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Exploring the causes of kinesiophobia in patients with breast cancer-related lymphedema: a comprehensive study

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ABSTRACT

Aims: Breast cancer is the most common cancer in women worldwide. Breast cancer survivors often experience arm and shoulder pain, limited shoulder range of motion, and lymphedema as the most common post-treatment morbidities. All these morbidities can be considered as the main causes of the fear of movement, called kinesiophobia. This is the first study aims to evaluate the biological and psychological causes of kinesiophobia in breast cancer-related lymphedema (BCRL), the relationship between kinesiophobia and BCRL, and the impact of kinesiophobia on patients' upper extremity function and quality of life. The biological and psychological causes of kinesiophobia in women with breast cancer-related lymphoedema were investigated for the first time in the literature.

Methods: Patients with BCRL were included in the study. Demographic and clinical information including age, educational status, body-mass index (BMI), and dominant upper extremity were recorded. BCRL stage (International Society of Lymphology (ISL) Scale), Quality of Life Scale [European Organisation for Research and Treatment of Cancer Quality of Life (EORTC QLO-C30)], upper extremity functional status [Quick-Disabilities of the Arm, Shoulder and Hand Score (Quick-DASH)], Tampa Kinesiophobia Scale (TKS), Kinesiophobia Causes Scale (KCS) were assessed.

Results: The mean age of the 114 patients included in the study was 58.25±9.41 years. A total of 100 patients exhibited a TKS score above 37, indicative of kinesiophobia. There was a statistically significant positive correlation between age and BMI and total TKS score ($p<0.05$). The TKS score (46.18±6.61) was significantly higher in 66 patients with a dominant limb affected by BCRL ($p<0.05$). No significant correlation was found between the lymphedema stage (ISL) and quick-DASH ($p>0.05$). However, the relationship between the Quick-DASH score and the TKS score was significant ($p<0.05$). A strong significant positive correlation was observed between the TKS score and the KCS score ($p=0.0001$).

Conclusion: In our study, the severity of kinesiophobia was higher in patients with more limited upper limb function. Psychological (self-acceptance, self-assessment of motor predispositions, body care) and biological causes (morphological, individual need for stimulation, energetic substrates, power of biological drivers) increased the severity of kinesiophobia. Biological causes were found to cause more kinesiophobia and affect upper limb function in MKBL. In particular, impairment in the strength of biological impulses was found to be one of the main causes of kinesiophobia. Understanding the causes of kinesiophobia in MDL may improve rehabilitation programs and lead to the development of new strategies to help patients support treatment to reduce fear of movement.

Keywords: Breast cancer, Kinesiophobia Causes Scale, Tampa Kinesiophobia Scale, lymphedema, EORTC QLO-C30

INTRODUCTION

Breast cancer is the most common cancer in women worldwide.[1] Breast cancer survivors often experience arm and shoulder pain (30-40%), shoulder range of motion limitation (15-30%), and lymphedema (10-40%) as the most common post-treatment morbidities.[2] Lymphedema is the accumulation of protein-rich interstitial cells in tissue as a result of impaired lymphatic function.[3] Breast cancer-related lymphoedema (BCRL) affects approximately one in five women with breast cancer.[4]

Kinesiophobia is defined as the fear and anxiety that develop about activity and physical movement, arising from a sense of sensitivity to injury.[5] Cancer patients are reluctant to exercise due to physical and mental illness.[6] The addition of kinesiophobia may have a negative impact on oncology rehabilitation.[7] A study demonstrates that following the recognition of survivors, the decline in activity level is as minimal as 3%.[8] There has been a high incidence of kinesiophobia in women after mastectomy, and a similar incidence of impairment of upper extremity function has been observed in these patients.[9]

Breast cancer survivors may develop shoulder pain, reduced shoulder range of motion, and avoid physical activity due

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to the risk of BCRL and kinesiophobia.[10] The fair avoidance model posits that the experience of pain directly causes avoidance behaviour, which in turn increases the risk of decreased activity, functional decline, and anxiety.[11] This situation, which is particularly evident in BCRL patients over the long term, represents a significant underlying factor in the development of kinesiophobia. Kinesiophobia, which has both biological and psychological origins, is a factor contributing to the development of shoulder pain and limited range of motion in breast cancer survivors,[12,13] yet its impact on BCRL has been minimally explored in the literature.[14]

The objective of this study is to examine the biological and psychological causes of kinesiophobia in BCRL using the Causes of Kinesiophobia Scale (KSC), which is a validated tool in our country. Furthermore, the relationship between kinesiophobia and BCRL is measured in conjunction with global health status (EORTC-QLQ-C30) in patients, to investigate its impact on quality of life.

METHODS

Study Design

The present study is a prospective investigation that included BCRL patients aged 18-75 years at the Oncological Rehabilitation Clinic of Dr. Abdurrahman Yurtaslan Ankara Oncology Training and Research Hospital between July 2022 and January 2023. The study was approved by the Ankara Dr. Abdurrahman Yurtaslan Ankara Oncology Training and Research Hospital Ethics Committee (Date: 27.07.2022, Decision No: 2022-07/1960). Informed consent forms were obtained from the patients. The study was conducted by generally accepted ethical principles for the conduct of research stemming from the 1975 Declaration of Helsinki.

Participant Characteristics

Inclusion criteria; patients diagnosed with breast cancer and presenting with breast cancer-related lymphoedema (tissue changes such as swelling, oedema, stiffness in the unilateral upper extremity) who have undergone treatment for breast cancer (total/subtotal mastectomy and/or chemotherapy and/or radiotherapy) at least three months ago.

Exclusion criteria for the study were multiple metastases, a history of orthopedic, neurological, or infectious disease affecting the function of the upper limb, acute pain anywhere in the body, paralysis, or loss of sensation in the limb with lymphedema.

Demographic and clinical information such as age, educational status, body-mass index (BMI), and the upper extremity affected by the dominant limb were recorded.

Measures (Patient Assessment Methods)

Lymphedema stage: The International Society of Lymphology Scale is used to stage lymphedema and Each patient is graded according to the following stages:[15]

- **Stage 1:** reversible edema is present,
- **Stage 2:** irreversible edema exists without tissue changes,
- **Stage 3:** Irreversible tissue changes, such as hyperkeratosis and papillomatosis.

Global Health Status (EORTC-QLQ-C30): The EORTC QLO-C30 (European Organisation for Research and Treatment of Cancer (EORTC) quality of life C-30), a cancer-specific quality of life scale, was applied to the patients. The scale is evaluated in 3 subgroups: a) functional scale, b) symptom scale, and c) general health status (global quality of life). In the QOL questionnaire; in the first 28 questions, including the functional scale and symptom scale, it is stated that the quality of life deteriorates as the number of scores increases. In the 29th and 30th questions, which express general health status, it is stated that the quality of life increases as the number of scores increases.[16] The effects of kinesiophobia and upper extremity function on general health were assessed.

Upper extremity functional status: The quick-disabilities of the arm, shoulder, and hand score (Quick-DASH), a disability questionnaire developed for the arm, shoulder, and hand, was used to assess patients' upper extremity function. The questionnaire is a five-point Likert-Type Scale with a total score of 100, with higher scores indicating a lower level of function, and consists of a total of 11 questions. It has been adapted into Turkish by Düger et al.[17]

Kinesiophobia: The Tampa Kinesiophobia Scale (TKS) is a 17-item tool used to measure fear of movement and re-injury. It includes parameters related to injury and fear avoidance in work-related activities. A Turkish validity and reliability study was conducted in 2016 by.[14] Patients with TKS scores above 37 are considered highly kinesiophobic.[7,18] The validity and reliability of the scale have been shown to measure the level of kinesiophobia in cancer patients.[19]

Causes of kinesiophobia: The Kinesiophobia Causes Scale (KCS) assesses an individual's fear of movement and consists of two domains: the biological domain (BD) and the psychological domain (PD). The total score of the KCS is the mean of the BD and PD. A high score on the questionnaire indicates a greater fear of movement. A validity and reliability study was conducted in Turkiye in 2020.[12]

The BD includes morphology, individual need for stimulation, energetic substrates, and power of biological drivers.

The PD includes self-acceptance, self-assessment of motor predispositions, and body care.

The total score of KCS is the mean value of BD and PD, and a high score on the questionnaire indicates that the individual has a greater fear of movement.[20]

Statistical Analysis

Descriptive statistics were presented using mean±standard deviation for normally distributed variables, median (min-max) for non-normally distributed variables, and the number of cases and percentages for nominal variables. The paired sample t-test was used for normally distributed, dependent numerical data, while the independent samples t-test was used to analyze independent data. The Chi-square test was applied to assess the difference between two categorical variables. Pearson correlation analysis was used to determine correlations. Results were considered statistically significant if $p<0.05$.

RESULTS

The STROBE flow diagram of our study is shown in Figure 1.

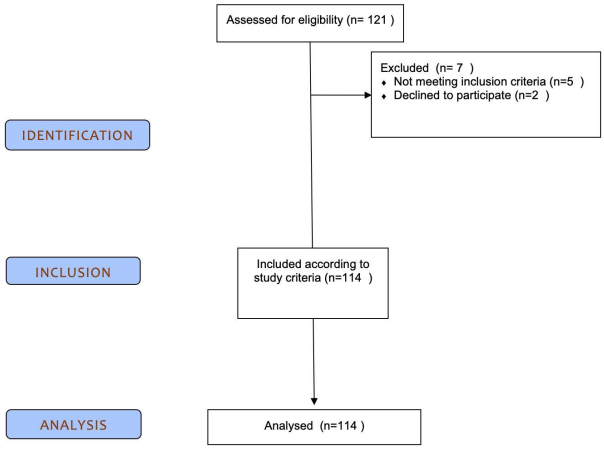

Figure 1. STROBE flow diagram

The mean age of the 114 patients included in the study was 58.25±9.41 years. Of the patients, 87% (100) had kinesiophobia based on having TKS total scores above 37. The sociodemographic and clinical characteristics of the 114 patients included in the study are summarized in Table 1.

Table 1. Sociodemographic and clinical characteristics of patients (n: 114)

Age, mean±SD (min-max) years	58.25±9.41 (37-75)
BMI, mean±SD (kg/m²)	30.25±4.77
Education level, n (%)	
Literate	4 (3.5)
Primary education	70 (61.4)
High school	17 (14.9)
University	23 (20.1)
Breast cancer subgroups, n (%)	
Hormone positive	75 (65.7)
Her-2 positive	26 (22.8)
Triple negative	13 (11.4)
Surgery, n (%)	
Total mastectomy	97 (85.0)
Subtotal mastectomy (breast conserving surgery)	17 (14.9)
The affected arm is dominant, n (%)	66 (57.8)
Stage of lymphedema, n (%) (ISL)	
Stage 1	14 (12.3)
Stage 2	68 (59.6)
Stage 3	32 (28.1)
Tampa Kinesiophobia Scale total score, mean±SD	44.78±7.54
Tampa Kinesiophobia Scale total score 37£ n (%)	100 (87.7)
Quick DASH, mean±SD	52.41±19.74
EORTC-QLQ-C30	
Physical function (EORTC-QLQ-C30), mean±SD	59.72±21.05
Symptom Scale (EORTC-QLQ-C30), mean±SD	34.73±22.05
Global Health Status (EORTC-QLQ-C30), mean±SD	54.33±21.40

SD: Standard deviation, min: Minimum, max: Maximum, BMI: Body-mass index, ISL: lymphedema stage, Quick-DASH: Quick-disabilities of the arm, shoulder, and hand score, EORTC-QLQ-C30: Global health status

The correlation between total TKS and increasing age was statistically significant (p=0.003, r: 0.2753).

There was no significant relationship found between education level and total TKS score (p=0.833) when analyzed.

In the study, 59.6% of patients had mild lymphedema and 28.1% had severe lymphedema. The relationship between lymphedema stages (ISL) and quick-DASH (p>0.05, r=0.01), as well as the total TKS score (p>0.05, r=0.06), was not significant.

The total TKS score of 66 (57.8%) patients whose limb affected by lymphedema was dominant (46.18±6.61) was higher than that of non-dominant patients (42.85±8.36) and was found to be statistically significant (p=0.019). There was a statistically significant relationship between BMI and total TKS score (p=0.018, r=0.28). The relationship between the quick-DASH score and the total TKS score was significant (p= 0.018, r=0.27) (Table 2).

Table 2. Correlation between lymphedema stages and quick-DASH, BMI, total tampa score, physical function score (n: 114)

		Stage of lymphedema	Quick DASH	BMI	Total tampa score	Physical function (EORTC-QLQ-C30)
Stage of lymphedema	r	1.0000	0.0106	0.1392	0.0606	-0.0130
	p		1.0000	0.7295	1.0000	1.0000
Quick DASH	r	0.0106	1.0000	0.1458	0.2790	-0.7223
	p	1.0000		0.7295	0.0185	<.0001
BMI	r	0.1392	0.1458	1.0000	0.2833	-0.1230
	p	0.7295	0.7295		0.0181	0.7697
Total tampa score	r	0.0606	0.2790	0.2833	1.0000	-0.3572
	p	1.0000	0.0185	0.0181		0.0009
Physical function (EORTC-QLQ-C30)	r	-0.0130	-0.7223	-0.1230	-0.3572	1.0000
	p	1.0000	<.0001	0.7697	0.0009	

Pearson correlation, Quick-DASH: Quick-disabilities of the Arm, Shoulder, and Hand score, BMI: Body-mass index, EORTC-QLQ-C30: Global Health Status

The statistical distribution of the total TKS score; biological domain and psychological domain subgroups are shown in Table 3. In the study, the mean of biological reasons was found to be higher than the mean of psychological reasons.

Table 3. Results of the Kinesiophobia Cause Scale (n: 114)

Components of kinesiophobia factors	mean±SD (min-max)
Morphologic	66.05±26.39 (20.0-100.0)
Individual need for stimulation	65.27±22.53 (20.0-100.0)
Energetic substrates	65.00±25.34 (20.0-100.0)
Power of biological drivers	69.08±24.33 (20.0-100.0)
Biological domain	65.61±19.46 (20.0-100.0)
Self-acceptance	65.17±25.83 (20.0-100.0)
Self-assessment of motor predispositions	39.45±24.37 (20.0-100.0)
Body care	65.42±18.24 (20.0-100.0)
Psychological domain	60.73±43.06 (20.0-95.6)
KCS total score	60.11±16.91 (26.45-93.6)

SD: Standard deviation, min: Minimum, max: Maximum, KCS: Kinesiophobia Causes Scale

When the correlation between quick-DASH and general health status and KCS total score, biological domain, and psychological domain was evaluated; a statistically significant positive correlation was observed between the quick-DASH and the KCS total score (p<.0001, r=0.47). Likewise, a statistically significant positive correlation was observed with the biological domain (p<.0001, r=0.51). The same statistical significance was not observed between quick-DASH and the psychological domain (p=0.35, r=0.08). A statistically significant negative correlation was observed between general health status and KCS total score (p=0.02, r=-0.25). The same statistical significance was not observed between general health status and biological domain (p=0.05, r=-0.21) and psychological domain (p=0.29, r=-0.13). However, the correlation between general health status and the biological domain was close to statistical significance. The association of KCS total score with quick-DASH and general health status is shown in Table 4.

Table 4. Correlation between quick dash, global health status, KCS total score, biological domain, psychological domain (n: 114)

		Quick-DASH	EORTC-QLQ-C30
KCS total score	r	0.4755	-0.2599
	p	<.0001	0.0261
Biological domain	r	0.5169	-0.2198
	p	<.0001	0.0564
Psychological domain	r	0.0879	-0.1366
	p	0.3521	0.2945

Pearson correlation, KCS: Kinesiophobia Causes Scale, Quick-DASH: Quick-Disabilities of the Arm, Shoulder, and Hand score, EORTC-QLQ-C30: Global Health Status

The study analyzed the correlations between the TKS total score and the KCS total score, in addition to the biological and psychological domains, using data from 114 patients. The results showed a positive and statistically significant correlation between the TKS total score and the KCS total score, as well as the biological domain (p=0.0001, r=038) (Table 5).

Table 5. Correlation between TKS total score and KCS total score, biological domain, psychological domain (n: 114)

		KCS total score	Biological domain	Psychological domain
TKS total score	r	0.3814	0.3656	0.1359
	p	0.0001	0.0003	0.1494

TKS: Tampa Kinesiophobia Scale, KCS: Kinesiophobia Causes Scale

DISCUSSION

Our study included 114 patients diagnosed with BCRL; 87.7% (n=100) were kinesiophobic (TKS total score 37£). In another study with a much smaller number of patients, the rate of kinesiophobia was found to be 30.8%.[14] It is important to remember that many social, psychological, and economic factors can be associated with the development of kinesiophobia.

In a study of fear of movement after breast cancer treatment, an increase in levels of kinesiophobia was found with age.[21] In line with the literature, it was observed in our study that the severity of kinesiophobia increased with increasing age.

In our study, no significant relationship was found between educational level and severity of kinesiophobia, supporting the findings of Gencay et al.[14] Karadibak et al.[22] found increased fear of exercise in lymphedema patients with higher levels of education in a study with a much smaller number of patients.

There is evidence that high BMI and severe physical inactivity may be associated with an increased risk of breast cancer.[23] Overweight women are known to report significantly more fear of exercise than women of normal weight.[7,21] Supporting the literature, our study found that women with breast cancer and a high BMI had high levels of kinesiophobia.

A comprehensive study that followed women for 11 years after mastectomy showed that 24% had developed BCRL.[24] Only a few studies have shown that BCRL affects the adduction, internal rotation, and flexion of the shoulder and is an important cause of disability in the upper extremities.[25-27] In a study by Dawes et al.,[28] it was found that the patient population, consisting of participants with only mild BCRL, had significantly higher Quick-DASH scores and limitations in upper extremity function. Supporting the findings of Smooth et al.,[26] our study found that the stage of BCRL did not affect upper limb function limitations. There are two reasons for this. Firstly, our study included patients with varying degrees of severity, from mild to severe. Secondly, patients may choose to avoid using the affected upper limb as part of their lymphedema treatment, regardless of the available limb volume.

Kinesiophobia is reported to increase BCRL risk in breast cancer patients, and women with BCRL have higher rates of kinesiophobia.[14] Based on the limited literature available, our study found that patients with BCRL affecting their dominant limb exhibited higher levels of kinesiophobia.

There was no correlation between the severity of kinesiophobia and the stage of lymphoedema in our study. This suggests that patients may experience fear of movement regardless of the stage of lymphedema, even in the early stages. While Gencay et al.[14] supported our study, Karadibak et al.[22] found a positive correlation between the stage of lymphedema and the severity of kinesiophobia in a smaller study. It is important to note that this correlation was observed in a smaller number of patients.

There are few studies in the literature on the relationship between kinesiophobia and upper extremity function.[29] In our study, the severity of kinesiophobia was higher in patients with more limited upper extremity function, supporting a small number of studies in the literature.

The significant correlation between the TKS, which is the gold standard for assessing kinesiophobia in breast cancer patients, and the KCS total score was evaluated in our study for the first time in the literature. Psychological and biological causes of kinesiophobia have been found to significantly increase the severity of kinesiophobia.

In breast cancer-related lymphoedema, biological causes (Morphologic, individual need for stimulation, energetic substrates, power of biological drivers) seem to cause more

kinesiophobia and affect upper extremity function. In particular, impairment of the power of biological drives is seen as one of the main causes of kinesiophobia.

While psychological causes of kinesiophobia were not found to be related to upper extremity function and general health status, it is seen that inadequate body care is the most common cause of kinesiophobia among psychological causes.

In our study, we found that the total score for kinesiophobia (KCS total score) was higher in patients with worse general health. It was observed that psychological and biological causes as a whole affected the general health status of the patients.

Limitations

The strength of the study is that it is the first study to examine the biological and psychological causes of kinesiophobia, its severity, and its effect on upper extremity functional status in a group of BCRL. A further strength of the current study is that it is the first time that the Kinesiophobia Causation Scale has been used in cancer survivors.

It should be noted that the study is not without limitations. Although kinesiophobia is a highly prevalent phenomenon among patients with BCRL, a multitude of economic, social, and psychological factors may interact with one another to influence kinesiophobia.

CONCLUSION

Fear of movement in cancer patients can have a negative impact on disease progression and can lead to reduced quality of life and even disability through increased mobility limitations. With lymphedema affecting one in five women who have had breast cancer, examining the causes of kinesiophobia may improve rehabilitation programs and lead to the development of strategies to help patients support treatment to reduce movement anxiety. Given the increasing number of breast cancer survivors, much more work is needed in the area of kinesiophobia to improve the overall well-being of patients.

ETHICAL DECLARATIONS

Ethics Committee Approval

The study was approved by the Dr. Abdurrahman Yurtaslan Ankara Oncology Training and Research Hospital Ethics Committee (Date: 27.07.2022, Decision No: 2022-07/ 1960).

Informed Consent

All patients signed and free and informed consent form.

Referee Evaluation Process

Externally peer-reviewed.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

Financial Disclosure

The authors declared that this study has received no financial support.

Author Contributions

All of the authors declare that they have all participated in the design, execution, and analysis of the paper, and that they have approved the final version.

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