

**Gynecological cancer survivors and community support services:
referral, awareness, utilization and satisfaction**

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Full title: Gynaecological cancer survivors and community support services: referral, awareness, utilisation and satisfaction

Short title: Gynaecological cancer survivors and community support services

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Abstract

Objectives. To quantify gynaecological cancer survivors' referral to, awareness of, utilisation of and satisfaction with community support services, as well as the factors associated with service use.

Methods. In 2004, 802 gynaecological cancer survivors, three months to five years post-diagnosis, completed a postal questionnaire (56% response rate). Descriptive statistics summarised outcome prevalences. Logistic regression models identified correlates of service utilisation.

Results. Substantial proportions of women were aware of the main cancer support organisation, Cancer Council Queensland (72%), and of information booklets (74%), helplines (66%), support groups (56%) and internet information (50%). Less than half were aware of other services. The most commonly used resources and services were information booklets (37%), the internet (23%), and helplines (20%). More broadly, 43% utilised information/internet support, 30% utilised psychosocial services and 27% utilised functional/practical services. Approximately one-fifth (19%) used more than one support types. Having a health care provider referral, being diagnosed with lymphoedema or living in northern Queensland were associated with higher odds of service use in all three of the support types. While most (86%) of those referred used a service, only a few women received referrals. Among users, satisfaction with services was high.

Conclusions. While gynaecological cancer survivors accessed a variety of support, there is a need to ensure women are aware of services. Given the low prevalence of referrals and that referral was a key influence on service use, clinician education may be necessary to improve service referral. Organisations should also consider strategies to keep services high on clinicians' radars.

Introduction

Gynaecological cancers are the second most common type of cancer among women worldwide, with global incidence rates estimated at 16, 7 and 7 per 100,000 for cervical, uterine and ovarian cancers respectively [1]. Most gynaecological cancer diagnoses, except ovarian cancer, are associated with relatively high, and improving, 5-year survival rates (75% cervical, 83% uterine and 55% ovarian cancer) [2]. With high incidence and improving survivorship there is a growing need to promote and support the longer-term health of cancer survivors [3-5]. Addressing their specific support needs, such as those caused by impaired fertility, treatment-related menopause, diminished sexual response and lower-limb lymphoedema [6-9], is crucial to improving quality of life outcomes [10].

Community-based organisations provide an ideal setting for delivery of evidence-based support services [11]. However research suggests that awareness of such services may be low among cancer survivors and that even among those aware of services, less than 40% utilise them [12, 13]. There has been no prior research in Australia focusing on the population utilisation of community-based services specifically by gynaecological cancer survivors, correlates of using support services, or satisfaction with services. Such information will assist in understanding how best to target support services to the appropriate groups.

Using a population-based survey, we aimed to establish the prevalence of community support service use among gynaecological cancer survivors, social-ecological correlates of use and the level of satisfaction associated with this utilisation. We also aimed to quantify referral to existing services by health care providers and the general awareness of these services within this group.

Methods

Participants and Procedures

Approval for this study was obtained from Queensland University of Technology Human Research Ethics Committee and from the ethics committees of all participating hospitals. A cross-sectional mail survey was conducted within a sample of Australian gynaecological cancer survivors in 2004. Women were selected from a quasi-population-based registry (the Queensland Gynaecological Cancer Registry, QGCR). Eligible women were between three months and five years post-diagnosis, at least 18 years old, physically and mentally able to complete a written questionnaire, and able to speak English. Stratified sampling was

conducted by cancer types (ovary, cervix, uterine and all other gynaecological cancers) and cancer survival phase (3-12 months, 1-3 years and 3-5 years post-diagnosis) for anticipated subgroup analyses.

After obtaining permission from treating doctors, approximately 200 patients within each of the four cancer types and three survival phases (mentioned above) were randomly selected and sent a letter signed by their doctor, study information sheet, consent form, questionnaire, and prepaid return envelope. Non-respondents were sent two reminder letters after two and six weeks and a telephone follow-up was conducted at week four.

Data collected within this study was guided by a social-ecological model. A further description of study procedures, the social-ecological model and the variables included and all the scales used is given elsewhere [14]. In brief, the questionnaire collected a broad range of potential service use correlates including: *demographic characteristics* (age, marital status, education, employment, household income, country of origin and number of children living at home); *diagnosis and treatment information* (cancer type, survival phase, disease stage, treatment centre, surgery, chemotherapy, radiotherapy, hormone therapy, lymph nodes removed and last admission for treatment); *physiological condition* (remission, lymphoedema, stoma, hospitalisation, co-morbidities, menopause, hormone replacement therapy and sexual activity); *supportive care needs* (psychological, sexuality, physical/daily living, patient care/support and health system/information needs); *current wellbeing* (physical, social/family, emotional and functional wellbeing); *health behavior characteristics* (alcohol consumption, smoking, physical activity, vegetable intake, fruit intake and body mass index); *social and health care support* (social support, complementary therapy use and service referral); *and geographical location* (Accessibility/Remoteness Index of Australia, Socio-Economic Indexes of Areas, Rural, Remote and Metropolitan Area classification and three Queensland zone classification).

Outcome measures: community support service awareness, referral, use and satisfaction

A list of community cancer support services was constructed using a literature search and a filtered search of OnCall (the Cancer Council Queensland (CCQ) service database) for services most commonly referred to gynaecological cancer patients by CCQ Helpline staff. Participants were then asked to indicate whether or not they were “aware of”, “had been referred to by a health care provider” or “ever utilised” each service (yes or no), and to rate

their satisfaction with each service they had used (0 = “not at all” to 4 = “very much satisfied”). We also asked whether they were “aware of” the CCQ.

Statistical methods

Prevalence of referral, awareness, and use of individual community support services were summarised with associated 95% confidence intervals (CIs) for key estimates. Reported prevalences were weighted by the inverse of each woman’s chance of selection from stratified sampling to reflect the original gynaecological cancer population. Logistic regression modeling was conducted to identify social-ecological correlates of users of: 1) information/internet support including information booklets, internet based information and internet support groups; 2) psychosocial services including telephone helplines, support groups, workshops/programs and counselling and; 3) functional/practical services including physiotherapy, financial assistance, respite care and community health nurses. Women were categorised as service users (ie, those who used at least one of the specified support services) and non-users. Multicollinearity was tested for suspected to be highly correlated variables; having a referral to functional/practical services and use of functional/practical services were highly correlated ($r = 0.79$) and thus referral was omitted from consideration of correlates of use of functional/practical services.

As the social-ecological framework is broad, including all variables in the models resulted in over specification. Therefore, independent variables were grouped into blocks (demographic characteristics; diagnosis and treatment information; supportive care needs; wellbeing; health behavior characteristics; social support; complementary therapy use, service referral; and geographical location). Blocks (excluding supportive care needs and wellbeing which were the focus) were entered alone, then contextually significant variables (defined as those related to service use with an odds ratio >1.80 or <0.55) identified in each block were included in a final model along with supportive care needs and wellbeing variables, and the study design stratification variables (cancer type and survival phase). Final results are reported for all contextually meaningful associations with a statement of whether the difference was supported statistically (at the conventional level of 0.05, two-tailed).

Results

Participants

A total of 1774 women were mailed the questionnaire, of whom 354 were ineligible for the

following reasons: 130 deceased, 121 incorrect or insufficient address, 62 too sick, 23 moved out of Queensland, 15 non-English speaking, and 3 indexed incorrectly on the QGCR. Of the remaining 1420, 56% (802) responded to the survey. Participants were representative of women in the sampling frame, except women 70 years and older who were under-represented. Key demographic, diagnosis and treatment characteristics of the sample are listed in Table 1. The majority of women were 50 years or older (74%) and either married or living with partner (66%). The similar percentages of women with cervical, endometrial, ovarian and other gynaecological cancers were due to the stratified sampling. Surgery was mostly open abdominal (73%) and the majority of women had neither chemo- nor radiotherapy after their surgery.

Referral to and awareness of community support services

Generally, 33% (CI: 29% to 37%) of women were referred to information/internet support (information booklets, internet-based information and internet support groups), 28% (CI: 25% to 32%) were referred to psychosocial services (telephone helplines, support groups, workshops/programs and counselling) and 24% (CI: 21% to 27%) were referred to functional/practical services (financial assistance, respite care and community health nurses). In particular, health providers referred more women to information booklets (31%) than any other service (Figure 1). Telephone helplines were the next most frequently referred support service (19%), while 15% or less of survivors were referred to other services (Figure 1).

Approximately three-quarters of women (74%) were aware of information booklets (Figure 1). Two-thirds (66%) were aware of telephone helplines and approximately half were aware of community support groups (56%), information on the internet (50%), workshops for coping with cancer (47%), and face-to-face counselling (46%) (Figure 1). Less than 40% were aware of other services (Figure 1). Of the women who were aware of support services, 67% had used at least one. Of the women who received a referral, 86% used a service. In regard to CCQ, which offers a range of the services discussed above, 72% of women reported being aware of this organisation.

Use of and satisfaction with community support services

Overall 54% (CI: 50% to 58%) of women reported having utilised at least one community support service since being diagnosed. More specifically, 43% (CI: 39% to 47%) utilised information/internet support, 30% (CI: 27% to 33%) utilised psychosocial services and 27%

(CI: 23% to 30%) utilised functional/practical services. Few women (13%) used all three types of support. Approximately one fifth (19%) used one or more type of support with the most common combination being information/internet support and psychosocial services (12%). Individually, the most commonly used cancer support services were: information booklets (37%), internet information (23%) and telephone helplines (20%) (Figure 1). On average, across all supportive care services, women were completely satisfied with the services they used (i.e. median rating of four, range 0-4). The exceptions to this were satisfaction rating for internet-based support groups and internet-based information, which each had a median rating of three and ranged widely (0-4).

Correlates of support service use

Demographic and referral factors associated with increased odds of using information/internet support, psychosocial services and functional/practical services are listed in Table 2, and associated diagnosis and health factors are listed in Table 3. Living in regional northern Queensland, having a health care provider referral or being diagnosed with lymphoedema was associated with use of each of the three service types.

Additional factors associated with higher odds of information/internet support use included being single, more highly educated, being pre- or peri-menopausal, having unmet psychological needs and lower physical wellbeing. Additional factors associated with higher odds of psychosocial support use included being younger than 60, being separated/divorced, being diagnosed with a gynaecological cancer other than cervical cancer, being pre- or peri-menopausal, having unmet health system/information or sexuality needs, having no unmet patient care/support needs. Moreover, factors associated with higher odds of functional/practical support use also included being younger or retired.

Discussion

This study considers the inter-relationships between community support service referrals, awareness, use and satisfaction, and considers service use correlates within the traditional biomedical model as well as social-ecological factors that are important in a community setting. It is the first population-based study to consider these outcomes specifically in Australian gynaecological cancer survivors. Our study highlights that service use among gynaecological cancer survivors was strongly correlated with having received a referral from a health care provider; however, few patients received such referrals. Similar to the present

study, Steginga *et al* [13] found that less than one-third of patients with solid tumors or hematological cancer reported being given advice during treatment about community support available outside of the hospital and only one-fifth were given this advice after treatment completion. Steginga *et al* [13] also found that despite the introduction of clinical guidelines for psychosocial care of cancer patients in 2003 [15], integration of such care into cancer patients' oncology pathways is not being applied systematically by health professionals [13]. This may be because clinicians do not always see it as their role to address psychosocial needs and hence may not formally assess distress [16, 17]. In addition, they may not be aware of the available services or local referral networks. To increase the likelihood of referral, community organisations may need to introduce innovative concepts to keep their services salient to clinicians such as, providing pre-printed referral pads or regularly relaying key messages clinicians may use to encourage service use.

Our findings indicate that in Queensland, gynaecological cancer survivors access multiple sources of supportive care, including information brochures, internet sites, psychosocial, functional and practical support services. Hutchison *et al* [18], in their tiered, psychosocial, community-based intervention model, identified cancer-related information as a resource important for all patients diagnosed with cancer, followed by educational and peer support for those exhibiting mild distress and counselling for those with moderate-to-severe distress. This triage model is supported by the results of this study, with women predominately utilising cancer information services (43%), where as face-to-face counselling was utilised by roughly one-tenth of participants.

Our study, like another interim report on cancer service use [19], indicated that user satisfaction with support services was high. However, this is not to say that all women considered their needs met fully nor that they had received appropriate supportive care. Unmet psychological needs have been identified as a top priority by gynaecological cancer survivors [14] and it has been estimated that if all cancer survivors with mental health problems did receive professional counselling, use of such services could increase by as much as 62% [12]. Our study may well support this; indicating that while women with unmet psychological needs were more likely to utilise the information/internet support, they were no more likely to use psychosocial support services. Women with unmet psychological needs possibly employ problem-focused coping strategies, seeking information rather than emotional support [20]. On the other hand, psychosocial services users probably adopt

emotion-focused coping strategies and seek out psychosocial services to meet their psychological needs [20], but these women appear less likely to also adopted problem-focused coping strategies as indicated in our study by their higher odds of unmet information needs and by our findings that 30% utilised psychosocial services but only 12% utilised psychosocial and information/internet support.

Overall service use among gynaecological survivors was low compared to Australian women diagnosed with breast cancer, where 30% or more utilised support groups, physiotherapy, or social workers [21]. Reasons for these differences could include the higher awareness of services within the breast cancer community, and different samples (metropolitan for the breast cancer study, compared to population-wide for this study). In Queensland, 30% of people live outside urban areas [11] away from where most support services and organisations are located. An American national-based sample reported that 9% of female cancer survivors utilised psychosocial support services [12]; our results are consistent. Interestingly though, it was the women who lived outside the highly-populated service-assessable south-east corner of Queensland who were more likely to utilise support services. With regard to functional/practical service use, this may reflect, in part, rural women taking advantage of financial schemes for travel assistance to treatment facilities or it may indicate an increased need for practical support. Previous research has shown that women living in rural or remote locations suffer heightened physical/daily living needs [14] possibly due to the physically high demands placed on them by agricultural, forestry and fishing employments [22].

To our knowledge, no previous study has measured correlates of support service use among gynaecological cancer survivors. Among breast cancer survivors, service use correlates include being single or divorced [23], having received chemotherapy [24], and younger age [21, 23, 24]. Our study found, even after age-adjustment, that being single was associated with use of information/internet support and being divorced was associated with psychosocial support utilisation. We also confirm that younger age was associated with psychosocial and functional/practical service use. Because we looked at service use within three classifications, we also identified a number of correlates that were sensitive to these distinctions. In particular, we additionally found that higher education was associated with utilisation of information/internet support. This could facilitate active decision making and allow women to engage their clinicians in discussions of care. This may well be one of the mediators of better treatment outcomes consistently observed in higher educated people [25].

There are several limitations to consider when interpreting our results. Firstly, this was a Queensland-based study and therefore may be limited in its generalisability to other national states and territories, or internationally, as service provision and access to community support modalities is different depending on location. Secondly, the exclusion of patients considered too ill to participate or unable to speak adequate English likely may have resulted in an under-estimation of service utilisation assuming that these women would be higher users of services due to greater support needs. Thirdly, this study achieved a 56% response rate. This is in line with current epidemiological study achievements in cancer populations [26]. It would be expected that, and indeed there was, some response bias, with older women (>70 years) being under-represented. This could potentially cause over-estimation of reported support use, as younger women were more likely to use support services.

Nevertheless, this study reveals a clear need to ensure that women are being made aware of appropriate cancer support services and further suggests that one of the most effective ways of ensuring service uptake is through increasing health care provider referrals. Clinician education could improve knowledge of psychosocial care guidelines and elevate referral rates to community services. While user satisfaction of support services is high, future research should consider if service use is appropriately triaged in relation to patients' needs, levels of distress, and coping styles.

Conflict of interest

The authors declare that there are no conflicts of interest.

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Table 1
Key demographic, cancer diagnosis and treatment characteristics of 802 study respondents, in Queensland, Australia, 2004

Characteristics	n	%
Age (years) ^a		
18-39	77	9.6
40-49	134	16.7
50-59	216	26.9
60-69	221	27.6
70+	154	19.2
Marital status ^a		
Single	65	8.2
Married/living with partner	527	66.3
Separated/divorced	89	11.2
Widowed	114	14.3
Type of gynaecological cancer ^b		
Cervical	197	24.6
Uterine	243	30.3
Ovarian	234	29.2
Other	128	16.0
Survival phase post-diagnosis ^b		
3-12 months	190	23.7
>1-3 years	335	41.8
>3-5 years	277	34.5
Stage ^b		
Early stage	558	69.6
Late stage	204	24.4
No stage/ don't know	40	5.0
Surgery ^b		
None	13	1.6
Vaginal or laparoscopic	120	15.0
Open abdominal	584	72.8
Open bowel resection	67	8.4
Unknown	18	2.2
Chemotherapy ^b		
Yes	297	37.0
No	505	63.0
Radiotherapy ^b		
No radiotherapy	598	74.6
Internal brachytherapy	41	5.1
External beam radiotherapy ± brachytherapy	163	20.3

^a patient self reported data

^b Queensland Gynaecological Cancer Registry data

TABLE 2

Demographic and referral correlates of reporting service use since cancer diagnosis (final main effects model)

		Information/internet support users	Psychosocial services users	Functional/practical services users
	n^a	Adjusted OR (95% CI)	Adjusted OR (95% CI)	Adjusted OR (95% CI)
Age (years)				
18-49	155-176		1.82 (0.63-5.22)	3.42 (1.40-8.50)*
50-59	135-146		1.89 (0.89-4.01)	2.80 (1.27-6.12)*
60+	172-182		1.00	1.00
Marital status				
Single	33-35	2.38 (0.93-6.11)	1.59 (0.57-4.49)	
Married/living with partner	325-335	1.00	1.00	
Separated/divorced	51-54	1.76 (0.82-3.77)	2.06 (0.87-4.86)	
Widowed	49-53	0.74 (0.29-1.90)	1.24 (0.47-3.25)	
Education Level				
A university or college degree	96	2.10 (1.08-4.06)*		
A technical certificate/diploma	68	2.08 (1.00-4.32)		
Senior high school	74	1.67 (0.83-3.35)		
Junior high school	192	1.00		
Primary school or no schooling	43	1.03 (0.40-2.65)		
Employment type				
Paid full- time	104			1.67 (0.77-3.64)
Paid part time or casual	103			1.00
Home duties	81			1.58 (0.67-3.73)
Retired	130			2.89 (1.12-7.47)*
Unable to work because of illness	38			1.48 (0.48-4.57)
Geographic location				
South east Queensland	329-359	1.00	1.00	1.00
Central and south west	70-75	1.33 (0.44-4.01)	2.81 (0.78-10.19)	3.60 (1.04-12.45)*
Northern zone	60-70	2.10 (0.54-8.17)	5.27 (1.04-26.60)*	2.53 (0.62-10.28)
Health care provider service referral ^b				
Not referred	302-331	1.00	1.00	^c
Referred to at least one service	131-171	9.94 (5.85-16.89)*	11.98 (6.58-21.83)*	

n: participant numbers; OR: odds ratio; CI: confidence interval; Adjusted: see text for full social-ecological correlates list

^a three models fitted and number of missing data varied

^b referral to services classified within the outcome variable only

^c referral and use were too highly correlated ($r = 0.79$) to be considered in the same model

*Statistically significantly different from the referent group, $p < 0.05$

Note: Blanks indicate no contextual or statistical significance

TABLE 3

Diagnosis and health correlates of reporting service use since cancer diagnosis (final main effects model)

		Information/internet support users	Psychosocial users	services	Functional/practical services users
	n^a	Adjusted OR (95% CI)	Adjusted OR (95% CI)		Adjusted OR (95% CI)
Type of gynaecological cancer					
Cervical	127		1.00		
Uterine	123		2.20 (0.94-5.16)		
Ovarian	148		2.52 (1.16-5.48)*		
Other	64		2.87 (1.18-7.02)*		
Lymphoedema status					
No lower limb swelling	354-391	1.00	1.00		1.00
LL swelling, but not diagnosed	60-64	1.45 (0.69-3.05)	2.47 (1.11-5.47)*		1.53 (0.74-3.16)
Diagnosed lymphoedema	45-49	1.90 (0.84-4.34)	1.92 (0.80-4.62)		3.44 (1.61-7.39)*
Menopausal Status					
Pre or peri menopausal	19-23	2.45 (0.53-11.36)	3.97 (1.04-15.23)*		
Post menopause prior to cancer	247-248	1.00	1.00		
Iatrogenic menopause	165-183	1.49 (0.74-3.02)	0.92 (0.42-2.01)		
Health system/information needs					
No unmet needs	306		1.00		
Some unmet needs	156		2.01 (0.98-4.15)		
Psychological needs					
No unmet needs	240	1.00			
Some unmet needs	233	1.97 (1.02-3.80)*			
Patient care/support needs					
No unmet needs	365		1.00		
Some unmet needs	97		0.40 (0.19-0.87)*		
Sexuality needs					
No unmet needs	341		1.00		
Some unmet needs	121		2.05 (1.00-4.20)		
Physical well-being					
Lowest quartile	125	1.82 (0.70-4.74)			
2 nd quartile	109	1.50 (0.67-3.38)			
3 rd quartile	142	1.12 (0.54-2.26)			
Highest quartile	97	1.00			

n: participant numbers; OR: odds ratio; CI: confidence interval; Adjusted: see text for full social-ecological correlates list

^a three models fitted and number of missing data varied

*Statistically significantly different from the referent group, $p < 0.05$

Note: Blanks indicate no contextual or statistical significance

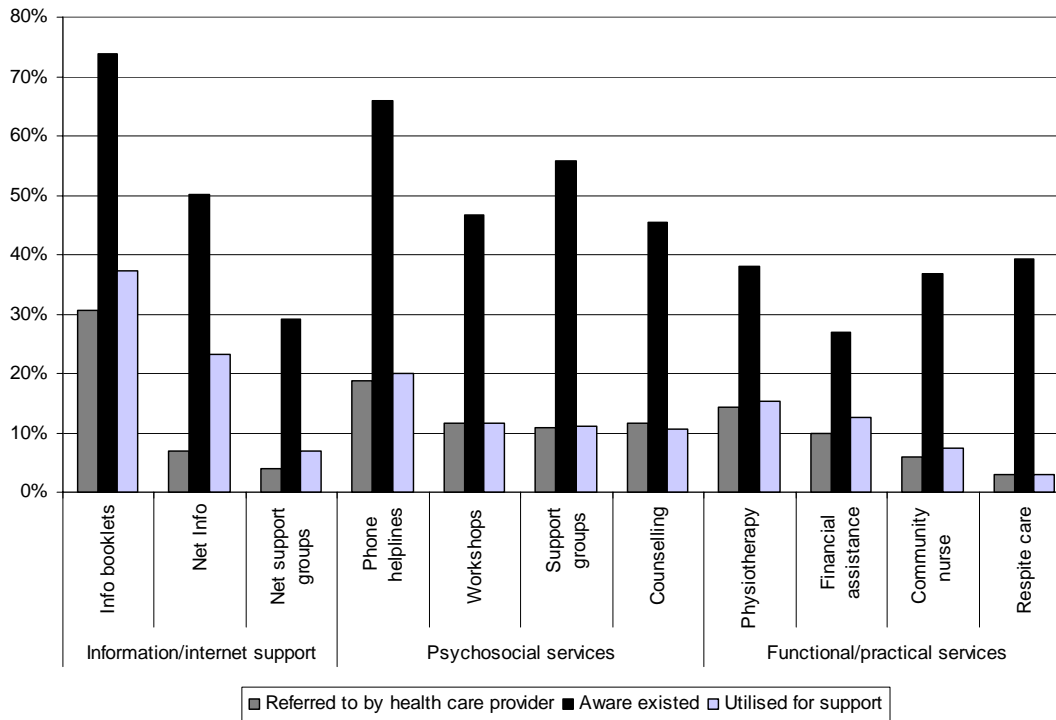


Fig. 1. Community support services referral, awareness and use by gynaecological cancer survivors (n=622)^a

^a % are based on available data for each item, items ranged between 579 and 682 responses from 802 participants. Participants could nominate each source independently.