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## Functional and Psychosocial Quality of Life in Gynecologic Cancer Survivors with and without Lymphedema Symptoms

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### Abstract

**Objective:** The goal of this study was to compare function, quality of life, body image and distress levels between gynecologic cancer survivors with and without lymphedema symptoms as well as to determine how many individuals received rehabilitation treatment following treatment for gynecological malignancy.

**Methods:** This prospective longitudinal cohort study sought to examine long-term physical and psychosocial outcomes among gynecologic cancer survivors.

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Conflict of Interest Statement:

None of the authors have any conflicts of interest pertinent to this manuscript.

**Results:** Participants in the symptomatic group reported lower quality of life, lower function scores, and greater cancer-related, with greater rates of clinically significant levels of distress. These results remained largely consistent in multivariable models.

**Conclusions:** We found lower extremity lymphedema to be associated with lower quality of life, lower limb function, greater distress, and negative body image.

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## Background:

Lymphedema and other physical impairments are common sequelae following diagnosis and treatment for gynecological cancer. Rates of lymphedema following treatment of a gynecologic malignancy are as high as 80% depending upon the type of malignancy present [1–5]. Treatment of most gynecologic cancers involves surgery (including sentinel lymph node biopsies or full lymphadenectomy), chemotherapy and/or radiotherapy. It is known that lymphadenectomy can lead to the development of lymphedema and that the addition of radiotherapy can increase the risk of lymphedema [1,4,6–8].

The symptoms of lower extremity lymphedema following gynecologic malignancy can be difficult to quantify, however the Gynecologic Cancer Lymphedema Questionnaire (GCLQ), a valid and reliable questionnaire, has been developed to measure a patient's subjective symptoms [9]. A prospective study examining the effects of lymphedema on the quality of life in gynecologic oncology patients showed a significant detrimental effect on quality of life, daily function and body image [10]. Effective treatment strategies for lower limb lymphedema, which could improve quality of life and function, include complete decongestive therapy consisting of compression bandaging, manual lymph drainage, remedial exercises, and patient education [11,12]. Unfortunately, not all patients receive treatment that could potentially reduce their lymphedema related symptoms.

The goals of this project were to 1) compare function, quality of life, body image and distress levels between gynecologic cancer survivors with and without lymphedema symptoms, and 2) to determine how many individuals received rehabilitation treatment following treatment for gynecological malignancy. We hypothesized individuals with lymphedema symptoms would have worse function, quality of life, distress, and body image compared with those patients without lymphedema symptoms. We also hypothesized that a minority of individuals (less than 50%) with lymphedema symptoms would have received treatment for lymphedema.

## Methods:

### Study design and measures

The methods of the University of Minnesota Gynecology Oncology Life after Diagnosis (GOLD) survivorship cohort study have been described in depth elsewhere [13,14]. Briefly, this prospective longitudinal cohort study sought to examine long-term physical and psychosocial outcomes among gynecologic cancer survivors. Eligible participants were at least 18 years old, able to read and write in English, and diagnosed with and/or treated for a gynecologic cancer (ovarian, endometrial, cervical, vaginal, vulvar) at the University of Minnesota. Recruitment took place between 2017 and 2020. Originally a longitudinal

study, in the spring of 2020 the study was transitioned to a cross-sectional design with participants asked to complete approximately biannual surveys (paper or online per participant preference). Study participants remained the same, but since then, questionnaires have no longer repeated prior surveys, but have been one-time surveys on specific research questions. Data for this analysis came from the spring 2021 cross-sectional survey. Of the 457 GOLD participants consented, 316 were alive and invited to the spring 2021 survey. The GOLD study was approved by the Institutional Review Board at the University of Minnesota. Participants provided signed informed consent and Health Insurance Portability and Accountability Act (HIPAA) forms for study participation and abstraction of clinical data from the electronic health record.

The exposure of interest for this analysis was lymphedema symptoms, measured using the Gynecologic Cancer Lymphedema Questionnaire (GCLQ). The GCLQ is a diagnostic questionnaire that screens gynecologic cancer patients with lower extremity lymphedema. It consists of 20 yes/no questions on lymphedema symptoms in the previous 4 weeks. A higher GCLQ score represents worse lymphedema symptoms [9,10]. Participants were categorized based on GCLQ scores as asymptomatic (<4, little to no lymphedema symptoms) and symptomatic (≥ 4, high number of lymphedema symptoms) as previously validated by Carter, and colleagues demonstrating good sensitivity and specificity using this clinical cut-off score. [9,10]. Outcomes of interest included cancer-related quality of life, as measured by the Functional Assessment of Cancer Therapy – General (FACT-G) [15,16], lower extremity function, measured by the Lower Extremity Function Scale (LEFS) [10], and cancer-related distress measured by the National Comprehensive Cancer Network's (NCCN) Distress thermometer [17]. Higher FACT-G and LEFS scores indicate greater quality of life and function; higher distress thermometer scores indicate greater distress. Body image was assessed using the following measures: *I am unhappy about a change in my appearance*, *I like the appearance of my body*, and *I feel sexually attractive* with the following possible responses: *not at all*, *a little bit*, *somewhat*, *quite a bit*, or *very much*.

Demographic variables measured included age at survey (years), time since initial gynecologic cancer diagnosis at the time of survey (years), race (non-Hispanic white, other), education (no college degree, at least college degree), annual household income (less than \$50,000, \$50,000-99,999, \$100,000 or more, prefer not to say), cancer site (ovarian, cervical, endometrial, vaginal/vulvar), Federation of Gynecology and Obstetrics (FIGO) stage at diagnosis (early [I/II] versus advanced [III/IV]), cancer-related surgery (yes, no), receipt of chemotherapy (yes, no), receipt of radiation (yes, no), lymphadenectomy (yes, no, unsure), treatment for lymphedema (yes, no), and receipt of physical or occupational therapy (yes, no).

### Statistical analysis

Differences in demographic and clinical characteristics and in outcomes were compared between the asymptomatic vs. symptomatic lymphedema groups (GCLQ <4 vs. ≥ 4) using descriptive statistics, including chi-squared, Fisher's exact, and Student's t-tests as appropriate. Adjusted multivariable linear regression models were conducted adjusting for cancer site, advanced FIGO stage, education, and income (all at time of baseline survey),

and age and time since diagnosis, both at time of survey. Finally, to examine differences in perceived physical appearance, Fisher's exact tests were used. Data were analyzed using SAS version 9.4 software (SAS Institute Inc., Cary, NC, USA) with p-values less than 0.05 considered statistically significant.

## Results:

A total of 199 (63.0%) participants completed the survey, with 185 (58.5%) providing sufficient data for this analysis. Over half (n=105, 56.8%) of participants were in the symptomatic group; the remaining 80 were considered asymptomatic.

The participants in this analysis were primarily non-Hispanic white women (98.3%) with an average age of  $63.1 \pm 10.3$  years at the time of survey. The average time since cancer diagnosis for all participants was  $4.8 \pm 2.6$  years at the time of survey. When compared to participants in the asymptomatic group, participants classified as asymptomatic were more likely to report an annual household income of less than \$50,000 ( $p=0.04$ ), receipt of lymphedema related treatment ( $p=0.04$ ), and receipt of physical or occupational therapy ( $p=0.001$ , Table 1). There were no other significant differences observed by lymphedema group.

In unadjusted comparisons, participants in the symptomatic group reported lower quality of life (e.g. FACT-G total score  $80.7 \pm 15.8$  vs  $89.3 \pm 13.3$ ,  $p=0.0001$ ), lower function scores (LEFS:  $54.4 \pm 20.1$  vs.  $71.2 \pm 11.2$ ,  $p<0.0001$ ), and greater cancer-related distress ( $3.2 \pm 2.7$  vs.  $1.5 \pm 1.9$ ,  $p<0.0001$ , Table 2), with greater rates of clinically significant levels of distress ( $>4$ ; 37.0% vs. 14.1%,  $p=0.0006$ ). These results remained largely consistent in multivariable models (Table 3); for example, comparing those with to those without lymphedema, overall quality of life score, coefficient:  $-7.35$ ; 95% CI:  $-11.64$ ,  $-3.07$ ,  $p=0.0009$ , and distress, coefficient:  $+1.39$ , 95% CI:  $+0.67$ ,  $+2.10$ ,  $p=0.0002$ . All FACT-G sub-scores were significantly different between the comparison groups except for the emotional subscale. Participants in the symptomatic group had significantly lower LEFS scores, indicating greater dysfunction when compared to participants in the asymptomatic group (Coefficient:  $-14.87$ ; 95% CI:  $-20.24$ ,  $-9.51$ ,  $p<0.0001$ ). We further analyzed these models additionally adjusting for radiation which may have confounded the effect of lymphedema; however the conclusions were the same (data not shown).

We observed significant differences in perceived physical appearance and body image by lymphedema group (Table 4). Symptomatic participants were more likely to report being unhappy with a change in their physical appearance ( $p=0.02$ ) and were less likely to report liking the appearance of their body ( $p=0.002$ ) or feeling sexually attractive ( $p=0.0002$ ) when compared to asymptomatic participants.

In the symptomatic group, 22.9% of participants reported having received treatment for lymphedema compared to 11.3% of participants in the asymptomatic group ( $p=0.04$ ), Table 1. Almost half (46.7%) of participants in the symptomatic group and 23.8% of those in the asymptomatic group received physical or occupational therapy ( $p=0.001$ ). Since income might have been related to receipt of lymphedema treatment or physical/occupational

therapy, we explored univariate associations between receipt of lymphedema treatment and income ( $p=0.37$ ) and physical and/or occupational therapy and income ( $p=0.01$ ), with individuals in the lowest income bracket ( $< \$50,000$ ) being the most likely to have received physical and/or occupational therapy. This study did not obtain details on the type of physical or occupational therapy treatment received.

## Discussion:

The study results suggests that gynecologic malignancy treatment-related lower extremity lymphedema has a negative impact on quality of life, lower limb function, distress, and body image. The results also showed that individuals with a low income had worse lymphedema symptoms and were more likely to undergo physical and/or occupational therapy. Regardless of severity of lymphedema, we found that less than one-quarter of patients with lymphedema symptoms received lymphedema treatment. This finding demonstrates a significant absence of essential lymphedema treatment for many participants who experienced gynecological lymphedema related symptoms. Results may also suggest that symptomatic individuals may be under-diagnosed with lymphedema and thus not identified by providers as needing treatment.

Our study is unique in that it is one of a few cohort studies evaluating lymphedema related to wellbeing in patients with gynecologic malignancies, particularly with longer term follow-up. In addition, our study showed that individuals with a low income experienced worse lymphedema symptoms. The negative impact of lower extremity lymphedema symptoms on quality of life and lower limb function from the present study is consistent with another 2014 study investigating physical quality of life in patients with lower extremity lymphedema or swelling associated with endometrial cancer treatment [20]. The largest study to date was performed by the Gynecologic Oncology Group and was a prospective assessment of the prevalence and effect of lymphedema on quality of life in patients undergoing surgical treatment of gynecologic malignancies [10]. This study reported an overall prevalence of 14% for lower extremity lymphedema. The study also reported that patients with clinical limb volume change had an associated decrease in quality of life as reported by the GCLQ, specifically in terms of heaviness, infection-related symptoms, and physical functioning.

In our study, less than one-quarter of patients with lymphedema symptoms received lymphedema treatment demonstrating a lack of necessary care that could reduce gynecological lymphedema related symptoms. Demographic factors, lack of access, referral patterns and other considerations may play a role in patients not receiving therapy. Financial difficulties have previously been shown to be an unmet need among patients with lymphedema and may be a barrier to appropriate treatment [18,19]. Interestingly, in our study, income was not associated with receipt of lymphedema treatment, and individuals with low incomes were the most likely to undergo physical and/or occupational therapy. The severity of the lymphedema symptoms may have increased the likelihood of referral to treatment since the low income group's symptoms were worse. These results may suggest that participants who experience milder gynecological lymphedema related symptoms may

be under-diagnosed and not receive essential lymphedema treatment that could reduce their symptoms and potentially prevent the progression of the disease.

Our study is one of the first to quantify the negative effects of lower extremity lymphedema on distress and body image. A retrospective report of forum-type responses to survey prompts revealed testimonials of lymphedema negatively affecting intimacy, causing distress, and informing clothing choices [21]. In the present study, negative body image was significantly associated with higher number of lymphedema symptoms (GCLQ score 4).

Limitations of this study include a study population that consisted of almost exclusively non-Hispanic white, educated, English-speaking patients from a single-academic center in Minnesota. Our results may not be generalizable to different populations. Of the 316 questionnaires sent out, 117 participants did not respond to the questionnaires, which may contribute to a non-response bias. Lymphedema symptoms were identified by survey, and therefore data are reliant on recognition and accurate self-reporting of symptoms. Notably, self-reported symptoms are usually more accurate than symptom reporting by providers. In assessing the percentage of patients who have had lymphedema treatment, patients who received physical therapy or occupational therapy interventions may not have recognized lymphedema treatment as the intervention provided. This survey was conducted during the COVID-19 pandemic which may have affected survey results due to cautiousness of patients in attending in person therapy visits. As a result, it is possible that the percentage of patients who received lymphedema treatment was lower than it would have been outside the pandemic. Additionally, specific symptoms and quality of life measures may not be reflected in established questionnaires due to factors unique to specific patients.

Potential benefits of prevention measures for lymphedema include improved radiation and surgical techniques such as sentinel lymph-node biopsy. Additional potential benefits consist of early education, early identification of signs/symptoms, identification of at risk patients, and early initiation of complete decongestive therapy but these potential preventative measures warrant more thorough investigation to inform clinical practice. For patients who have undergone gynecologic cancer treatment, it is unclear how much quality of life, distress, and body image are actively addressed in clinical settings.

## **Conclusion:**

We found lower extremity lymphedema to be associated with lower quality of life, lower limb function, greater distress, and negative body image. The quality of life of patients with lower extremity lymphedema may benefit from therapy to reduce swelling, and decrease risk of infection. It is important to further explore the reasons behind why many patients do not receive treatment for their lymphedema, and how to increase those numbers. Research in gynecologic malignancy-related lymphedema specifically has been limited to date, and further research to prevent and inform interventions in more diverse populations is needed. In the meantime, education of patients and providers and use of quantitative (limb measurements in clinic) and qualitative (patient-reported outcome assessments)



measurements can help with early identification of and intervention on lymphedema in clinical practice [10].

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**Highlights**

1. Lower extremity lymphedema has a negative impact on quality of life, lower limb function, distress, and body image.
2. Less than one-quarter of patients with lymphedema symptoms received lymphedema treatment.
3. This is one of the first to quantify the negative effects of lower extremity lymphedema on distress and body image.

**Table 1.**

Distribution of participant demographic and clinical characteristics

	Symptomatic (GCLQ = 4) N=105	Asymptomatic (GCLQ <4) N=80	
Characteristic	Average (SD)	Average (SD)	P value
Age at survey, years	63.3 (10.0)	62.7 (11.1)	0.7
Time since diagnosis at survey, years	4.7 (2.7)	5.0 (2.7)	0.53
	N (%)	N (%)	
Race			
Asian	2 (1.9%)	0 (0.0%)	0.51
Black	1 (1.0%)	0 (0.0%)	
Non-Hispanic White	102 (97.1%)	79 (100.0%)	
Education			
No college degree	60 (60.6%)	37 (48.1%)	0.1
At least college degree	39 (39.4%)	40 (52.0%)	
Income			
Less than \$50,000	35 (35.7%)	20 (26.0%)	0.04
\$50,000-99,999	32 (32.7%)	30 (39.0%)	
\$100,000 or more	20 (20.4%)	25 (32.5%)	
Prefer not to say	11 (11.2%)	2 (2.6%)	
Primary cancer site			
Cervical	10 (9.5%)	11 (13.8%)	0.82
Endometrial	49 (46.7%)	35 (43.8%)	
Ovarian	38 (36.2%)	29 (36.3%)	
Vaginal/Vulvar	8 (7.6%)	5 (6.3%)	
FIGO stage at diagnosis			
Stage I	55 (52.4%)	43 (55.1%)	0.78
Stage II	12 (11.4%)	11 (14.1%)	
Stage III	31 (29.5%)	21 (26.9%)	
Stage IV	7 (6.7%)	3 (3.9%)	
Cancer-related surgery			
Yes	99 (94.3%)	73 (91.3%)	0.42
No	6 (5.7%)	7 (8.8%)	
Lymphadenectomy (among those who had cancer-related surgery)			
Yes			0.3
No	51 (58.0%)	43 (66.2%)	

	Symptomatic (GCLQ = 4) N=105	Asymptomatic (GCLQ <4) N=80	
Characteristic	Average (SD)	Average (SD)	P value
<i>Unknown</i>	37 (42.1%) <i>11</i>	22 (33.9%) <i>8</i>	
Receipt of radiation			
<i>Yes</i>	34 (32.4%)	27 (33.8%)	0.84
<i>No</i>	71 (67.6%)	53 (66.3%)	
Undergone lymphadenectomy			
<i>Yes</i>	51 (49.0%)	44 (55.0%)	0.67
<i>No</i>	43 (41.4%)	28 (35.0%)	
<i>Unsure</i>	10 (9.6%)	8 (10.0%)	
Received treatment for lymphedema			
<i>Yes</i>	24 (22.9%)	9 (11.3%)	0.04
<i>No</i>	81 (77.1%)	71 (88.8%)	
Received physical and/or occupational therapy			
<i>Yes</i>	49 (46.7%)	19 (23.8%)	0.001
<i>No</i>	56 (53.3%)	61 (76.3%)	

**Table 2.**

Differences in average FACT-G, LEFS, and Distress scores, by GCLQ category

<b>Outcome</b>	<b>Symptomatic GCLQ ≥ 4</b>	<b>Asymptomatic GCLQ &lt;4</b>	<b>P value</b>
FACT-G score (SD)			
<i>Total score</i>	80.7 (15.8)	89.3 (13.3)	0.0001
<i>Physical</i>	22.2 (5.1)	25.5 (3.1)	<0.0001
<i>Social</i>	20.0 (6.2)	22.1 (5.5)	0.02
<i>Emotional</i>	19.4 (3.1)	19.9 (3.6)	0.35
<i>Functional</i>	19.1 (5.7)	21.8 (5.2)	0.0008
LEFS (SD)	54.4 (20.1)	71.2 (11.2)	<0.0001
Distress scale, continuous (SD)	3.2 (2.7)	1.5 (1.9)	<0.0001

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**Table 3.**

Associations between GCLQ score and outcomes of interest

Outcome	Symptomatic (GCLQ = 4) Adjusted Estimate <sup>†</sup> (95% CI)	P value
FACT-G score		
<i>Total score</i>	-7.94 (-12.40, -3.497)	0.0006
<i>Physical</i>	-2.98 (-4.29, -1.66)	<0.0001
<i>Social</i>	-2.04 (-3.84, -0.23)	0.03
<i>Emotional</i>	-0.18 (-1.22, +0.85)	0.73
<i>Functional</i>	-2.74 (-4.42, -1.07)	0.001
LEFS	-15.17 (-20.46, -9.87)	<0.0001
Distress Thermometer	+1.47 (+0.73, +2.21)	0.0001

Reference group: participants with GCLQ &lt;4

<sup>†</sup>Models adjusted for cancer site, FIGO stage (stage I/II versus III/IV), age at survey, time since diagnosis at time of survey, education, and income

**Table 4.**

Differences in perceptions regarding physical appearance

	Symptomatic GCLQ 4 N=105	Asymptomatic GCLQ <4 N=80	P value
I am unhappy about a change in my appearance			0.02
<i>Not at all</i>	32 (30.8%)	43 (53.8%)	
<i>A little bit</i>	31 (29.8%)	13 (16.3%)	
<i>Somewhat</i>	22 (21.2%)	16 (20.0%)	
<i>Quite a bit</i>	12 (11.5%)	4 (5.0%)	
<i>Very much</i>	7 (6.7%)	4 (5.0%)	
I like the appearance of my body			0.002
<i>Not at all</i>	24 (22.9%)	7 (8.8%)	
<i>A little bit</i>	22 (21.0%)	15 (18.8%)	
<i>Somewhat</i>	41 (39.1%)	29 (36.3%)	
<i>Quite a bit</i>	17 (16.2%)	19 (23.8%)	
<i>Very much</i>	1 (1.0%)	10 (12.5%)	
I feel sexually attractive			0.0002
<i>Not at all</i>	37 (36.6%)	17 (22.4%)	
<i>A little bit</i>	24 (23.8%)	15 (19.7%)	
<i>Somewhat</i>	36 (35.6%)	24 (31.6%)	
<i>Quite a bit</i>	1 (1.0%)	13 (17.1%)	
<i>Very much</i>	3 (3.0%)	7 (9.2%)	

P-values calculated using Fisher's exact tests