

Türkiye'deki Fiziksel Tıp ve Rehabilitasyon Hekimlerinde Lipödem Farkındalığı: Kesitsel Çalışma**Lipedema Awareness Among Physical Medicine and Rehabilitation Physicians in Turkey: A Cross-Sectional Study**

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ÖZ

Giriş: Lipödem farkındalığı tıp profesyonelleri arasında düşük seviyededir. Lipödem, yaygın olarak ağrıya neden olur. Bu nedenle Fiziksel Tıp ve Rehabilitasyon (FTR) uzmanları arasında farkındalığın artırılması önemlidir. Bu çalışmanın amacı FTR hekimleri arasında lipödem hakkında bilgi ve farkındalık düzeyini değerlendirmek ve bu durumu etkileyen faktörleri belirlemektir.

Yöntem: Bu kesitsel çalışma Türkiye'de görev yapan FTR hekimleri arasında çevrimiçi bir anket kullanılarak yapılmıştır. Çalışmaya, yaşları 24-64 arasında değişen toplam 151 FTR asistanı ve uzmanı katılmıştır. Anket iki bölümden oluşmuştur. İlk bölümde demografik ve meslekle ilgili bilgiler yer alırken, ikinci bölümde lipödem hakkındaki bilgi ve farkındalığı değerlendirmeye yönelik 14 soru yer almıştır.

Bulgular: Katılımcıların çoğunluğu (%80,1) kadındı. Katılımcıların medyan yaşı 38 yıl idi. Bilgi puanları 0 ile 14 arasında değişmekte olup, medyan 8 olarak belirlenmiştir. Puanlar 0 ile 8 arasında olduğunda yetersiz bilgi, 9 ile 14 arasında olduğunda yeterli bilgi olarak kabul edilmiştir. Katılımcıların %45,7'si (N=69) lipödem tanımı, patogenezi, tanı araçları, ayırıcı tanı ve tedaviler hakkında yeterli bilgiye (Grup 1) sahipken, %54,3'ü (N=82) yetersiz bilgiye (Grup 2) sahiptir. Grup 1'de lipödem hakkında yeterli bilgiye sahip katılımcıların, Grup 2'ye göre 10 yıldan az deneyime sahip olma oranı anlamlı derecede yüksektir ($p<0.05$). Grup 1'deki katılımcıların 40 yaşın altında olma oranı, Grup 2'ye göre anlamlı derecede yüksektir ($p<0.05$).

Sonuç: FTR uzmanları arasında lipödem farkındalığı düşük olma eğilimindedir. İlginç bir şekilde, daha genç hekimler lipödem hakkında daha yüksek farkındalık düzeyine sahip olma eğilimindedirler.

Anahtar Kelimeler: lipödem, farkındalık, fiziksel tıp ve rehabilitasyon

ABSTRACT

Objective: Awareness of lipedema is still low among medical professionals. Pain is a prevalent symptom of lipedema, it is crucial to increase awareness among physical medicine and rehabilitation (PMR) physicians. The primary objective of this study is to evaluate the level of knowledge and awareness about lipedema among PMR physicians and to identify the factors influencing these.

Method: A cross-sectional survey was conducted using an online questionnaire administered to PMR physicians, including both residents and specialists, practicing in Turkey. A total of 151 PMR residents and specialists aged 24-64 years participated in the study. The survey consisted of two parts. The first part included demographic and profession-related information. The second part consisted of 14 questions focusing on assessing knowledge and awareness of lipedema.

Results: The majority of the 151 participants (80.1%) were female. The median age of the participants was 38 years. Knowledge scores ranged from 0 to 14, with a median of 8. Scores of 0 to 8 indicated insufficient knowledge, while scores of 9 to 14 indicated sufficient knowledge. Of the participants, 45.7% (N=69) had sufficient knowledge (Group 1) of lipedema's definition, pathogenesis, diagnostic tools, differential diagnosis, and treatments, while 54.3% (N=82) had insufficient knowledge (Group 2). Group 1 participants with sufficient knowledge had significantly ≤ 10 years of experience proportion compared to Group 2 ($p<0.05$). Group 1 had a significantly higher proportion of participants under the age of 40 compared to Group 2 ($p<0.05$).

Conclusion: The awareness of lipedema among PMR physicians tends to be low. Interestingly, younger physicians tend to have higher levels of awareness about lipedema.

Keywords: lipedema, awareness, physical medicine and rehabilitation

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INTRODUCTION

Lipedema, first described by Allen in 1940, is a chronic disease characterized by abnormal subcutaneous fat storage and distribution (1-3). It affects about 11% of adult women worldwide (2,4), and though rare, can also occur in men (5).

Even though lipedema was first described by Allen in 1940 (3), public awareness of the condition remains limited, resulting in a significant number of misdiagnosed patients (6-8). The etiopathogenesis of lipedema is unclear, but genetic and endocrinological factors are emphasized. It typically begins during hormonal changes like adolescence, pregnancy, or menopause (9). The disease causes visual body disturbances, heaviness in the lower extremities, bruising, and pain. Patients often have symmetrical swelling of the extremities, excluding the hands and feet, with a significant difference in adiposity between the extremities and trunk (1,2,10,11). Pain or hypersensitivity triggered by light touch and/or palpation is also common (11). These disturbances in body image, pain, mobility, and physical function can significantly affect the quality of life for those with lipedema. Delays in diagnosis may have physical, psychological, and social repercussions (12,13).

Despite accepted clinical diagnostic criteria for lipedema, the absence of specific laboratory and genetic tests complicates the definitive diagnosis of lipedema (11,14). First defined by Wold et al., these criteria have been updated through international consensus (15,16). Key diagnostic features include pain, symmetrical extremity involvement excluding the hands and feet, heaviness in the extremities, and a negative Stemmer sign. Lipedema is often mistaken for obesity, lymphedema, and Dercum's disease. The presence of overweight and obesity can complicate diagnosis (11,17).

Lipedema is classified into three stages and five types based on anatomical location. Stage 1 features a normal skin surface with enlarged subcutaneous fat tissue and small nodules. Stage 2 presents a rough skin surface with large palpable nodules. Stage 3 shows lobular deformation of the skin surface, especially around the hips, thighs, and knees. When pitting edema is present, the condition is termed lipo-lymphedema (18).

In studies conducted so far, the skin and subcutaneous tissue in lipedema have been evaluated using ultrasound (US), computed tomography (CT), and magnetic resonance imaging (MRI). However, no distinctive qualitative or quantitative pathognomonic findings have been identified (19-23). In lipedema, US often shows an increase in subcutaneous fat tissue thickness and hypoechogenicity in the lower extremities (19).

Women with lipedema may experience significant psychosocial difficulties affecting their daily activities (12,24). Conservative treatments include physiotherapy, movement therapy, compression therapy, weight control, and psychosocial therapy. Liposuction is a surgical treatment for lipedema (2,25,26).

Awareness of lipedema is still low among medical professionals (6-8). Pain is a prevalent symptom of lipedema, it is crucial to increase awareness among physical medicine and rehabilitation (PMR) physicians. This can help ensure early and accurate diagnosis, leading to correct treatment.

The primary objective of this study is to assess PMR physicians' knowledge and awareness of lipedema, as well as the factors influencing them.

MATERIALS AND METHODS

Study Design and Participants

This cross-sectional study was performed after approval was obtained from the Hamidiye University of Health Sciences Scientific Research Ethics Committee (approval number: 24/283). Between June 1 and July 1, 2024, a cross-sectional survey was conducted using an online questionnaire for PMR physicians in Turkey. A total of 151 PMR residents and specialists aged 24-64 years participated. The study required a minimum sample size of 148 participants, with a 5% margin of error and an 80% confidence interval (27).

Participants voluntarily completed the survey and provided their consent online. Before answering the survey, participants were informed about the study and asked if they would like to volunteer. Participants who agreed proceeded with the online survey created using Google Forms, while those who declined were unable to continue.

Survey Development

The survey had two parts. The first section covered demographic and profession-related information, including age, gender, marital status, job title, institution, average daily patient evaluations, years of experience, participation in PMR training in the last 3 years, and lipedema diagnosis (yes/no). The second part included 14 questions assessing knowledge of lipedema's definition, symptoms, pathogenesis, diagnostic methods, differential diagnosis, and treatment options.

Participants completed a multiple-choice survey using a Likert-type scale with options of yes, no, and I don't know. Yes responses were scored as 1 point, while no and I don't know were scored as 0 points. Correct answers were marked as "aware," and incorrect or "don't know" responses as "unaware." Scores below the mean indicated insufficient knowledge, while scores above the mean indicated sufficient knowledge (28). The maximum score was 14, and the minimum was 0. Scores from 0 to 8 indicated insufficient knowledge, and scores from 9 to 14 indicated sufficient knowledge.

The survey was developed by the authors to align with current guidelines and reviews (29,30). Created using Google Forms, it was distributed to PMR physicians via online portals, professional emails, and social media. Participants received a survey link with an information sheet outlining the study's objectives. Data collection, managed by the principal investigator, followed a standardized email protocol. The complete survey is available as Supplemental Material (S1)

Statistical Analysis

Statistical analysis was conducted using IBM SPSS Statistics 28.0 software. Normality was assessed with the Kolmogorov-Smirnov test. Descriptive statistics included mean, standard deviation, and frequency. Student's t-test was used for normally distributed data, and the Mann-Whitney U test for non-normally distributed data. Qualitative data comparisons employed Chi-Square, Fisher's Exact, Fisher-Freeman-

Halton Exact, and Continuity (Yates) Correction tests. Statistical significance was set at $p < 0.05$.

RESULTS

Participant Characteristics

Of the 151 participants, 80.1% were female, with a median age of 38 years (range: 24-64). In the past three years, 90.1% attended PMR training, and 72.8% of doctors had previously diagnosed lipedema in their patients. Participant characteristics and clinical experience details are summarized in Table 1.

Characteristics	N (%)
Age	
<40	91 (60.3%)
≥40	60 (39.7%)
Gender	
Female	121 (80.1%)
Male	30 (19.9%)
Marital status	
Single	42 (27.8%)
Married	109 (72.2%)
Job title	
Resident	34 (22.5%)
Specialist	107 (70.9%)
Associate Professor	5 (3.3%)
Assistant Professor	1 (0.7%)
Professor	4 (2.6%)
Place of work	
Training and Research Hospital	73 (48.3%)
Public hospital	27 (17.9%)
Private hospital	25 (16.6%)
University Hospital	6 (4.0%)
Others	20 (13.2%)
Years of experience	
<10 years	63 (41.7%)
≥10 years	88 (58.3%)
Average number of patients seen daily	
<30	59 (39.1%)
≥30	92 (60.9%)
Attendance of PMR training /workshop/ seminar in last 3 years	
No	15 (9.9%)
Yes	136 (90.1%)
Have you ever diagnosed patient with lipedema?	
Yes	110 (72.8%)
No	41 (27.2%)

Of the participants, 45.7% (N=69) had sufficient knowledge (Group 1) of lipedema's definition, pathogenesis, diagnostic tools, differential diagnosis, and treatments, while 54.3% (N=82) had insufficient knowledge (Group 2). There was no significant difference between groups in gender, marital status, job title, average daily patient evaluations, or recent training attendance ($p > 0.05$) (Table 2).

	Group 1 (n=69)	Group 2 (n=82)	P value
Age			
<40	50 (72.5%)	41 (50.0%)	0.005*
≥40	19 (27.5%)	41 (50.0%)	
Gender			
Female	57 (82.6%)	64 (78.0%)	0.484
Male	12 (17.4%)	18 (22.0%)	
Marital status			
Married	46 (66.7%)	63 (76.8%)	0.165
Single	23 (33.3%)	19 (23.2%)	
Job title			
Resident	19 (27.5%)	15 (18.3%)	0.176
PMR specialist	50 (72.5%)	67 (81.7%)	
Years of experience			
<10 years	37 (53.6%)	26 (31.7%)	0.007*
≥10 years	32 (46.4%)	56 (68.3%)	
Average number of patients seen daily			
<30	23 (33.3%)	36 (43.9%)	0.185
≥30	46 (66.7%)	46 (56.1%)	
Attendance of PMR training /workshop/ seminar in last 3 years			
No	5 (7.2%)	10 (12.2%)	0.311
Yes	64 (92.8%)	72 (87.8%)	

Chi-Square test; exact test; $p < 0.05$; * distributional difference between groups is statistically significant

Impact of PMR Physician Tenure on Lipedema Knowledge and Awareness

Participants were divided based on their years of experience: less than 10 years (n=63) and equal or more than 10 years (n=88). Group 1 participants with sufficient knowledge had significantly ≤ 10 years of experience proportion compared to Group 2 ($p < 0.05$). This categorization was guided by clinical training and working experience in PMR in Turkey (Table 2, Figure 1). The distribution of the answers given to lipedema knowledge questions is presented in Table 3.

Table 3. The Distribution of the Answers Given to Lipedema Knowledge Questions		
	Answer	Number of the subjects
Lipedema is a chronic disorder predominantly impacting the lower extremities and female patients	True	147(97.4%)
	False	2(1.3%)
	Don't know	2(1.3%)
Clinical features include pain, symmetrical extremity swelling including hands and feet, and easy bruising in lipedema	True	74(49.0%)
	False	65(43.0%)
	Don't know	12(7.9%)
Lipedema can rarely occur in men	True	125(82.8%)
	False	4(2.6%)
	Don't know	22(14.6%)
Lipedema makes patients fat	True	73(48.3%)
	False	63(41.7%)
	Don't know	15(9.9%)
Lipedema is classified into five types based on fat distribution and five stages morphologically	True	47(31.1%)
	False	14(9.3%)
	Don't know	90(59.6%)
Lipedema is characterized by pain and/or hypersensitivity triggered by light touch and palpation. Most patients with lipedema have lower extremity involvement.	True	125(82.8%)
	False	8(5.3%)
	Don't know	18(11.9%)
One of key diagnostic feature a positive Stemmer sign.	True	27 (17.9%)
	False	78 (51.7%)
	Don't know	46 (30.5 %)
In differential diagnosis of lipedema obesity, lymphedema, and lipodystrophy should be kept in the mind	True	145(96.0%)
	False	0(0%)
	Don't know	6(4.0%)
In lipedema, US often shows an increase in subcutaneous fat tissue thickness and edema in the extremities	True	132(87.4%)
	False	6(4.0%)
	Don't know	13(8.6%)
The etiopathogenesis of lipedema has not been fully explained, but genetic and endocrinological factors are emphasized	True	140(92.7%)
	False	0(0%)
	Don't know	11(7.3%)
Weight loss in lipedema patients can lead to symptom improvement and even remission	True	110(72.8%)
	False	16(10.6%)
	Don't know	25(16.6%)
Conservative treatment methods for lipedema include physiotherapy, movement therapy, compression therapy, weight control, and psychosocial therapy	True	141(93.4%)
	False	3(2.0%)
	Don't know	7(4.6%)
Compression therapy is particularly notable for both reducing pain and reduce fatty tissue volume(if the patient gains weight)	True	62(41.1%)
	False	39(25.8%)
	Don't know	50(33.1%)
Liposuction is a surgical treatment method used for lipedema	True	73(48.3%)
	False	30(19.9%)
	Don't know	48(31.8%)
Accuracy of the correct answer is marked bold		

Effect of Participants' Age on Lipedema Knowledge and Awareness

Participants were divided based on age: less than 40 years (n=91) and equal or more than 40 years (n=60). Group 1 had a significantly higher proportion of participants under the age of 40 compared to Group 2 (p<0.05) (Table 2, Figure 1).



Figure 1. Impact of experience and age on awareness

DISCUSSION

This study assessed health professionals' knowledge and awareness using a knowledge score. About 45.7% of PMR physicians had sufficient knowledge of lipedema, while 54.3% had insufficient knowledge. Factors such as gender, marital status, job title, average daily patient evaluations, and recent training did not significantly influence awareness. Interestingly, younger participants showed higher levels of lipedema awareness.

Despite increased recognition, lipedema still faces misdiagnosis or oversight by society and healthcare professionals (30). A UK survey found only 9% of patients were diagnosed initially, with 37% diagnosed by medical doctors and the rest by other healthcare professionals (31). Studies report lipedema prevalence from 7% to 9.7% (31-35). No prevalence studies are available in our country. In our study, 45.7% of PMR physicians had sufficient knowledge, 54.3% had insufficient knowledge.

Lipedema is primarily diagnosed based on clinical findings. Physicians' experience and patient history are key factors in identifying potential lipedema cases. A positive family history, the correlation between hormonal changes and symptoms are important considerations in the differential diagnosis (10,11,13). In our study, the correct response rates for questions on lipedema's definition, clinical features, the rare gender affected, and whether it causes weight gain were 97.4 %, 43 %, 82.8 % and 41.7 %, respectively.

Lipedema typically manifests as bilateral, symmetrical swelling, pain, and bruising in the lower and upper extremities, excluding the hands and feet — a characteristic feature indicative of the condition (1,2,10,11). It is important to note that lipedema does not result in obesity (29). While 97.4% of PMR physicians understood the definition of lipedema, their knowledge of its clinical findings was lacking. Romejin et al. found the average time from initial lipedema symptoms to diagnosis to be 18.3 years (13). Bauer et al. reported a similar period of 15 years (36). This lengthy duration before diagnosis can lead to disease progression and functional losses. In our study, 56.9% of physicians identified symmetrical swelling, including the hands and feet, suggesting they may have mistakenly

considered lymphedema as lipedema in their differential diagnosis. Lymphedema typically presents as asymmetrical swelling, may involve the hands and feet, and usually lacks pain (37,38).

The high percentage (58.3%) of physicians who believe lipedema causes obesity indicates confusion in differentiating from obesity. In contrast, obesity generally does not cause pain, with adipose tissue distribution being widespread (37).

Lipedema is classified into three stages based on progression and five types based on anatomical location (11,25). Stemmer's sign is negative in lipedema but positive in lymphedema. Pain in lipedema can be triggered by touch and pressure, with hypersensitivity. The condition commonly affects the lower extremities (11,25). The correct response rates of PMR physicians were 9.3% for classification, 82.8% for pain characteristics, and 51.7 % for the Stemmer sign, indicating a low level of knowledge regarding the physical examination findings especially in classification .

The correct response rates of PMR physicians were 96.0% for differential diagnosis, 4% for imaging findings, and 92.7% for pathogenesis. Despite lipedema's unclear etiopathogenesis, differential diagnosis should include lymphedema and obesity (7,10). The knowledge level among physicians regarding diseases to be considered in the differential diagnosis was sufficient. Studies showed a high prevalence of obesity among lipedema patients, with Dudek et al. reporting 81.3% and Romejin et al. 61.9% (12,13,39). Obesity can exacerbate lipedema symptoms (29).

Notably, PMR physicians correctly identified US imaging findings in lipedema, in a very small proportion . While an increase in extracellular fluid in lipedema compared to control groups has been documented, US imaging typically does not reveal a visible increase in fluid in lipedema tissue. Instead, an increase in fat tissue is commonly detected through US (17,19,40). Histological examination of lipedema patients shows a localized increase in adipose tissue without edema (29). In contrast, lymphedema typically presents with edema and fibrosis in the subcutaneous tissue (19,41). When accompanied by pitting edema, it is referred to as lipo-lymphedema (18,41). Physicians may face challenges in differentiating between lymphedema and lipedema based on imaging, raising concerns about potential misdiagnosis.

Weight management is crucial in lipedema due to its association with obesity (13,39). Weight loss in lipedema patients can lead to symptom improvement and even remission (29). PMR physicians demonstrated a high correct response rate of 72.8% regarding the effect of weight control on lipedema.

Conservative treatments for lipedema include physiotherapy, movement therapy, compression therapy, weight control, and psychosocial therapy (29). While compression therapy effectively reduces pain, it does not reduce fat tissue volume if the patient gains weight (29). Despite 93.4% of PMR physicians correctly identifying conservative treatments, only 25.8% correctly understood the effects of compression therapy. Many (74.2%) either incorrectly believed that it reduces fat tissue or lacked information about its effects.

Liposuction is a surgical method in lipedema, alleviating pain and improving functionality (29,41,42). Physicians referring patients should

have qualifications in lymphology or phlebology, and surgeons should meet defined quality standards (29). 48.3% of PMR physicians answered this question correctly.

Our study showed that younger PMR physicians had higher awareness about lipedema. Awareness of lipedema has increased significantly in the past decade (26). Older PMR physicians may lack comprehensive lipedema education from medical school, probably affecting their knowledge levels.

Our study has limitations, the relatively small number of participants and the lack of a reliability assessment. Although we designed our study in accordance with current guidelines on lipedema, future research may include larger participant samples and validation surveys to further assess lipedema awareness.

In conclusion, it is imperative to enhance lipedema awareness among PMR physicians. Younger PMR physicians appear to have higher levels of awareness. Increased awareness can facilitate early diagnosis and treatment, preventing disease progression and improving the quality of life for lipedema patients.

Ethics Committee Approval: Ethical approval for the study was obtained from the Hamidiye University of Health Sciences Scientific Research Ethics Committee (approval number: 24/283).

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Conflict of Interest: None

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Informed Consent: Participants voluntarily completed the survey and provided their consent online. Before answering the survey, participants were informed about the study and asked if they would like to volunteer. Participants those who declined were unable to continue.

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