



Queensland University of Technology

Brisbane Australia

This is the author's version of a work that was submitted/accepted for publication in the following source:

Rowlands, Ingrid J., Janda, Monika, McKinnon, Loretta, Webb, Penelope M., & Beesley, Vanessa L. (2015)

Prevalence, predictors, and correlates of supportive care needs among women 3-5 years after a diagnosis of endometrial cancer. Supportive Care in Cancer, 23(5), pp. 1205-1214.

This file was downloaded from: https://eprints.qut.edu.au/78711/

© Copyright 2014 Springer-Verlag Berlin Heidelberg

Notice: Changes introduced as a result of publishing processes such as copy-editing and formatting may not be reflected in this document. For a definitive version of this work, please refer to the published source:

https://doi.org/10.1007/s00520-014-2456-0

Prevalence, predictors and correlates of supportive care needs among women 3-5 year	rs
after a diagnosis of endometrial cancer	

Ingrid J. Rowlands ^{a,b§} , Monika Janda ^c , Loretta McKinnon ^a , P. M. Webb ^a , Vanessa L.
Beesley ^a on behalf of the Australian National Endometrial Cancer Study Group ^a
^a Gynaecological Cancers Group, QIMR Berghofer Medical Research Institute, Brisbane,
Queensland, Australia
^b School of Population Health, University of Queensland, Herston, Queensland, Australia
^c School of Public Health and Social Work, Institute of Health and Biomedical Innovation,
Queensland University of Technology, Brisbane, Queensland, Australia
§Corresponding Author:
Ingrid Rowlands
School of Population Health, University of Queensland,
Herston, Queensland,
Australia

Abstract

Purpose: To examine the prevalence, sociodemographic and clinical predictors, and physical and psychosocial correlates of unmet needs among women 3-5 years following treatment for endometrial cancer.

Methods: Women with endometrial cancer completed a survey around the time of diagnosis and again 3–5 years later. The follow-up survey asked women about their physical and psychosocial functioning and supportive care needs (CaSUN). Multivariable-adjusted logistic regression identified the predictors and correlates of women's unmet needs 3-5 years after diagnosis.

Results: Of the 629 women who completed the CaSUN, 24% (n=153) women reported one or more unmet supportive care needs in the last month. Unmet needs at 3-5 years post-diagnosis were predicted by younger age (OR=4.47; 95% CI:2.09-9.56) and advanced disease stage at diagnosis (OR=2.47; 95% CI:1.38-4.45) and correlated with greater cancer symptoms (OR=1.78; 95% CI: 1.05-3.02); lower-limb swelling (OR=2.50; 95% CI:1.51-4.15); symptoms of anxiety (OR=2.21; 95% CI:1.31-3.72) and less availability of social support (OR=3.42; 95% CI:1.92-6.11). Women with a history of comorbidities (OR=0.47; 95% CI:0.27-0.82) and those living in a rural area at the time of diagnosis (OR=0.56; 95% CI:0.34-0.92) were less likely to report unmet needs.

Conclusions: Sociodemographic, health and psychosocial factors seem important for identifying women who will, or will not have, unmet needs several years following endometrial cancer. Longitudinal assessments of people's needs over the course of their cancer trajectory may be an effective way to identify areas that should receive further attention by health providers.

Keywords: Endometrial cancer, gynecological cancer, supportive care needs, psychosocial

INTRODUCTION

Endometrial cancers stem from the cells lining the uterus, with two common subtypes described [40]. Five-year survival rates among women are high and treatment is often well tolerated [1]; however, for some women treatment can be associated with significant longterm reductions in quality of life, including bowel and urinary problems, lymphedema, and sexual concerns, contributing to reduced psychosocial wellbeing [28, 31]. Although quality of life measures are an effective way to assess the impact of having cancer on people's physical, psychological and social wellbeing, asking women about their supportive care needs after cancer provides much needed context to what actions and resources might enhance or maintain wellbeing [32, 33]. Measures of cancer-specific supportive care needs examine, for example, how well the patient perceives their care and treatment; professional and social relationships and individual concerns across the cancer trajectory (e.g. fear of cancer recurrence) [8, 25]. Well-validated measures of supportive care needs are also highly correlated with, but distinct from measures of psychological distress and overall quality of life [6, 19]. Assessing supportive care needs can, therefore, identify areas where people require help and this information can inform psychosocial interventions and optimize health care practice [8].

By comparison to breast cancer, relatively little is known about the supportive care needs of the large, and increasing, numbers of women living with endometrial cancer. A previous Australian study, found that women with endometrial cancer had more unmet supportive care needs 3 months to 5 years after diagnosis than women with other gynecological cancer types [3] and in two small, qualitative and mixed methods studies, women with endometrial cancer who were up to 5 years post-diagnosis described a need for follow-up appointments where information was offered to address their concerns [20, 39].

However, there are no large, representative studies that quantify the long-term needs of women with endometrial cancer.

Among women with breast cancer, younger age, advanced disease stage, greater symptom burden, shorter time since diagnosis, and higher levels of distress have been associated with greater needs [13]. Although younger age, advanced disease stage and psychological distress also appear strongly related to unmet needs among women with gynecological cancers [16, 37], the specific factors that may differentiate between women with and without unmet needs following endometrial cancer have not been examined.

Although treatment side effects such as lymphedema are associated with reduced quality of life among women with gynecological cancer [12, 27], few studies have examined whether lymphedema is associated with increased supportive care needs beyond three years post-diagnosis [3, 4], and none have focused specifically on women with endometrial cancer. Family and friends may play an important, positive role in alleviating women's concerns following gynecological cancer, but the association between social support and women's supportive care needs is inconsistent [3, 5].

Supportive care needs can change over the course of the cancer trajectory [23] and can differ among the gynecological cancer types [3]. The assessment of women's needs several years following endometrial cancer is, therefore, important to determine the extent to which ongoing support is required. The study aims to examine the prevalence of supportive care needs among women 3-5 years following their diagnosis of endometrial cancer and to identify the sociodemographic, clinical, physical health and psychosocial factors associated with having unmet needs.

METHODS

The women described here are from the *Australian National Endometrial Cancer*Study (ANECS), an Australia-wide, population-based, case-control study of women diagnosed

with endometrial cancer between 2005 and 2007, with methods reported previously [30]. Briefly, women completed a survey around the time of diagnosis. About 3-5 years later, they were recontacted and invited to complete a follow-up survey regarding their current lifestyle, supportive care needs, and physical and psychological wellbeing [29]. Fig 1 shows the participant recruitment and retention for the study. Briefly, of the 1399 original ANECS participants, 1283 were still alive and of these, 644 women (50%) completed the survey. Of these, 629 (49%) provided valid data on the questions assessing women's supportive care needs and are included in this analysis. Compared to women who did not respond to the follow-up survey or provide valid data (n = 654; excluding those who had died), those who did respond had higher levels of education and were more likely to have grade 3 cancers and to have had adjuvant treatment including brachytherapy alone and chemotherapy and/or radiation therapy or brachytherapy (all p < 0.05). There were no significant differences at the time of diagnosis between women who participated and those who did not on stage of disease and the other clinical or sociodemographic variables of interest. The study was approved by the Human Research Ethics Committees at the QIMR Berghofer Medical Research Institute and all participating hospitals.

Measures

Outcome variable (3-5 years post-diagnosis)

Supportive Care Needs were assessed using the Cancer Survivors' Unmet Needs (CaSUN) [19]. This 35-item self-administered questionnaire measures cancer-specific needs across five domains – existential survivorship, comprehensive cancer care, information, quality of life and relationships. Participants are asked to indicate for each item whether or not they had that specific need in the last month. Those who have a need are asked to report whether the need has been met or remains currently unmet, and those reporting an unmet need are asked to rate the strength of the need (weak, moderate or strong). The scale can be

used to calculate the number of total needs, met needs, unmet needs and strength of needs overall, and for the five subscales. Scores range from 0-35, with higher scores indicating a greater number of unmet needs. Overall the scale has high internal consistency (Cronbach's alpha = 0.96) and the five subscales have satisfactory internal consistency with Cronbach's alphas ranging between 0.78 and 0.93 [19].

Time 1 variables (at diagnosis)

Sociodemographic variables. Age, marital status, education, employment status, area of residence (urban, rural or remote), state of diagnosis and parity were collected at the initial survey around the time of diagnosis.

Clinical variables. Information on tumor stage and grade at diagnosis, surgery type (laparotomy, laparosopic or vaginal hysterectomy), treatment type (surgery, chemotherapy, radiotherapy, brachytherapy, other), and number of lymph nodes examined was abstracted from the diagnostic histopathology reports and medical records of consenting women.

Time 2 variables (3-5 years post-diagnosis)

Health and health-related variables

<u>Smoking status</u> was self-reported and women were classified as current smokers, exsmokers, or never smokers.

Body mass index (kg/m²) was calculated using women's self-reported weight and height [coded as underweight/normal (<25), overweight (25-29.9), obese (\ge 30)].

<u>Major comorbidities</u> (e.g., heart disease, rheumatoid arthritis) as listed in the Charlson comorbidity index [10] were identified and counted to form one overall comorbidity score, categorized as "none", "1" or "≥2" comorbidities.

<u>Cancer-specific physical wellbeing</u>: A list of nine cancer symptoms (e.g. night sweats, trouble digesting food, urinary/bowel symptoms) from the Functional Assessment of Cancer Therapy Endometrial Cancer Subscale (FACT-EN) was used to assess physical well-being in

the previous four weeks [9]. Responses are on a five-point Likert scale ranging from 1 (not at all) to 4 (very much) with a maximum score of 36. Scores are recoded so that higher scores indicate better physical functioning. For the current analysis, the overall score was split according to the sample median (score 33) because data were not normally distributed; women with scores below the median were classified as having lower levels of physical wellbeing.

<u>Lymphedema</u>. A series of questions, with satisfactory face validity, from another Australian study of women with gynecological cancer [4] was used to categorize women into three groups: without lymphedema or lower limb swelling; lower limb swelling only; medically diagnosed lower limb lymphedema.

Psychosocial variables

Symptoms of anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS) [42], a 14-item measure of psychological distress that is widely used among people with cancer [38]. Higher scores represent greater psychological distress and the following cut-offs are used to define clinical symptom levels of anxiety and depression: Normal (0-7), subclinical depression/anxiety (8-10), clinical depression/anxiety (11-21).

Social support. The question, "Is there someone available to you whom you can count on to listen to you when you need to talk?" was used as a proxy for current level of social support (categorized as: none/little/some vs. all of the time).

Statistical analysis

Women were categorized, first, as having "no need" or "a need" and then those reporting a need were further classified according to whether these needs were "met" or "unmet". Binary logistic regression was used to screen the potential correlates of having at least one unmet need in any domain. Because of the low prevalence of unmet needs, we did

not conduct separate analyses to examine the correlates of unmet needs within each of the five need domains. Those variables significant (p < 0.05) in these analyses were entered into a multivariable logistic regression model to examine the inter-correlations among the variables and their associations with having unmet needs. Variables that remained significant in these models, or that were considered theoretically relevant, were retained for further analysis. The only exception was for treatment variables where stage, number of lymph nodes removed and adjuvant treatment were highly correlated, so only stage was retained. The final model was reduced to only those variables that were theoretically relevant or statistically significant. All statistical analyses were performed using SAS version 9.2 (SAS Institute Inc., Cary, NC, USA).

RESULTS

Participant characteristics

Table 1 shows the characteristics of participating women around the time of diagnosis. Most women had stage I (85%) cancers and more than half had surgery without adjuvant treatment (67%). At diagnosis, around half of the women were between 50 and 65 years (55%), most had a partner (71%) and lived in urban areas (64%) and 48% had a high school education. At the follow-up survey, women were on average 4.1 years post-diagnosis (SD = 0.7, range = 2.9–6.3 years).

Prevalence of needs

Overall, 56% (n=351) of women reported at least one need: 31% (n=198) reported that their all needs were currently being met and 24% (n=153) reported an unmet need in the last month, with 20% (n = 128) reporting that the strength of the unmet need was moderate-to-high.

Table 2 shows the needs, met and unmet, reported by the women 3-5 years following their diagnosis. Although the most common needs were in the comprehensive cancer care

domain these were also the needs that were most likely to be met (by 78-81% of those with a need). These included a need to know that their doctors were talking to each other to coordinate their care; to feel like they were maintaining their health together with the medical team; access to local health care services when required and the very best medical care. Women reported the highest unmet needs in the existential survivorship domain and specific items included a need to reduce stress in their lives (8.3%); cope with others not acknowledging the impact that cancer had on their lives (7.9%) and manage concerns about the cancer coming back (7.2%). The relationship and comprehensive cancer care domains were also endorsed with women needing help to address problems with their sex lives (7.5%) and accessible hospital parking (6.6%).

Predictors and correlates of unmet needs

Table 3 shows the predictors and correlates of having at least one unmet need during the last month. Unadjusted logistic regression analyses showed that women who were younger, with higher levels of education and who were in the workforce at the time of diagnosis had higher odds of reporting an unmet need whereas women living in rural or remote areas had lower odds of reporting an unmet need than women in major cities. In addition, women who had an advanced stage of disease at diagnosis, 15 or more lymph nodes removed, adjuvant treatment, who were current smokers, had lower levels of physical wellbeing and lower-limb lymphedema or lower-limb swelling also had higher odds of reporting an unmet need. Women with comorbidities had lower odds of reporting an unmet need whereas women reporting symptoms of anxiety and depression and less availability of social support had higher odds of reporting an unmet need. Parity, surgery type, grade of cancer and BMI were not associated with having unmet needs.

The final, adjusted model, showed that having at least one unmet need was predicted by sociodemographic and clinical factors. Women with higher odds of reporting an unmet need at 3-5 years post-diagnosis were those who were younger and who had advanced disease at the time of diagnosis while women residing in rural or remote areas were less likely to have unmet needs. In addition, physical health and psychosocial factors were strongly correlated with unmet needs: Women who reported lower levels of physical functioning, lower-limb swelling, more symptoms of anxiety and less availability of social support were more likely to report unmet needs whereas women with a history of comorbidities were less likely to report unmet needs. Taking into account these variables, employment status, level of education, parity, adjuvant treatment, number of lymph nodes removed, smoking and depressive symptoms were not significantly associated having at least one unmet need.

DISCUSSION

Among these women with endometrial cancer who were surveyed 3-5 years after diagnosis, 56% reported having one or more needs in the last month and, of these, most reported that their needs were largely being met by existing health care professionals and services. A quarter of women reported at least one unmet need in the last month. Another study using the CaSUN to assess the supportive care needs of people with varying types of cancer also found that the prevalence of unmet needs was relatively low (47%) at five or more years after diagnosis, particularly for those who had a more favorable prognosis [15]. The prevalence of unmet needs in our study is noticeably lower than has been reported in other studies of women with gynecological cancers (52%-56%) [16, 37], which may be due to the variations among these studies regarding the time since diagnosis when needs were assessed, the specific questionnaire used, the time since diagnoses, or the variable treatment and prognostic factors for women with cancers at different gynecological sites.

While the prevalence of unmet needs was comparatively lower, women's needs were similar to what has been reported in other studies of people with reproductive cancers [16, 35]. In our study, the top five most commonly reported need items were largely related to

comprehensive care and to a lesser extent existential issues, whereas unmet needs were more commonly related to existential issues (than to comprehensive care). Specifically, the longer-term unmet needs of the women in our study were largely related to their psychosocial wellbeing. At 3-5 after their diagnosis, some women wanted greater acknowledgement from others of their experience of cancer, or needed help dealing with their own or others expectations of them as a "cancer survivor". In a qualitative analysis of free-text comments from a subset of these same women [28] we also found that many women described difficulties coping with the long-term effects of cancer while others were not focused on their cancer and struggled to form meaningful identities post-cancer in the context of a cancer "survivorship" culture [28] . Family and health care professionals may, therefore, need to be mindful about the diversity of women's experiences and the potential negative impact of cancer survivorship stereotypes on women's lives [21].

Although slightly more than half of women felt that their need for help with managing their concerns that the cancer might come back was being met, this was the fourth most common unmet need among women. Fears of cancer recurrence are common among many people treated for cancer, irrespective of the type or severity of the cancer [2, 33], and our findings reinforce the importance of acknowledging this, regardless of the time since diagnosis or the medical prognosis of the patient. Women also reported having an unmet need for help when trying to make decisions about their life in the context of uncertainty. Most women diagnosed with endometrial cancer have a favorable prognosis, and their need for reassurance about being cured may be overlooked several years following their diagnosis, or not well understood, by family and health professionals. Other studies have found that women want more opportunities for follow-up appointments [39]; this may offer women the opportunity to have their concerns and needs validated and addressed.

Sociodemographic, health and psychosocial factors were important for identifying women who did, and did not have, unmet needs several years following endometrial cancer. Consistent with previous studies of women with breast [13] and gynecological cancer [16, 37], younger women, those with more advanced disease at diagnosis, and those with lower levels of physical wellbeing and symptoms of anxiety 3-5 years following their diagnosis were more likely to report one or more unmet needs in the long-term survivorship phase. Women who had less social support available to them were also more likely to report unmet needs and this has been reported in other studies [14, 34]. Increasing social support may, therefore, reduce women's need for help by improving psychosocial wellbeing. Social support has also been associated with increased quality of life [24] and also possibly cancer survival [22]. Interventions that mobilize social and health care support may, therefore, provide multi-level benefits across the cancer trajectory.

Support for women with symptoms similar to lymphedema may be particularly important. In this study, women who self-reported lower-limb swelling without a diagnosis of lymphedema were more likely to have unmet needs. This is consistent with a previous analysis we conducted, which showed that these women reported lower levels of physical and mental health than women without lymphedema or swelling [27]. While a previous study showed that undiagnosed lower limb swelling was not associated with unmet needs, the majority of women in that study were less than three post-diagnosis [3]. Our data may suggest that symptom burden at 3-5 years after diagnosis increases women's need for support for physical, emotional and social difficulties.

Somewhat unexpectedly, women from rural or remote areas and those with comorbidities were less likely to report unmet needs 3-5 following their diagnosis. While women living in rural areas tend to have more limited access to health services than women from major cities, and their expectations for support may be lowered [7], they may have a

greater sense of community connectedness and participation in their community [26, 41], which may enable them to gain help for emotional and relationship difficulties. Similarly, women with comorbidities may have prior experience with the health care system or effective health care support already accessible to them. Alternatively, comorbidites may take precedence over the cancer. We have previously found that some women with endometrial cancer describe their comorbidities as having a greater physical and psychosocial impact on their lives than the cancer [28]. Consequently, their focus is on their pre-existing health condition and not their cancer. In support of this, is the finding that women reporting reduced cancer-specific physical wellbeing were more likely to have unmet needs, suggesting that the CaSUN effectively distinguishes between supportive care needs that are, and are not, associated with the cancer.

Although this study included a large sample of women with endometrial cancer from across Australia, we had a relatively low response rate (50%), which is consistent with other studies using mailed surveys [11, 33]. Women who participated were more likely to have grade 3 cancers and to have had adjuvant treatment than those who did not. The higher refusal rates among women low grade cancers may suggest that they had moved on with their lives and were, therefore, less likely to have needs. Similarly, because education was related to greater needs in our study, it is possible that we have over-estimated the prevalence of needs.

Overall, although around half of women with endometrial cancer had at least one supportive care need several years after their diagnosis, most women reported that these needs were being met. Women who had unmet needs reported needing help with personal and social aspects of their lives and having no or little social support available was associated with unmet needs. Health professionals may assist by directing women to the support services available within their community as well as providing women with reputable sources of

online support and information. Examining the types of social support and people most helpful to women following endometrial cancer, in conjunction with needs assessments of family members [17, 18, 35, 36], may provide a rich picture of how to effectively support women following endometrial cancer. Because needs may change in response to effective support, this also reinforces the value of longitudinal assessments of people's needs over the course of their cancer trajectory to effectively identify areas that should receive further attention by health providers.

Acknowledgements

We thank all the women who participated in the study.

We gratefully acknowledge the cooperation of the following institutions: NSW: John Hunter Hospital, Liverpool Hospital, Mater Misericordiae Hospital (Sydney), Mater Misericordiae Hospital, Liverpool Hospital, Mater Misericordiae Hospital (Newcastle), Newcastle Private Hospital, North Shore Private Hospital, Royal Hospital for Women, Royal Prince Alfred Hospital, Royal North Shore Hospital, Royal Prince Alfred Hospital, St George Hospital; Westmead Hospital, Westmead Private Hospital; Qld: Brisbane Private Hospital, Greenslopes Hospital, Mater Misericordiae Hospitals, Royal Brisbane and Women's Hospital, Wesley Hospital, Queensland Cancer Registry; SA: Adelaide Pathology Partners, Burnside Hospital, Calvary Hospital, Flinders Medical Centre, Queen Elizabeth Hospital, Royal Adelaide Hospital, South Australian Cancer Registry; Tas: Launceston Hospital, North West Regional Hospitals, Royal Hobart Hospital; Vic: Freemasons Hospital, Melbourne Pathology Services, Mercy Hospital for Women, Royal Women's Hospital, Victorian Cancer Registry; WA: King Edward Memorial Hospital, St John of God Hospitals Subiaco & Murdoch, Western Australian Cancer Registry.

The ANECS Group comprises: AB Spurdle, P Webb, J Young (QIMR Berghofer Medical Research Institute); Consumer representative: L McQuire; Clinical Collaborators: NSW: S Baron-Hay, D Bell, A Bonaventura, A Brand, S Braye, J Carter, F Chan, C Dalrymple, A Ferrier (deceased), G Gard, N Hacker, R Hogg, R Houghton, D Marsden, K McIlroy, G Otton, S Pather, A Proietto, G Robertson, J Scurry, R Sharma, G Wain, F Wong; Qld: J Armes, A Crandon, M Cummings, R Land, J Nicklin, L Perrin, A Obermair, B Ward; SA: M Davy, T Dodd, J Miller, M Oehler, S Paramasivum, J Pierides, F Whitehead; Tas: P Blomfield, D Challis; Vic: D Neesham, J Pyman, M Quinn, R Rome, M Weitzer; WA: B Brennan, I Hammond, Y Leung, A McCartney (deceased), C Stewart, J Thompson.

Conflict of Interest Statement

The authors have declared that no conflict of interest exists.

Funding

The Australian National Endometrial Cancer Study was supported by the National Health and Medical Research Council (NHMRC) of Australia (#339435) and Cancer Council Tasmania (#403031 and 457636). The ANECS Quality of Life study and clinical data collection were funded by a Cancer Australia grant (#552468). IJ Rowlands and VL Beesley are funded by NHMRC program grant (#552429), M Janda is funded by a Career Development Award from the NHMRC (#1045247), and PM Webb is funded by a Senior Research Fellowship from the NHMRC.

Fig 1 Flow of participant recruitment

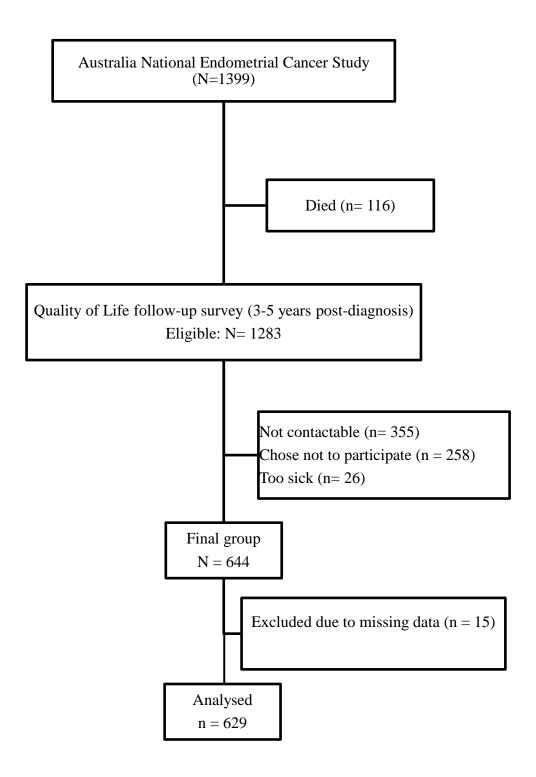


Table 1. Characteristics of women who did, and did not, respond to the follow-up survey at the time of diagnosis (N=629)

survey at the time of diagnos	Respondents (N = 629)		Non-respondents ^a (N= 654)		
	n ^b	%	n ^b	%	р
Age (years)					0.07
<50	61	10	90	14	
50-65	346	55	335	51	
>65	222	35	229	35	
, ••			,		
Relationship status					0.20
Partnered	438	71	423	68	
No partner	176	29	199	32	
Education (highest level					
completed)					0.003
High school	302	48	368	56	0.005
	302	52	286	44	
Technical college/University	341	32	∠ 0 0	44	
Area of residence					0.46
Major city	397	64	399	62	
Rural or remote centre	220	36	241	38	
State recruited in					0.84
	125	21	120	21	0.84
New South Wales	135	21	139	21	
Queensland	193	31	214	33	
Victoria	148	24	135	21	
South Australia	68	11	69	11	
Western Australia	58	9	66	10	
Tasmania	27	4	31	5	
Stage of disease at diagnosis (FIGO	2009)				0.04
I	530	85	573	88	0.01
II-IV	98	16	76	12	
11-1 V	98	10	70	12	
Grade of disease at diagnosis					0.002
Well differentiated	326	52	382	59	
Moderately differentiated	163	26	173	27	
Poorly differentiated	140	22	97	15	
Surgery					0.12
<u> </u>	117	<i>4</i> 7	402	62	0.12
Laparotomy	417	67 22	402	63	
Laparoscopic/vaginal hysterectomy	205	33	238	37	
A 1°					0.02
Adjuvant treatment	200	- -	4.70	72	0.03
No	399	65	453	72	
Brachytherapy alone	77	13	63	10	
External beam \pm brachytherapy	63	10	58	9	

	Respondents $(N = 629)$		Non-respondents ^a (N= 654)		
	n ^b	%	n^{b}	%	p
Chemotherapy ± external beam radiation or brachytherapy	69	11	45	7	
Other ^c	8	1	12	2	

^aWomen who had died were excluded ^bNumbers may not sum to total because some data are missing ^cWomen who had hormonal therapy

Table 2. The 15 most common needs reported by women with endometrial cancer 3-5 years after diagnosis (N = 629)

	CaSun item description	Total		Total Met		net	
Rank ^a	In the last month I needed	N	% ^b	% ^c	Rank ^a	% ^b	CaSUN domain
1	To know that doctors are talking to each other to coordinate my care	169	27.0%	78%	7	5.9%	Comprehensive cancer care
2	To feel like I was managing my health together with the medical team	168	26.9%	80%	10	5.5%	Comprehensive cancer care
3	Help to reduce stress in my life	149	23.8%	65%	1	8.3%	Existential survivorship
3	Local health care services that were available when I required them	147	23.8%	79%	11	5.0%	Comprehensive cancer care
5	The very best medical care	140	22.5%	81%	15	4.2%	Comprehensive cancer care
6	Help to manage my concerns about the cancer coming back	105	16.8%	57%	4	7.2%	Existential survivorship
7	Help to manage ongoing side effects and/or complications of treatment	103	16.5%	70%	11	5.0%	Quality of life
8	Emotional support to be provided for me	103	16.4%	63%	6	6.1%	Existential survivorship
9	Any complaints regarding my care to be properly addressed	96	15.4%	71%	13	4.5%	Comprehensive cancer care
9	Access complementary and/or alternative therapy services	96	15.4%	72%	14	4.3%	Non-specific factor
11	Help to cope with others not acknowledging the impact that cancer has had on my life	75	12.1%	35%	2	7.9%	Existential survivorship
12	More accessible hospital parking	74	11.7%	43%	5	6.6%	Comprehensive cancer care
13	Help to address problems with my/our sex life	68	10.9%	31%	3	7.5%	Relationships
14	Help to try to make decisions about my life in the context of uncertainty	68	10.8%	46%	7	5.9%	Existential survivorship
15	Help to deal with my own and/or others expectations of me as a "cancer survivor"	60	9.6%	38%	7	5.9%	Existential survivorship

^a Ranking based on total proportion (N = 629)
^bPercentage based on total proportion (N = 629)
^cPercentage based on those reporting a need

Table 3. The association between sociodemographic, clinical, physical and psychosocial variables and having an unmet need at 3-5 years after a diagnosis of endometrial cancer (N = 629)

	N	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a
MEASURED AT DIAGNOSIS		((* - * * * *)
Sociodemographics			
Age at diagnosis (years)			
<50	61	5.17 (2.79 - 9.60)*	4.47 (2.09 - 9.56)*
50-65	346	1.82 (1.18 -2.81)*	1.87 (1.10 - 3.16)*
65	222	Referent	Referent
Marital status			
Partner	438	Referent	
Unpartnered	176	1.38 (0.93 - 2.05)	
Education		() () () () ()	
High school	302	Referent	
Technical college/ University	327	1.79 (1.23 - 2.60)*	
Employment Status	02,	1117 (1126 2100)	
Out of the workforce	333	Referent	
Employed	283	1.91 (1.31 - 2.78)*	
Area of residence	203	1.91 (1.51 2.70)	
Major cities	397	Referent	Referent
Rural/ Remote	220	0.58 (0.39 - 0.87)*	0.56 (0.34 - 0.92)*
State recruited in	220	0.30 (0.3) 0.01)	0.50 (0.54 0.72)
NSW	135	Referent	
QLD	193	0.86 (0.52 - 1.43)	
VIC	148	1.02 (0.60 - 1.72)	
SA	68	0.71 (0.35 - 1.44)	
WA	58	0.71 (0.33 - 1.44)	
TAS	27	0.63 (0.22 - 1.77)	
Parity	21	0.03 (0.22 - 1.77)	
None	111	Referent	
One or more children	518	0.64 (0.41 - 1.00)	
Clinical variables	316	0.04 (0.41 - 1.00)	
Surgery	417	Deferent	
Laparoscopia/yaginal hystoractomy	205	Referent	
Laparoscopic/vaginal hysterectomy Stage of disease at diagnosis (FIGO 2009)	203	0.81 (0.55 - 1.21)	
stage of disease at diagnosis (FIGO 2009)	520	Referent	Referent
I II-IV	530 98	2.05 (1.30 - 3.24)*	2.47 (1.38 - 4.45)*
Grade of disease at diagnosis	90	2.03 (1.30 - 3.24)	2.47 (1.36 - 4.43)
1	326	Referent	
1			
2 3	163	1.24 (0.80 - 1.92)	
MEASURED 3-5 YEARS POST-DIAGNO	140 OSIS	1.24 (0.79 - 1.97)	
	0919		
Clinical variables Number of lymph nodes removed ^b			
Number of lymph nodes removed ^b	264	Deferent	
0	264	Referent	
1-14	224	1.18 (0.77 - 1.81)	

	N	Unadjusted OR	Adjusted OR
	11	(95% CI)	(95% CI) ^a
<u>≥ 15</u>	116	1.78 (1.09 - 2.91)*	(7370 C1)
Adjuvant treatment ^b	110	1.76 (1.0) - 2.71)	
No	399	Referent	
Yes	217	1.83 (1.26 - 2.67)*	
Physical health variables	217	1.65 (1.20 - 2.07)	
Smoking status			
Never	414	Referent	
Ex	174		
		1.47 (0.98 - 2.21)	
Current	37	2.86 (1.43 - 5.72)*	
BMI (18.50 to 24.00)	105	Referent	
$\leq 18.50 \text{ to } 24.99$	185		
25 to 34.99	300	0.95 (0.61 - 1.47)	
$35.00 \text{ to} \ge 40.00$	143	1.42 (0.87 - 2.33)	
Comorbidities (based on Charlson index) ^c	214	D - f 4	D - f
0	214	Referent	Referent
1	195	0.54 (0.34 - 0.84)*	0.55 (0.32 - 0.97)*
≥2	220	0.57 (0.37 - 0.88)*	0.47 (0.27 - 0.82)*
Cancer-specific physical wellbeing (FACT-I	*	D.C.	D C .
High	232	Referent	Referent
Low	371	3.36 (2.14 - 5.27)*	1.78 (1.05 - 3.02)*
Lymphoedema	207	5 . 0	T 0
Nil	385	Referent	Referent
Swelling only	172	3.01 (2.01 - 4.52)*	2.50 (1.51 - 4.15)*
Lymphoedema	71	2.03 (1.14 - 3.61)*	1.44 (0.71 - 2.93)
Psychosocial variables			
Anxiety (HADS)			
Normal	463	Referent	Referent
Subclinical/Clinical	160	4.88 (3.28 - 7.26)*	2.21 (1.31 - 3.72)*
Depression (HADS)			
Normal	556	Referent	Referent
Subclinical/Clinical	67	5.52 (3.26 - 9.36)*	1.83 (0.90 - 3.74)
Social Support			
All of the time	299	Referent	Referent
Most of the time	180	1.98 (1.24 - 3.17)*	1.93 (1.12 - 3.36)*
None/little/some of the time	146	4.65 (2.93 - 7.36)*	3.42 (1.92 - 6.11)*

Note. N = participant numbers as per unadjusted analyses; OR = odds ratio; 95 % CI = 95% confidence interval *Statistically significant, p < 0.05 aAdjusted for variables in this column bData was collected 3-5 years after diagnosis and follow-up survey data were combined to expect this variable. to create this variable.

References

- 1. Amant F, Moerman P, Neven P, Timmerman D, Van Limbergen E, Vergote I (2005) Endometrial cancer Lancet 366: 491-505
- 2. Armes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, Palmer N, Ream E, Young A, Richardson A (2009) Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey J Clin Oncol 27: 6172-6179
- 3. Beesley V, Eakin E, Steginga S, Aitken J, Dunn J, Battistutta D (2008) Unmet needs of gynaecological cancer survivors: implications for developing community support services Psycho-oncology 17: 392-400
- 4. Beesley V, Janda M, Eakin E, Obermair A, Battistutta D (2007) Lymphedema after gynecological cancer treatment: prevalence, correlates, and supportive care needs

 Cancer 109: 2607-2614
- 5. Beesley VL, Price MA, Webb PM, O'Rourke P, Marquart L, Australian Ovarian Cancer Study G, Australian Ovarian Cancer Study-Quality of Life Study I, Butow PN (2013) Changes in supportive care needs after first-line treatment for ovarian cancer: identifying care priorities and risk factors for future unmet needs Psycho-oncology 22: 1565-1571
- 6. Boyes A, Girgis A, Lecathelinais C (2009) Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34) Journal of evaluation in clinical practice 15: 602-606
- 7. Butow PN, Phillips F, Schweder J, White K, Underhill C, Goldstein D, Clinical Oncological Society of A (2012) Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer 20: 1-22

- 8. Carlson LE, Waller A, Mitchell AJ (2012) Screening for distress and unmet needs in patients with cancer: review and recommendations J Clin Oncol 30: 1160-1177
- 9. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, Silberman M, Yellen SB, Winicour P, Brannon J, et al. (1993) The Functional Assessment of Cancer Therapy scale: development and validation of the general measure J Clin Oncol 11: 570-579
- 10. Charlson M, Szatrowski TP, Peterson J, Gold J (1994) Validation of a combined comorbidity index Journal of clinical epidemiology 47: 1245-1251
- 11. Eaker S, Bergstrom R, Bergstrom A, Adami HO, Nyren O (1998) Response rate to mailed epidemiologic questionnaires: a population-based randomized trial of variations in design and mailing routines American journal of epidemiology 147: 74-82
- 12. Finnane A, Hayes SC, Obermair A, Janda M (2011) Quality of life of women with lower-limb lymphedema following gynecological cancer Expert Rev Pharmacoecon Outcomes Res 11: 287-297
- 13. Fiszer C, Dolbeault S, Sultan S, Bredart A (2014) Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review Psycho-oncology 23: 361-374
- 14. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ (2009) What are the unmet supportive care needs of people with cancer? A systematic review Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer 17: 1117-1128
- 15. Harrison SE, Watson EK, Ward AM, Khan NF, Turner D, Adams E, Forman D, Roche MF, Rose PW (2011) Primary health and supportive care needs of long-term cancer survivors: a questionnaire survey J Clin Oncol 29: 2091-2098

- 16. Hodgkinson K, Butow P, Fuchs A, Hunt GE, Stenlake A, Hobbs KM, Brand A, Wain G (2007) Long-term survival from gynecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes Gynecologic oncology 104: 381-389
- 17. Hodgkinson K, Butow P, Hobbs KM, Hunt GE, Lo SK, Wain G (2007) Assessing unmet supportive care needs in partners of cancer survivors: the development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN)

 Psycho-oncology 16: 805-813
- 18. Hodgkinson K, Butow P, Hobbs KM, Wain G (2007) After cancer: the unmet supportive care needs of survivors and their partners J Psychosoc Oncol 25: 89-104
- 19. Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, Wain G (2007)

 The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure)

 Psycho-oncology 16: 796-804
- 20. Jones JM, Ferguson S, Edwards E, Walton T, McCurdy N, Howell D (2012)
 Experiences of care delivery: endometrial cancer survivors at end of treatment
 Gynecologic oncology 124: 458-464
- 21. Kaiser K (2008) The meaning of the survivor identity for women with breast cancer Soc Sci Med 67: 79-87
- 22. Lutgendorf SK, De Geest K, Bender D, Ahmed A, Goodheart MJ, Dahmoush L, Zimmerman MB, Penedo FJ, Lucci JA, 3rd, Ganjei-Azar P, Thaker PH, Mendez L, Lubaroff DM, Slavich GM, Cole SW, Sood AK (2012) Social influences on clinical outcomes of patients with ovarian cancer J Clin Oncol 30: 2885-2890
- 23. McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK (2010) Predictors of change in unmet supportive care needs in cancer Psycho-oncology 19: 508-516

- 24. Parker PA, Baile WF, de Moor C, Cohen L (2003) Psychosocial and demographic predictors of quality of life in a large sample of cancer patients Psycho-oncology 12: 183-193
- 25. Richardson A, Medina J, Brown V, Sitzia J (2007) Patients' needs assessment in cancer care: a review of assessment tools Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer 15: 1125-1144
- 26. Romans SE, Walton VA, Herbison GP, Mullen PE (1992) Social networks and psychiatric morbidity in New Zealand women The Australian and New Zealand journal of psychiatry 26: 485-492
- 27. Rowlands IJ, Beesley VL, Janda M, Hayes SC, Obermair A, Quinn MA, Brand A, Leung Y, McQuire L, Webb PM, Australian National Endometrial Cancer Study G (2014) Quality of life of women with lower limb swelling or lymphedema 3-5 years following endometrial cancer Gynecologic oncology 133: 314-318
- 28. Rowlands IJ, Lee C, Beesley VL, Janda M, Nagle CM, Webb PM (2014) Women's Perceptions of Their Lifestyle and Quality of Life Several Years After a Diagnosis of Endometrial Cancer Cancer Nurs
- 29. Rowlands IJ, Lee C, Janda M, Nagle CM, Obermair A, Webb PM, Australian National Endometrial Cancer Study G (2013) Predicting positive and negative impacts of cancer among long-term endometrial cancer survivors Psycho-oncology 22: 1963-1971
- 30. Rowlands IJ, Nagle CM, Spurdle AB, Webb PM, Australian National Endometrial Cancer Study G, Australian Ovarian Cancer Study G (2011) Gynecological conditions and the risk of endometrial cancer Gynecologic oncology 123: 537-541
- 31. Salani R (2013) Survivorship planning in gynecologic cancer patients Gynecologic oncology 130: 389-397

- 32. Sanson-Fisher R, Carey M, Paul C (2009) Measuring the unmet needs of those with cancer: a critical overview. In: Editor (ed)^(eds) Book Measuring the unmet needs of those with cancer: a critical overview. The Cancer Council Australia, City, pp. 200.
- 33. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P (2000) The unmet supportive care needs of patients with cancer. Supportive Care Review Group Cancer 88: 226-237
- 34. Schmid-Buchi S, Halfens RJ, Muller M, Dassen T, van den Borne B (2013) Factors associated with supportive care needs of patients under treatment for breast cancer European journal of oncology nursing: the official journal of European Oncology Nursing Society 17: 22-29
- 35. Smith AB, King M, Butow P, Luckett T, Grimison P, Toner GC, Stockler M, Hovey E, Stubbs J, Hruby G, Gurney H, Turner S, Alam M, Cox K, Olver I (2013) The prevalence and correlates of supportive care needs in testicular cancer survivors: a cross-sectional study Psycho-oncology 22: 2557-2564
- 36. Stafford L, Judd F (2010) Partners of long-term gynaecologic cancer survivors: psychiatric morbidity, psychosexual outcomes and supportive care needs Gynecologic oncology 118: 268-273
- 37. Urbaniec OA, Collins K, Denson LA, Whitford HS (2011) Gynecological cancer survivors: assessment of psychological distress and unmet supportive care needs J Psychosoc Oncol 29: 534-551
- 38. Vodermaier A, Linden W, Siu C (2009) Screening for emotional distress in cancer patients: a systematic review of assessment instruments Journal of the National Cancer Institute 101: 1464-1488

- 39. Walton LM, Reeve J, Brown PM, Farquhar CM (2010) Gynaecologic cancer patients' needs and experiences of supportive health services in New Zealand Psycho-oncology 19: 201-208
- 40. Wright JD, Barrena Medel NI, Sehouli J, Fujiwara K, Herzog TJ (2012)

 Contemporary management of endometrial cancer Lancet 379: 1352-1360
- 41. Ziersch AM, Baum F, Darmawan IG, Kavanagh AM, Bentley RJ (2009) Social capital and health in rural and urban communities in South Australia Australian and New Zealand journal of public health 33: 7-16
- 42. Zigmond AS, Snaith RP (1983) The hospital anxiety and depression scale Acta psychiatrica Scandinavica 67: 361-370