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HEALTH STATUS, CORONAPHOBIA, QUALITY OF LIFE, ANXIETY AND DEPRESSION IN PATIENTS WITH LYMPHEDEMA DURING COVID-19 PANDEMIC

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ABSTRACT

Covid-19 has physical damage as well as serious impact on the mental health in the community. Symptoms such as anxiety, depression, fear, stress, and sleep problems were more commonly reported during Covid-19 pandemic. The aim of this study was to assess the health status, psychological conditions, quality of life, and possible risk factors of patients with lymphedema during the pandemic. The study included male and female patients aged ≥18 years with primary or secondary upper or lower extremity lymphedema (stage 1, 2, or 3) who were followed in our outpatient clinic. The patients were interviewed by phone. Health and social status were examined using a questionnaire, Covid-19 phobia was assessed using Covid-19 Phobia Scale (C19P-S), and quality of life was assessed using Lymphedema Quality of Life Questionnaire Arm or Leg (LYMQOL). Anxiety and depression were evaluated using the Hospital Anxiety and Depression Scale (HADS). The HADS scores showed that 35% of the patients had severe risk for depression and 10% had severe risk for anxiety. Factors with negative effect on HADS were lower education level, sedentary lifestyle, failure to perform lymphedema exercises, weight gain, and lymphedema duration. The C19P-S scores were higher indicating greater phobia in the overall score and subscores in patients with

primary lymphedema and secondary lymphedema without malignancy, younger patients, those who are not able to walk regularly, and those who are not able to perform self manual lymphatic drainage (self-MLD). Factors with negative effects on LYMOOL were stage 3 lymphedema, female gender, younger age, and longer disease duration. Patients who performed regular self-MLD and lymphedema exercises demonstrated positive effects on LYMOOL. The results of this study suggest that patients with lymphedema affected by the COVID-19 pandemic are mostly younger patients, individuals with primary lymphedema, individuals with non-malignant etiology. individuals who unable to perform regular walking, and those unable to perform self-MLD.

Keywords: anxiety, Covid-19, depression, phobia, lymphedema

Coronavirus was declared as pandemic on March 11, 2020, by the World Health Organization (WHO) and it continues to spread worldwide (1). Covid-19 infection has physical damage as well as serious impact on the mental health of the public (2). As similar to previous epidemics such as H1N1, SARS, MERS, Ebola and Zika, the symptoms such as anxiety, depression, fear, stress, and sleep problems were more commonly reported during Covid-19 pandemics (3, 4).

Phobias are specific types of anxiety disorders characterized by a constant and extreme fear of an object or a situation. Coronaphobia has been defined as a persistent and extreme fear of the new coronavirus, which is classified as a specific phobia (5). In a study investigating the effects on the psychological state caused by coronavirus in the general population in China, it was found that the rates of depression, anxiety, and phobia were 27.1%, 19.8% and 10.1%, respectively (6). Anxiety and depression could be observed in lymphedema patients before the pandemic. In patients with lower extremity lymphedema, depression was 21% and anxiety was 24% (7).

Lymphedema (LE) is a progressive chronic condition characterized by accumulation of fluid in the tissue spaces resulting from insufficiency of the lymphatic system and impaired lymph transport (8). Primary LE is an inherited or congenital condition that, most often due to genetic mutation, causes a malformation of the lymphatic system (9). Secondary LE is attributed to the impairment of lymphatic vessels due to an acquired condition such as trauma, tumor, surgery, infection, and post venous thrombosis (10).

Chronic edema is associated with high levels of functional impairment, anxiety, depression, social impairment, and physical symptoms including discomfort and pain (11). Primary LE has significant impact on quality of life (12). It is known that patients with breast cancer-related lymphedema are more affected in different aspects of quality of life (e.g., physical, psychological, social and mood) in their quality of life compared to patients without breast cancer (13). Gynecological cancer-related lower limb lymphedema has a negative impact on domestic work, physical activity, mobility, social activities, and psychological well-being (14).

In patients with lymphedema, depression and anxiety levels may have been increased with Covid-19 pandemic and coronaphobia may have been developed. Thus, we aimed to investigate the health status, psychological conditions, quality of life, and possible risk factors of patients with lymphedema during the pandemic period in this study.

MATERIAL AND METHODS

This cross-sectional study was carried out on outpatients with lymphedema who were followed-up at physical medicine and rehabilitation outpatient clinic of Fatih Sultan Mehmet Training and Research Hospital Physical Medicine and Rehabilitation Clinic. The inclusion criteria were age >18 years age, presence of primary or secondary etiology lower or upper extremity lymphedema rated as stage 1, 2, or 3.

The patients were interviewed over the phone. Overall, 100 patients with lymphedema were invited, 60 of which agreed to participate to the interview. The questions on the form and scales were read clearly to the patients included. The study protocol was approved by the Clinical Research Ethics Committee of Fatih Sultan Mehmet Training and Research Hospital, Health Sciences University, Istanbul (approval#2020/67). The study protocol is registered on clinicaltrials.gov (NCT04568005). All participants gave informed consent in accordance to the principles of Helsinki Declaration.

Procedures

The demographic data and detailed medical history were extracted from registered files. Edema stages were defined according to International Society of Lymphology (ISL) lymphedema staging (8). Only patients with stage 1, 2, or 3 lymphedema were included in the study.

The pandemic process was evaluated in terms of mobilization, whether he/she or his/her relative was diagnosed with coronavirus infection, whether his/her swelling was increased, whether he/she had a cellulite episode, whether he/she performed regular selfmanual lymphatic drainage and/or exercise, and whether he/she received supplemental treatment. The weight gain and whether he/she used compression garments regularly were also questioned. In addition, the patients completed the Coronavirus 19 Phobia Scale (C19P-S), Lymphedema Quality of Life Questionnaire Arm or Leg (LYMQOL), and the Hospital Anxiety and Depression Scale (HADS).

Coronaphobia

Coronavirus 19 Phobia Scale (C19P-S) was developed in Turkey to assess the phobia against coronavirus by Arpaci et al (4). The C19P-S included 20 self-reported items rated using a 5-point Likert scale: "strongly disagree (1)" to "strongly agree" (5). The total score ranges from 20 to 100 points with higher scores indicating greater phobia in the overall score and subscores (psychological, psychosomatic, economic and social) (4). This scale has 20 questions and 4 categories. C19P-S includes 6 questions for the psychological subgroup, 5 for the psycho-somatic subgroup, 4 for the economic subgroup, and 5 for the social subgroup.

Quality of Life

Lymphedema Quality of Life Questionnaire (LYMQOL) is a disease specific, valid, and reliable questionnaire developed to evaluate the effect of lymphedema on quality of life by Keeley et al (Cronbach's alpha= 0.83-0.88) (15).

The LYMOOL arm was developed to assess the impact of lymphedema of the arms on the quality of life of the patients. It consists of four domains including 28 items rated using 4-points Likert scale (1= not at all, 2= a little, 3= quite a bit, 4= a lot). Each item received a score between 1 and 4 and higher scores indicate worse quality of life. The four domains with relevant questions include: function with questions 1 (a-h), 2 and 3; appearance with questions 4,5,6,7 and 8; symptoms with questions 9,10,11,12,13 and 14; and emotion with questions 15,16,17,18,19 and 20. Overall quality of life (Q21) is rated by patient on a 10point scale. In Q21, a higher score indicates better quality of life (Cronbach's alpha=0.85-0.90) (16). The LYMOOL leg was developed to assess the impact of lymphedema of the legs

on the quality of life of the patients. It consists of 27 items including 26 multiple-choice questions and 1 rating question which are rated similar to the arm scale. However, following differences exist: function with questions 1 (af), 2 and 3; appearance with questions 4,5,6,7, 8,9 and 10; symptoms with questions 11,12,13, 14 and 15: and emotion with questions 16.17. 18,19,20 and 21. Overall quality of life (Q22) is rated by the patient on a 10-point scale. In Q22, a higher score indicates better quality of life (Cronbach's alpha=0.89-0.92) (17). The Turkish version of the LYMOOL Arm is a valid and reliable for evaluating OOL in female patients with upper limb lymphedema related with breast cancer (16). The Turkish version of the LYMQOL Leg is a valid and reliable for evaluating QOL in patients with lower limb lymphedema (17).

Anxiety and Depression

The Hospital Anxiety and Depression scale (HADS) was developed to assess depression and anxiety by Zigmond and Snaith (1983). Its validity and reliability have been proven as well as the validity and reliability of Turkish version (18). It consists of two subscales with 14 items (seven items for anxiety and seven items for depression). Each item is scored by 0-3 points. The total subscale ranges from 0 to 21. The scale does not diagnose anxiety or depression; rather, it determines the risk group by screening short-term anxiety and depression in patients with physical diseases. The cut-off points for the Turkish version were determined as 10 for the anxiety subscale and 7 for the depression subscale (18).

Statistical Analysis

Data were analyzed using IBM SPSS version 22.0 (SPSS IBM, Turkey). The normal distribution was assessed using Shapiro-Wilk test. Descriptive data are given as mean, standard deviation and frequency. Kruskal-Wallis test was used to compare quantitative data with skewed distribution between groups while Dunn's test was used to determine the group causing difference. Student's t-test was

		Min-Max	Mean±SD
Age		21-76	51.63±14.47
BMI		18.8-45.7	30.68 ± 6.82
Lymphedema Duration(median)		0.75-40	7.39±7.72 (4.5)
		n	%
Gender	Male	7	11.7
	<u>Female</u>	53	88.3
Education	No education/poor literacy	0 10	10
	Frimary school Secondary school	19	31./ 20
	Secondary School Lligh school	10	30 28 3
Morital Status	Married	17	<u></u> 75
Maritar Status	Single	15	25
I vmnhadama Etialaav	- Singk Primary	23	38.3
Lymphedema Etiology	Secondary	37	617
Most common etiologies (top 3)	Secondary.breast cancer	21	35
Wrost common chologies (top 5)	Primary-precox	13	21.7
	Primary process Primary-tarda	10	16.7
Presence of malignancy	Yes	32	53.3
g,	No	28	46.7
Lymphedema side	Right leg	9	15
	Left leg	14	23.3
	Both legs	15	25
	Right arm	11	18.3
	Left arm	11	18.3
Presence of surgery	No	28	46.7
	Yes	32	53.3
Three most common surgeries	MRM+ALND	11	18.3
	TAH+BSO+PLND	6	10
	BCS+ALND	3	5
Radiotherapy	No	32	53.3
	Yes	28	46.7
Chemotherapy	No	38	63.3
	Yes	22	36.7
Lymphedema stage	1	24	40
	2	31	51.7
	<u>5</u>	5	8.3
Comorbidity	INO N	22	36.7
	Yes	38	63.3
I hree most common comorbid chronic illnesses	Hypertension	6	10
	Thyroid	4	6.7
	Cardiovascular system disease	4	6.7

TABLE 1

BMI: Body Mass Index; MRM+ALND: Modified Radical Mastectomy + Axillary Lymph Node Dissection; TAH+BSO+PLND: Total Abdominal Hysterectomy + Bilateral Salpingo-oophorectomy + Pelvic Lymph Node Dissection; BCS+ALND: Breast Conserving Surgery + Axillary Lymph Node Dissection

TABLE 2Evaluation of Age, Gender and Comorbidity According to Presence of Malignancy and Lymphedema Etiology							
_		Malignancy Etiology			Lymphedema Etiology		р
		Yes	No	— P	Primary	Secondary	1
Age(mean _{±SD})		56.66±10.78	45.89±16.13	¹ 0.004*	44.30±15.99	56.19±11.46	¹ 0.004*
Gender n(%)	Male	3 (%9.4)	4 (%14.3)	² 0.695	2 (%8.7)	5 (%13.5)	² 0.697
	Female	29 (%90.6)	24 (%85.7)		21 (%91.3)	32 (%86.5)	
Comorbidity	Yes	12 (%37.5)	10 (%35.7)	³ 1.000	9 (%39.1)	13 (%35.1)	³ 0.971
	No	20 (%62.5)	18 (%64.3)		14 (%60.9)	24 (%64.9)	
¹ Student t test	² Fisher's	s Exact Test	³ Cor	ntinuity (Yate	es) correction	*p<0.05	

TABLE 3Distribution of Information on Working Parameters

		Min-Max	Mean±SD
		n	%
Pre-pandemic mobilization	Sedentary	9	15
-	Walk for leisure	21	35
	Regular walk	30	50
During pandemic mobilization	Sedentary	46	76.7
	Walk for leisure	5	8.3
	Regular walk	9	15
Covid-19 infection	Yes	0	0
	No	60	100
Covid-19 infection in relatives or friends	Yes	10	16.7
	No	50	83.3
Increased swelling during the pandemic	Yes	21	35
	No	39	65
Cellulite attack during the pandemic	Yes	1	1.7
	No	59	98.3
CDT during the pandemic	Yes	10	16.7
	No	50	83.3
Self-MLD application	Yes	35	58.3
	No	25	41.7
Performing lymphedema exercises regularly	Yes	29	48.3
	No	31	51.7
Weight gain	Yes	24	40
	No	36	60
Wearing compression garments	Yes	25	41.7
	No	21	35
	No compression garments	14	23.3
Food supplement against Covid-19 infection	Yes	16	26.7
	No	44	73.3
Four most common food supplements	Herbal supplements	6	37.5
	Vitamin C	2	12.5
	Vitamin D	1	6.3
	Zinc	1	6.3

CDT: Complex Decongestive Therapy; Self-MLD: Self Manuel Lymphatic Drainage

Information ab	out C19P-S Total Scores and and QOL and HADS	l Subscores, LYM(Subscores	QOL Subscores
		Min-Max	Mean±SD
C19P-S	Total	31-78	51.15±10.28 (50)
	Psychological	12-30	17.92±4.65 (17)
	Psycho-somatic	5-40	10.63±4.56 (10)
	Social	8-25	14.42±3.98 (14)
	Economic	4-18	8.85±2.33 (9)
LYMOOL	Function	1-4	1.67 ± 0.58 (1.5)
-	Appearance	1-3.7	1.98 ± 0.7 (2)
	Symptom	1-4	1.72 ± 0.62 (1.6)
	Emotion	1-6	1.58 ± 0.81 (1.3)
	QOL	0-10	6.67±1.89(7)
HADS	Depression	0-17	6.52±4.03 (6)
	Anxiety	0-19	5.53±4.05 (6)
		n	%
Risk for depression	Low	39	65
_	High	21	35
Risk for anxiety	Low	54	90
-	High	6	10

TABLE 4

C19P-S: Covid 19 phobia scale; LYMQOL: Lymphedema quality of life; QOL: Quality of life; HADS: Hospital depression anxiety scale

used to compare parameters with normal distribution and the Mann Whitney U test was used to assess parameters with skewed distribution between two groups. Pearson's correlation analysis was used to examine the relationships among parameters with normal distribution while Spearman's rho correlation coefficient was used to examine the relationships between parameters with skewed distribution. The qualitative data were compared using Fisher's exact test and Continuity (Yates) correction. A value p < 0.05 was considered as statistically significant.

RESULTS

Demographics

Overall, 60 patients (7 men [11.7%] and 53 women [88.3%]) aged 21-76 years were included in the study. Table 1 shows the sociodemographic, physical, and clinical characteristics of the patients. The mean duration of lymphedema was 7.39 ± 7.72 years (median: 4.5 years). No patients had a history of Covid-19 infection. Table 2 contains main demographic characteristics according to etiology and the presence of malignancy. The only significant difference was age between patients with and without malignancy, and between patients with primary and secondary lymphedema. The mean age was significantly higher (p=0.004) in patients with malignancy compared to those without and in the secondary lymphedema group compared to the primary lymphedema group (p=0.004). Table 3 presents parameters related to pandemic. Table 4 presents C19P-S total scores and subscores, QOL and LYMQOL subscores, and HADS subscores.

Gender

When the scales were evaluated by gender, it was found that only LYMQOL appearance subscore was significantly lower in men compared to women (p=0.014). When the scales were evaluated by educational status, it was found that the HADS depression score was significantly lower in high school graduates compared to those with no formal education and/or poor literacy and primary

TABLE 5a Evaluation of C19P-S, LYMQOL and HADS Subscores According to Lymphedema Etiology Lymphedema Etiology **Primary** Secondary P Mean±SD (median) Mean±SD (median) **C19P-S** Total $54.65 \pm 11.04(53)$ 48.97±9.28 (49) 0.046* 16.92±3.64 (17) 0.135 **Psychological** 19.52 ± 5.65 (18) 10.39±2.43 (10) 10.78±5.51 (10) 0.654 **Psycho-somatic** Social $15.74 \pm 4.43(15)$ $13.59 \pm 3.48(14)$ 0.068 Economic 0.815 $9\pm 2.3(8)$ 8.76±2.37 (9) LYMQOL Function 1.69±0.46(1.7) $1.65 \pm 0.64 (1.5)$ 0.377 Appearance $2.08 \pm 0.74(2)$ $1.92 \pm 0.68(2)$ 0.474 Symptom 1.72±0.53 (1.6) 1.72±0.68 (1.6) 0.854 Emotion 1.57±0.48 (1.5) $1.59 \pm 0.96(1.2)$ 0.165 OOL 6.61±2.08(7) 6.7±1.79(7) 0.681 HADS Depression 7±4.45(7) 6.22±3.78(6) 0.516 Anxiety 6.3±3.95(6) 0.175 $5.05 \pm 4.1(5)$

Mann Whitney U Test *p<0.05

C19P-S: Covid 19 phobia scale; LYMQOL: Lymphedema quality of life; QOL: Quality of life; HADS: Hospital depression anxiety scale

school graduates (p1= 0.009; p2= 0.022). No significant difference was detected in the scores or subscores of scales for marital status (p> 0.05).

Etiology

When assessed according to etiology, it was found that total C19P-S values are significantly higher in the primary lymphedema group than in the secondary lymphedema group (p= 0.046) (*Table 5a*). When assessed according to presence of malignancy, total C19S-P scores and social subscores were found to be significantly lower in the group with malignancy than the group without malignancy (p= 0.025 and p= 0.039) (*Table 5b*).

Site of lymphedema and adjuvant cancer treatment

There was no significant difference in the

scores or subscores of scales according to the extremity (upper / lower) involved, and chemotherapy or radiotherapy in patients (p > 0.05).

When assessed according to lymphedema stage, only significant differences were found in LYMQOL function, appearance, and QOL subscores (p=0.004, p=0.04 and p=0.049, respectively). It was found that LYMQOL function and appearance subscores were significantly higher in patients with stage 3 lymphedema compared to stage 1 or 2 lymphedema (p1=0.001; p2=0.008; and p1=0.001; p2=0.022) while QOL score was significantly lower in patients with stage 3 lymphedema compared to stage 1 lymphedema (p=0.016).

Activity levels

When the scales were evaluated according to their mobilization status during the

		Malignancy		
		Yes	No	P
		Mean±SD (median)	Mean±SD (median)	
C19P-S	Total	48.53±9.82 (47)	54.14±10.14 (53)	0.025*
	Psychological	16.72±3.83 (17)	19.29±5.17 (18)	0.061
	Psycho-somatic	10.91±5.9 (10)	10.32±2.28 (10)	0.707
	Social	13.41±3.58 (13.5)	15.57±4.15 (15)	0.039*
	Economic	8.44±1.9 (8.5)	9.32±2.7 (9)	0.324
LYMQOL	Function	1.65±0.64 (1.5)	1.69±0.51 (1.6)	0.427
	Appearance	1.96±0.7 (2)	2.01±0.71 (2)	0.766
	Symptom	1.67±0.59 (1.6)	1.77±0.67 (1.6)	0.660
	Emotion	1.65 ± 1.02 (1.3)	1.5±0.47 (1.4)	0.528
	QOL	6.41±1.68 (6.5)	6.96±2.1(7)	0.319
HADS	Depression	6.44±3.88(6)	6.61±4.27 (6)	0.964
	Anxiety	5.03±4.31 (4.5)	6.11±3.73 (6)	0.152

TABLE 5b Evaluation of C19P-S, LYMQOL and HADS Subscores According to Presence of Malignancy in the Etiology

Mann Whitney U Test *p<0.05

C19P-S: Covid 19 phobia scale; LYMQOL: Lymphedema quality of life; QOL: Quality of life; HADS: Hospital depression anxiety scale

pandemic, it was found that C19P-S psychosomatic subscore was significantly lower in patients who could go for a walk regularly when compared to sedentary patients and those walking for leisure (p1: 0.005; p2: 0.024; p < 0.05). In addition, HADS depression scores were found to be significantly higher in sedentary patients than those walking for leisure and those who could go for a walk regularly (p1: 0.006; p2: 0.011).

Self-lymphedema treatment

The C19P-S somatic subscore and LYMQOL function subscores were found to be statistically significantly lower in patients performing self-MLD during the pandemic when compared to those who did not (p=0.028 and p=0.032). It was found that the LYMQOL symptom subscores and HADS depression score were significantly lower in

patients who performed lymphedema exercises than those who did not during the pandemic (p=0.004 and p=0.040). In addition, the HADS depression score was significantly higher in patients who gained weight when compared to those who did not (p=0.024).

Age and lymphedema duration

Correlations between age, lymphedema duration, and C19P-S, LYMQOL, and HADS scores were evaluated. There was a significant, inverse relation between age and CP19-S psychological subscore at the 38.7% level (p= 0.002). Again, there was a significant, inverse relation between age and LYMQOL appearance at the 25.7% level (p= 0.047). It was found that lymphedema duration was positively correlated with LYMQOL appearance subscore (41.4%; p= 0.001), LYMQOL emotion subscore (30%; p= 0.020), and HADS anxiety

subscore (26.8%; p= 0.038).

DISCUSSION

The coronavirus has rapidly spread worldwide, resulting in Covid-19 pandemic. The increasing case numbers and uncertainties about the disease have caused physical and mental trauma in humans. The symptoms such as anxiety, depression, fear, stress, and sleep problems are more common during the Covid-19 outbreak (7). In this study, we evaluated coronaphobia, quality of life, anxiety, depression, and health status in patients with lymphedema.

In our study, the HADS scores showed that 35% of patients had severe risk for depression and 10% had severe risk for anxiety. In studies on general population with no specific disease, it was shown that during the pandemic period depression rates were lower while anxiety rates were higher than those found in our study (2,6,20). This may be attributed to more depressive states in our patients due to the current lymphedema disease (21,22). In addition, the lower anxiety rate may be attribed to the fact that none of our patients had experienced Covid-19 infection with lower infection rates among their relatives.

In agreement with our study, it was found that low education level was associated with depression in the studies conducted during the pandemic (23,24), implying that high education level can have a protective effect for negative emotions. The individuals with higher education levels have better under-standing and attitudes towards Covid-19 (19). Cui et al argued that the individual's rational judgement rates for new things were increased by enhancing in academic competence; there-by reducing the corresponding psychological burden (25). Education level and financial income level can show parallelism. In a study conducted during the pandemic, the relationship between weekly financial income and anxiety and depression was examined, but no significant relationship was found (26).

In our study, it was found that sedentary lymphedema patients were more depressed than those walking for leisure or those who could go walking regularly. This was also true for lymphedema patients who did not perform lymphedema exercises. In a systematic review Baumann et al. indicated that physical exercise can improve quality of life, mood and general health on breast cancer related lymphedema (27). It was shown that physical exercise im-proved psychosocial well-being (28) while lower physical activity was associated with distress in patients with breast cancer (29). All these reasons make physical activity and exercise essential, particularly during the pandemic.

In the literature, it was found that anxiety, depression or stress scores were associated with weight gain or change (30, 31). Although a correlation has been found between anxiety scores and weight gain in healthy individuals in a previous one-year study, our study shows that the HADS depression scores were significantly higher in patients with weight gain, but no such relationship was found for anxiety scores (32).

We found that the C19P-S psychological subscore was inversely correlated with age while the total score was higher in primary lymphedema patients with younger age. Also, we found that the total score and social subscore were higher in younger patients without malignancy in the etiology. Although Liu et al. suggested that younger people suffer more from state anxiety, depression, and psychological abnormalities when faced with the pandemic, perhaps this younger population tends to become more education about these issues from more exposure to the media. In addition, they also have core responsibilities for social productivity and their families; thus, they experience greater psychological pressure (6). Coronaphobia may be attributed to responsibilities of person, the presence of pre-pandemic psychiatric illness, crisis management power, and environmental factors.

In our study, in physically active patients, self-MLD and lymphedema exercises had positive effect on coronaphobia. In a review, Puyat et al proposed that home-based activities can help to improve mental health during the Covid-19 outbreak (33). In the literature, other studies also support this finding (34). Given all these factors, we can recommend patients to perform home-based exercises for their mental and physical health. When applied to patients with lymphedema, self-MLD and lymphedema exercises are major activities recommended.

In studies on quality of life in breast cancer with or without lymphedema in female patients, it was found that QOL scores were significantly lower in patients with lymphedema (35). In our patients, the mean scores of LYMQOL function, appearance, symptom, and emotional subscales were comparable to those reported in the LIMPRINT, an international, multicenter, prospective study (9). When compared to LIMPRINT study, there was no component that worsened significantly due to the pandemic. We can attribute this to the fact that our patients are functionally limited compared to the normal population and therefore may not have experienced a significant deterioration in quality of life during this period. LYMQOL function, appearance, and QOL subscores were worse in patients with stage 3 lymphedema, but lymphedema severity had no effect on symptom and emotional subscores in our study. Lee et al found that the appearance subscore was higher in patients with severe lymphedema (36) while Orhan et al. found that the function, appearance and symptom subscores were higher in patients with severe lymphedema (37). In our study, no effect was observed in symptom subscore. which may be attributed to the fact that chronic lymphedema patients with a soft, fatty limb have less stretching in their interstitial tissue mechanoreceptors: thus, less symptomatic pain and discomfort, resulting in smaller effect on function and quality of life in these patients (38). Again, no significant difference was observed in emotion subscore. It was concluded that patients' ability to cope with the problem and their personalities are important when evaluating the quality of life in the literature (39,40).

In our study, female gender, younger age and longer disease duration were identified as factors that negatively affected the LYMQOL appearance subscore. In the literature, it has been shown that women with lymphedema have concerns about the appearance of their arms, hands, and shoulders due to swelling (38). In our study, LYMQOL appearance subscore showed negative correlation with age with younger individuals being at higher risk. There are studies supporting this finding in the literature (39,40).

In the study by De Vrieze et al, it was found that long-term lymphedema was associated with a greater problem in home and mobility activities (40). In our study, our finding of significant difference only in appearance and emotional subscores may be attributed to the chronic nature of the disease and the adaptation of the patients to their current state in terms of functional, symptom and general QOL. In the literature, lymphedema is also considered as a chronic health problem similar to diabetes or osteoarthritis, and patients adapt to this problem and learn to live with chronic health disabilities (36).

Our patients who regularly performed lymphedema exercises were better in LYM-QOL symptom subscore while those who could perform self-MLD were better in function subscore. Studies in the literature have found that increased exercise and activity are beneficial in reducing pain associated with lymphedema and relieving swelling (38). Melam et al found that the quality of life was better in the study group that included remedial exercises (41).

This study has some limitations. The results cannot be generalized to all lymphedema patients due to smaller sample size. Since the patients were interviewed over the phone, only self-rated evaluations could be assessed. Further comprehensive comparative studies are needed for better understanding about lymphedema patients.

In conclusion, patients with lymphedema affected by the COVID-19 pandemic are mostly younger, with primary lymphedema, non-malignant etiology, unable to perform regular walking, and unable to perform self-MLD (significantly higher C19P-S scores in these groups). Thus, psychological support measures should have to be prioritized in this patient group.

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CONFLICT OF INTEREST AND DISCLOSURE

The authors declare no competing financial interests exist.

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