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The Impact of Health Literacy of Primary Caregivers of Hemiplegic Patients on Functional Level and Mobility

İnmeli Hastaların Primer Bakım Verenlerinin Sağlık Okuryazarlığının Fonksiyonel Düzey ve Mobilite Üzerindeki Etkisi

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Abstract

Objective: Although rehabilitation patients make significant progress during the rehabilitation period, many of them face long-term physical, functional, and cognitive disabilities upon discharge. Patients' primary caregivers also play an important role during this process. The aim of this study was to investigate the relationship between primary caregivers' health literacy and hemiplegic patients' functional status and mobility.

Method: This cross-sectional study included hemiplegic patients aged 18-75 who were attending Başkent University, Department of Physiotherapy and Undergoing Rehabilitation. Patients in the acute phase (first 3 months) with uncontrolled systemic disease or psychiatric disease, aphasia, recurrent stroke, impaired swallowing, or psychiatric disease that may prevent them from answering the questions, or more than one neurologic disease were excluded from the study. Demographic information of all participants was recorded. Patients were evaluated with the functional impairment measurement, and patients' primary caregivers were evaluated with the Turkish health literacy scale-32. The effect of primary caregivers' health literacy on hemiplegic patients' function and mobility was statistically analyzed. A p-value <0.05 is considered statistically significant.

Results: A total of 107 patients and their primary caregivers were analyzed: 59 male patients, 48 female patients, 45 male caregivers, and 62 female caregivers. The average patient age was 52.23±22.92 years, and caregivers' average age was 49.40±14.72 years. Among patients, 62.6% had ischemic and 37.4% had hemorrhagic cerebrovascular disease. The mean disease duration was 71.78±36.32 months. The health literacy of primary caregivers was found to be correlated with the functional

Öz

Amaç: Rehabilitasyon hastaları önemli ilerlemeler kaydetmelerine rağmen taburcu olduktan sonra fonksiyonel ve bilişsel engellerle karşı karşıya kalabilmektedir. Primer bakım veren de bu süreçte önemli bir rol oynamaktadır. Bu çalışmanın amacı hemipleji hastalarının primer bakım verenlerinin sağlık okuryazarlığı ile hemiplejik hastaların fonksiyonel durumu ve mobilitesi arasındaki ilişkiyi araştırmaktır.

Yöntem: Kesitsel bir çalışmadır. Çalışmaya Başkent Üniversitesi Fiziksel Tıp ve Rehabilitasyon Polikliniği'ne hemipleji tanısıyla başvuran ve aktif rehabilitasyon programına alınan 18-75 yaşları arasındaki hastalar dahil edildi. Akut dönemdeki (ilk 3 ay içinde bulunan), afazisi, rekürren hemipleji öyküsü, yutma güçlüğü, kontrol edilemeyen sistemik hastalığı veya sorulara cevap verilmesini engelleyecek psikiyatrik hastalığı veya birden fazla nörolojik hastalığı olan hastalar çalışma dışı bırakıldı. Tüm katılımcıların demografik bilgileri kaydedildi. Hastaların fonksiyonel düzeyleri fonksiyonel bağımsızlık ölçümüyle, hastaların primer bakım verenlerinin sağlık okuryazarlık düzeyleri ise Türkçe sağlık okuryazarlığı ölçeği-32 ile değerlendirildi. Hemipleji hastalarının primer bakım verenlerin sağlık okuryazarlığının bu hastalarının fonksiyonel düzeyi, mobilitesi ve kognitif düzeyi üzerindeki etkisi istatistiksel olarak analiz edildi. P<0,05 olması istatistiksel olarak anlamlı olarak kabul edildi.

Bulgular: Toplamda 107 hemiplejik hasta ve primer bakım vereni analiz edildi. Hastaların 48'i kadın, 59'u erkekti. Primer bakım verenlerinin 62'si kadın, 45'i erkekti. Hastaların yaş ortalaması 52,23±22,92, primer bakım verenlerin yaş ortalaması 49,40±14,72 idi. Hastaların %62,6'sında iskemik nedenli serebrovasküler hastalık, %37,4'ünde ise hemorajik nedenli serebrovasküler hastalık tanısı mevcuttu. Ortalama hastalık süresi 71,78±36,32 ay olarak saptandı. Primer bakım verenlerin sağlık

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Abstract

impairment measurement scores (p<0.05). Additionally, it was found that health literacy was correlated with both motor and cognitive subscores of functional impairment measurement (p<0.05). It was determined that the health literacy of primary caregivers predicted the functional independence score and its subparameters (p<0.05).

Conclusion: These findings suggest that the health literacy of primary caregivers of hemiplegic patients was correlated with patients' motor and cognitive outcomes. Primary caregivers' health literacy level may affect these patients' functional outcomes.

Keywords: Cerebrovascular disease, health literacy, hemiplegia, rehabilitation

Öz

okuryazarlığının fonksiyonel bağımsızlık ölçümü puanları ile ilişkili olduğu tespit edildi (p<0,05). Ayrıca sağlık okuryazarlığın fonksiyonel bağımsızlık ölçümünün hem motor hem de bilişsel alt puanlarıyla ilişkili olduğu belirlendi (p<0,05). Sağlık okuryazarlık oranının Fonksiyonel bağımsızlık puanı ve alt parametrelerini yordadığı (p<0,05) tespit edildi.

Sonuç: Bu bulgular, hemiplejik hastaların primer bakım verenlerinin sağlık okuryazarlığının hastaların fonksiyonel motor aktivite ve kognitif fonksiyon düzeyi ile ilişkili olduğunu göstermektedir. Primer bakım verenlerin sağlık okuryazarlığı düzeyi bu hastaların fonksiyonel düzeylerini etkileyebilir.

Anahtar kelimeler: Hemipleji, rehabilitasyon, sağlık okuryazarlığı, serebrovasküler hastalık

Introduction

Stroke is characterized by the sudden interruption or significant reduction of blood flow to the brain. Less frequently, it may result from the rupture of a cerebral blood vessel, leading to hemorrhaging either within the brain tissue itself or in the surrounding membranes, a condition referred to as a cerebral hemorrhage (1). Given that distinct regions of the brain are responsible for specific bodily functions, the area directly affected by the stroke, along with adjacent tissues, typically experiences impairment (2). Depending on the site of damage, individuals may suffer from deficits in speech, motor strength, coordination, balance, vision, or memory. While some patients achieve complete recovery, others may endure long-term disabilities (3).

Recovery outcomes vary significantly among individuals. Some patients fully recover, while others continue to have lasting impairments. These sequelae depend largely on the location and extent of cerebral damage. Common post-stroke complications include cognitive deficits (such as memory and attention problems), language and communication disorders, emotional disturbances like depression, and impairments in balance, gait, and fine motor control (4). Consequently, thorough evaluation of cognitive status, mobility, and overall functional capacity is crucial in this patient population. Functional recovery largely depends on the patient's overall health and medical condition (5).

Health literacy refers to an individual's capacity to acquire, comprehend, and effectively utilize health-related information to make informed decisions and adhere to medical recommendations. Although many individuals demonstrate notable improvements during inpatient rehabilitation, the majority of stroke survivors continue to experience persistent physical, functional, and cognitive impairments following discharge (6).

Proficient literacy skills are essential for adults to navigate daily life effectively. Research indicates that limited literacy can hinder an individual's ability to interact efficiently with the healthcare system, potentially leading to adverse health outcomes. Inadequate health literacy remains a prevalent concern and has been linked to diminished access to health information; worsening health conditions; poor utilization and understanding of preventive services; increased risk of medication errors; higher healthcare expenditures; and elevated rates of hospital admissions. Furthermore, low health literacy has been associated with increased mortality, reduced self-efficacy, and insufficient knowledge and self-management capabilities in relation to chronic diseases (7). This study aims to examine the impact of health literacy among primary caregivers of hemiplegic patients on the patients' functional status, cognitive functions, and mobility outcomes.

Materials and Methods

It is a cross-sectional study. Approval was obtained from the Başkent University Non-Interventional Clinical Research Ethics Committee (approval number: E-94603339-604.01-458957, date: 06.05.2025). The research was conducted according to the rules of the Helsinki Declaration. A consent form was obtained from all participants.

Sampling, Patient Selection, and Randomization

The required sample size was calculated using the G*Power 3.1.9.4 software. For the multiple linear regression model, the parameters were set as a medium effect size (f^2=0.15), 95% statistical power (1-β=0.95), and a significance level of 5% (α=0.05). The analysis accounted for two tested independent variables and five predictor variables. The

results indicated that a minimum of 107 participants were necessary to detect a statistically significant effect within the model.

Patients aged 18 to 65 years, diagnosed with hemiplegia, who sought treatment at the Başkent University Physical Medicine and Rehabilitation Clinic, and the primary caregiver neighbor, who was an unpaid and informal caregiver, were enrolled in the study following their informed consent. The study excluded patients in the acute phase (within the initial 3 months), patients with aphasia, recurrent stroke, impaired swallowing, unmanaged systemic diseases that might affect results, patients with psychiatric conditions limiting their capacity to answer, and patients diagnosed with multiple neurological disorders.

Evaluation of the Patients

All patients and primary caregivers had an interview with a physiatrist who had more than ten years of experience in neurologic rehabilitation. All participants were reviewed by the same specialist. Demographic information of the patients and their primary caregivers, including age, gender, educational attainment, occupation, type of cerebrovascular disease, and disease duration, was collected and documented. Patients were assessed using the functional independence scale, while their relatives completed the health literacy-32 scale.

The Turkish health literacy scale-32 (TSOY-32) is a psychometrically validated instrument designed to accurately assess the health literacy levels of adults in Turkey. Comprising 32 items, the scale evaluates health literacy across four fundamental domains: access, comprehension, appraisal, and decision-making/ implementation. Items are primarily rated on a Likert-type scale, with higher scores reflecting more advanced abilities in obtaining, understanding, interpreting, and applying health information in everyday life (8).

The functional independence measure (FIM) is a widely utilized instrument in rehabilitation that assesses individuals' levels of independence in activities of daily living. The scale comprises 18 items divided into two primary domains: motor (physical) and cognitive. It evaluates fundamental functions such as eating, personal hygiene, toileting, mobility, communication, and social interaction. Each item is scored on a scale from 1 (complete dependence) to 7 (complete independence), yielding a total score ranging from 18 to 126, with higher scores indicating greater independence. The FIM is a validated and reliable tool commonly employed to monitor functional progress and to inform care planning for patients recovering from stroke, spinal cord injuries, orthopedic surgeries, and chronic illnesses (9).

The study aimed to examine the influence of the primary caregivers' health literacy on the patients' functional status and mobility.

Statistical Analysis

Statistical analyses were conducted using SPSS version 25.0. Descriptive statistics for categorical variables were expressed as frequencies and percentages. The Shapiro-Wilk test was employed to assess the normality of numerical variables. For variables demonstrating a normal distribution, descriptive statistics were presented as mean ± standard deviation, whereas variables not conforming to normality were summarized using median (minimum-maximum) values. Since the data did not satisfy parametric assumptions, Spearman correlation was used to examine links between health literacy, functional level, and mobility. Linear regression helped identify risk factors affecting function and mobility. For all hypothesis tests, the Type I error rate was set at α=0.05, and p-values less than 0.05 were considered statistically significant.

Results

A total of 107 patients and their primary caregivers were included in the analysis. Among the patients, 59 were male and 48 were female, while the primary caregivers comprised 45 males and 62 females. The mean age of the patients was 52.23±22.92 years, and the mean age of the primary caregivers was 49.40±14.72 years. Of the patients, 62.6% were diagnosed with ischemic cerebrovascular disease, whereas 37.4% had hemorrhagic cerebrovascular disease. The mean duration of illness was 71.78±36.32 months. The demographic characteristics of patients and primary caregivers are presented in Table 1. As there was no normal distribution among values, median and min-max values, of the functional independence scale and TSOY-32 were given in Table 2.

A statistically significant positive correlation was found between the health literacy levels of primary caregivers and the FIM total scores (r_s=0.324, p=0.001). Furthermore, health literacy was significantly correlated with both the motor (r_s=0.262, p=0.006) and cognitive (r_s=0.278, p=0.004) subscales of the FIM. However, these correlations were revealed as weak. Accordingly, variation in health literacy accounted for approximately 10% of the variance in the total FIM score, 6% of the variance in motor function, and

Table 1. Demographic properties of participants

Patients' gender	n (%)
Female	48 (44.9)
Male	59 (55.1)
Patients' age (years) (mean ± std deviation)	52.23±22.92
Disease duration (months) (mean ± std deviation)	71.78±36.32
Disease etiology	
Ischemic	67 (62.6)
Hemorrhagic	40 (37.4)
Primary caregivers' gender	
Female	62 (57.9)
Male	45 (42.1)
Primary caregivers' age (years) (mean ± std deviation)	49.40±14.72
Primary caregivers' education	
Illiterate	3 (2.8)
Primary school	28 (26.2)
Secondary school	9 (8.4)
High school	30 (28.0)
University	37 (34.6)
Primary caregivers' occupation	
Unemployed	52 (48.6)
Lecturer	7 (6.5)
Health professional	5 (4.7)
Desk worker	3 (2.8)
Worker	40 (37.4)

Table 2. Median and range (min-max) values of functional independence scale and Turkish health literacy scale-32

Functional independence scale (min-max)	84 (18-126)
Motor function (min-max)	68 (13-91)
Cognitive function (min-max)	29 (5-35)
Turkish health literacy scale-32 (min-max)	57 (32-139)

Functional independence scale is scored ranging from 18 to 126 with subscales of motor function (13 to 91) and cognitive function (5 to 35). Turkish health literacy scale-32 is scored ranging from 32 to 160

7% of the variance in cognitive function. Although these associations were statistically significant, the effect sizes indicate that the strength of the relationships was weak.

The predictive influence of primary caregivers' health literacy on FIM scores, including motor and cognition subscores, was assessed using simple linear regression analysis. The results demonstrated that the health literacy level of primary caregivers significantly predicts FIM total scores (F=12.277, p=0.001). Health literacy levels of primary caregivers explain 10% of the variance (R-squared=0.105). A one-point increase in health literacy corresponds to a 0.353 unit rise in FIM scores [95% confidence interval (CI): 86.010 to 114.350]. Additionally, the health literacy level of primary caregivers significantly predicts the motor subscore (F=7.734, p=0.006). Health literacy levels of primary caregivers explain 6.9% of the variance (R-squared=0.069). A one-point increase in health literacy corresponds to a 0.247 unit rise in motor subscores. Ensure that the 95% confidence interval (63.925 to 88.852) is correctly paired with the relevant figure in your data presentation. The health literacy level of primary caregivers significantly predicts cognitive subscore (F=8.766, p=0.004). Health literacy levels of primary caregivers explain 7.7% of the variance (R-squared=0.077). A one-point increase in health literacy corresponds to a 0.091 unit rise in cognitive subscore [95% CI: (review needed for accuracy)]. The predictive power of the TSOY-32 on functional, motor, and cognitive scores is presented in Table 3.

Discussion

In the current study, a significant positive relationship was identified between the health literacy of primary caregivers

Table 3. The predictive power of the Turkish health literacy scale-32 on functional, motor and cognitive scores

	Unstandardized coefficients		Standardized coefficients	t	p	95.0% CI
	B	SE	β			
Constant	100.180	7.146		14.018	0.001	86.010 to 114.350
FIM[μ]	-0.353	0.101	-0.324	-3.504	0.001*	-0.554
Durbin-Watson =1.753 F=12.277 p=0.001* R=0.324 R^2=0.105 Adjusted R^2=0.096						
Constant	76.388	6.286		12.153	0.001	63.925 to 88.852
Motor function[μ]	-0.247	0.089	-0.262	-2.781	0.006*	-0.423
Durbin-Watson =1.677 F=7.734 p=0.006* R=0.262 R^2=0.069 Adjusted R^2=0.060						
Constant	31.656	2.166		14.612	0.000	27.361 to 35.952
Cognitive function[μ]	-0.091	0.031	-0.278	-2.961	0.004*	-0.151
Durbin-Watson =1.788 F=8.766 p=0.004* R=0.278 R^2=0.077 Adjusted R^2=0.068						

CI: Confidence interval, SE: Standard error, β: Standardized regression coefficient, FIM: Functional independence measure, [μ]: Lineer regression analysis, *: p<0.05 statistically significant

and the total scores on the FIM. Additionally, the health literacy of primary caregivers showed a notable association with the motor and cognitive components of the FIM. Nonetheless, these associations were found to be relatively weak. It was found that primary caregivers' health literacy was predictive of the total FIM score and its motor and cognitive subscales.

Health literacy is a person's ability to understand, evaluate, and use health information to manage their own well-being. It involves basic skills needed to navigate healthcare, make informed decisions, and lead a healthy lifestyle. This includes understanding medical information, accessing care, and choosing actions that prevent or manage illness (10). Proficient health literacy improves health, helps prevent disease, and makes healthcare work better. On the other hand, low health literacy can lead to a misunderstanding of medical information, difficulty following treatment regimens, and poor health choices. This lack of health literacy can cause serious problems like missed treatments, miscommunication, spread of false information, delayed care, higher costs, and poor self-care (11).

For hemiplegic patients, health literacy is crucial because it affects their quality of life, treatment adherence, complication prevention, and independence. Low health literacy can slow recovery, extend rehabilitation, and increase the risk of problems (12-16). Health literacy is vital not just for patients but also for their primary caregivers, who play a key role in care. Caregivers' understanding of health information affects the patient's recovery by ensuring correct treatment, timely emergency response, ongoing care, clear communication with doctors, emotional support, and avoidance of misinformation. For hemiplegic patients, caregivers' health literacy directly impacts care quality, treatment follow-through, and the patient's quality of life. Since hemiplegic patients often need help with medication, therapy, nutrition, and daily tasks, caregivers with good health literacy make fewer mistakes and better support recovery and monitoring (12-15).

Başaran and Doğan (12) studied 50 hemiplegic patients using the Turkish version of the European health literacy scale. They evaluated patients' conditions with the Brunnstrom stages and Nottingham health profile, and measured pain using the numeric rating scale. Results showed that health literacy had a strong impact on the quality of life, especially energy, emotional well-being, sleep, and physical activity, but no clear link with functional status (12). In the current study, there was a weak correlation between caregivers' health literacy and patients' functional scores.

Hahn et al. (13) studied people with hemiplegia, spinal cord injury, and traumatic brain injury, assessing cognitive function, literacy, and patient-reported outcomes over two days. They found strong links between functional literacy, health literacy, and cognitive function (13). The current study supports this, showing a correlation between caregivers' health literacy and the cognitive subscale.

Kolunsağ and Ardıç (14) conducted a study using interviews with home healthcare caregivers and assessed their performance using the Lawton daily living scale and the adult health literacy scale. They found that caregivers' health literacy was linked to education, job status, and income, with education being the strongest predictor. Understanding caregivers' health knowledge gaps and educational needs can help improve care quality and patient well-being (14). Both their study and the current one found a connection between caregivers' health literacy and patient functional outcomes.

Tony et al. (15) studied 50 hemiplegic patients and their family caregivers at home. Caregivers' knowledge about hemiplegia was measured with a 29-item open-ended questionnaire, and patient function was assessed using the barthel index. Half the caregivers had moderate knowledge, but 78.6% showed incorrect care practices. Caregivers' education and job were linked to their knowledge, but no connection was found between knowledge and patient function (15). Unlike the methodology employed by Tony et al. (15), this study used the validated TSOY-32 questionnaire instead of open-ended questions. Meanwhile, Hess Engström et al. (16) argued that health literacy is not a burden for caregivers. Everyone agrees that health literacy shouldn't be a burden. This study found a positive link between caregivers' health literacy and patients' FIM scores, suggesting, that improving health literacy can help outcomes.

Levasseur and Carrier (17) highlighted that improving patients' health literacy is key to better rehabilitation outcomes. Blázquez-González et al. (18) showed in a randomized trial that virtual reality can boost health literacy in stroke patients. Smith and Magnani (19) emphasized the important role of technology and digital health literacy in increasing patient knowledge. Cook and Pompon (20) offered recommendations on health literacy and communication for stroke recovery.

Study Limitations

Unlike Tony et al. (15), who used open-ended questions, this study's main strength is using the validated TSOY-32. It also focuses solely on hemiplegic patients, unlike broader studies by Hahn et al. (13) and Kolunsağ and Ardıç (14). The main limitations are the lack of objective tests beyond the FIM, a single-center design, and a small sample size. Although caregivers' health literacy shows some correlation with functional, motor, and cognitive outcomes, this link is weak. Larger, multicenter studies using technology are needed to confirm these findings and apply them in healthcare.

Conclusion

These findings indicate that the health literacy of primary caregivers of hemiplegic patients is associated with the patients' motor and cognitive outcomes. The level of health literacy among primary caregivers may influence the functional recovery of these patients. A statistically significant positive correlation was observed between caregivers' health literacy and the total scores on the FIM, including both its motor and cognitive subscales. Nevertheless, the strength of these correlations was found to be weak. Health literacy proved to be a predictor for the overall FIM score as well as its motor and cognitive sections, while age did not serve as a predictor.

Ethics

Ethics Committee Approval: The study approved by Başkent University Non-Interventional Clinical Research Ethics Committee (approval number: E-94603339-604.01-458957, date: 06.05.2025).

Informed Consent: The consent forms were obtained from all participants and primary caregivers.

Footnotes

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