$). Bakım veren erkeklerin S, kişilerarası duyarlılık (KD), H ve P ortalama puanları kadın bakıcılardan daha yüksek olduğu tespit edilmiştir. Bakım verenin gelir-gider durumuna göre depresyon (D), A, fobik anksiyete (FA) ve PD KSE alt ölçeklerinden alınan ortalama puanlar arasında anlamlı farklılıklar belirlenmiştir ($p<0,05$).

Sonuç: Kronik hastalıkların tedavileri Türkiye’de toplum temelli çalışmalar ile sürdürülmektedir. Bundan sonraki hayatını bu hastalıkla mücadele etmek zorunda kalacak olan hasta ve bakım verenler yaşayacakları sorunlar hakkında uzmanlar tarafından bilgilendirilmelidir. Yaşadıkları durumlarla ilgili baş etme stratejileri önerilmelidir.

Anahtar kelimeler: Kısa semptom envanteri, bakım verici, ruh sağlığı, palyatif bakım.

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Introduction

Currently with the development of health services and medicine, human life has lengthened. In spite of this positive development, new problems have occurred such as an increase in the number of people who are living with the consequences of a variety of chronic diseases, are bedridden and require care (1).

Chronic diseases are that generally have slow progression, require intervention in the long term and cannot be treated medically. It is important to keep the ability levels for functioning and fulfilling responsibilities of patients requiring care at the highest level (2). Statistics have found that chronic diseases are increasing and this does not have significant correlation with the development level of the country (3). Together with chronic diseases, the individual may experience cognitive degradation, loss of competence and economic losses, cannot fulfil their expected roles and continue living with family support (4).

With the increase in the number of dependent people, the concept of caring has begun to attract significant attention. Caring may be assessed as taking care or responsibility for the patient. The carer is the person responsible for ensuring support of the sick individual in terms of physical, social, economic and emotional aspects (5). As caring, which needs to be dealt with in multiple dimensions, is an unchosen and later emerging situation, adaptation is important (6), and may require making changes in the person’s life (7,8,9). This situation may be perceived as one-way, problematic, intense and long-term (9,10). The carer experiences role confusion (11, 12) and struggles with being insufficient and feelings of hopelessness. Thinking they have lost control, they may perceive themselves as powerless and failing to meet expectations and experience feelings of guilt (13).

The heavy load and psychological stress experienced in the long term negatively affect the person (14). It is important that the carer, providing emotional, physical, social and economic support to the sick individual, be aware of changes in emotions, attitudes to the situation and linked emotional responses in order to be able to help the patient in a healthy fashion (15). Some research has revealed that carers use more medication compared to non-carers and apply to health organizations more frequently (16). In addition, there are positive effects of caring, which contributes to personal development (17).

Aim of the study is to reveal the mental health status of carers of patients in the home health unit and palliative care service. The research will determine a range of sociodemographic characteristics of carers, and will attempt to determine the risk groups linked to these characteristics. Additionally; this research will contribute to the literature in terms of creation of support groups, planning and development of services and identification of resources according to these characteristics.

Material and Method

Population and sample of the research

The research sample comprised 140 patients and patient relatives monitored and treated in the Home Health Unit and Palliative Care Unit linked to Ordu University Education and Research Hospital from January-November 2017. The inclusion criteria for the research was being older than 18 years, caring for the patient every day for a certain portion or the whole of the day and accepting participation in the research.

Data collection tools

In the study, carers first completed the “Personal Information Form” and then the “Brief Symptom Inventory (BSI)”.

Personal Information Form is used to determine the demographic characteristics of patient and patient relatives was created by the researchers.

Brief Symptom Inventory was adapted by Hisli and Durak (2002) (18) with the aim of identifying psychiatric problems in a variety of medical situations. The scale comprises 53 items chosen from among items on the 90-item Symptom Checklist (SCL-90-R). Three separate studies found the Cronbach alpha internal consistency coefficients for total points vary from 0.96 to 0.95, with coefficients for the subscales varying from 0.55 to 0.86. The 9 subscales of the scale are somatization (S) (items 2,7,23,29,30,33,37), obsessive compulsive disorder (OCD) (items 5,15,26,27,32,36), interpersonal sensitivity (IS) (items 20,21,22,42), depression (D) (items 9,16,17,18,35,50), anxiety disorder (AD) (items 1,12,19,38,45,49), hostility (H) (items 6,13,40,41,46), phobic anxiety (PA) (items 8,28,31,43,47), paranoid thoughts (PT) (items 4,10,24,48,51) and psychotism (P) (items 3,14,34,44,53). Additional items (AI) (items 11,25,39,52) include items related to eating disorders, sleep disorders, thoughts about or related to death and feelings of guilt. Each item is answered according to the choices of “not at all, a little, moderately, a lot, and extremely”, given points of 0, 1, 2, 3, and 4, respectively.

Data Collection Method

Data were collected with the face-to-face interview technique during interviews with patients treated at home and in hospital and relatives on a determined date. Carers who agreed to participate in the research were informed about the aim of the research and consent was given. Later the Personal information form and BSI were applied, which took about 20 minutes.

Ethical aspect of the research

For the study to include relatives of patients in the palliative unit and home health unit of the hospital, permission was granted by Ordu Provincial Union of Public Hospitals General Secretary. Participation in the research was based on volunteerism, with no names written on the data collection forms.

Statistical analysis

Data obtained in the study were first assessed with the Shapiro Wilk test for the assumption of normality ($p>0.05$). Differences in the points obtained on S, OCD, D, AD, H, PT, P and AI subscales according to carer gender were assessed with the student t test, with differences according to educational level and income-expenditure status of carers assessed with the one-way analysis of variance and Tukey multiple comparison test. The correlations between ages of patient and carer, disease duration and care duration with the S, OCD, D, AD, H, PA, PT, P and AI subscale mean points were evaluated with the Pearson correlation coefficient. The research findings are given as n, mean and standard deviation. Significance of 0.05 was accepted as significant. All statistical calculations were completed with SPSS 21.0 statistical program.

Results

The study comprised 76 female (54.3%) and 64 male (45.7%) patients. The carers included 70 females (50%) and 70 males (50%). The age of carers varied from 20 to 87 years, with mean age of 46.79 (sd=12.96). The patient age range varied from 24 to 99, with mean age of 77.73 (sd=12.62). The disease duration of patients varied from 2 to 168 months with mean of 47.13 months (sd=33.04).

As the age of patients increased, the carer mean points for the S and D subscales of the BSI increased, with other subscale points reducing. As the carer age and disease duration increased, the mean points of all BSI subscales, apart from PD, appeared to increase. There was a positive significant correlation identified between caring duration and carer mean points for all BSI subscales. Stated differently, as the caring duration increased, the BSI subscale points increased ($p<0.01$) (Table 1).

There was a significant difference identified in BSI subscale points for S, OCD, AD, H, PT, P and AI depending on the carer's educational level ($p<0.05$) (Table 2). While the mean points for somatization among BSI subgroups were lowest for illiterate carers, it was highest among literate carers. The anxiety mean points were highest for carers who were university

graduates. Hostility mean points were highest for middle school graduate carers, and lowest for literate carers. Again, the mean points for paranoid thoughts were identified to be highest for university graduate carers, the highest mean points for psychotism were identified in the literate group.

There were significant differences identified in the mean points for the somatization (S), interpersonal sensitivity (IS) and hostility (H) BSI subscales depending on the gender of the carer ($p < 0.05$). There were no statistically significant differences identified in terms of points for other subscales ($p > 0.05$). The mean points for S, IS, H and P were identified to be

higher among male carers compared to female carers (Table 3).

There were significant differences in the mean points obtained for the depression (D), anxiety (AD), phobic anxiety (PA) and paranoid thoughts (PT) BSI subscales depending on the income-expenditure status of carers ($p < 0.05$). There were no statistically significant differences identified for the other subscale points ($p > 0.05$). Carers with income less than expenditure (with material difficulties) had high points for depression, while those with income equal to expenditure had low points for depression ($p < 0.001$) (Table 4).

Table 1. Correlation of patient and carer age and disease duration with S, OCD, D, AD, H, P, PT, and AI subscale points

		S	OCD	IS	D	AD	H	FA	PT	P	AI
Patient age	<i>r</i>	0.184	- 0.271	- 0.041	0.178	- 0.402	- 0.231	- 0.312	- 0.286	- 0.230	- 0.042
	<i>p-value</i>	0.030	0.001	0.629	0.035	<0.001	0.006	<0.001	0.001	0.006	0.618
Carer age	<i>r</i>	0.309	0.292	0.111	0.012	0.122	0.172	0.215	- 0.163	0.056	0.214
	<i>p-value</i>	<0.001	<0.001	0.192	0.887	0.152	0.042	0.011	0.054	0.512	0.011
Disease duration	<i>r</i>	0.309	0.292	0.111	0.012	0.122	0.172	0.215	- 0.163	0.056	0.214
	<i>p-value</i>	<0.001	<0.001	0.192	0.887	0.152	0.042	0.011	0.054	0.512	0.011
Care duration	<i>r</i>	0.361	0.480	0.435	0.226	0.197	0.582	0.467	0.409	0.425	0.435
	<i>p-value</i>	<0.001	<0.001	<0.001	0.007	0.020	<0.001	<0.001	<0.001	<0.001	<0.001

Table 2. Differences in points for S, OCD, D, AD, H, PA, PT, P and AI subscales according to carer educational level

Educational level	Illiterate	Literate	P	M	H	Univ	P-value
n	13	18	18	11	72	8	
S	0.70±0.55 c	2.29±0.71 a	1.36±1.01 bc	1.70±0.97 ab	1.36±0.79 bc	1.35±1.19 bc	<0.001
OCD	1.38±0.24 ab	1.43±1.08 a	0.63±0.27 b	1.05±0.99 ab	1.29±0.60 ab	1.18±1.15 ab	0.008
IS	1.23±0.44	1.67±1.28	0.78±0.73	1.00±0.89	1.08±0.90	1.00±1.31	0.110
D	1.32±0.61	1.66±1.11	1.38±0.68	1.43±0.87	1.46±0.79	1.00±1.26	0.599
AD	1.22±0.22 b	1.02±0.34 b	0.76±0.41 b	1.42±1.04 b	1.30±0.83 b	2.25±0.87 a	<0.001
H	0.50±0.00 c	1.10±0.61 abc	0.76±0.34 bc	1.62±1.73 a	0.76±0.45 bc	1.28±1.20 ab	<0.001
FA	0.72±0.04	1.06±0.78	0.63±0.46	1.31±1.51	0.94±0.47	1.28±1.28	0.069
PT	0.58±0.40 cd	1.68±0.90 ab	0.36±0.28 d	1.61±1.56 ab	1.12±0.48 bc	2.13±0.84 a	<0.001
P	0.62±0.77 bc	1.40±0.90 a	0.16±0.25 c	1.25±1.15 ab	0.76±0.59 abc	0.85±0.40 abc	<0.001
AI	0.77±0.44 bc	1.44±0.51 a	0.17±0.38 c	1.00±0.89 ab	1.15±0.52 ab	1.00±1.31 ab	<0.001

a,b,c letters show differences in BSI subscale points depending on educational level ($p < 0.05$)

Table 3. Points obtained for S, OCD, IS, D, AD, H, PA, PT, P and AI subscales according to carer gender

<i>Gender</i>	<i>n</i>	<i>Mean</i>	<i>Std. Deviation</i>	<i>P-values</i>
Somatization (S)				
Male	70	1.799	0.847	<0.001
Female	70	1.086	0.824	
OCD				
Male	70	1.234	0.689	0.671
Female	70	1.181	0.777	
Interpersonal Sensitivity (IS)				
Male	70	1.314	0.860	0.016
Female	70	0.929	0.997	
Depression (D)				
Male	70	1.373	0.689	0.419
Female	70	1.489	0.976	
Anxiety (AD)				
Male	70	1.313	0.767	0.354
Female	70	1.190	0.795	
Hostility (H)				
Male	70	1.029	0.726	0.015
Female	70	0.729	0.710	
Phobic Anxiety (PA)				
Male	70	0.973	0.697	0.615
Female	70	0.913	0.712	
Paranoid Thoughts (PT)				
Male	70	1.171	0.793	0.630
Female	70	1.104	0.851	
Psychotism (P)				
Male	70	0.919	0.766	0.059
Female	70	0.670	0.714	
Additional Items (AI)				
Male	70	1.029	0.680	0.716
Female	70	0.986	0.712	

Discussion

This study included patient groups requiring care with different characteristics (terminal cancer, stroke, Alzheimer and Parkinson). Additionally, the demographic characteristics and mental health status of these patients' carers were dealt with. During literature screening; a variety of studies revealed that those caring for patients have more disease and symptoms compared to non-carers. Another emphasis in the literature is that carers use health services more often (15, 19). As revealed by much research, caring for a patient makes the whole of life more

difficult for patient and relative, and limits freedom. However, individuals experience this process differently. Factors affecting this may be due to patient characteristics (age, gender, disease duration, etc.) or due to carer characteristics (age, gender, any discomfort present, care duration, etc.). Interviews with carers have found some individuals feel obstructed by patient care (9), while some individuals find satisfaction in this situation (17). Additionally, there may be carers who do not predict how this situation will become more difficult at the beginning of caring.

Table 4. Points obtained for S, OCD, IS, D, AD, H, PA, PT, P and AI subscales according to carer income-expenditure state

<i>Income-expenditure state</i>	<i>N</i>	<i>Mean</i>	<i>Std. Deviation</i>	<i>P-value</i>
Somatization				
Income less than expenditure	68	1.59	0.85	
Income equal to expenditure	59	1.25	0.88	0.102
Income greater than expenditure	13	1.55	1.18	
OCD				
Income less than expenditure	68	1.14	0.59	
Income equal to expenditure	59	1.21	0.74	0.141
Income greater than expenditure	13	1.58	1.19	
Interpersonal Sensitivity				
Income less than expenditure	68	1.12	1.02	
Income equal to expenditure	59	1.22	0.81	0.192
Income greater than expenditure	13	0.69	1.11	
Depression				
Income less than expenditure	68	1.76	0.81	
Income equal to expenditure	59	1.08	0.70	<0.001
Income greater than expenditure	13	1.29	1.01	
Anxiety				
Income less than expenditure	68	1.14	0.79	
Income equal to expenditure	59	1.27	0.74	0.044
Income greater than expenditure	13	1.73	0.78	
Hostility				
Income less than expenditure	68	0.99	0.85	
Income equal to expenditure	59	0.72	0.40	0.101
Income greater than expenditure	13	1.01	1.06	
Phobic Anxiety				
Income less than expenditure	68	0.96	0.75	
Income equal to expenditure	59	0.79	0.46	0.002
Income greater than expenditure	13	1.54	1.04	
Paranoid Thoughts				
Income less than expenditure	68	1.14	0.88	
Income equal to expenditure	59	0.95	0.58	<0.001
Income greater than expenditure	13	2.00	0.90	
Psychotism				
Income less than expenditure	68	0.75	0.88	
Income equal to expenditure	59	0.78	0.64	0.394
Income greater than expenditure	13	1.06	0.34	
Additional Items				
Income less than expenditure	68	0.91	0.73	
Income equal to expenditure	59	1.12	0.56	0.247
Income greater than expenditure	13	1.00	1.00	

The analysis in the study revealed that as the carers' age, care duration and disease duration of the patient increased, the carers'

psychological problems increased. These findings comply with observations, interviews and literature screening related to carers

(20,16, 21). They may experience problematic periods dealing with anger toward the patient and loneliness (1). Literature studies have shown that the caring duration is an important factor in psychological health (20). Additionally, just as psychological problems may increase with care age (16,21), the reverse is also possible (22). Research involving carers for cancer patients compared the patient relatives with older age with those of younger age and revealed the older patient relatives had more appetite and sleep problems. Additionally, research revealed that the quality of life of carers with advanced age was more disrupted. The carer's age is an important factor in this process (23). In one research, it is shown that older carers experience more difficulties compared to younger carers (24). Contrary to this data, it is reported that younger carers feel more distress due to the presence of responsibility toward their own partners, children and work (25).

There are studies revealing that caring negatively affects people and increases the dimensions of psychological problems. Especially when research results are examined, somatization appears to be significant. This finding complies with other findings in the literature. Akbıyık (26) determined that carer's problems may be expressed as bodily symptoms. Studies related to carers have found common problems like tiredness, lack of appetite, digestive system and sleep pattern disruption. The desire to cry, especially, inappropriate laughing and behavior, excessive talking or not talking, feelings of distress, powerlessness and hopelessness were identified. Additionally, there appeared to be problems following daily work and reduction in family and neighbor relationships (27). In our study, there was a positive significant correlation between the carers' depression, OCD, hostility, phobic anxiety and psychotism. Another research into the carer's gender observed no significant difference between the genders (28).

Research has shown that men and women perceive the difficulties related to caring differently. Men stated that they experience distress due to not feeling appreciated and requiring more social support; while women

reported distress due to disruption of relationships with other family members and worsening health status (29). A study revealed that the carer being male caused more psychological distress compared to women (30,31). The reason for this situation is considered to be the responsibilities attributed to the genders and acceptance.

In the research, it was shown that expenditure exceeding income plays a role in the occurrence of some psychological problems. With carers reporting serious alterations in their lives due to caring, 55% cannot work due to caring, while 54% stated that their economic situations were affected by disease (7). Carers stating their income situation as not good experience worry that they will not access the services, tools, materials and medical treatment required for the patient at sufficient levels (32).

It was found that educated people were better at coping with psychological symptoms (33). It is considered that educated individuals can find routes to cope with stress more easily (34). However, though this is supported by some subscales in our research (OCD, P, AI); contrarily, some subscales (S, AD, H, PT) revealed that uneducated people coped better.

Conclusion

Society-based studies continue about treatment of chronic diseases in Turkey. Experts need to be informed about problems experienced by patients and carers, who will struggle with these diseases for the rest of their lives, and when necessary, they should be referred to different disciplines for support. Experts should determine the educational requirements related to this topic for carers and they should be referred to the relevant people and organizations. Considering the limitations of studies about this topic in the literature, the importance of research in this area to determine the risk factors for patient and carer and transmit the correct approaches to them is indisputable.

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