

Women with self-reported lower limb lymphedema after treatment for gynecological cancers: are they more likely to self-report psychosocial symptoms and less likely to use services?

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Background Survivorship for gynecological cancers has increased because of improved screening and treatment. Use of supportive care services after treatment is important to improve patient quality of life.

Objective To assess self-reported lower-limb lymphedema (LLL), depression, anxiety, quality of life, unmet supportive care needs, and service use among gynecological cancer survivors.

Methods In 2010, a population-based, cross-sectional mail survey was conducted among 160 gynecological cancer survivors 5-30 months after their diagnoses (response rate, 53%).

Results Overall, 30% of women self-reported symptoms of LLL, 21% and 24% self-reported symptoms of depression or anxiety, respectively. Women with LLL were more likely to also report symptoms of depression or anxiety, and had higher unmet supportive care needs. Services needed but not used by 10%-15% of women with LLL, anxiety, or depression were those of a lymphedema specialist, pain specialist, and physiotherapist for LLL, and a psychiatrist, psychologist, and pain specialist for anxiety and depression.

Limitations Small sample size, self-reported data, limited generalization to other countries, underrepresentation of older women (age >70 years) and women from non-Caucasian backgrounds.

Conclusions Women with LLL or high distress were less likely to use services they needed.

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Cancers arising from female reproductive organs account for about 18% of all female cancers worldwide. Improved screening and treatments programs have led to increase in survival rates.¹ Research concerning supportive care needs and services after treatment is important to further improve the long-term patient quality of life (QoL) of gynecological cancer survivors.^{2,3} Survivors of these cancers are likely to need good access to supportive care to help them with problems specifically related to gynecological cancer treatment such as lower-limb swelling or lymphedema (LLL), problems with sexuality and impaired fertility, premature menopause, bladder dysfunction, depression, and anxiety.^{1,3,4} Wide estimates of the prevalence of LLL after treatment for gynecological cancer

have been reported as ranging from 5%-70%.⁵⁻¹² The prevalence of LLL seems highest after treatment for vulvar cancer (36%-47%) and lowest after ovarian cancer (4%-7%).⁷ Evidence suggests that most cases of LLL will develop in the first 24 months after treatment, especially in those women who had lymph-node dissection and/or radiation therapy.^{7,11,12} Women with LLL may experience a range of other physical symptoms apart from swelling such as heaviness, pain, and discomfort, which can lead to physical dysfunction and inability to perform daily activities.⁷ LLL has also been associated with sexual, social, financial, and psychological problems,^{6,9} which in their accumulation have been reported to lower QoL and increase unmet supportive care needs.⁷

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Similar to LLL, the reported prevalence of depression (6%–58%) and anxiety (20%–53%) among gynecological cancer survivors varies widely across studies.^{3,13–17} Younger age, pessimism, being white, physical impairment, unsupportive family and friends, higher stage of cancer, and recent diagnosis of cancer are factors that have been associated with higher levels of psychological distress.^{3,15,18} Women who use avoiding coping strategies, including self-blame and wishful thinking, have also been reported to experience higher levels of psychological distress.¹⁵ Women with high levels of psychological distress have been found to have a poorer compliance with treatment, and lower QoL compared with women with lower distress levels.¹⁹ Gynecological cancer survivors with depression and anxiety are also more likely to report unmet supportive care needs.^{14,17}

The supportive care needs of women with LLL, depression, or anxiety have been studied in isolation, but little research has assessed these symptoms and their effect on supportive care needs and service use after gynecological cancer simultaneously.^{6,7,14,17,19} Besides describing the prevalence of LLL, anxiety, and depression among gynecological cancer survivors, this study aimed to determine factors associated with these conditions as well as those associated with the survivors not using available and needed services to alleviate these conditions.

Methods

This study was conducted at the Queensland Centre for Gynaecological Cancer (QCGC) located at the Royal Brisbane and Women's Hospital (RBWH) in Australia. Potentially eligible women were selected from the records in the QCGC Registry. Eligibility criteria included having been diagnosed with gynecological cancer at least 5 months and no more than 30 months before the study date, female, 18 years or older, and providing written informed consent. Exclusion criteria were not being able to understand or write English or mental impairment. Overall, 327 potential participants met the eligibility criteria and were sent a letter of invitation to participate in the study. Of those, 173 patients (response rate, 53%) provided written informed consent and mailed back their questionnaires. Data was incomplete for 13 patients, and 160 complete questionnaires were included in analysis. The data manager extracted information from the cancer registry about the participants' age, cancer diagnosis (type and stage), and treatment information (treatments received). Ethical approval was obtained from RBWH Human Research Ethics Committee.

Materials

The questionnaire included the following items:

- Demographic characteristics, including age, marital sta-

tus, income, education, and employment.

- The Gynecologic Cancer Lymphedema Questionnaire (GCLQ), for measuring symptoms of lymphedema in the previous 4 weeks. This 20-item, self-administered questionnaire assesses various aspects of leg heaviness, swelling, infection, numbness, and physical functioning. The questionnaire is a reliable tool with a good sensitivity and specificity for LLL if the patient reports 4 or more symptoms of lymphedema.²⁰
- The Hospital Anxiety and Depression Scale (HADS), a reliable and valid self-administered screening tool of anxiety and depression that is particularly suitable for cancer populations.^{21,22}
- The short form of the Supportive Care Needs Survey (SCNS-SF34), for determining the number of unmet supportive care overall and within the 5 domains of psychological, physical and daily living, patient care and support, and sexuality needs. The survey is a validated measurement tool specifically developed for cancer populations.²³ In addition, patients completed the Need for Services module of the SCNS. The first 5 questions of the module, related to hospital facilities were omitted, because the women were at least 5 months post diagnosis.
- The Functional Assessment of Cancer Therapy-General (FACT-G), for measuring QoL in the physical, social, functional, and emotional well-being domains. The FACT-G is a validated measurement tool that is widely used in cancer populations.²⁴

Statistical analyses

Descriptive statistics were used to summarize the participants' demographic and clinical characteristics, as well as prevalence of LLL, depression, and anxiety. For the purpose of this report, we define LLL if women self-reported swelling and an additional 3 or more other leg symptoms according to Carter and colleagues.²⁰ To define high levels of anxiety and depression, a HADS cut-off level of 8 points was used, as described by Bjelland and colleagues.²¹

Chi-square tests and logistic regression analyses were used to explore the associations between LLL, depression or anxiety, and demographic and clinical patient characteristics. Those found to be associated at a *P* value <.2 were entered into multivariable logistic regression models to determine the independent factors associated with each of the outcome variables. For continuous variables, *t*-tests were used to compare the means of women with or without LLL depression or anxiety. We plotted the proportions of women with and without LLL, high levels of depression and/or anxiety against their need for and use of services to establish whether services reached the women of greatest need. We created a variable of psychological distress for women who had high scores of anxiety and/or depression

(>8) on the HADS. We grouped women by whether they reported a need for a service but had not used it and we conducted a multivariable logistic regression to establish the factors associated with not using services as needed, entering distress, LLL, and sociodemographic and clinical details by forced entry and retaining only those factors with significant contribution only. A standard *P* value of .05 was used.

Results

Sample

Most of the participating women were older than 50 years (80%) with a mean age of 61 (59-63) years. Most women were treated for endometrial cancer (49%), and a few were treated for vulval cancer (6%). Sixty-seven percent were married or lived together with a partner. Surgery was the main treatment received by 88% of the women, chemotherapy by 44%, and radiotherapy by 22%. The prevalence of self-reported LLL was 30%. High levels of depression or anxiety were reported by 21% and 24% of women, respectively (Table 1). Depression (29%) or anxiety (31%) was more commonly reported by women with LLL than by those without LLL (19% and 21%, respectively).

Impact of LLL

Women with LLL had significantly higher mean scores of unmet needs in psychological ($P = .01$), physical and daily living ($P = .04$), health needs ($P = .02$), and patient care needs ($P = .02$) compared with women without LLL. Women with LLL also had a significantly lower physical well-being ($P = .008$) compared with survivors without LLL. Functional well-being ($P = .08$) and overall QoL ($P = .08$) were also somewhat worse in women with LLL than without, but only achieved borderline significance.

Use of services

Women with LLL needed more services in every domain, especially a lymphedema specialist (34%), physiotherapist (37%), psychologist (23%), exercise physiologist (21%), and dietician (21%). In all, 15% of the women with LLL needed but did not use the service of a lymphedema specialist, and 10% needed but did not use a physiotherapist and/or a pain specialist (Table 2).

Impact of depression and anxiety

Women without a partner were somewhat more likely to have higher depression levels ($P = .06$). Older women (>70 years) were less likely to report higher levels of anxiety ($P = .04$). Participants who were unemployed reported higher levels of depression and anxiety ($P = .01, .02$, respectively) as did those who were retired ($P = .02, .07$). Of those factors, being unemployed (odds ratio [OR], 11.34; 95% confidence index [CI], 2.12- 60.45; $P < .01$) and being

retired (OR, 10.82; CI, 2.08-56.31; $P = .01$) remained independently significant and were associated with high levels of depression in multivariable analyses. Older age (OR, 0.29; CI, 0.13- 0.64; $P < .01$), being unemployed (OR, 5.80; CI, 1.56- 21.51; $P = .01$), and retired (OR, 7.77; CI, 2.15-28.07; $P = .01$) remained independently significant in women with high levels of anxiety in multivariable analyses. Women with high levels of depression and/or anxiety had significantly higher mean scores of unmet needs than women with low levels of depression and/or anxiety in all domains: psychological ($P \leq .01$), physical and daily living ($P \leq .01$), health needs ($P \leq .01$), patient care ($P \leq .01$), and sexuality ($P \leq .01$). Women with high levels of depression and/or anxiety had significantly lower QoL in all domains: physical ($P \leq .01$), social-family ($P \leq .01$), emotional ($P \leq .01$), functional ($P \leq .01$), and total well-being ($P \leq .001$).

Use of services

Women with high levels of depression needed more services in every domain compared with women with low levels of depression. The women needed but did not use a psychologist (23%), psychiatrist (18%), and a pain specialist (21%). Women with high levels of anxiety needed more services in every domain compared with women with low levels of anxiety. The women needed but did not use a pain specialist (26%), psychologist (24%), lymphedema specialist (18%), and psychiatrist (18%; Table 2).

Factors associated with unused services

In bivariate analyses women with psychological distress ($P < .01$) were more likely to need but not use services, whereas who were women treated with radiotherapy ($P = .03$) were less likely to need but not use services. Of those factors, psychological distress (OR, 6.52; CI, 2.79-15.23; $P < .01$) remained independently significant in multivariable analyses.

Discussion

In this study, women with LLL, or those with elevated levels of depression and/or anxiety after treatment for gynecological cancer had higher supportive care needs and reported lower QoL compared with women without LLL, depression, and anxiety. Having experienced LLL also meant that women were more likely to report psychosocial distress. Women with these sequelae needed more services than did other women, but a substantial proportion (10%-15%) did not use them. The only factor independently associated with not using needed services was depression. As in this study, previous studies have also found higher unmet supportive care needs and lower QoL in women with LLL, depression, and anxiety.^{6,7,14,17,19} Our study expands on previous studies by assessing services needed and used, and factors associated with not using services.

TABLE 1 Patient characteristics

Characteristic	No. of patients (%) N = 160	Characteristic	No. of patients (%) N = 160
Age, y		Endometrial	
<49	32 (20)	Ovarian	78 (49)
50-69	89 (56)	Vulval	42 (26)
>70	39 (24)	Stage (figo)	
Marital status		1-2	113 (71)
Married/living together	107 (67)	3-4	47 (29)
Living without partner	53 (33)	Time since diagnosis, mo.	
Education^a		5-12	32 (20)
No schooling/elementary school	27 (17)	13-24	97 (61)
Junior high school	56 (35)	25-29	31 (19)
Senior high school	29 (18)	Surgical resection	
Trade/diploma/technical certificate	16 (10)	Yes	141 (88)
University/college	29 (18)	No	19 (12)
Income, AUS^a		Chemotherapy	
<20,000	51 (32)	Yes	71 (44)
20,001-40,000	40 (25)	No	89 (56)
>40,001-60,000	22 (14)	Radiotherapy	
>60,000	21 (13)	Yes	35 (22)
Prefer not to answer	25 (16)	No	125 (78)
Ethnicity^a		Lymph-node resection	
British/Scottish/Welsh/Irish	122 (76)	Yes	80 (50)
European	16 (10)	No	80 (50)
Other	16 (10)	BMI^a	
Work^a		<30	39 (24)
Employed	41 (26)	≥30	87 (54)
Unemployed/home duties	23 (14)	Anxiety	
Retired	93 (58)	<8	121 (76)
Time to travel to reach primary care provider, min		≥8	39 (24)
<15	101 (63)	Depression	
>15	59 (37)	<8	126 (79)
Clinical		≥8	34 (21)
Cancer type		Lower-limb lymphedema	
Cervical	31 (19)	No	48 (30)
		Yes	109 (70)

^aNumbers vary slightly due to some missing responses.

Clinical (such as tumor type) or demographic factors (such as age) were expected to be associated with service need and use, but the only factor to be associated with not using needed services to alleviate symptom burden was psy-

chological distress. Of note is that the use of services was not different depending on women's distance from their regular general practitioner, which indicates that other reasons than immediate access need to be explored in future

TABLE 2 Services needed and used or not used by women with or without lower-limb lymphedema, depression, or anxiety

Service	Lower-limb lymphedema, n (%)				Depression, n (%)				Anxiety, n (%)			
	No		Yes		No		Yes		No		Yes	
	Needed + used	Needed, not used	Needed + used	Needed, not used	Needed + used	Needed, not used	Needed + used	Needed, not used	Needed + used	Needed, not used	Needed + used	Needed, not used
General practitioner	64 (60)	2 (2)	34 (71)	1 (2)	73 (58)	2 (2)	28 (82)	1 (3)	68 (56)	2 (2)	33 (85)	1 (3)
Gynecologist	35 (32)	2 (2)	16 (33)	3 (6)	41 (33)	2 (2)	11 (32)	3 (9)	34 (28)	3 (2)	18 (46)	2 (5)
Pain specialist	5 (5)	6 (6)	4 (8)	5 (10)	6 (5)	2 (2)	3 (9)	9 (26)	5 (4)	3 (2)	4 (10)	8 (21)
Lymphedema specialist	2 (2)	4 (4)	9 (19)	7 (15)	8 (6)	5 (4)	3 (9)	6 (18)	8 (7)	6 (5)	3 (8)	5 (13)
Exercise physiologist	2 (2)	6 (6)	6 (13)	4 (8)	3 (2)	6 (5)	5 (15)	4 (12)	4 (3)	4 (3)	4 (10)	6 (15)
Physiotherapist	12 (11)	8 (7)	13 (27)	5 (10)	17 (13)	9 (7)	8 (24)	4 (12)	17 (14)	7 (6)	8 (21)	6 (15)
Psychologist	2 (2)	6 (6)	7 (15)	4 (8)	3 (2)	2 (2)	6 (18)	8 (24)	2 (2)	1 (1)	7 (18)	9 (23)
Psychiatrist	0 (0)	6 (6)	1 (2)	3 (6)	0 (0)	3 (2)	1 (3)	6 (18)	0 (0)	2 (2)	1 (3)	7 (18)
Social worker	10 (9)	0 (0)	6 (13)	2 (4)	10 (8)	1 (1)	6 (18)	1 (3)	10 (8)	0 (0)	6 (15)	2 (5)
Dietician	9 (8)	3 (3)	7 (15)	3 (6)	9 (7)	3 (2)	7 (21)	3 (9)	12 (10)	1 (1)	4 (10)	5 (13)

studies as barriers to service use. It may be that women with psychological distress tend to use problem-focused or avoiding coping strategies, which make them less likely to attend services even if they are available.¹⁵ Beesley and colleagues found that women with greater psychological stress used more information support from non-medical sources and suggested that they may therefore not seek sufficient emotional support or help.^{6,15} Online support services have been tested for their ability to lower psychological distress by providing online group support sessions or one-to-one counseling sessions with psychologists. In contrast to the findings by Beesley and colleagues, these online support services have been found to reduce psychological distress, pain, and improve QoL and coping.²⁵⁻²⁸ Further testing of such online services for women with high symptom burden could provide evidence whether needs can be met without physical contact with a health care provider, though it can be suspected that this would be less likely for physical ailments.

The prevalence of LLL in this sample was 30%, which corresponds to prevalence rates in previous reports.⁵⁻¹² However, as noted before in this article, there is a large variability in reported prevalence rates because of differences in the measurements used and the proportion of women with different types of gynecological cancers. This study used the Gynecologic Cancer Lymphedema Questionnaire, which was specifically developed for this population and is thus likely to accurately report LLL. Services needed and not used by a relatively large proportion of women with LLL were those of a lymphedema specialist, pain specialist, and

physiotherapist (10%-15% of women needed but did not use these services), and the reason for these women with high needs not using available services should be investigated in future studies.

The prevalence of depression and anxiety in our sample was 21% and 24%, respectively, which is similar to those reported in other studies.^{3,13-17} About 15%-20% of women with high levels of depression and anxiety did not use the services of a psychiatrist, psychologist, and pain specialist, although they needed to, and women with high levels of anxiety and/or depression did not use a lymphedema specialist although they needed to, indicating that distress can also impede women in getting the support for physical ailments.

Women with high levels of depression and/or anxiety were more likely to be unemployed and retired, but older age seemed to be protective against high levels of anxiety, which is concordant with previous findings.^{15,18} According to the outcomes of this study, there are still not enough women with physical and psychological sequelae who are using services. Women reported low QoL in different domains, which may be due to these unmet supportive care needs and unused services.²⁹ Previous reports have found that awareness of available services may be low in cancer patients, and that even if they are aware, only 40% use the services. Service use is strongly correlated with referral from a health care provider.² However, Steginga and colleagues found that less than one-third of cancer patients reported receiving advice about community support outside of the hospital during their treatment and that only

one-fifth received the advice after their treatment.³⁰

Other possible reasons for low service uptake could be that the available services do not match the women's needs or the out-of-pocket costs that are often associated with using allied health care services. In a recent international comparison of health care in 11 countries, 55% of Australian patients reported gaps in their discharge planning, 39% reported carrying AUS\$1,000 or more of out-of-pocket costs, and 30% reported cost-related access problems.³¹ There are already guidelines available about optimal psychosocial support for cancer patients, but health care providers have been found to not apply them systematically.² This may be due to an underestimation of the psychological needs of the cancer patient by nurses and physicians.¹⁹ Okuyama and colleagues found that oncologists were not able to accurately detect physical symptoms and borderline depression and/or anxiety.³² The International Psycho-Oncology Society has identified distress as the sixth vital sign in cancer care. The value of integrating routine screening for distress is currently being evaluated in several randomized trials. Results to date indicate that such screening leads to more appropriate referral for and better uptake of psychosocial services.³³⁻³⁶ The findings of this study indicate the need to better direct services toward gynecological cancer patients who currently underuse needed services, in particular women with LLL. Additional or alternative service delivery using innovative routes such as telephone, internet, or e-mail may help increase the awareness and use of services among women with LLL, depression, and anxiety after gynecological cancer treatment.³⁷

Some important limitations of this study need to be considered when interpreting the results. We did not ask women for pre-existing diagnosis of psychiatric conditions, and are thus not able to determine whether the levels of distress and unmet needs were higher depending on such preexisting condition. Although the sample is a good reflection of the distribution of gynecological cancers within Queensland, the sample size was small, with only 160 women overall completing the questionnaire and 30% reporting LLL, thus limiting the statistical power to detect factors associated with low service use. Furthermore, the sample consisted of mostly of white women with European background (90%) and other ethnicities were not well represented. The survey used self-report to determine LLL, depression, and anxiety, and that may not completely overlap with the clinical assessment of these symptoms; however the prevalence rates were similar to those in previous studies indicating that women accurately reported their symptoms. Older women (>70 years) were underrepresented and the prevalence rates of depression and anxiety may therefore be somewhat higher than in previous reports.¹⁵ The findings on supportive care needs and service use in this study may be difficult to generalize to

other countries, states, and territories because of differences in service provision and access to supportive care. Lastly, women who selected to participate might have been more outspoken than those who did not respond. If these women were less likely to experience distress, then this would likely cause an underestimation of the prevalence of unmet needs in the present report.

In summary, our study has highlighted the unmet supportive care needs, service needs and QoL in gynecological cancer survivors with LLL and high levels of depression and/or anxiety. Still more needs to be done to better direct women with high supportive care and service needs toward those services, possibly by introducing routine screening for distress³⁸ or developing survivorship care plans for the women before they are discharged from the hospital.³⁹ The focus in the future should be on the testing of interventions to prevent development of LLL, depression and anxiety in randomized clinical trials.

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