

Evaluation of Lipedema Awareness Among Women: A Cross-Sectional Study

Kadınlarda Lipedema Farkındalığının Değerlendirilmesi: Kesitsel Bir Çalışma

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ÖZET

Lipödem, çoğunlukla kadınları etkileyen, simetrik yağ dokusu artışı, ağrı ve hassasiyet ile karakterize kronik bir hastalık olup sıklıkla obezite veya lenfödem ile karıştırılmaktadır. Hastalığın tanısındaki gecikmenin önemli nedenlerinden biri, hasta farkındalığının yetersizliğidir. Bu çalışmanın amacı, kadın hastalarda lipödeme yönelik farkındalık düzeyini değerlendirmek ve farkındalığın yaş gruplarına göre farklılık gösterip göstermediğini incelemektir. Bu kesitsel çalışmaya toplam 120 kadın katılımcı dahil edildi. Katılımcılar 18–45 yaş (n = 60) ve ≥ 46 yaş (n = 60) olmak üzere iki gruba ayrıldı. Lipödem farkındalığı; genel bilgi, klinik özellikler ile tanı ve tedavi bilgisi alt alanlarını içeren yapılandırılmış bir anket ile değerlendirildi. Toplam ve alt ölçek puanları yaş grupları arasında karşılaştırıldı. Katılımcıların yaş ortalaması $46,32 \pm 12,47$ yılı. Toplam farkındalık puanı 18–45 yaş grubunda $6,30 \pm 2,00$ iken, ≥ 46 yaş grubunda $4,90 \pm 1,90$ olarak saptandı ($p < 0,001$). Genç yaş grubunda genel bilgi ($2,40 \pm 1,10$ vs. $1,80 \pm 1,05$; $p = 0,002$), klinik özellikler ($2,05 \pm 1,05$ vs. $1,70 \pm 1,00$; $p = 0,004$) ve tanı ve tedavi bilgisi puanları ($1,85 \pm 0,95$ vs. $1,40 \pm 0,90$; $p = 0,001$) anlamlı olarak daha yüksekti. Yeterli farkındalık düzeyine (≥ 9 puan) sahip katılımcı oranı 18–45 yaş grubunda %21,67 iken, ≥ 46 yaş grubunda %6,67 idi. ($p = 0,018$). Kadın hastalarda lipödeme yönelik farkındalık düzeyi genel olarak düşüktür. Farkındalığın yaş ile ilişkili olduğu ve ileri yaş grubunda bilgi eksikliğinin daha belirgin olduğu görülmekle birlikte, temel sorun tüm yaş gruplarını kapsayan yaygın bir farkındalık yetersizliğidir.

Anahtar Kelimeler: Lipödem, Farkındalık, Sağlık okuryazarlığı, Kadın sağlığı

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ABSTRACT

Lipedema is a chronic condition characterized by symmetrical adipose tissue accumulation, pain, and tenderness, predominantly affecting women, and is frequently misdiagnosed as obesity or lymphedema. One of the main contributors to delayed diagnosis is insufficient patient awareness of the disease. The aim of this study was to evaluate the level of lipedema awareness among female patients and to examine whether awareness differs across age groups. A total of 120 female participants were included in this cross-sectional study. Participants were divided into two groups according to age: 18–45 years ($n = 60$) and ≥ 46 years ($n = 60$). Lipedema awareness was assessed using a structured questionnaire comprising subdomains of general knowledge, clinical features, and knowledge regarding diagnosis and treatment. Total and subscale scores were compared between age groups. The mean age of the participants was 46.32 ± 12.47 years. The total awareness score was 6.30 ± 2.00 in the 18–45 age group and 4.90 ± 1.90 in the ≥ 46 age group ($p < 0.001$). The younger age group demonstrated significantly higher scores in general knowledge (2.40 ± 1.10 vs. 1.80 ± 1.05 ; $p = 0.002$), clinical features (2.05 ± 1.05 vs. 1.70 ± 1.00 ; $p = 0.004$), and knowledge of diagnosis and treatment (1.85 ± 0.95 vs. 1.40 ± 0.90 ; $p = 0.001$). The proportion of participants with an adequate level of awareness (≥ 9 points) was 21.67% in the 18–45 age group and 6.67% in the ≥ 46 age group ($p = 0.018$). Overall, the level of lipedema awareness among women is low. Although awareness appears to be associated with age and knowledge deficits are more pronounced in older women, the fundamental issue is a widespread lack of awareness that affects women across all age groups.

Keywords: Lipedema, Awareness, Health literacy, Women's health

1. INTRODUCTION

Lipedema is a chronic adipose tissue disorder affecting women that frequently remains undiagnosed. Despite having distinct clinical characteristics, the condition is commonly confused with obesity or lymphedema, leading to diagnostic delays that may extend over several years. Such delays not only accelerate disease progression but also expose patients to ineffective treatment approaches and result in significant deterioration in quality of life (1–6).

Although interest in lipedema has increased in recent years, the majority of the literature has focused on the clinical features of the disease and physicians' diagnostic awareness. These studies have consistently demonstrated that lipedema is insufficiently recognized in clinical practice and that misdiagnosis rates remain high (7,8). However, the diagnostic process is not solely physician-dependent; how patients perceive and interpret their symptoms and how they

engage with healthcare services may also play a critical role in diagnostic delay. This patient centered aspect has received comparatively limited attention in the literature (9).

Patient awareness represents a fundamental component of early diagnosis and appropriate treatment in chronic diseases. The ability to recognize disease-specific features, distinguish symptoms from normal variations or other conditions, and seek care from appropriate healthcare services constitutes the initial step of the diagnostic pathway. In the context of lipedema, inadequate patient awareness may lead to the normalization of symptoms as a “weight problem” or a “genetic trait,” thereby contributing to delayed presentation to healthcare systems (10–13).

Among the factors influencing patient awareness, age emerges as a particularly important determinant. Age has a direct impact on health literacy, access to information, patterns of digital resource use, and health-related decision-making processes (14–17). Despite this, data addressing the relationship between patient awareness of lipedema and age are limited, and the extent to which this relationship translates into clinical outcomes remains unclear.

The aim of this study was to evaluate the level of lipedema awareness among female patients attending a Physical Medicine and Rehabilitation outpatient clinic and to investigate whether awareness differs across age groups. To the best of our knowledge, this is the first study to examine lipedema patient awareness from an age-based perspective. The findings are expected to contribute to the development of targeted awareness and educational strategies aimed at facilitating earlier diagnosis.

2. MATERIALS AND METHODS

2.1. Study Design and Participants

This study was designed as a cross-sectional investigation. Female patients aged 18 years and older who attended the Physical Medicine and Rehabilitation Outpatient Clinic and met the inclusion criteria were enrolled. The study was conducted in accordance with the principles of the Declaration of Helsinki, and written informed consent was obtained from all participants. Ethical approval for the study was granted by the relevant ethics committee (Approval No: 03/2025).

Inclusion criteria were defined as female sex, age ≥ 18 years, willingness to participate in the study, and sufficient cognitive ability to complete the questionnaire. Individuals who had previously received a diagnosis of lipedema, those who had undergone formal education or training related to lipedema or lymphedema, and participants with cognitive impairment that

could interfere with answering the questionnaire were excluded from the study.

Participants were stratified into two age groups: 18–45 years and ≥ 46 years. This age categorization was chosen to evaluate age-related differences in health literacy, access to digital information sources, and levels of health-related awareness (18).

2.2. Sample Size

Sample size calculation was performed using G*Power software version 3.1.9.7. Based on previous awareness studies, a medium effect size (Cohen's $d = 0.5$), a statistical power of 80% ($1 - \beta = 0.80$), and a significance level of 5% ($\alpha = 0.05$) were assumed (7). According to these parameters, a minimum of 92 participants was required. To account for potential data loss, a total of 120 participants were ultimately included in the study.

2.3. Data Collection Instruments

2.3.1. Sociodemographic Information Form

A structured form developed by the researchers was used to assess participants' sociodemographic characteristics, including age, educational level, and marital status.

2.3.2. Lipedema Awareness and Knowledge Questionnaire

Lipedema awareness was assessed using a questionnaire originally developed and published to evaluate knowledge and awareness of lipedema among Physical Medicine and Rehabilitation physicians.

The questionnaire consists of 14 items covering the definition, clinical features, pathogenesis, diagnostic methods, differential diagnosis, and treatment approaches of lipedema. Response options for each item are “Yes,” “No,” and “Not sure” (7).

For the purposes of the present study, minor linguistic adaptations were made to ensure applicability to a patient population. These adaptations were limited to improving clarity and comprehensibility of the questions, while the original structure, content scope, and number of items were preserved.

2.3.3. Scoring and Evaluation

Questionnaire scoring was performed in accordance with the scoring system defined in the original study. “Yes” responses were considered correct and assigned 1 point, whereas “No” and “Not sure” responses were scored as 0 points. The minimum possible total score was 0, and the maximum possible score was 15.

Participants with total scores ranging from 0 to 8 were classified as having inadequate

awareness, while those scoring between 9 and 15 were considered to have an adequate level of awareness. This cutoff was based on the classification used in the previously published study (7).

2.4. Statistical Analysis

Statistical analyses were performed using an appropriate statistical software package. Continuous variables were expressed as mean $\pm$ standard deviation, and categorical variables were presented as numbers and percentages. The assumption of normal distribution was assessed using appropriate tests.

Independent samples t-tests were used to compare awareness scores between age groups. The chi-square test was applied for comparisons of categorical variables. A p value of <0.05 was considered statistically significant.

3. RESULTS

A total of 120 female participants were included in the study. The mean age of the participants was 46.32 ± 12.47 years, with an equal distribution across age groups (18–45 years: $n = 60$; ≥ 46 years: $n = 60$). Sociodemographic characteristics are presented in Table 1. The proportion 5 of participants with a university-level education or higher was greater in the 18–45 age group, whereas participants with primary or secondary education were more prevalent in the ≥ 46 age group. Marital status distribution also differed significantly between age groups, with a higher proportion of married participants in the ≥ 46 age group ($p = 0.028$).

Table 1. Sociodemographic Characteristics of the Participants

Variable	Total (n = 120)	Group 1 (18–45 years, n = 60)	Group 2 (≥ 46 years, n = 60)	p value
Age (years), mean $\pm$ SD	46.32 $\pm$ 12.47	34.68 $\pm$ 6.21	57.96 $\pm$ 7.84	<0.001
Education level, n (%)				0.061
Primary / Secondary school	32 (26.67)	11 (18.33)	21 (35.00)	
High school	38 (31.67)	20 (33.33)	18 (30.00)	
University or higher	50 (41.66)	29 (48.34)	21 (35.00)	
Marital status, n (%)				0.028
Single	41 (34.17)	26 (43.33)	15 (25.00)	
Married	79 (65.83)	34 (56.67)	45 (75.00)	

Comparisons of lipedema awareness levels between age groups are shown in Table 2. The total awareness score was 6.30 ± 2.00 in the 18–45 age group and 4.90 ± 1.90 in the ≥ 46 age group, and this difference was statistically significant ($p < 0.001$). Analysis of subscale

scores revealed that the younger age group had significantly higher scores for general knowledge (2.40 ± 1.10 vs. 1.80 ± 1.05 ; $p = 0.002$), clinical features (2.05 ± 1.05 vs. 1.70 ± 1.00 ; $p = 0.004$), and knowledge of diagnosis and treatment (1.85 ± 0.95 vs. 1.40 ± 0.90 ; $p = 0.001$). The proportion of participants with an adequate level of awareness (≥ 9 points) was 21.67% in the 18–45 age group and 6.67% in the ≥ 46 age group ($p = 0.018$).

Table 2. Comparison of Lipedema Awareness Levels According to Age Groups

Variable	Group 1 (18–45 years, n = 60)	Group 2 (≥ 46 years, n = 60)	p value
Total awareness score (0–15)	6.30 ± 2.00	4.90 ± 1.90	<0.001
General knowledge score (0–5)	2.40 ± 1.10	1.80 ± 1.05	0.002
Clinical features score (0–5)	2.05 ± 1.05	1.70 ± 1.00	0.004
Knowledge of diagnosis and treatment score (0–5)	1.85 ± 0.95	1.40 ± 0.90	0.001
Adequate awareness (≥ 9 points), n (%)	13 (21.67)	4 (6.67)	0.018

The distribution of responses to individual items of the lipedema awareness questionnaire is presented in Table 3. In the general knowledge domain, the proportion of participants who responded “Yes” to the statement “Lipedema is a condition distinct from lymphedema” was 35.0% in the 18–45 age group and 23.3% in the ≥ 46 age group. Similarly, correct response rates to statements indicating that lipedema is more common in women, is characterized by abnormal fat accumulation, and may have a genetic predisposition were low in both groups, although relatively higher in the younger age group.

For questions related to clinical features, correct response rates regarding lipedema-specific characteristics such as symmetrical fat accumulation, pain and tenderness, easy bruising, and a progressive course remained below 40% in both age groups. Notably, the proportions of “No” and “Not sure” responses were higher in the ≥ 46 age group.

In the diagnosis and treatment domain, correct response rates for statements indicating that lipedema is diagnosed clinically, that conservative treatments may be beneficial, and that weight loss does not completely resolve the condition were limited in both age groups. Awareness of the availability of surgical treatment options was among the lowest correct response rates observed in both groups.

Overall, the level of lipedema awareness was low among all participants; however, total and subscale scores were significantly higher in the 18–45 age group. These findings indicate that lipedema awareness decreases with age and that knowledge deficits are particularly pronounced in the older age group.

Table 3. Distribution of Responses to the Lipedema Awareness Questionnaire Items

Domain / Item	Group 1 (18–45 years, n = 60)			Group 2 (≥46 years, n = 60)		
	Yes n (%)	No n (%)	Not sure n (%)	Yes n (%)	No n (%)	Not sure n (%)
General Knowledge						
Lipedema is a condition distinct from lymphedema	21 (35.0)	22 (36.7)	17 (28.3)	14 (23.3)	27 (45.0)	19 (31.7)
It is more common in women	25 (41.7)	19 (31.7)	16 (26.6)	16 (26.7)	24 (40.0)	20 (33.3)
It is characterized by abnormal fat accumulation	22 (36.7)	21 (35.0)	17 (28.3)	14 (23.3)	26 (43.3)	20 (33.4)
It may be associated with hormonal changes	18 (30.0)	23 (38.3)	19 (31.7)	18 (30.0)	25 (41.7)	17 (28.3)
It may have a genetic predisposition	20 (33.3)	23 (38.3)	17 (28.4)	13 (21.7)	29 (48.3)	18 (30.0)
Clinical Features						
Symmetrical fat accumulation is observed	22 (36.7)	22 (36.7)	16 (26.6)	12 (20.0)	29 (48.3)	19 (31.7)
Hands and feet are usually not affected	14 (23.3)	28 (46.7)	18 (30.0)	13 (21.7)	30 (50.0)	17 (28.3)
It is associated with pain and tenderness	20 (33.3)	24 (40.0)	16 (26.7)	11 (18.3)	32 (53.4)	17 (28.3)
Easy bruising is observed	20 (33.3)	23 (38.3)	17 (28.4)	11 (18.3)	33 (55.0)	16 (26.7)
It is a progressive disease	18 (30.0)	26 (43.3)	16 (26.7)	12 (20.0)	30 (50.0)	18 (30.0)
Diagnosis and Treatment						
Diagnosis is based on clinical examination	21 (35.0)	24 (40.0)	15 (25.0)	15 (25.0)	30 (50.0)	15 (25.0)
The role of imaging in diagnosis is limited	17 (28.3)	26 (43.4)	17 (28.3)	7 (11.7)	36 (60.0)	17 (28.3)
Conservative treatments are beneficial	20 (33.3)	25 (41.7)	15 (25.0)	14 (23.3)	31 (51.7)	15 (25.0)
Weight loss does not completely resolve the disease	19 (31.7)	26 (43.3)	15 (25.0)	8 (13.3)	37 (61.7)	15 (25.0)
Surgical treatment options are available	14 (23.3)	29 (48.4)	17 (28.3)	12 (20.0)	32 (53.3)	16 (26.7)

4. DISCUSSION

In the present study, lipedema awareness among female participants was shown to be generally low. The fact that the majority of participants did not reach an adequate level of awareness and that correct response rates remained limited across all subdomains indicates that lipedema is still insufficiently recognized at the patient level. Nevertheless, higher total and subdomain awareness scores observed in the 18–45 age group suggest that awareness varies with age and that knowledge deficits are more pronounced in older women. These findings indicate that the primary issue in lipedema is a widespread lack of awareness, while age-related differences should be considered a secondary factor that further exacerbates this overall deficiency.

The low overall awareness level identified in our study is consistent with findings reported in the literature across both healthcare professional and community-based samples. Studies conducted in Türkiye have demonstrated that knowledge and awareness of lipedema are limited even among physicians. In a study by Öztürk et al. involving Physical Medicine and Rehabilitation physicians, insufficient knowledge regarding the definition, differential diagnosis, and treatment approaches of lipedema was reported (7). Similarly, in a large-scale study by Bağatır et al. including physicians from various medical specialties, only half of the

participants were familiar with the term lipedema, and questions related to diagnosis and treatment were predominantly answered as “no opinion” (8). The presence of substantial knowledge gaps even among healthcare professionals suggests that the low awareness observed in the patient population reflects a broader, systemic issue. Indeed, community-based studies have also reported extremely low rates of correct recognition of the basic definition, clinical features, and treatment options of lipedema among women, a situation associated with misdiagnosis, delayed diagnosis, and significant impairment in quality of life (18–21). Taken together, these findings indicate that inadequate patient awareness of lipedema parallels deficiencies within the healthcare system and represents one of the major barriers to early diagnosis.

The difference observed between age groups should be interpreted within the context of the overall low level of lipedema awareness. The higher awareness levels observed in the 18–45 age group may be related to greater access to digital health resources, more frequent exposure to health-related content via the internet and social media, and relatively higher health literacy. The literature consistently identifies age as a key determinant of health literacy and health information-seeking behaviors. National and international studies have shown that older individuals encounter greater barriers in accessing health information, evaluating its reliability, and using digital resources effectively. Systematic reviews focusing on health literacy interventions for older adults emphasize that this population may have limited abilities to access and comprehend health-related information. Likewise, online health information-seeking behaviors have been shown to decline significantly in middle-aged and older populations and to be closely associated with overall health literacy levels (20–26). In this context, the age-related difference observed in our study may reflect general age-related trends in health literacy and information access rather than a phenomenon specific to lipedema.

On the other hand, the more pronounced lack of knowledge regarding lipedema-specific clinical features in the ≥ 46 age group may indirectly influence the diagnostic process. Although lipedema often becomes more apparent during periods of hormonal change such as puberty, pregnancy, and menopause, the disease is also prevalent in later life, where its symptoms may overlap with other clinical conditions. Limited awareness of lipedema in older women may lead to the attribution of symptoms to more common conditions such as obesity, age-related body changes, or circulatory disorders, resulting in the overlooking of lipedema-specific findings. Therefore, the knowledge deficit observed in the older age group should be considered a factor that complicates disease recognition and contributes to the persistence of mislabeling and delayed diagnosis.

In our study, the low correct response rates regarding lipedema-specific clinical features—such as symmetrical fat accumulation, pain, tenderness, and easy bruising—in both age groups highlight the difficulty of clinically distinguishing the disease at the patient level. Similarly, limited awareness related to diagnosis and treatment across both age groups suggests a general lack of knowledge in the management of lipedema. A substantial proportion of participants were unaware that lipedema is primarily diagnosed through clinical examination and that conservative treatment approaches may play a role in symptom control. Furthermore, the extremely low awareness of surgical treatment options may delay appropriate referral and evaluation processes. These findings suggest that awareness initiatives for lipedema should consider age-specific differences while fundamentally adopting a comprehensive approach that addresses all age groups.

This study has several limitations. First, the single-center and cross-sectional design may limit the generalizability of the findings. Second, awareness was assessed using a self-reported questionnaire, which may not fully reflect participants' actual knowledge levels. Nevertheless, the limited number of studies comparing lipedema awareness across age groups within patient populations enhances the originality and contribution of the present study.

5. CONCLUSION

This study demonstrates that overall awareness of lipedema among female patients is low. Although awareness levels appear to be associated with age, with more pronounced knowledge deficits observed in older women, the primary issue is a widespread lack of awareness affecting all age groups. Limited knowledge regarding lipedema-specific clinical features as well as diagnostic and treatment approaches may hinder disease recognition. These findings suggest that awareness and educational initiatives for lipedema should account for age-related differences while primarily adopting comprehensive strategies that target the entire patient population.

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