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REVIEW ARTICLE

A systematic literature review of the prevalence of and risk factors for supportive care needs among women with gynaecological cancer and their caregivers

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Abstract

Purpose This review aimed to determine the prevalence of met and unmet needs, and the risk factors for unmet needs among people affected by gynaecological cancer.

Methods The review was undertaken using the PRISMA guidelines. Eligible studies were identified though a range of electronic databases in October and November 2016. Study quality was independently appraised by two people.

Results Thirty-seven studies were included (1 review, 24 quantitative and 12 qualitative). The evidence was of mixed quality. The total burden of needs affecting women with gynaecological cancer and also their caregivers predominately related to comprehensive care and psychological concerns. The major moderate-to-high-level unmet needs of women with gynaecological cancer were for help explicitly with fear of recurrence, worries of caregivers and fatigue, and for women who developed lymphoedema were with pain and associated costs. Qualitative studies identified disease-specific needs related to sexuality issues (including fertility, sexual functioning, relationship concerns, managing vaginal changes, pregnancy care, premature menopause), genetic testing and disease-specific peer support. Women at risk of having unmet needs include those who are younger, with advanced disease, with lymphoedema or a high symptom burden, are unable to work, have mental health issues, have poor social support or live in rural or remote locations.

Conclusions Understanding the needs of women with gynaecological cancer and their caregivers is essential to improving care and outcomes. Current data are limited thus there is a need for qualitative studies of patient-caregiver dyad and vulnerable subgroups and well-designed quantitative studies of women with each type of gynaecological and their caregivers.

Keywords Gynaecological cancer · Caregivers · Supportive care needs · Unmet needs · Risk factors

Background

Gynaecological cancers (including cancers of the ovary, uterus, cervix, vulva and other female genital organs) account for more than 16% of all reported cancer cases in females worldwide [1]. At the end of 2012, over three million women had been diagnosed in the previous 5 years [1]. As a result of the ageing and growth of the population in many developed countries, the overall number of females diagnosed with gynaecological cancers is increasing and this trend is expected to continue [2]. In addition, an increase in women with endometrial cancer in particular is expected due to the increase in risk factors such as obesity [3]. The projected increases will result in a growth in demand for services along the cancer control continuum, especially in follow-up and survivorship care [4]. It is therefore vital that we understand the supportive care requirements of this population and their caregivers to inform future approaches to support women and their

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caregivers during their gynaecological cancer diagnosis, treatment and beyond.

In addition to the many common experiences of people diagnosed with cancer (such as pain, fatigue, anxiety, coping with hair loss, financial stress and managing treatment regimens), women with gynaecological cancer may face specific problems associated with he following: lower leg lymphoedema; surgically or chemically induced menopause; loss of fertility; sexual dysfunction; bowel dysfunction, faecal and urinary incontinence; and emotional and psychological issues related to body image, sexuality and relationships [4]. Cancer and its treatment affect not only the patient but also their family caregivers. It is possible that caregivers of women with gynaecological cancer also face specific issues related to the effects of the disease and treatment on their relationship, role and future plans [5], in addition to the tasks that are common to caregivers of people with any cancer such as treatment monitoring, symptom management, personal care and emotional and financial support and the common psychological burden of the possibility of losing their loved one.

A great deal of research dedicated to understanding the issues facing people living with cancer and caregivers has shown that it is imperative that supportive care is person-centred and that it provides the necessary services for those living with or affected by cancer [6]. Quality of life measures fail to link patients' experience directly with service desires [7]. They require a conceptual leap to determine survivors' and/or caregivers' service needs and are unable to reveal what those affected ideally want from the health care system or the extent to which their needs are being satisfied. Good quality of care must be based on an understanding of the person's need, desire and expectation of some help or resource [8]. The aim of this review was therefore to examine the current evidence regarding the supportive care needs of women with gynaecological cancers and their caregivers to identify the following: (1) the total burden of supportive care needs (met and unmet); (2) the major unmet needs (moderate-to-high-level) and; (3) the main risk factors for unmet supportive care needs among this population? In particular, we were interested as to whether needs vary by population (cancer survivor, caregiver); gynaecological cancer type (ovarian, endometrial, cervical, vulval and other); phase of cancer care continuum (pre-treatment, primary treatment, post-treatment, recurrence, end of life, bereavement); life stage (adolescents and young adults, middle-aged adults, older adults) or; potentially vulnerable groups (e.g. Indigenous people, Culturally and Linguistically Diverse (CALD) groups, refugees, rural and remote women). We also examined the instruments used to measure supportive care needs for their specificity for people affected by gynaecological cancer and hence ability to capture findings about cancer site-specific needs.

Methods

This systematic literature review is reported according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [9].

Eligibility criteria

To be considered eligible for inclusion, studies had to be published in English after 2005 (as supportive care is likely to have been very different before this date), have a major focus on gynaecological cancer and focus on the period post-cancer diagnosis. All types of study designs were included including systematic reviews if they focused on true needs (i.e. where participants identified an issue and expressed a desire for help with it). Individual publications within systematic reviews were excluded so as not to duplicate content.

Information sources

Studies were identified via searching electronic databases including PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsycINFO, EMBASE (Excerpta Medica database), the Cochrane Library and, for theses, the Australian National Library (TROVE). In addition, reference lists of the eligible studies were scanned to identify any additional papers missed by the previous searches.

Search

Searches were conducted as part of a larger review of both (a) observational studies focused on identifying supportive care needs and risk factors for unmet needs and (b) intervention studies that aimed to meet supportive care needs or improve wellness [10]. The searches were conducted between 24 October 2016 and 1 November 2016. Search strategies were amended to the requirements of each database. In general they included the following combinations of terms and were combined as (#1 OR #3) AND ((#2 OR #4 OR #5) OR (#6 AND #7)):

Medical Subject Headings (MeSH) terms:

1. Ovarian Neoplasms OR Uterine Neoplasms OR Vaginal Neoplasms OR Vulvar Neoplasms OR Fallopian Tube Neoplasms OR Uterine Cervical Neoplasms OR Genital Neoplasms, female
2. Needs Assessment

Text terms included in titles and abstract:

3. (gynaecologic* OR gynecologic* OR ovari* OR endometri* OR uter* OR cervi* OR vulva*) AND (cancer OR neoplasm OR carcinoma OR oncology)

4. (supportive care OR support OR unmet OR assessment OR information OR communication OR emotional OR psychological OR psychosocial OR psychosexual OR social OR sexual* OR relationship OR spiritual OR existential OR cultural OR physical OR daily living OR functional) AND need*
5. (lymphoedema OR lymphedema OR menopause OR body image OR incontinen* OR fertility OR fear of recurrence) AND (need* OR support*)
6. quality of life OR wellness OR wellbeing OR health promotion OR weight OR exercise OR activity OR diet OR eating OR food OR smoking OR alcohol OR drinking OR self-care OR psychosocial care OR symptom management OR treatment side-effect*
7. intervention OR trial

Where possible, filters were applied across databases to limit inclusion to publication years from 2006 to 2016, all studies except protocols, studies reported in English and studies including humans.

Search selection

At the first stage, one quarter of the titles of articles identified were scanned by two reviewers, Chalachew Alemayehu (CA) and Vanessa Beesley (VB), and coded independently as 'clearly include', 'clearly exclude' or 'unsure'. Disagreement regarding inclusion codes was resolved by discussion between the two reviewers. This was repeated for the second quarter of titles and, as there was negligible disagreement, the remaining titles were reviewed by CA alone. At the second stage, abstracts for papers classified as 'unsure' were scanned by CA and inclusion codes were refined. At the third stage, we retrieved the full articles of all remaining papers identified as 'clearly include' or 'unsure' for detailed evaluation by CA and additional evaluation by VB when CA remained unsure.

Data collection and items

Data items were abstracted by CA, using standard tables (see Supplementary Table). All abstracted information was reviewed by VB.

Risk of bias

The quality of individual studies was assessed independently by CA and VB and classified as good, fair or poor. Study quality of observational studies was assessed based on the characteristics of the study design (longitudinal, cross-sectional, qualitative), sampling frame (population-based, multi-site, single-site), sample size, response rate, methods for adjusting or avoiding selection bias, psychometric properties of the outcome measure, statistical methods to adjust for confounding or missing data. Studies including all levels of quality are included in the data synthesis.

Summary measures

Needs (met and unmet) and unmet needs are measured in proportions. Associations between risk factors and needs are measured as odds ratios.

Synthesis of results

The results of the searches are shown quantitatively in Tables 1, 2, and 3 and summarised qualitatively in text, both overall and where possible for pre-specified subgroups to address the research questions.

Results

Study selection

The search of electronic databases retrieved 6907 citations (Fig. 1). After removal of duplicates, 5556 remained and were evaluated on the basis of title and abstract. Of these, 5344 were discarded because they did not meet the inclusion criteria. The full text of 212 potentially relevant articles was assessed in more detail. Of these, 140 were excluded for the reason documented in Fig. 1. One additional study was identified by hand search of the reference list of included studies. Of the 73 finally eligible papers, 37 reported on supportive care needs.

Study characteristics

Table 1 summarises the characteristics of the 37 studies. Only three studies included caregivers. Most of the studies (*n* = 20) included a mix of gynaecological cancer types with ovarian cancer being the individual gynaecological cancer type most commonly studied (*n* = 10). Studies were mainly cross-sectional, incorporating participants from a mix of phases across the care continuum. Almost half of the quantitative studies (9 of 24) were from Australia, while the qualitative studies were mainly from the USA, Canada and Sweden. None of the studies focused on a particular life stage or on potentially vulnerable subgroups.

The studies used nine different instruments to measure the supportive care needs among women with gynaecological cancer [11–19] and two to measure their caregivers' needs [20, 21]. Only one of the instruments (the Supportive Care Needs Survey-Gynaecology (SCNS-Gyn) [12]) measures need for help with issues specific to gynaecological cancer as well as those general to any cancer. This was used in 3 of the 24 quantitative studies. In addition, the Supportive Care Needs Survey-Supplementary lower limb lymphoedema needs module (SCNS-LLL) [14] was used in two studies to

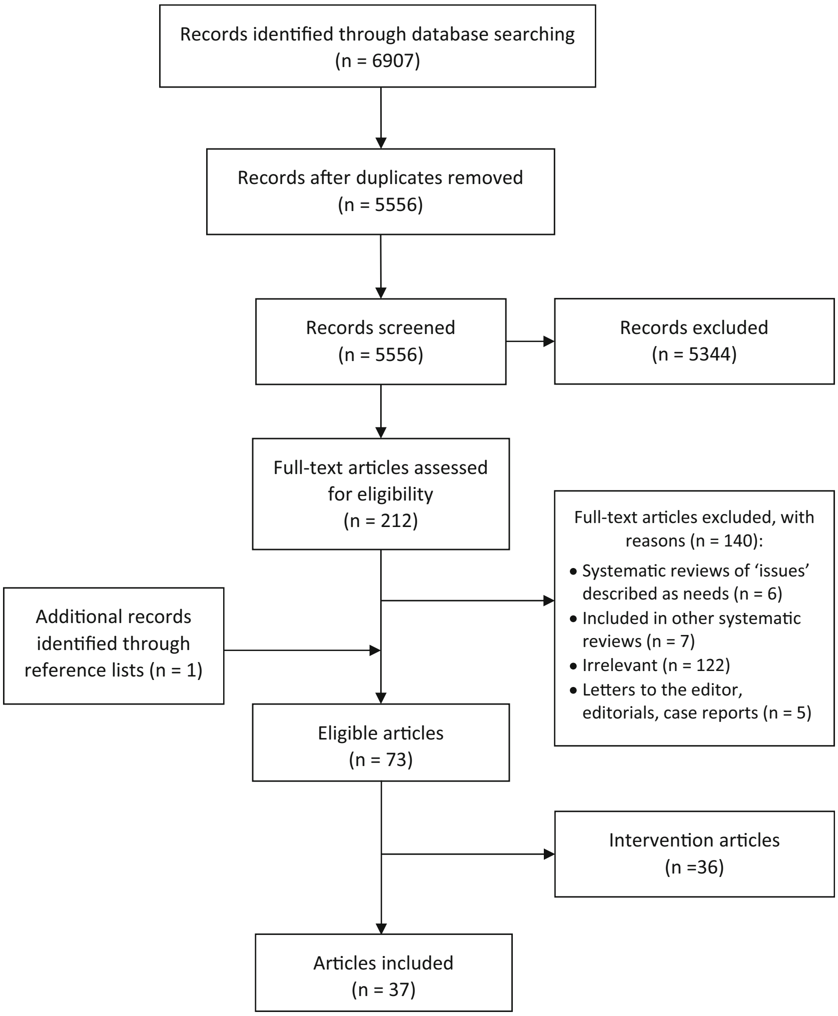

Fig. 1 Flow diagram of study selection

measure the specific needs of women who developed secondary lower limb lymphoedema following treatment for gynaecological cancer. The remaining 19 quantitative studies measured only the needs generic to any cancer.

Risk of bias within the studies

Evidence from the 24 observational quantitative studies was mixed with eight studies considered to be of good methodological quality, seven considered to be fair and nine considered to be poor (see Supplementary Table). All qualitative studies were considered of poor quality for the purpose of identifying the extent of needs in this population.

Studies that quantified supportive care needs (met and unmet)

Only three studies (one good quality, one fair, one poor) clearly measured the total burden of need among women with gynaecological cancer via specific assessment of combined met and unmet needs. Two of these used the CaSUN (Cancer Survivors' Unmet Needs measure [15]) and reported that the top needs were related to care coordination and psychological concerns (Table 2). However, the frequency of these needs varied across the two studies; the study including Australian women with gynaecological cancers of any type and at any phase of the care continuum found approximately 60% of women reported the top need items [22], whereas only approximately 25% of Australian women with endometrial cancer who were 3–5 years post-diagnosis reported these same top needs [23]. The third study used the 3LNQ (Three-Levels-of-Needs–Questionnaire [17]) and found that more than 50% of Turkish women in palliative care with gynaecological cancers needed help with physical symptoms [24] (Table 2).

Studies that identified important supportive care needs

An additional four studies (all fair quality) asked women to rate the importance of a 'need' but did not measure met or unmet needs. These identified common important 'needs' for information in general [25] or specifically information related to the likelihood of cure [26, 27], and for help with or

Table 1 Descriptive summary of included articles ($n = 37$) by study type

	Reviews	Quantitative studies	Qualitative studies
Total articles	1	24	12
Population			
Survivors	1	21	12
Caregivers	0	2	0
Survivors and caregivers	0	1	0
Gynaecological cancer type			
Ovarian	1	5	4
Endometrial	0	3	0
Cervical	0	1	2
Vulval	0	0	1
Mixed	0	15	5
Phase of care continuum			
Newly diagnosed/primary treatment	0	1	1
Post primary treatment/early survivorship	0	6	7
Long-term survivorship	0	2	0
Recurrence	0	0	2
Palliative	0	2	0
Mixed	1	13	2
Country			
Australia	0	9	1
USA	1	3	3
Canada	0	3	2
Netherlands	0	3	0
Turkey	0	2	0
Thailand	0	2	0
UK	0	1	0
Denmark	0	1	0
Sweden	0	0	3
New Zealand	0	0	1
Japan	0	0	1
Spain	0	0	1

information about coping with spread of disease [26], coping with fear of recurrence [27], different types of treatment [27], side effects of disease and or treatment [26–28], coping with pain [27, 28], managing bowel changes [27], managing fatigue [27], managing nausea and vomiting [27], daily living activities [28], psychological support [28], relaxation techniques [28], alternative therapies [28], nutrition [28], sexual life [28] and the cancer risk to their family members [27].

Studies that quantify unmet supportive care needs

The majority of the quantitative studies (16 studies of survivors and 3 studies of caregivers) focused on unmet needs, measured either as any unmet needs or moderate-to-high-level unmet needs. Among the 16 studies focused on survivors, nine included women with a mix of gynaecological subtypes, while four specifically included women with ovarian cancer, two included women with endometrial cancer and one included women with cervical cancer.

Studies of major (moderate-to-high-level) unmet needs

Only three studies (two good quality, one poor) used the moderate-to-high-level unmet need threshold. An Australian cross-sectional study of women living with any gynaecological cancer at any phase of the cancer continuum used the Supportive Care Needs Survey-Short Form 34 (SCNS-SF34 [13]) and found one in six or seven women had moderate-to-high-level unmet needs for help with psychological and physical concerns [29] (Table 3). An Australian longitudinal study of women diagnosed with ovarian cancer, using the same measure, found similar psychological and physical moderate-to-high-level needs in women immediately after first-line treatment (Table 3). In addition, they showed that the prevalence of these needs remained constant over the following 2 years [30], whereas health system/information, patient care and sexuality needs decreased significantly over time [30]. A Canadian study of women receiving follow-up care in a regional centre also identified similar need items but at a somewhat higher frequency (Table 3) [31]. They used the SCNS-Gyn and additionally identified sexual concerns, both physical and emotional, in about one-in-four women during follow-up [31].

Studies of any (low-to-high-level) unmet needs in women with a mix of gynaecological cancers

Two Australian studies [22, 32] and one Canadian study [12] (one fair quality, two poor) found that that less than 30% of women with gynaecological cancer reported having an unmet need for help (any level) with any of the need items measured [12]. In contrast, a poor quality American study found between 31 and 57% of women with gynaecological cancer reported having an unmet need for many items in the psychological, physical and practical need domains; with the most frequently reported being fears about the cancer spreading (57%), concerns about the worries of those close to them (55%) and lack of energy/tiredness (49%) [33]. Another fair quality study found Turkish women with gynaecological cancers receiving palliative care had prevalent unmet needs with tiredness (61%), depression (47%), lack of appetite (39%) and general worry (33%) [24].

Table 2 Top supportive care needs (met and unmet) of women with gynaecological cancer

	Australian women with gynaecological cancers of any type and at any phase of the care continuum [22]	Australian women who were 3–5 years post-diagnosis with endometrial cancer [23]	Turkish women in palliative care with gynaecological cancers of any type [24]	Domain
Needing to know that their doctors were talking to each other to coordinate their care	64%	27%	Not measured	Comprehensive care
Feeling like they were managing their health together with the medical team	64%	27%	Not measured	Comprehensive care
Needing help to manage concerns about their cancer coming back	62%	17%	Not measured	Psychological
Needing the very best medical care	60%	23%	Not measured	Comprehensive care
Needing local health care services that are available when required	58%	24%	Not measured	Comprehensive care
Needing help to reduce stress/worry	49%	24%	47%	Psychological
Needing help with tiredness	Not measured	Not measured	71%	Physical
Needing help with depression	Not measured	Not measured	60%	Psychological
Needing help with lack of appetite	Not measured	Not measured	56%	Physical
Needing help with pain	Not measured	Not measured	55%	Physical

Studies [22, 23] used the Cancer Survivors' Unmet Needs measure. Study [24] used the Three-Levels-of-Needs-Questionnaire

Studies of any (low-to-high-level) unmet needs in women with ovarian cancer

In two small poor quality cross-sectional studies of American women at any phase of the care continuum and in long-term survivorship, the top unmet needs (any level) were reported to be sexual issues (25–44%) [34, 35]. In a poor quality cross-sectional study of Dutch women at any phase of the care continuum, the top unmet needs (any level) were to be informed about 'the things you can do to help yourself get well' (36%) and to get help with feelings of sadness (30%) [36].

Studies of any (low-to-high-level) unmet needs in women with other cancers

A fair quality study of women from Denmark found that worry constituted an unmet need in 71% of women with cervical and 35% of women with endometrial cancer and that unmet needs for fatigue were consistently high prior to treatment (32–35%) and 3 months later (38–44%) in this group of women [37]. While a good quality study of long-term Australian endometrial cancer survivors found that less than 10% reported having an unmet need for any of the items measured [23]. One good quality Dutch study focused on specifically on sexual needs among women with cervical cancer and found 51% of the participants reported an unmet need for information and/or professional help with sexual issues [38]. No studies have focused specifically on the unmet needs of women with vaginal or vulvar cancer.

Lymphoedema-specific needs

Two good quality studies, both from Australia, have assessed the specific needs of women with lymphoedema. In the first, women treated for any type of gynaecological cancer who were symptomatic or diagnosed with secondary lymphoedema reported moderate-to-high-level unmet needs to be more informed about the causes, preventions and treatment of lymphoedema (25%), to be given written information about ways to manage symptoms of lymphoedema (25%), for help with pain or discomfort in the legs or groin (20%) and to be given more help in managing the symptoms of lymphoedema (19%) [14]. In the second study of Australian women treated for endometrial cancer, over half (55%) of those who developed lymphoedema reported unmet needs including a moderate-to-high-level unmet need with the cost of having lymphoedema (18%) and pain or discomfort in the legs or groin (17%) [39]. In contrast, the information needs in this group were lower than in the previous study.

Findings of studies that included caregivers

Three studies (two good quality, one fair) focused on caregivers [38, 40, 41]. Among Australian caregivers of long-term gynaecological cancer survivors, one fifth reported unmet needs (any level) to know that doctors communicate to coordinate the survivor's care, to have more accessible hospital parking, and to reduce stress in the survivor's life [41]. A second Australian study found that among caregivers of women with ovarian cancer, in the year before the patient's

Table 3 Top moderate-to-high-level unmet needs of women with gynaecological cancer

Needing help with:	Australian women with gynaecological cancers of any type and at any phase of the care continuum [29]	Australian women with ovarian cancer immediately after first-line treatment [30]	Australian women with ovarian cancer 12 months after first-line treatment [30]	Australian women with ovarian cancer 24 months after first-line treatment [30]	Regional Canadian women receiving follow-up care for gynaecological cancer [31]	Domain
Fear about the cancer spreading	17%	25%	16%	21%	33%	Psychological
Concerns about the worries of those close to them	15%	20%	16%	18%	25%	Psychological
Lack of energy or tiredness	14%	18%	15%	15%	26%	Physical/daily living
Uncertainty about the future	14%	19%	16%	19%	23%	Psychological
Not able to do the things they used to do	14%	–	–	–	23%	Physical/daily living
Feelings about death and dying	–	–	–	–	23%	Psychological
Changes in sexual feelings	–	–	–	–	22%	Sexuality
Being informed about things to help get well	–	20%	11%	6%	–	Information
Fear of the cancer returning	Not measured	Not measured	Not measured	Not measured	44%	Psychological
Changes in ability to have sex	Not measured	Not measured	Not measured	Not measured	24%	Sexuality
Fear of physical disability	Not measured	Not measured	Not measured	Not measured	22%	Psychological

Studies [29, 30] used the Supportive Care Needs Survey-Short Form 34. Study [31] used the Supportive Care Needs Survey—gynecologic version

– item not one of the top reported needs included in the publication

death the severity of unmet needs increased over time, peaking 3–6 months before death [40]. Almost 90% of these caregivers reported at least one unmet need (any level) during this time. The highest unmet needs in the last 3 months related needing help with reducing the patient's stress (42%), disappointment about lack of recovery (42%), fear of the cancer spreading (39%) and making decisions in context of uncertainty (39%). A study of partners of Dutch women with cervical cancer, that specifically focussed on sexual needs, found that 65% of partners considered it desirable that they were involved in sexual healthcare provision [38].

Studies that reported a qualitative assessment of supportive care needs

Given the lack of specificity in measuring needs that are particular to gynaecological cancer survivors and their caregivers, qualitative studies were included to provide a deeper understanding about services that may be necessary specifically for this population. Fourteen articles provided qualitative information including one literature review.

The studies indicated a need for information and/or support with sexuality and relationship needs for both women and their caregivers [42–44], in particular with effect of treatment on fertility [44, 45], options for preserving fertility among younger women [45–47], whether/when sexual intercourse becomes safe [45], managing vaginal changes [45], coping with the effects of premature menopause [45], being seen by a female health professional [48] and being offered disease-specific peer support [44, 47, 49]. A study of women with cervical cancer also identified the need for pregnancy care recommendations [47]. Studies among women with ovarian cancer further indicated the need for information on treatment-focused genetic testing (TFGT) [50], help with making sense of disease information after recurrence [51] and the need for end of life communication to others [52].

More generally, women described a need for distress screening and support [43, 45, 47], the opportunity to ask questions [45, 53], information about complementary/alternative treatment options [46] and to be offered appropriate services or follow-up after treatment [44, 45, 48, 54, 55].

Studies that identified risk factors for unmet needs

Seven studies looked at risk factors for unmet supportive care needs. In general, the women with gynaecological cancer who are more likely to report unmet needs are those who are younger [22, 23, 32], have more advanced disease [18, 22, 23, 30], have undergone more recent treatment [29], are not in remission [29], live with lymphoedema or lower limb swelling [23, 29], are unable to work due to illness [29], have anxiety, depression, insomnia or posttraumatic stress [22, 23, 30, 32], have poorer quality of life/greater cancer symptoms [23, 32], report less availability of social support [18, 23, 30], live in rural or remote locations [29] and additionally in America, have lower income and minority status [33].

Discussion

Understanding the supportive care needs of women with gynaecological cancer and their caregivers is a developing area of research; many existing studies have methodological limitations that reduce specificity of findings and generalisability of results. Overall, the total burden of needs for women with gynaecological cancer and their caregivers both appear to predominately relate to comprehensive care and psychological concerns. While towards the end of women's lives, needs relate to physical symptoms and depression. It is likely that needs vary by phase of the cancer continuum, type of gynaecological cancer and population subgroup, both for women with gynaecological cancers and caregivers, although comparisons across different instruments and study designs are difficult.

To date, most quantitative studies have lacked measures of needs that are specific to gynaecological cancer and thus have been limited to reporting of issues that are generic to any cancer, which creates a bias across studies towards underreporting of specific issues related to this disease. Moreover, few studies have used the moderate-to-high-level unmet needs threshold that is insightful for distinguishing when supportive care provision may require improvement. Those that did indicated that the major generic unmet needs of women with gynaecological cancer relate to psychological and physical/daily living issues. In particular, service providers should consider how to better address fear of recurrence, concerns about the worries of caregivers and fatigue. There was also an indication that changes in sexual feelings and ability to have sex may be a major unmet need in some samples, and for women who develop lymphoedema, pain and associated costs were the major unmet needs.

Through qualitative enquiry, women with gynaecological cancer have voiced a range of needs that are specific to this type of cancer including the desire for information or help with issues such as fertility, sexual functioning, relationship concerns, managing vaginal changes, pregnancy care, premature menopause, genetic testing or disease-specific peer support. While these studies are able to elicit specific needs, they have small biased samples and we cannot generalise their findings to all gynaecological cancer survivors.

Analysis of risk factors indicated special consideration may need to be given when planning the care of women with gynaecological cancer who are younger; have advanced disease/are not in remission; live with lymphoedema or lower limb swelling; are unable to work due to illness; have anxiety, depression, insomnia or posttraumatic stress; have a high symptom burden; have poor social support; or live in rural or remote locations. There is a risk of bias across studies to detect potentially vulnerable subgroups as being at risk either because they did not seek to identify vulnerable subgroups within their populations, or because these subgroups are too small in numbers to be quantitatively analysed as potential predictors of need.

Recommendations

The findings of this review indicate a number of gaps in our understanding of the needs of people affected by gynaecological cancer. There is no research focused on potentially vulnerable groups and little-to-none on women with cervical or vulval cancer and on gynaecological cancer caregivers. Qualitative studies focused on women with gynaecological cancer from potentially vulnerable subgroups (e.g. indigenous peoples, CALD groups or refugees) are a priority. Qualitative studies are also recommended to explore the dynamics of the patient-caregiver dyad and their collective and individual supportive care needs related to gynaecological cancer. Finally, well-designed quantitative studies by gynaecological cancer subtype, including caregivers, should be conducted to determine total burden of needs, major moderate-to-high-level needs, and how needs change over the care continuum in these groups.

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References

1. International Agency for Research on Cancer and World Health Organization (2012) GLOBOCAN 2012: estimated cancer incidence, mortality and prevalence worldwide in 2012. In: Editor (ed)^(eds) Book GLOBOCAN 2012: estimated cancer incidence, mortality and prevalence worldwide in 2012, City
2. Australian Institute of Health and Welfare (2012) Gynaecological cancers in Australia: an overview. In: Editor (ed)^(eds) Book Gynaecological cancers in Australia: an overview, City
3. Sankaranarayanan R, Ferlay J (2010) Worldwide burden of gynaecological cancer Handbook of Disease Burdens and Quality of Life Measures: 803–823

4. Cancer Australia (2016) National framework for gynaecological cancer control. In: Editor (ed)^(eds) Book national framework for gynaecological cancer control. Cancer Australia, City
5. Teskereci G, Kulakaç O (2016) Life experiences of caregivers of women with gynaecological cancer: a mixed-methods systematic review. Eur J Cancer Care (Engl)
6. Hui D (2014) Definition of supportive care: does the semantic matter? Curr Opin Oncol 26:372–379
7. Bonevski B, Sanson-Fisher R, Hersey P, Paul C, Foot G (1999) Assessing the Perceived Needs of Patients Attending an Outpatient Melanoma Clinic. J Psychosoc Oncol 17:101–118
8. Nelson CW, Niederberger J (1990) Patient satisfaction surveys: an opportunity for total quality improvement. Hosp Health Serv Adm 35:409–427
9. Moher D, Liberati A, Tetzlaff J, Altman DG (2010) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Int J Surg (London, England) 8:336–341
10. Cancer Australia (2017) Supporting women to live well with gynaecological cancers: systematic literature review. In: Editor (ed)^(eds) Book Supporting women to live well with gynaecological cancers: systematic literature review. Cancer Australia, City
11. Bonevski B, Sanson-Fisher R, Girgis A, Burton L, Cook P, Boyes A (2000) Evaluation of an instrument to assess the needs of patients with cancer. Supportive care review group. Cancer 88:217–225
12. Steele R, Fitch MI (2008) Supportive care needs of women with gynecologic cancer. Cancer Nurs 31:284–291
13. 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). J Eval Clin Pract 15:602–606
14. 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
15. 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). Psychooncology 16: 796–804
16. Houts PS, Yasko JM, Kahn SB, Schelzel GW, Marconi KM (1986) Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania. Cancer 58:2355–2361
17. Johnsen AT, Petersen MA, Pedersen L, Groenvold M (2011) Development and initial validation of the three-levels-of-needs questionnaire for self-assessment of palliative needs in patients with cancer. J Pain Symptom Manag 41:1025–1039
18. Somjai A, Chaipoom A (2006) Psychosocial needs of women with cancer of the reproductive system: a comparison between Buddhist and Muslim patients in Thailand. Ment Health Relig Cult 9:379–388
19. Bubela N, Galloway S, McCay E, McKibbon A, Nagle L, Pringle D, Ross E, Shamian J (1990) The Patient Learning Needs Scale: reliability and validity. J Adv Nurs 15:1181–1187
20. Girgis A, Lambert S, Lecathelinais C (2011) The supportive care needs survey for partners and caregivers of cancer survivors: development and psychometric evaluation. Psychooncology 20:387–393
21. 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). Psychooncology 16: 805–813
22. 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. Gynecol Oncol 104:381–389
23. Rowlands IJ, Janda M, McKinnon L, Webb PM, Beesley VL (2014) Prevalence, predictors, and correlates of supportive care needs among women 3–5 years after a diagnosis of endometrial cancer. Support Care Cancer 23:1205–1214
24. Seven M, Sahin E, Yilmaz S, Akyuz A (2016) Palliative care needs of patients with gynaecologic cancer. J Clin Nurs 25:3152–3159
25. Phianmongkhol Y, Suwan N (2008) Symptom management in patients with cancer of the female reproductive system receiving chemotherapy. Asian Pac J Cancer Prev 9:741–745
26. Beaver K, Booth K (2007) Information needs and decision-making preferences: Comparing findings for gynaecological, breast and colorectal cancer. Eur J Oncol Nurs 11:409–416
27. Papadakos J, Bussière-Côté S, Abdelmutti N, Catton P, Friedman AJ, Massey C, Urowitz S, Ferguson SE (2012) Informational needs of gynecologic cancer survivors. Gynecol Oncol 124:452–457
28. Akkuzu G, Kurt G, Guvenc G, Kok G, Simsek S, Dogrusoy S, Ayhan A (2016) Learning needs of gynecologic cancer survivors. J Cancer Educ
29. 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
30. Beesley VL, Price MA, Webb PM, O'Rourke P, Marquart L, Butow PN (2012) 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
31. McCallum M, Jolicoeur L, Lefebvre M, Babchishin LK, Robert-Chauret S, Le T, Lebel S (2014) Supportive Care Needs After Gynecologic Cancer: Where Does Sexual Health Fit in? Oncol Nurs Forum 41:297–306
32. 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
33. Simonelli LE, Pasipanodya E (2014) Health disparities in unmet support needs of women with gynecologic cancer: an exploratory study. J Psychosoc Oncol 32:727–734
34. Matulonis UA, Kornblith A, Lee H, Bryan J, Gibson C, Wells C, Lee J, Sullivan L, Penson R (2008) Long-term adjustment of early-stage ovarian cancer survivors. Int J Gynecol Cancer 18:1183–1193
35. Kornblith AB, Mirabeau-Beale K, Lee H, Goodman AK, Penson RT, Pereira L, Matulonis UA (2010) Long-term adjustment of survivors of ovarian cancer treated for advanced-stage disease. J Psychosoc Oncol 28:451–469
36. Fitch MI, Steele R (2010) Identifying supportive care needs of women with ovarian cancer. Can Oncol Nurs Jl 20:66–74
37. Jeppesen MM, Mogensen O, Dehn P, Jensen PT (2015) Needs and priorities of women with endometrial and cervical cancer. J Psychosom Obstet Gynecol 36:122–132
38. Vermeer WM, Bakker RM, Kenter GG, de Kroon CD, Stiggelbout AM, ter Kuile MM (2014) Sexual issues among cervical cancer survivors: how can we help women seek help? Psycho-Oncology 24:458–464
39. Beesley VL, Rowlands IJ, Hayes SC, Janda M, O'Rourke P, Marquart L, Quinn MA, Spurdle AB, Obermair A, Brand A, Oehler MK, Leung Y, McQuire L, Webb PM (2015) Incidence, risk factors and estimates of a woman's risk of developing secondary lower limb lymphedema and lymphedema-specific supportive care needs in women treated for endometrial cancer. Gynecol Oncol 136:87–93
40. Butow PN, Price MA, Bell ML, Webb PM, deFazio A, Friedlander M (2014) Caring for women with ovarian cancer in the last year of life: a longitudinal study of caregiver quality of life, distress and unmet needs. Gynecol Oncol 132:690–697
41. Stafford L, Judd F (2010) Partners of long-term gynaecologic cancer survivors: psychiatric morbidity, psychosexual outcomes and supportive care needs. Gynecol Oncol 118:268–273
42. Rasmusson E-M, Thomé B (2008) Women's wishes and need for knowledge concerning sexuality and relationships in connection with gynecological cancer disease. Sex Disabil 26:207–218

43. Nicolaije KAH, Husson O, Ezendam NPM, Vos MC, Kruitwagen RFPM, Lybeert MLM, van de Poll-Franse LV (2012) Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry. Patient Educ Couns 88:427–435
44. Toubassi D, Himel D, Winton S, Nyhof-Young J (2007) The informational needs of newly diagnosed cervical cancer patients who will be receiving combined chemoradiation treatment. J Cancer Educ 21:263–268
45. McCallum M, Lefebvre M, Jolicoeur L, Maheu C, Lebel S (2012) Sexual health and gynecological cancer: conceptualizing patient needs and overcoming barriers to seeking and accessing services. J Psychosom Obstet Gynecol 33:135–142
46. Trivers KF, Patterson JR, Roland KB, Rodriguez JL (2013) Issues of ovarian cancer survivors in the USA: a literature review. Support Care Cancer 21:2889–2898
47. Lloyd PA, Briggs EV, Kane N, Jeyarajah AR, Shepherd JH (2014) Women's experiences after a radical vaginal trachelectomy for early stage cervical cancer. A descriptive phenomenological study. Eur J Oncol Nurs 18:362–371
48. Rodríguez MAP, Suess A, Cerdá JCM, Carretero ME, Danet A (2011) Opinions and expectations of women in the treatment of cervical and uterine cancer in Spain. Women’s Health 7:709–718
49. Jefferies H, Clifford C (2009) Searching. Cancer Nurs 32:E30–E36
50. Gleeson M, Meiser B, Barlow-Stewart K, Trainer AH, Tucker K, Watts KJ, Friedlander M, Kasparian N (2013) Communication and information needs of women diagnosed with ovarian cancer regarding treatment-focused genetic testing. Oncol Nurs Forum 40:275–283
51. Ekwall E, Ternestedt B-M, Sorbe B, Graneheim UH (2011) Patients’ perceptions of communication with the health care team during chemotherapy for the first recurrence of ovarian cancer. Eur J Oncol Nurs 15:53–58
52. Ekwall E, Ternestedt B-M, Sorbe B, Sunvisson H (2014) Lived experiences of women with recurring ovarian cancer. Eur J Oncol Nurs 18:104–109
53. Oshima S, Kisa K, Terashita T, Habara M, Kawabata H, Maezawa M (2011) A qualitative study of Japanese patients’ perspectives on post-treatment care for gynecological cancer. Asian Pac J Cancer Prev 12(9):2255–2261
54. 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
55. Lydon A, Beaver K, Newbery C, Wray J (2009) Routine follow-up after treatment for ovarian cancer in the United Kingdom (UK): patient and health professional views. Eur J Oncol Nurs 13:336–343