

Research Article / Arastırma

Hemodiyaliz hastalarına bakım veren kadınların sağlık okuryazarlık düzeyi afet süreçlerinin yönetimini kolaylaştırır mı?

Does the health literacy level of women who care for hemodialysis patients facilitate the management of disaster processes?

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ABSTRACT

Aim: This study was conducted to evaluate the relationship between health literacy level and disaster attitudes of women who provide informal care to hemodialysis patients.

Material and Methods: This descriptive and correlational study was conducted with 120 women who provided informal care to patients in two dialysis units, one in a university hospital and the other in a training and research hospital in the Marmara Region of Turkey and who agreed to participate in the study. Data were collected between December 2023 and February 2024 using the Caregiver Information Form, Turkish Health Literacy Scale-32 and Disaster Attitude Scale.

Results: Patients who were younger than 65 years of age, mothers, had high school or higher education, had been in care for more than 10 years, and received hemodialysis treatment three times a week or more had significantly higher health literacy levels and attitudes towards disasters compared to others (p=0.001). At the same time, increasing health literacy level has a moderate positive effect on attitudes towards disasters (p=0.001). Two units of a three-unit increase in attitudes towards disasters were attributed to those with a good level of health literacy. In addition, mothers caring for their children caused a 3% increase in health literacy level.

Conclusion: High levels of health literacy among mothers providing care for children undergoing hemodialysis positively enhance disaster awareness.

ÖΖ

Amaç: Bu çalışma, hemodiyaliz hastalarına informal bakım veren kadınların sağlık okuryazarlık düzeyi ile afet süreçlerini yönetmeleri arasındaki ilişkiyi değerlendirmek amacıyla yapıldı.

Gereç ve Yöntemler: Tanımlayıcı ve ilişki arayıcı tipindeki çalışma Türkiye'nin Marmara Bölgesi'nde biri üniversite diğeri eğitim ve araştırma hastanelerindeki iki diyaliz ünitesindeki hastalara informal bakım veren, çalışmaya katılmayı kabul eden 120 kadın ile yapıldı. Veriler, Bakım Veren Bilgi Formu, Türkiye Sağlık Okuryazarlığı Ölçeği-32 ve Afet Tutum Ölçeği ile Aralık 2023-Şubat 2024 tarihlerinde toplandı. Veriler SPSS 21 ve Process makro kullanılarak tanımlayıcı, nonparametrik, korelasyon, regresyon ve düzenleyici etki testleri ile analiz edildi.

Bulgular: 65 yaşından küçük, anne, lise ve üzeri eğitim mezunu, 10 yılı aşkın süredir bakımı sürdüren, haftada üç kez ve üzerinde hemodiyaliz tedavisi alan hastası olanların sağlık okuryazarlık düzeyleri ile afetlere yönelik tutumlarının diğerlerine göre anlamlı derecede yüksek olduğu saptanmıştır (p=0,001). Aynı zamanda artan sağlık okuryazarlık düzeyi afet tutumunu orta düzeyde pozitif yönde etkilemektedir (p=0,001). Afete yönelik tutumda üç birimlik bir artışın iki birimini iyi düzey sağlık okuryazarlığı olanlar oluşturmaktadır. Ayrıca çocuğuna bakım veren anneler sağlık okuryazarlık düzeyinde %3'lük artışa neden oldu.

Sonuç: Hemodiyaliz hastası çocuklarına bakım veren annelerin iyi düzey sağlık okuryazarlığı afete yönelik farkındalığı olumlu yönde artırmaktadır.

ARTICLE INFO/MAKALE BILGISI

Key Words: Care, disaster, health literacy, renal dialysis, woman.
Anahtar Kelimeler: Afetler, bakım, böbrek diyalizi, kadın, sağlık okuryazarlık
DOI: 10.5281/zenodo.14588511
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Received Date/Gönderme Tarihi: 23.06.2024 Accepted Date/Kabul Tarihi: 01.10.2024 Published Online/Yayımlanma Tarihi: 31.12.2024

Introduction

Hemodialysis is the most commonly used method in the treatment of end-stage renal disease (1,2). It is known that there are approximately 70,000 hemodialysis patients in Turkey, and the number of patients increases by about 4% to 7% annually (2). Since hemodialysis involves a complex and chronic treatment process, patients require care. Care can be defined in two forms: formal and informal care. Formal care refers to care provided by professional groups providing health care and personal care services in private or public institutions, and informal care refers to care provided by family members, relatives and neighbors (2,3). Studies have shown that women involved in the care of hemodialysis patients face challenges such as role conflict within the family, difficulties in accessing the healthcare system, and lack of information regarding treatment and disease (4-6). Additionally, changing climate conditions have led to an increase in the number of disasters over the past decade, altering the needs of hemodialysis patients and their caregivers (7). During the recent coronavirus pandemic in 2020, it became evident that hemodialysis caregivers lacked adequate knowledge and preparation for disaster situations (9). While the effects of the pandemic persisted, the Kahramanmaraş earthquake on February 6, 2023, in our country temporarily disrupted the treatment of hemodialysis patients. Furthermore, during disaster times, informal caregivers, predominantly women, had to take on increased responsibilities within the family while ensuring the continuity of daily treatments, nutrition, and hygiene for hemodialysis patients (8). During the earthquake and tsunami in Japan in 2011, it was observed that caregivers with low health literacy levels were inadequate in accessing healthcare and managing the treatment

process (7,9). Health literacy emerges as a protective factor for caregivers in disaster situations (7,10,11). The ability of caregivers to acquire, understand, and use health information and make effective decisions is closely related to their level of health literacy (10). During pandemic periods, it has been determined that caregivers try to access the necessary health information through social media (9-13). Akyol et al. (2023) found in their study with caregivers during the pandemic that a good level of health literacy facilitated access to accurate information and increased motivation in disease care (11). There is no study evaluating the relationship between the awareness, knowledge, and attitudes toward disasters and the health literacy levels of informal female caregivers who are always by the side of hemodialysis patients. This study is expected to fill a gap in the literature by assessing the relationship between the health literacy level and disaster-related attitudes of women providing informal care to hemodialysis patients.

Materials ans Methods

Type of Study

This is a descriptive and correlational study.

Study Population and Sample

The study population consists of 130 women providing informal care to patients undergoing treatment at a dialysis center of a university and a training and research hospital in the Marmara Region of Turkey. The study aimed to reach the entire population without selecting a sample. The sample consists of 120 women who met the participation criteria and agreed to participate voluntarily. The power of the study is 92.3%.

Inclusion and Exclusion Criteria

The inclusion criteria for the study are:

- Women aged over 18,

- Providing informal care to the same hemodialysis patient for at least 6 months,

- Having no mental disorders,

- Willingness to participate in the study voluntarily.

The exclusion criteria are:

- Not answering the study questions,

- Voluntarily withdrawing from the study.

Data Collection Tools

Caregiver Information Form: This form, prepared by the researcher based on the literature,5-8 includes questions about the caregiver's age, education level, degree of kinship with the patient, how long they have been providing care, and the frequency of the patient's hemodialysis sessions.

Turkish Health Literacy Scale-32 (THLS-32): Developed by Okyay et al. (2016), the scale has a Cronbach's alpha value of 0.93. Scores range from 0-25 indicating "inadequate," 26-33 "problematic (limited)," 34-42 "sufficient," and 43-50 "excellent" health literacy (12). In this study, the Cronbach's alpha value of the scale was found to be 0.86.

Disaster Attitude Scale (DAS): Developed by Türkan and Kılıç (2017), the scale has a Cronbach's alpha value of 0.82. Higher scores indicate more positive attitudes towards disasters (13). In this study, the Cronbach's alpha value of the scale was found to be 0.80.

Data Collection

Data were collected by the researcher through face-to-face interviews with the participants, lasting 15-20 minutes, using the scales between December 2023 and February 2024.

Data Analysis

Data analysis was conducted using the SPSS (IBM SPSS Statistics 21.0, Turkey) statistical package program and the Process macro developed by Hayes (14,15). The normal distribution of variables was assessed using the Kolmogorov-Smirnov test. For parametric variables. arithmetic mean. standard deviation, and minimum-maximum values were used; a t-test was used for comparing the means of two groups, and one-way analysis of variance (ANOVA) was used for comparing the means of more than two aroups.

The relationship between the DAS and THLS-32 scales was evaluated using Pearson correlation analysis, where r values were interpreted as follows: 0.00 (no relationship), 0.01-0.29 (low relationship), 0.30-0.70 (moderate relationship), 0.71-0.99 (high relationship), and 1.00 (perfect relationship). The regulatory effect of THLS-32 and demographic variables on DAS and the slope test were applied. In this study, statistical significance was accepted at p<0.05 with a 95% confidence interval (15).

Ethical Aspects of The Study

Ethical approval was obtained from the Istanbul University-Cerrahpaşa Social and Humanities Research Ethics Committee (date: 03.10.2023; no: 2023/335), and institutional permissions were secured for the hospitals involved. A "voluntary informed consent form" was used to inform participants, and all procedures were conducted in accordance with the principles of the Declaration of Helsinki.

Results

More than half of the participants (62,5%) are under the age of 65, and the majority (32,5%) are providing care to their spouses. Nearly half of the participants (45,0%) are literate, more than half (55,8%) are not employed, 58.3% have been providing care for less than 10 years, and more than half of the patients (53,3%) undergo hemodialysis less than three times a week. The most common difficulty faced by women in hemodialysis care is managing the medical treatment process (44,2%) (Table 1).

Under 65 years of age (THLS-32, Z:4,546; DAS, Z:1,399, p=0,001), caregivers of children (THLS-32, F:1004,185; DAS, F:169,952, p=0,001), those with high school education

Table 1. Evaluation of demographic characteristics according to health literacy and disaster attitude levels (n=120)

Demographic	n(%)	THLS-32	DAS	
Characteristics				
Age				
<65	75 (62,5)	34,83±6,45	70,18±16,96	
≥ 65	45 (37,5)	30,07±5,74	66,91±5,45	
Z/p		4,546/p=0,001	1,399/ p=0,001	
Caregiver's Relationship	1		· -	
Wife	39 (32,5)	30,61±1,46	63,27±0,97	
Daughter-in-law	33 (27,5)	27,45±0,90	38,23±12,45	
Daughter	26 (21,7)	35,26±0,42	72,12±0,24	
Mother	22 (18,3)	42,22±0,52	75,02±0,32	
F/p		1004,185/ p=0,001	169,952/ p=0,001	
Education		• ·	· · · ·	
Literate	54 (45,0)	31,62±2,24	46,88±3,38	
Primary education	52 (43,3)	32,94±7,15	65,81±16,64	
High school and above	14 (11,7)	35,07±0,47	75,32±0,15	
F/p		12,7598/p=0,045	41,154/ p=0,001	
Employment			·	
Employed	53 (44,2)	32,90±2,41	59,75±13,18	
Unemployed	67 (55,8)	32,40±6,54	57,45±20,15	
Z/ p		-2,966/p=0,003	-2,011/p=0,044	
Duration of caregiving				
≤10 years	70 (58,3)	28,95±1,76	48,86±15,32	
>10 years	50 (41,7)	37,79±3,54	72,59±2,59	
Z/p		-17,831/ p=0,001	-10,715/ p=0,001	
Frequency of hemodialysis				
Less than 3 times per	64 (53,3)	28,92±1,71	47,90±15,28	
week				
3 times or more per week	56 (46,7)	36,87±4,33	71,10±6,27	
Z/p		-8,448/ p=0,001	-9,063/ p=0,001	
Difficulty in caregiving				
Fluid intake	40 (33,3)	32,94±7,15	65,81±3,38	
Medical treatment	53 (44,2)	35,26±0,42	75,04±0,16	
Diet adherence	27 (22,5)	30,61±5,11	38,23±12,45	
F/p		19,814/ p=0,001	90,860/ p=0,001	

THLS-32:Turkey Health Literacy Scale-32, DAS: Disaster Attitude Scale

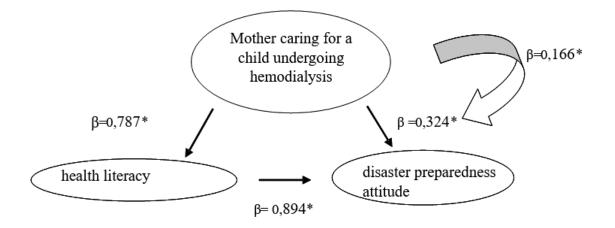


Figure 1. Moderating effect of health literacy on disaster preparedness attitude among mothers caring for children undergoing hemodialysis

and above (THLS-32, F:12,7598; DAS, F:41,154, p=0,045), employees (THLS-32, Z:-2,966/p=0,003; DAS, Z:-2,011/p=0,044), caregivers for more than 10 years (THLS-32, F:-17,831; DAS, F:-10,715, p=0,001), those whose patients undergo hemodialysis three times a week or more (THLS-32, Z:-8,448; DAS, Z:-9,063, p=0,001) and those who have difficulty in managing medical treatment (THLS-32, F:19,814; DAS, F:90,860, p=0,001)

have significantly more positive health literacy levels and attitudes towards disasters compared to others (Table 1).

There is a moderate significant relationship between health literacy and disaster attitudes in mothers caring for their children (r=0,518; r=0,324, p=0,001) and those providing care for patients undergoing hemodialysis for ten years or more (r=0,337; r=0,264, p=0,001).

Table 2. The relationship between caregiving duration, kinship level, health literacy, and attitude towards disasters among female caregivers (n=120)

		THLS-32	DAS
THLS-32	r	1	0,486
	р		0,001
DAS	r	0,486	1
	р	0,001	
The kinship level with the care recipient (mother)	r	0,518	0,324
	р	0,001	0,001
Hemodialysis treatment duration (10 years and above)	r	0,337	0,264
	р	0,001	0,001

THLS-32: Turkey Health Literacy Scale-32, DAS: Disaster Attitude Scale

r: 0.00 no relationship; 0.01-0.29 low level of relationship; 0.30-0.70 moderate level of relationship; 0.71-0.99 high level of relationship; 1.00 perfect relationship

DAS				
	β	t	р	Model R ²
THLS-32	0,486	6,087	<0,001	0,236
The kinship level of the caregiver with the patient (daughter-in-law, spouse, daughter, mother)	0,324	3,753	<0,001	0,098
THLS-32	β	t	р	Model R ²
The kinship level of the caregiver with the patient (daughter-in-law, spouse, daughter, mother)	0,518	6,637	<0,001	0,269

Table 3. Regression analysis of caregiver's kinship level with the patient on disaster attitude and health

 literacy variables

THLS-32: Turkey Health Literacy Scale-32, DAS: Disaster Attitude Scale

Additionally, increased health literacy levels moderately positively affect disaster attitudes (r=0,486, p=0,001) (Table 2).

Regression analyses indicate that attitudes towards disasters are significantly associated with health literacy and the caregiver's degree of kinship with the patient (p<0,001). Both health literacy (β =0,518) and the caregiver's kinship with the patient (β =0,324) are significant predictors of attitudes towards disasters (p<0,001) (Table 3).

The sociodemographic characteristics of the participants (age, education level, employment

status) and questions related to caregiving (duration of caregiving, frequency of the patient's hemodialysis treatment, difficulties experienced in caregiving) were not found to have a significant moderating effect on the THLS-32 and DAS (p > 0.05). However, it was found that mothers caring for their children undergoing hemodialysis had a moderating (buffering) effect between the THLS-32 and DAS (F = 131,976; p=0,047) (Figure 1).

As a result, health literacy affects approximately 72% of the attitude towards disasters, and mothers caring for their

Table 4. The moderating role of care provided by the patient's mother on the influence of health literacy on disaster-related attitudes

Model	Variables	β	t	р	%95 CI
Model	THLS-32	0,894	14,957	<0,001	6,397-8,349
1	Caregiver's kinship level with the patient	0,787	13,176	<0,001	7,471-5,519
Model 2	Interaction Effect TSOY-32, Caregiver's kinship level with the patient (Mother)	0,166	2,003	=0,047	0,015-2,679
Model	R ²	SD	R ² difference	F difference	р
Model 1	0,689	4,637	0,689	131,976	<0,001
Model 2	0,722	4,580	0,033	4,013	=0,047

CI: Confidence Interval, SD: Standart Deviation,

THLS-32: Turkey Health Literacy Scale-32, DAS: Disaster Attitude Scale

children have a moderating effect of about 3.3% on this effect (Table 4). These findings indicate that both health literacy and informal caregiving by mothers significantly impact attitudes towards disasters, answering the research question.

Discussion

It was observed that caregivers for patients requiring continuous treatment, such as hemodialysis, were not adequately equipped for disaster situations during the new coronavirus pandemic in March 2020 and the Kahramanmaraş earthquake on February 6, 2023. The concept of health literacy emerges as a crucial factor in building resilient communities. This study evaluated the relationship between disaster attitudes and health literacy among women providing informal care to hemodialysis patients.

A positive and moderate correlation was found between disaster attitudes and health literacy in this study. In disaster situations, the knowledge and skills of caregivers are essential for treatments like hemodialysis, which require uninterrupted electricity, water, and human resources. In Japan, following the earthquake and tsunami in 2011, it was determined that family members with low health literacy levels who cared for chronic patients faced greater difficulties in maintaining patient care and accessing medical aid after the disaster (7).

Similarly, after the hurricane in Puerto Rico in 2017, a caregiver trapped at home managed to operate the dialysis machine on their own, saving the life of a patient with kidney failure. However, due to inadequate adherence to hygiene protocols, the patient developed an infection and subsequently died (16). This highlights the importance of health literacy levels among caregivers in ensuring patient care and preventing complications during disasters.

Atalay et al. (2021) emphasized in their study that caregivers of individuals with chronic illnesses had insufficient disaster awareness, increasing the risk of vulnerability during disasters (17). The findings from this study align with this perspective, indicating that higher health literacy among caregivers can significantly impact their ability to manage patient care and reduce risks during disaster situations.

This study, which presents correlations similar to those in the literature, underscores the necessity of enhancing health literacy among caregivers due to increasing occurrences of disasters, facilitating access to healthcare services, and developing interdisciplinary plans tailored to specific disaster scenarios (17,18). In this study, it was determined that caregivers who are aged 65 and older, literate, not employed, providing care for less than 10 years, and facing the greatest challenge in diet adherence while caring for hemodialysis patients receiving treatment less than three times a week exhibited lower levels of health literacy and disaster preparedness. Studies conducted during the pandemic have observed that individuals with a high level of health literacy effectively maintain interactions with their surroundings and utilize various information sources such as the internet, predominantly comprising young individuals with advanced educational backgrounds, employment, and extensive caregiving experience (11,17). Consistent with the literature, the findings of this study highlight the importance of addressing caregivers, who serve as a crucial link between patients and the healthcare system in ensuring the continuous provision of hemodialysis treatment, and contribute to organizing educational programs based on the assessment of both the deficiencies and

strengths of this group.

In this study, a striking finding is the varying levels of health literacy and disaster caregivers, preparedness among with daughters-in-law exhibiting the lowest and mothers having the highest average scores. Literature includes several studies indicating that mothers caring for autistic children tend to have higher health literacy levels compared to fathers, and mothers caring for children undergoing hemodialysis exhibit better knowledge of the disease and treatment than other caregivers. Additionally, mothers of children with cancer voluntarily participate in educational programs to ensure adequate care (19-21). However, there is a lack of research specifically examining the health literacy and disaster preparedness of daughters-in-law, despite their significant presence as informal caregivers. Many studies conducted by nurses have explored the health and disease knowledge levels of caregiver mothers and spouses (19-23). Therefore, it is believed that the findings of this study will shed light on an overlooked aspect among caregivers.

The study's advanced analyses reveal that health literacy levels influence approximately 72% of disaster preparedness, with mothers caring for children undergoing hemodialysis exhibiting a regulatory effect in approximately 3% of cases. These results underscore the importance of developing different programs led by nurses to provide counseling, education, and support tailored to daughters-in-law who require assistance as caregivers. The findings highlight the crucial role of mothers in maintaining effective care by actively engaging with healthcare teams during future disaster scenarios. Sever et al. (2022) emphasized the importance of educating family members during disasters to ensure the continued care of hemodialysis patients before, during, and after emergencies (24).

In the literature, health literacy is noted as a crucial factor in managing behavioral and emotional responses during unforeseen events such as pandemics and natural disasters. Therefore, it is recommended to investigate factors influencing caregivers' preparedness for disasters and their health literacy levels in larger cohorts.

Study Limitations

This study has several limitations: Firstly, the participant pool is limited as data were collected from only two hospitals in a specific region of Turkey within a defined timeframe. Secondly, data on disaster preparedness were collected using a single scale.

Conclusion

According to the findings of this study, caregivers who exhibit higher health literacy and disaster preparedness scores are typically under the age of 65, have a high school education or higher, are employed, have been caregiving for more than 10 years, and provide care for hemodialysis patients receiving treatment at least three times per week. Informal caregivers, particularly mothers of hemodialysis patients, exert a regulatory effect contributing to approximately 3% of disaster preparedness influenced by health literacy, which affects more than two-thirds of disaster preparedness attitudes.

The health literacy of women providing informal care for hemodialysis patients may act as a defense shield against disasters. Given the variability in disaster and health literacy preparedness among informal caregivers, particularly mothers, it is recommended to develop tailored educational programs under nursing leadership. These programs should account for the diverse needs and capabilities related to disaster preparedness and health literacy among informal caregivers and other women.

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