

**Original Article** 

# Is kinesiophobia associated with lymphedema, upper extremity function, and psychological morbidity in breast cancer survivors?

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#### ABSTRACT

**Objectives:** This study aims to the effects of kinesiophobia on lymphedema, upper extremity function, depression/anxiety, and quality of life in breast cancer survivors.

**Patients and methods:** Between January 2015 and January 2016, a total of 81 breast cancer survivors (mean age 54.1±10.8 years; range 44 to 70 years) were included. Lymphedema was evaluated based on the circumference measurements. The Tampa Scale for Kinesiophobia (TSK), the Quick Disabilities of Arm, Shoulder, and Hand (Q-DASH) Questionnaire, the Hospital Anxiety and Depression Scale (HADS), and the Short Form-36 (SF-36) were applied to all patients.

**Results:** We found a significantly higher rate of lymphedema in the patients with kinesiophobia. Kinesiophobic patients had also significantly higher mean scores of TSK, Q-DASH, HADS-A, and HADS-D and lower mean scores of the SF-36 physical scores. Correlation analysis demonstrated that presence of lymphedema, Q-DASH, HADS-A, and HADS-D scores were significantly associated with the TSK scores.

**Conclusion:** Kinesiophobia increases the risk for lymphedema, depression/anxiety, and decreased upper extremity functioning in breast cancer survivors. Identifying kinesiophobia in breast cancer survivors, psychosocial providers may help to prevent undesirable effects of kinesiophobia.

Keywords: Breast cancer; kinesiophobia; lymphedema; upper extremity functioning.

Breast cancer is the most common type of cancer in women worldwide, representing 25% of all cancer.<sup>[1]</sup> A significant number of breast cancer survivors develops complications due to axillary lymph node dissection, chemotherapy or radiotherapy.<sup>[2]</sup>

Breast cancer-related side effects occur in up to 80% of patients and may persist after the end of the treatment. Upper extremity morbidity is one of the major side effects which adversely affects daily activities, psychosocial function, and quality of life (QoL).<sup>[3]</sup> Arm/shoulder pain, numbness, restricted arm/shoulder mobility, and lymphedema are common upper extremity morbidities in breast cancer survivors. During five-year follow-up, the prevalence of arm/shoulder pain is about 30 to 40%, numbness is about 30 to 80%, restricted arm/shoulder mobility is about 15 to 30%, and lymphedema is about 10 to 40%.<sup>[3,4]</sup>

Breast cancer survivors may develop avoidance of physical activity and fear of movement which is called kinesiophobia due to upper extremity pain, numbness, restricted arm/shoulder range of motion, and risk of lymphedema.<sup>[5]</sup> Kinesiophobia is defined as an excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability due to painful injury or reinjury.<sup>[6]</sup> According to the fair avoidance model, fair of pain directly causes avoidance behavior and consequently increases the risk for decreased activity, functional decline and anxiety.<sup>[7]</sup> Kinesiophobic patients often avoid activities related to pain/re-injury and have impairments in daily living activities. It has been

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shown that kinesiophobia plays a significant role in evaluating functioning and QoL in patients with chronic pain.<sup>[8-10]</sup> To the best of our knowledge, there is only one study in the literature to evaluate the effects of kinesiophobia on education and severity of upper extremity lymphedema in patients with breast cancerrelated lymphedema; however, in the aforementioned study, the authors did not attempt to examine the relationship between kinesiophobia and presence of lymphedema, functioning, QoL, and psychological morbidity.<sup>[11]</sup>

In the present study, we aimed to investigate the effects of kinesiophobia on lymphedema, upper extremity function, depression, anxiety, and QoL in breast cancer survivors.

# PATIENTS AND METHODS

Between January 2015 and January 2016, a total of 81 breast cancer survivors (mean age 54.1±10.8 years; range 44 to 70 years) who were admitted to the lymphedema outpatient clinic were included in this study. All patients had cancer-related surgery at least six months ago. Patients with bilateral breast cancer were excluded from the study. A written informed consent was obtained from each patient. The study protocol was approved by the local Ethics Committee. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Demographic and clinical characteristics of the patients were recorded. Lymphedema of the arm was evaluated by bilateral circumference measurements. Measurements were taken at four levels: metacarpal, wrist, 10-cm below the lateral epicondyle and 10-cm above the lateral epicondyle with a standard retractable fiberglass tape in sitting position with shoulder 90° shoulder flexion, elbow extension, and forearm pronation. Measurements were taken by a single clinician and recorded in cm unit. A difference of  $\geq 2$  cm at any single location in the affected arm confirmed the diagnosis of lymphedema.

The Tampa Scale for Kinesiophobia (TSK) was used to assess fear of movement/kinesiophobia. It was developed in 1991 by Miller et al.<sup>[12]</sup> It consists of 17 items. Each item is scored on a 4-point Likert-type scale, ranging from "strongly disagree" to "strongly agree". Items 4, 8, 12, and 16 are reversely scored. Total score ranges between 17 and 68. Vlaeyen et al.<sup>[8]</sup> developed a cut-off score and reported patients that scored greater than 37 were high-responders. Similarly, we used this cut-off score to identify the patients with kinesiophobia. The validity and reliability of the Turkish version of the TSK have been previously performed by Tunca-Yilmaz et al.<sup>[13]</sup>

The upper extremity functions of patients with breast cancer were evaluated using the Quick Disabilities of Arm, Shoulder, and Hand (Q-DASH) Questionnaire. This tool has 11 items and each item is scored from 1 to 5. Higher scores indicate lower functional level. The validity and reliability of the Turkish version of the Q-DASH have been carried out by Düger et al.<sup>[14]</sup>

We used the Hospital Anxiety and Depression Scale (HADS) to evaluate anxiety and depression of the patients with breast cancer.<sup>[15]</sup> It consists of 14 items with anxiety and depression subscales. Each item is scored between 0 and 3. Each subscale is scored between 0 and 21. Higher scores indicate greater levels of anxiety and depression. The cut-off score for HADS was defined by a score of  $\geq 8$ . Aydemir et al.<sup>[16]</sup> performed the validity and reliability of the Turkish version of the scale.

The QoL in patients with breast cancer was measured using the Short Form-36 (SF-36). It is a 36-item questionnaire with eight domains measuring physical and mental components (PCS and MCS, respectively). Each item is scored and summed according to a standardized scoring protocol. Each domain is scored between 0 and 100. Higher scores indicate better health status. The validity and reliability of the Turkish version of the SF-36 in cancer patients have been carried out by Pinar.<sup>[17]</sup>

## Statistical analysis

Statistical analysis was performed using the PASW version 17.0 software (SPSS Inc., Chicago, IL, USA). Descriptive data were expressed in %, mean±SD or median (min-max). The Kolmogorov-Smirnov test was used to evaluate the distribution of normality. The unpaired t-test for normally distributed data and the Mann-Whitney U test for non-normally distributed data to compare the demographic and clinical characteristics between the groups were conducted. The Pearson's chi-square test was used to analyze categorical data. The Spearman's rank correlation coefficients were used to evaluate the relationship between the TSK scores and education duration, comorbidity, time since surgery, dominant extremity involvement, presence of lymphedema, stage and severity of lymphedema, upper extremity functioning, depression, anxiety, and QoL. The Spearman's rank correlation coefficients were accepted as follows: 0.81-1.0 as excellent, 0.61-0.80 very good, 0.41-0.60 good, 0.21-0.40 fair, and 0-0.20 poor.<sup>[18]</sup> A p value of less than 0.05 was considered statistically significant.

# RESULTS

The demographic and clinical characteristics of all patients with breast cancer are shown in Table 1. Of all patients, 25 (30.8%) had kinesiophobia. There was no significant difference between patients with kinesiophobia and patients without kinesiophobia in terms of demographic and clinical characteristics (p>0.05) (Table 2).

We found upper extremity lymphedema in 49.4% of patients with breast cancer. The mean TSK scores were significantly higher in the patients with lymphedema than those without lymphedema ( $36.9\pm10.4$  vs.  $31.2\pm8.8$ , respectively) (p=0.02). While 47.5% of the patients with lymphedema had

Table 1. Demographic an	d clinical c	haracteristics of breast	cancer survivors (n=81)
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01	%	Mean±SD	Median	Min-Max
Age (year)	,,,	54.1±10.8		
Education duration (year)		6.4±3.9		
Marital status				
Married	74.1			
Single	25.9			
Occupation				
Housewife	76.5			
Worker	16			
Retired	7.4			
Breast cancer type				
Infiltrative ductal carcinoma	90.1			
Infiltrative lobular carcinoma	6.2			
Tubular carcinoma	2.5			
Medullary carcinoma	1.2			
Breast cancer stage				
Stage 1	24.7			
Stage 2	48.1			
Stage 3	27.2			
Type of operation				
MRM+ALND	98.8			
MRM+SLNB	1.2			
Lymph nodes removed (n)		20.2±9.1		
Positive lymph nodes (n)			1.0	0-33
Adjuvant therapy				
Radiotherapy	64.2			
Chemotherapy	82.7			
Endocrine therapy	71.6			
Time from surgery (month)			22	3-170
Presence of lymphedema	49.4			
Stage of lymphedema Stage 1	10			
Stage 2	90			
	20			
Severity of lymphedema	25			
Mild Moderate	25 52 5			
Severe	52.5 22.5			
	22.3			
Comorbidity				
No medical problem	50.6			
One or more medical problems	49.4			

SD: Standard deviation; Min: Minimum; Max: Maximum; MRM: Modified radical mastectomy; ALND: Axillary lymph node dissection; SLNB: Sentinel lymph node biopsy.

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	%	Mean±SD	Median	Min-Max	%	Mean±SD	Median	Min-Max	t, Z, $\chi^2$	p
Age (year)		52.2±8.8				54.8±11.5			t=-1.00	0.27
Education duration (year)		$6.9 \pm 3.4$				6.2±4.1			t=0.74	0.56
Marital status									$\chi^2 = 0.31$	0.57
Married	68				76.8					
Single	32				23.2					
Occupation									$\chi^2 = 3.08$	0.21
Housewife	80				75					
Worker	20				14.3					
Retired	0				10.7					
Breast cancer type									χ <sup>2</sup> =2.92	0.40
Infiltrative ductal carcinoma	84				92.9				~	
Infiltrative lobular carcinoma	12				3.6					
Tubular carcinoma	4				1.8					
Medullary carcinoma	0				1.8					
Breast cancer stage									$\chi^2 = 5.21$	0.07
Stage 1	20				26.8					
Stage 2	36				33.6					
Stage 3	44				39.6					
Type of operation									$\chi^2 = 3.42$	0.18
MRM+ALND	100				87.5					
MRM+SLNB	0				12.5					
Lymph nodes removed (n)			23	12-40			21.5	6-42	Z=-0.57	0.23
Positive lymph nodes (n)			1	0-33			1	0-22	Z=-1.11	0.12
Adjuvant therapy										
Radiotherapy	72				66.7				$\chi^2 = 0.53$	0.46
Chemotherapy	84				82.1				$\chi^2 = 0.04$	0.83
Endocrine therapy	68				73.2				$\chi^2 = 0.04$	0.83
Time from surgery (month)			22	3-120			22	3-170	Z=-0.15	0.87
Comorbidity									$\chi^2 = 1.34$	0.51
No medical problem	48				51.8				A 1.01	0.01
One or more medical problems	52				48.2					
robrems										

Table 2. Demographic and clinical characteristics of patients with and without kinesiophobia

SD: Standard deviation; Min: Minimum; Max: Maximum; MRM: Modified radical mastectomy; ALND: axillary lymph node dissection; SLNB: Sentinel lymph node biopsy; t= Independent sample t test; Z= Mann-Whitney U test;  $\chi^2$ = Chi-square test.

kinesiophobia (TSK score >37), only 14.6% of the patients without lymphedema had kinesiophobia, indicating a statistically significant difference (p=0.001).

We also found upper extremity lymphedema in 76% of the patients with kinesiophobia. Only 37.5% of the patients without kinesiophobia had upper extremity lymphedema. The difference was

Table 3. Tampa Scale for Kinesiophobia, C	Q-DASH, HADS and SF-36 scores of	breast cancer survivors
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	Mean±SD	Median	Min-Max	Mean±SD	Median	Min-Max	t, Z	p
TSK	45.4±5.9			28.2±5.8			t=12.31	< 0.001*
Q-DASH	51.2±18.1			37.2±9.1			t=3.11	0.003*
HADS		4	0-16					
Anxiety		4	0-12		3	0-10	Z=-2.71	0.007*
Depression					2	0-16	Z=-2.53	0.01*
SF-36		38.9	17.8-75		52.6	11.4-91.7	Z=-2.46	0.01*
PCS		58.6	38.5-95		65.6	43.1-92.8	Z=-1.91	0.06
MCS								

SD: Standard deviation; Min: Minimum; Max: Maximum; TSK: Tampa Scale for Kinesiophobia; Q-DASH: Quick-The Disabilities of the Arm, Shoulder and Hand; HADS: Hospital Anxiety and Depression Scale; SF-36: Short Form-36; PCS: Physical component summary; MCS: Mental component summary; \* Statistically significant difference; t= Independent sample t test; Z= Mann-Whitney U test;  $\chi^2$ = Chi-square test.

**Table 4.** Correlation of TSK scores with education duration and clinical characteristics of the patients

	TSK (r)
Education duration	0.01
Comorbidity	0.06
Presence of lymphedema	0.25*
Dominant involvement	< 0.001
Stage of lymphedema	0.01
Severity of lymphedema	0.04
Q-DASH	0.22*
HADS-Anxiety	0.28*
HADS-Depression	0.26*
SF-36 PCS	-0.12
SF-36 MCS	-1.15

TSK: Tampa Scale for Kinesiophobia; r: Spearman's correlation coefficient; Q-DASH: Quick-The Disabilities of the Arm, Shoulder and Hand; HADS: Hospital Anxiety and Depression Scale; SF-36: Short Form-36; PCS: physical component summary; MCS: Mental component summary; \* Statistically significant difference.

statistically significant (p=0.002). While 90% of the patients had Stage 2 lymphedema, only 10% had Stage 1 lymphedema in both groups. More than half of the patients in both group had moderate-to-severe lymphedema. There was no significant difference between the groups with respect to stage and severity of lymphedema (p1=0.91 and  $p_2$ =0.62, respectively).

The patients with kinesiophobia had significantly higher mean scores on TSK, Q-DASH, HADS-A, and HADS-D than those without kinesiophobia (p<0.05). The SF-36 PCS and MCS scores were lower in the kinesiophobic patients, although only the difference in the SF-36 PCS scores was found to be statistically significant (p=0.01). The TSK, Q-DASH, HADS, and SF-36 scores are shown in Table 3.

The Spearman's correlation analysis revealed that presence of lymphedema, Q-DASH, HADS-A, and HADS-D scores were weakly, but significantly correlated with the TSK scores (p<0.05). However, there was no significant correlation between the TSK scores and education duration, comorbidity, dominant extremity involvement, stage and severity of lymphedema, and SF-36 PCS and MCS scores (p>0.05). Correlation of TSK scores with education duration and clinical characteristics of the patients is presented in Table 4.

## DISCUSSION

Physical activity is of utmost importance to prevent adverse effects of breast cancer and cancer treatment.<sup>[19-21]</sup> Patients with breast cancer are often advised to limit physical activity after surgery to avoid overloading the lymphatic system and to decrease the risk of developing lymphedema. However, patients usually consider this recommendation as the avoidance of using the affected arm. As a result, reduced motivation for physical activity and increased fear of movement/kinesiophobia may occur in patients with breast cancer, leading to lymphedema.<sup>[22-24]</sup> On the other hand, patients who develop lymphedema following breast cancer treatment often do not use their affected arms, due to the belief that their arms would become more swollen. Consequently, kinesiophobia may occur over time in patients with lymphedema.<sup>[11]</sup>

In the present study, the rate of kinesiophobia in all patients with breast cancer was found to be 30.8% (TSK score >37). The rate of kinesiophobia in the patients with lymphedema was significantly higher than those without lymphedema (47.5% vs. 14.6%). In addition, the rate of lymphedema in the patients with kinesiophobia was significantly higher than those without kinesiophobia (76% vs. 37.5%). However, there is no study in the literature to evaluate the rate of kinesiophobia in breast cancer survivors and the rate of upper extremity lymphedema in kinesiophobic breast cancer patients.

It is well-known that breast cancer survivors with decreased physical activity are at an increased risk for upper extremity lymphedema, and physical activity and exercise are important to improve the lymphatic drainage via the muscles to contract.<sup>[25]</sup> The National Lymphedema Network recommends carefully progressive physical activity with monitoring for symptoms to reduce the risk of lymphedema.<sup>[26]</sup> However, kinesiophobia has been accepted as an important barrier for physical activity in patients with breast cancer and/or lymphedema.<sup>[11,27]</sup> In the present study, we demonstrated that kinesiophobia scores were significantly higher in the patients with lymphedema than those without lymphedema. We also found a significant relationship between kinesiophobia and the presence of lymphedema, indicating high scores of kinesiophobia in association with the presence of lymphedema. However, we did found no significant correlation between kinesiophobia and the stage and severity of lymphedema in our study. In a recent study, Karadibak et al.[11] evaluated the effects of kinesiophobia in patients with lymphedema, but not the relationship between kinesiophobia and the presence of lymphedema. In contrast to our study results, they observed that severity of lymphedema was higher in patients with more severe kinesiophobia and there was a positive correlation between the lymphedema severity and kinesiophobia. The discrepancy in both

study results can be attributed to the different sample size and different characteristics of the patients. According to our results, kinesiophobia seems to be an independent factor for developing lymphedema, but not for stage and severity.

In the previous study, Karadibak et al.<sup>[11]</sup> found those lymphedema patients with higher education level had an increased fear of movement. They also found a significant positive correlation between kinesiophobia and educational level. Contrastly, we found no significant correlation between kinesiophobia and educational level in breast cancer survivors. There was no significant difference in the educational level between the patients with kinesiophobia and those without kinesiophobia. This can be explained by the different characteristics of the study populations. While Karadibak et al.<sup>[11]</sup> included patients with lymphedema, we included breast cancer survivors. Based on our study results, educational level appears not to be a contributing factor to kinesiophobia in breast cancer survivors; however, education on kinesiophobia and its effects are important issues for breast cancer survivors.

Previous studies have shown that breast cancer survivors also suffer from decreased health-related QoL.<sup>[28-30]</sup> The side effects of surgery and adjuvant therapies including upper extremity pain, fatigue and lymphedema, sleep disturbance, anxiety/depression, and loss of family support may lead to a decline in the QoL in breast cancer survivors.<sup>[28]</sup> As a psychological factor which adversely affects physical activity, kinesiophobia may also contribute to a poor QoL.[11,27,31] Altug et al.<sup>[31]</sup> found that scores of kinesiophobia were highly and negatively correlated with scores of QoL in patients with chronic low back pain. The authors reported that kinesiophobia adversely affected the QoL in patients with chronic low back pain. According to our literature review, there is no study to investigate the effect of kinesiophobia on the QoL in breast cancer survivors. In the present study, we found a significant decrease in the scores of physical health quality in patients with kinesiophobia. We also found decreased scores of mental health quality, although the difference did not reach statistical significance. On the other hand, we observed no significant correlation between kinesiophobia and QoL in breast cancer survivors. This result can be attributed to small sample size and the QoL assessment tool used.

Furthermore, breast cancer survivors often experience increased levels of anxiety and depression. About one-third of breast cancer survivors have psychopathology during the year following surgery.<sup>[32]</sup> Anxiety and depression are potential factors which can contribute to the development of kinesiophobia.<sup>[33]</sup> To the best of our knowledge, there is no study to evaluate the relationship between anxiety/depression and kinesiophobia in breast cancer survivors in the literature. Anxiety and depression levels have been found significantly associated with the fear of movement/ kinesiophobia in patients with cardiovascular disease and a significantly higher proportion of patients with a high level of anxiety and/or depression experience kinesiophobia.<sup>[33]</sup> Similarly, we observed a significant positive association between anxiety/depression and kinesiophobia in breast cancer survivors. Breast cancer patients with kinesiophobia had significantly higher scores on anxiety and depression. Therefore, early recognition and diagnosis of anxiety/depression may prevent kinesiophobia and reduced physical activity in these patients.

It has been reported that breast cancer survivors have certain limitations in daily activities related with the use of the arm.<sup>[34]</sup> They usually suffer from limited shoulder range of motion, shoulder girdle muscle weakness, and upper extremity lymphedema. As a consequence, many patients with breast cancer experience loss of upper extremity function.<sup>[35]</sup> Kinesiophobia, which is associated with the avoidance of activities that result in pain, may also contribute to the limited upper extremity functions.<sup>[11]</sup> Das De et al.<sup>[36]</sup> reported that kinesiophobia was positively and significantly correlated with the upper extremity functions in patients with upper extremity problems. The authors suggested that asking patients about their thoughts on the avoidance of activities was, therefore, critical. However, there was no study about the effects of kinesiophobia on the upper extremity functioning in breast cancer survivors in the literature. In the present study, we found that kinesiophobia was related to decreased upper extremity functions, indicating that it may be a predictor for upper extremity dysfunction in breast cancer survivors.

On the other hand, our study has several limitations. First, the sample size is small and no power analysis was performed to calculate the study sample size. A greater sample size would have been more powerful. Second, our study has a cross-sectional design; therefore, it is not possible to evaluate the temporal nature of any observed associations. Third, we used the arm circumferential measurement to identify lymphedema. Although circumferential measurement has limited accuracy in the diagnosis of lymphedema, we preferred this method owing to its simplicity and ease of use. Of note, the circumferential measurement is the most common method used in the clinical practice.<sup>[37]</sup> Finally, we were able to assess only relationship between kinesiophobia and the presence of lymphedema. However, it would be more valuable to evaluate the effects of exercise and lymphedema treatment on kinesiophobia.

In conclusion, kinesiophobia increases the risk for upper extremity lymphedema, depression, anxiety, and decreased upper extremity functioning in breast cancer survivors. All patients, therefore, should be encouraged to increase their physical activity and to use the upper extremities as functionally as possible without heavy strain on the affected arm. Lack of awareness may result in developing fear of motion/kinesiophobia. Nonetheless, further largescale, prospective studies are needed to confirm the relationship between kinesiophobia and lymphedema, psychological morbidities, and dysfunctioning in breast cancer survivors.

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