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A literature review of the social and psychological needs of ovarian cancer survivors

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Abstract

Objective: To identify and comprehensively present the psychosocial needs of ovarian cancer (OvCa) survivors, including young survivors <45 years of age.

Methods: A literature review was conducted using keywords specific to psychosocial health and OvCa survivorship to identify peer-reviewed, original research articles published in English between January 2000 and December 2010; 28 articles were identified as relevant. Articles were abstracted and results categorized according to six psychosocial domains: quality of life (QoL), social support and relationships, self-image and sexual functioning, psychological distress and functioning, fear of death/recurrence, and personal growth and coping. Findings unique to young survivors are presented when applicable. Psychosocial measurement tools used in relevant studies are also presented.

Results: Physical complications and side effects have significant impact on OvCa survivors' psychosocial health. Access to social support services and relational support is critical, as feelings of isolation are common. Survivors report low levels of sexual activity and satisfaction, potentially causing strain on personal relationships, and survivors experience high levels of distress, depression, and anxiety. However, QoL can improve after diagnosis for some OvCa survivors, many of whom report spiritual growth and strengthened personal relationships. Younger survivors are likely to have greater distress and lower QoL compared with older survivors.

Conclusions: OvCa is the deadliest of all gynecologic cancers, greatly impacting the psychosocial health of survivors. Increased awareness of psychosocial health among OvCa survivors themselves, their social support system, and their health care providers is necessary to adequately address their unique needs.

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Conflict of interest
The authors declare they have no conflict of interest.

Introduction

Ovarian cancer (OvCa) is the deadliest of all gynecologic cancers; in 2008, more women died from OvCa than from all other gynecologic cancers combined. Each year in the United States, approximately 21,200 women are diagnosed with OvCa (2200 < 45 years of age), and 14,300 die from the disease (470 < 45 years of age) [1]. There are relatively few OvCa survivors, defined as women living with a history of OvCa [2], compared with other cancer survivors [3] primarily because there is no recommended screening test [4,5] causing late-stage diagnosis [6] and high risk of recurrence [3]. However, the population of cancer survivors in the United States is growing, both in number and as a percentage of the population, with the majority being female, and those persons 65 years of age or older [7]. The estimated 5-year relative survival for women diagnosed with OvCa in 2008 was 44.0%, an increase from 36.1% for those diagnosed between 1975 to 1977 [6].

Due in part to the high mortality and often advanced stage of disease upon diagnosis, OvCa can have a strong psychological impact on the survivor, yet psychological support may be secondary to medical intervention [8]. A growing cancer survivor population and the associated psychological and social (psychosocial) impact therefore reinforces the need to address the effects of OvCa on survivors' psychosocial health and well-being [7]. Identifying risk factors and needs associated with poor psychosocial health is important to developing and appropriately targeting interventions [9–13]; timely and effective translation of research to practice is paramount in supporting cancer survivors [7,14–16].

Studies have identified many of the psychosocial burdens and needs faced by OvCa survivors. However, because of the complexity and myriad of constructs associated with psychosocial health, many studies may examine only one or two common constructs, such as quality of life (QoL) or social support. To comprehensively identify and synthesize published work on the psychosocial needs of OvCa survivors, we conducted a literature review on OvCa survivor's psychosocial health relating to QoL, social support and relationships, self-image and sexual functioning, psychological distress and functioning, fear of death/recurrence, and personal growth and coping. When available, this review also presents needs of young survivors (defined as <45 years of age), a particularly vulnerable population [16].

Methods

This literature review of the psychosocial health needs of OvCa survivors was conducted as one component of a larger review on OvCa survivorship. Keywords used in the search were developed by the authors and included ovarian neoplasm, disease-free survival, survivor(ship), epithelial tumor, germ cell tumor, sex cord tumor, stromal tumor, posttreatment and long-term survivor, adaptation, psychological, anxiety, body image, counseling, cognition, depression, family relations, fatigue, marriage, mental health, pain, patient satisfaction, recurrence, sexual dysfunction, physiological, resilience, quality of life, sexuality, social isolation, social support, spirituality, and stress. Searches were conducted using PubMed, PsycINFO, CINAHL, Cochrane, and Web of Knowledge databases. Peer-reviewed articles published in English between December 2000 and December 2010 on human subjects were included in the review.

Publications were imported into a database and all abstracts were assessed for relevancy. Review articles, case studies, articles that had a study sample of less than 20, were not specific to OvCa survivors, reported on efficacy of treatment or drug therapies, or were conducted outside of the United States were excluded. Studies conducted outside the United States were excluded because of differences in the healthcare systems, access and treatment options, and because this review will guide US Federal research and programmatic initiatives. Abstracts were classified as relevant, somewhat relevant, or not relevant. The full texts of papers classified as somewhat relevant were later reviewed to determine a final classification of relevant or not relevant. For quality assurance, a second reviewer was randomly assigned to review 25% of all abstracts for relevance classification, with 99% concordance. Snowball sampling was also conducted. (i.e., upon full text review of all relevant articles, references that seemed relevant on the basis of the title were retrieved and reviewed.)

Data were abstracted from relevant articles into an Excel spreadsheet according to six psychosocial domains: QoL, social support and relationships, self-image and sexual functioning, psychological distress and functioning, fear of death/recurrence, and personal growth and coping. These domains were generated for this study based upon keywords used in the psychosocial search. Findings from one article may have been abstracted to multiple domains when appropriate.

Data related to young survivors were abstracted separately. For this review, young survivors are defined as women <45 years of age because common public health measures, such as the US National Survey of Family Growth, and the US Healthy People 2020 objectives, define young women or women of reproductive age as 15–44 years. Information was considered relevant to young OvCa survivors if it either 1) specifically addressed young survivors in the results or 2) came from studies that included women with germ cell tumors (because germ cell tumors are typically diagnosed in young women [17]). Findings unique to young survivors are highlighted within each section when appropriate.

Of the 1634 papers related to OvCa survivorship that were identified, 47 were either relevant, and snowball sampling identified an additional 21 articles. Of the final 68 articles, 28 were related to the psychosocial health of OvCa survivors (Table 1). The psychosocial measurement tools used in each article are presented in Table 2.

Results

Literature review

Quality of life (QoL)—Overall, OvCa survivors report good QoL when compared with the general population [18–21] and other cancer survivors [22], with potential improvements over time [19] and well into survivorship. Some survivors report being happy, feeling loved, and having interest in daily activities [20]. However, one study found subscale QoL scores were lower for physical, functional, and emotional well-being but higher for social well-being compared with the nonsurvivor female adult population [18]. Poorer QoL in OvCa survivors was significantly associated with increased levels of anxiety and depression [23], and some women described uncertainty and hopelessness after experiences with cancer [24].

Several factors are associated with improved QoL, such as supportive relationships [25,26] currently not receiving treatment [23,26], and experiencing fewer physical symptoms [23,27]. Optimism was positively associated with health-related QoL and lower levels of distress in patients undergoing chemotherapy [28]. Compared with the nonsurvivor US population, OvCa survivors report higher levels of social well-being [18], and one study found divorced or separated survivors reported higher social/family well-being than those who were married [23].

Some women expressed spiritual changes as a result of their experiences with OvCa. Women reported that spirituality helped them discern meaning from their cancer experience and maintain hope [24], and that their faith was important to them as it brought comfort and strength [20]. Wenzel *et al.* found that almost half of the sample reported high spiritual QoL similar to controls. Spiritual well-being is positively associated with personal growth and ability to integrate the cancer experience [22]. However, some women may experience a loss of faith after experiences with cancer [24].

Fox *et al.* found that pain was significantly correlated with fatigue, and that fatigue and depression were correlated with QoL and remain with survivors well into survivorship period [21]. Survivors had lower QoL scores in physical and fatigue domains postoperatively when compared with the preoperative cohort [29]. Although some interventions may address physical QoL in survivors, a 10-week yoga intervention did not significantly change QoL scores for survivors posttreatment [30].

The relationship between QoL and stage at diagnosis is unclear. Ferrell *et al.* found women diagnosed with earlier stage OvCa had higher average QoL scores than those diagnosed at later stages [26]. However, Mirabeau-Beale *et al.* reported no difference in overall QoL between women with early- and advanced-stage OvCa, though this sample included long-term survivors, the majority of whom were not currently reporting OvCa-related symptoms or physical side effects [31].

Young survivors: Young OvCa survivors have lower QoL scores when compared with older survivors [18,23,26], but younger age at diagnosis is associated with better physical functioning [19].

Social support and relationships

Greater social support is related to higher self-esteem [32], decreased depression and anxiety [19,33], and overall good health for OvCa survivors [19]. Better social functioning [31] and social support [20] have been reported among advanced-stage survivors, compared with early stage survivors.

Women with OvCa may experience social isolation, stemming from diagnosis with a less common cancer with fewer long-term survivors [8,24]. OvCa survivors need social support from [34] and have a desire to build relationships with other OvCa survivors [35,36]. Fellow survivors understand the physical and psychological challenges of living with the disease, as loved ones often have difficulty fully comprehending a life with cancer [24,37]. Support groups offer OvCa survivors an opportunity to meet and network with women who have experienced the same issues, providing comfort and confidence, and an opportunity to share symptom management techniques [24,37]. However, some OvCa survivors report difficulty accessing support resources [24]. Wenzel *et al.* found that more than half of their study sample would have joined a support group at diagnosis if it had been offered, with most expressing a desire to participate in individual counseling [22].

OvCa survivors report stronger, more positive relationships with significant others, compared with controls [35], but fewer years in a relationship is a significant predictor of poorer adjustment among women with recurrent OvCa [38]. Physical fatigue can impact ability to provide support to their families, often causing frustration and guilt [39]; some OvCa survivors report needing assistance to resolve personal family problems [38].

Young survivors: Greater social support has been associated with less depression, less physical pain, and better general health among young survivors [19]. When compared with age-matched controls of women without cancer, young survivors experienced greater social support from their relationships, especially in the area of emotional social support [40]. Like older survivors, young OvCa survivors desire support from fellow survivors and peers who have had similar diagnosis, treatment, and survivorship experiences, as they are often disappointed when friends and family are not able to empathize [34].

Self-image and sexual functioning

Abdominal scars, hair loss, weight gain, and prophylactic procedures, such as bilateral oophorectomy and hysterectomy that remove organs symbolic of female identity, considerably impact body image among survivors [24,31,34]. Patients who experience more significant physical changes, and therefore impact to self-image, perceive less control over the consequences of their illness and treatment [32]. Regrowth of hair helps survivors in remission to ‘heal psychological wounds’ and ‘refocus their lives’ [8].

OvCa survivors report low sexual activity and sexual satisfaction [27,41,42], causing strain on their personal relationships [25,34,37]. Multiple studies reported increased sexual problems and sexual dysfunction and decreased sexual activity postdiagnosis [31,41,42]. Chemotherapy and surgically induced menopause from oophorectomy can result in vaginal dryness, painful intercourse, fatigue, and decreased libido [31], and survivors cite lack of interest, fatigue, decreased libido, decreased arousal, and problems with orgasm as reasons for sexual inactivity [22,41,42]. Sexual discomfort was highest among women with greater menstrual/gynecological symptoms and more reproductive concerns [19]. Kornblith *et al.* found that sexual issues (decreased interest in sex, decreased sexual activity, and pain during intercourse) were the greatest of unmet needs, with almost half of survivors reporting that less help was received than needed for sexual issues [20]. Women with more time since diagnosis and those not receiving treatment were more likely to be sexually active [41], and sexual pleasure was higher for women who had fewer gynecological symptoms and were married [19].

Young survivors: Among young survivors, OvCa greatly impacts sexuality [40]. Although younger age at diagnosis is related to better overall sexual functioning with increased social support and fewer gynecologic symptoms [19], young survivors report decreased libido [34], less sexual pleasure and satisfaction, and worse sexual functioning compared with women without OvCa [35,40]. Survivors who had an oophorectomy showed significantly greater sexual discomfort when compared with survivors who had not undergone this surgery [40].

Psychological distress and functioning

OvCa survivors can experience high levels of distress, depression, and anxiety [23,26,33,42,43], compared with the general population and nongynecologic cancer survivors [23,33,42,43]. Although some survivors may report positive well-being, some OvCa survivors may be ‘emotionally at risk’ [22], feeling sad and depressed, and having problems with memory and concentration [34].

A period of great distress for OvCa survivors is at diagnosis, when one abruptly transitions from healthy woman to a cancer patient [8,22,26,33]. Diagnosis may illicit feelings of loss of control, fear, and uncertainty for the future [2,24]. Some survivors report feeling the equivalent of a death sentence due to the low survival and high recurrence associated with OvCa [8]. Some research indicates that survivors with more advanced-stage OvCa experience greater distress [20,33], whereas one study found no association between stage of disease and distress [23]. OvCa survivors who report higher levels of optimism at the start of chemotherapy reported lower levels of distress [28].

Several studies report significant levels of depression among OvCa survivors [23,33,43,44]. Increased time since diagnosis may decrease levels of depression [22,31], and anxiety appears to be more problematic than depression in women with stage III or IV OvCa [27]. OvCa survivors experiencing greater physical symptoms have higher levels of distress, depression, and anxiety [23,32,41], possibly because of symptoms being perceived as disease progression [8,44]. Physical symptoms can result in lower functioning and impaired ability to complete daily activities [23,32]. Depression and fatigue remain with OvCa survivors well into survivorship [21]. Both low knowledge of OvCa and increased preoccupation with CA125 levels were associated with symptoms of depression and anxiety [43].

Young survivors: Young OvCa survivors were more likely to have higher levels of distress and depression compared with older survivors [23,33,38]. However, one study found long-term germ cell survivors and age-matched controls reported similar levels of depression [40].

Fear of death/recurrence

Many survivors report significant concern regarding recurrence and dying [25,44]. More physical symptoms, depression [44], and emotional maturity [18] can increase an OvCa survivor's fear of death. One study found cancer stage was not associated with fear of death, indicating women at all stages are equally at risk for anxiety associated with fear of death [44].

Studies report 56–67% of both early- and advanced-stage OvCa survivors fear recurrence [20,42]. Fear of recurrence may continue for years, postdiagnosis [22] can impact QoL and cause emotional distress among survivors [8,20,22,23,26,31,42]. OvCa survivors viewed a recurrence as an indication that their disease was incurable and considered it the 'beginning of the end' [8]. Some women experienced fears upon completion of treatment, as they were not actively fighting the disease [8]. Fear of recurrence can cause anxiety for survivors in remission and may dampen the joy of being disease-free [8,24].

Young survivors: Younger age is significantly associated with fear of death [44].

Personal growth and coping

Despite the many challenges of living with OvCa, survivors often experience personal growth [22,24,38,40] through their spiritual lives, personal relationships [8,22,24,25,40], and renewed perspectives on life [8,20,24,25]. Many OvCa survivors report continuing to experience hope during their illness but higher levels of depression, lower levels of social support/well-being, and increased number of treatments were associated with a higher risk for losing hope [44]. Several studies found a majority of OvCa survivors 'quite a bit' or 'very much' felt a sense of purpose in their lives and had a reason for living [20,31,42]. However, this may be attributed to the survivors being an average of 6 years posttreatment and therefore any psychosocial issues had lessened with time [20,42]. Wenzel *et al.* reported that survivors were generally optimistic, and that the cancer experience positively changed their views on life, relationships, and spirituality [22]. Although survivors mourn the changes in their lives as the result of OvCa, through their losses, many discovered new personal beliefs [34].

Survivors attempt to alleviate the psychological burden of treatment through being active, traveling, and increasing quality time with family and friends [8]. Supporting other OvCa survivors, participating in OvCa advocacy, maintaining a positive attitude, disregarding statistics, living for the moment, as well as focusing on the future, and journaling are important adaptive and coping techniques [8]. A sense of spirituality is also associated with personal growth and the capacity to derive a positive meaning from the OvCa experience [22].

Young survivors: Young OvCa survivors may struggle more with spiritual coping compared with older survivors [19]. In contrast, Monahan *et al.* found that long-term survivors of ovarian germ cell tumors reported more positive changes as a result of their cancer and retrospectively reported more positive changes in the areas of relating to others, appreciation of life, and spiritual change compared with age-matched controls [40].

Measure and scales

Among the 28 articles included in this review, 66 unique psychosocial scales were identified (Table 2), including four developed for their respective studies to measure self-image and sexual functioning ($n = 1$) [22], psychological distress and functioning ($n = 1$) [43], and general knowledge and perceived control, categorized as 'Other' ($n = 2$) [32,43]. Additionally, Swensen *et al.* used seven unspecified QoL tools [34]. The remaining 55 measures were used to assess QoL ($n = 17$), social support and relationships ($n = 5$), self-image and sexual functioning ($n = 6$), psychological distress and functioning ($n = 19$), fear of death/recurrence ($n = 1$), and personal growth and coping ($n = 6$). The Unmet Needs tool was used to measure multiple domains and categorized as 'Other'.

Discussion

This review consolidates the wide-ranging psychosocial needs and concerns reported by OvCa survivors and articulates priority areas that may necessitate attention and intervention. A survivor's psychosocial health is comprised of personal, social, and environmental factors unique to her life. It is important to acknowledge the interrelationship of these psychosocial needs, and that for many women, one issue can complement or exacerbate another.

Some of the greatest needs identified were those related to physical complications and side effects, which profoundly impact OvCa survivors across all six psychosocial domains presented in this review. Impaired physical functioning and fatigue predicts poor QoL; women with physical changes as a result of OvCa perceive having less control over their illness. Physical symptoms increase distress, can impact self-image, and sexual satisfaction, causing a strain on personal relationships, and possibly increase fear of death. OvCa survivors of all ages need access to social support services, and relational support is critical when survivors feel uncertainty, depression, and anxiety. This review has also identified inherent assets of OvCa survivors that may be strengthened by the cancer experience. QoL of an OvCa survivor can improve after diagnosis, despite the challenges of living with cancer. OvCa survivors cite opportunities for reflection and renewed perspectives, and experience personal growth in their spiritual lives and relationships.

Psychosocial survivorship needs of young survivors are particularly important to consider. The literature suggests young survivors are likely to have higher levels of distress and depression than older survivors. Although younger age at diagnosis is related to better sexual and physical functioning, young survivors have lower QoL scores when compared with older survivors. However, like older survivors, young OvCa survivors desire support from fellow survivors and peers who have had similar diagnosis, treatment, and survivorship experiences and report decreased libido, less sexual satisfaction and functioning compared with women without OvCa.

A variety of psychosocial measures were used to measure psychosocial health of OvCa survivors in the studies included in this review. As studies are planned, it is important to continue to use measures and scales that have been validated with OvCa survivors, ensuring that domains and constructs are measured appropriately, and comparison of results between studies.

Studies included in this review recommend that research and interventions should target QoL of survivors and aim to reduce and alleviate distress, fear of recurrence, and sexual dysfunction [31]. Future opportunities should also address whether reducing the physical side effects of treatment improve functional well-being [27], the degree to which self-esteem affects long-term QoL [40], and whether sexual activity and reproductive concerns questions are appropriate to screen for referral to counseling [40]. How survivors acquire information about diagnosis and treatment, whether levels of knowledge impact psychosocial adjustment over time [43], and if survivors are participating in psychosocial services and support, and whether failure to do so reflects choice, poor access, or lack of awareness also should be explored [33]. Finally, larger, more rigorous studies are needed with sufficiently large numbers of racial/ethnic minorities to support comparisons among groups and to assess the role of culture and ethnicity on long-term outcomes [44].

Several studies in this review stress the importance in training healthcare professionals to identify survivors who may require ongoing psychological treatment or psychiatric intervention, as symptoms such as depression are often underdiagnosed [21,33]. It is recommended psychological and emotional evaluations be given routinely throughout the disease trajectory from diagnosis, through treatment, and into long-term survivorship [8,20,21,25,29,42]. Providers should also be aware that survivors experiencing low levels of emotional and social support, self-efficacy, and family functioning have increased need for referral to counseling and psychosocial support and evaluation [23,40]. Support services that incorporate husbands and/or partners and children and provide access to other OvCa survivors are vital [37]. Survivorship care plans that include medical and treatment history, psychosocial issues, and recommendations for future care should be given to the patient and all providers upon the completion of treatment [20]. Psychological support should include interdisciplinary collaboration among oncologists, nurses, and social workers [8,38]. Improving survivors’ knowledge of OvCa and teaching cognitive strategies and positive adaptation skills can help manage and reduce stress and improve emotional well-being [18,43].

There are inherent limitations both of this literature review and of the studies included in the review. Because our analysis only included research conducted in the United States, many otherwise relevant findings were excluded. Likewise, relevant articles may have been inadvertently excluded on the basis of the configuration of search terms used to search databases. Additionally, the scales presented in Table 2 are categorized for the purposes of this paper and are not officially representative of the domain within which they are categorized. The scales categorized in one particular domain in Table 2 may not have been abstracted and presented in the same domain in the results section. Limitations to the articles reviewed included modification of valid psychometric instruments, use of nonvalidated questionnaires, not reporting scales used to assess psychosocial issues, homogenous study samples recruited from academic health centers, cross-sectional study design, small study samples, no control group, or reporting of statistical significance. The treatment of OvCa has changed dramatically over the past decade which significantly impacts QoL; some of the studies in this review may have enrolled women with less novel treatment approaches. There are several strengths to this study. The included reference of measures in Table 2 could be used for future research and study design. To the author’s knowledge, this is the first paper to synthesize OvCa survivor's needs according to common psychosocial domains in one publication, and the first review to include the psychosocial health needs of young OvCa survivors (<45 years of age).

In conclusion, OvCa broadly and radically impacts the immediate and long-term psychosocial health outcomes of a survivor. This review highlights not only the essential work already completed in understanding OvCa survivor's psychosocial health needs but also the unanswered questions and areas for further inquiry and improvement. More research is needed to further explore the relationship between age at diagnosis and survivorship, and larger, more rigorous studies are needed to understand the longterm outcomes for survivors. Without an effective screening tool for early detection of OvCa, it is additionally critical to continue to focus on improving survivor's psychosocial health and QoL. As survivorship increases and lengthens for cancer survivors of all ages, supporting and exploring the evolving needs and assets of OvCa survivors will aid in further developing and reinforcing comprehensive programs and nuanced, targeted intervention.

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Table 1.

Articles included in the psychosocial literature review ($n = 28$)

Study	Study design	Sample size	Average age of participant (years)	Average time since diagnosis of participant (years)	Date of original data collection	Recruitment strategy
Bodurka-Bevers *et al.* [23]	Cross-sectional	246	56.7	2.4	Not available	Upon presentation to the Gynecologic Oncology Center or hospital.
Carmack-Taylor *et al.* [41]	Cross-sectional	232	56.6	4.3	Not available	Outpatients with appointments at the University of Texas MD Anderson Gynecologic Oncology Center over a 6 month period.
Champion *et al.* [19]	Cross-sectional	132	35.9	10.2	Not available	Participants in 4 GOGs. Eligible patients were identified through GOG Statistical Office.
Danhauer *et al.* [30]	Pilot/feasibility intervention	51	58.9	1.25	Not available	Identified by physicians from a comprehensive cancer center and regional cancer center.
de Moor *et al.* [28]	Prospective	90	59.3	2.6	Not available	University of Texas MD Anderson Cancer Center from 1999 to 2003.
Ferrell, B. *et al.* [26]	Cross-sectional	1383	Not available	4	November 2002–February 2003	November 2002 issue of *Conversations! The International Newsletter for Those Fighting Ovarian Cancer*
Ferrell, B. *et al. Symptom concerns of women with ovarian cancer.* [39]	Qualitative analysis of written correspondence	21,806 pieces of correspondence	Not available	Not available	1993–2000	Not available
Ferrell, B. *et al. Psychological well being and quality of life in ovarian cancer survivors.* [8]	Qualitative analysis of written correspondence	21,806 pieces of correspondence	Not available	Not available	January 1994–December 2000	Not available
Ferrell, B.R. *et al. A qualitative analysis of social concerns of women with ovarian cancer.* [37]	Qualitative analysis of written correspondence	21,806 pieces of correspondence	Not available	Not available	January 1994–December 2000	Not available
Ferrell, B.R. *et al. Meaning of illness and spirituality in ovarian cancer survivors.* [24]	Qualitative analysis of written correspondence	21,806 pieces of correspondence	Not available	Not available	January 1994–December 2000	Not available
Fox *et al.* [21]	Secondary data analysis	76	52.5	2.9	Not available	Association of Cancer Online Resources using an advertisement.
Gershenson *et al.* [35]	Case-control	132	35.9	10.2	Not available	Women treated in GOG at the University of Texas MD Anderson Cancer Center.
Jackson *et al.* [36]	Retrospective	421	67	Not available	1995–2000	Not available
Kornblith *et al.* [20]	Cross-sectional	42	61.2	6.1	2007	not found

Study	Study design	Sample size	Average age of participant (years)	Average time since diagnosis of participant (years)	Date of original data collection	Recruitment strategy
Matulonis *et al.* [42]	Cross-sectional	58	56.2	5.8	Not available	Patients were originally contacted by mail, after permission had been granted by their oncologist.
Mirabeau-Beale *et al.* [31]	Cross-sectional	100	55.7 (early stage) 61.2 (advanced stage)	7.4 (early stage) 6.1 (advanced stage)	June 2005–November 2007	Survivors were contacted by mail or during routine clinic visits.
Monahan *et al.* [40]	Case-control	132	35.9 (survivor), 35.7 (control)	10.2	Not available	GOG or MD Anderson Cancer Center via mail or phone
Norton *et al.* [33]	Cross-sectional	143	55.45	1.8	Not available	Approached in outpatient oncology clinics.
Norton *et al.* [32]	Cross-sectional	143	55.2	1.6	Not available	Outpatient clinics of 3 cancer centers and 2 community hospitals. Screened for eligibility by a study assistant and approached after an appointment with their oncologist.
Otis-Green *et al.* [25]	Case-control	33	58	not found	Not available	not found
Parker *et al.* [43]	Cross-sectional	126	58.7	2.7	Not available	Outpatient medical visits at The University of Texas MD Anderson Cancer Center
Ponto *et al.* [38]	Cross-sectional	60	59	5.4	Not available	Network and snowball sampling through the National Ovarian Cancer Coalition.
Shinn *et al.* [44]	Secondary data analysis from cross-sectional study	254	59.1	Not available	Not available	Women were approached during their chemotherapy clearance.
Swenson *et al.* [34]	Cross-sectional	109	35.4	9.9	Not available	Contacted by their treatment sites.
von Gruenigen *et al.* [27]	Cross-sectional	361	57	Not available	June 1994–January 2001	not found
von Gruenigen *et al.* [18]	Case-control	361	Not available	Not available	Not available	not found
von Gruenigen *et al.* [29]	Prospective cohort	42	56.4	Not available	December 2000–June 2004	Two gynecologic oncology offices.
Wenzel *et al.* [22]	Cohort	49	64.6	8.7	Not available	Identified through GOG statistical office database. Physician verbally invites woman to participate.

GOG, Gynecologic Oncology Group.

Table 2.

Measurement tools according to psychosocial domain[a,b]

Instruments	Study
Quality of life [c]	
Cancer Rehabilitation Evaluation System [45]	Norton *et al.* [32]
Complimentary Therapy Assessment [46]	Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]; von Gruenigen *et al.* [29]
European Organization for Research and Treatment of Cancer QoL	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Questionnaire (EORTC QLQ-C30); and European Organization for Research and Treatment of Cancer Ovarian (EORTC OV28) [47,48]	
Fox Simple Quality of Life Scale (FSQOLS) [49]	Fox *et al.* [21]
Functional Assessment of Cancer Therapy (FACT)	Bodurka-Bevers *et al.* [23]; Carmack-Taylor *et al.* [41]; Champion *et al.* [19]; Danhauer *et al.* [30]; de Moor *et al.* [28]; Kornblith *et al.* [20]; Mirabeau-Beale *et al.* [31]; Monahan *et al.* [40]; Shinn *et al.* [44]; von Gruenigen, *et al.* [29]; von Gruenigen *et al.* [27]; von Gruenigen *et al.* [18]; Wenzel *et al.* [22]
General (FACT-G) [50];	
Ovarian Cancer (FACT-O) [51]	
Neurotoxicity (FACT-NTX) [52]	
Gynecologic Oncology Group Neurotoxicity (FACT/GOG-Ntx) [52]	
Functional Assessment of Chronic Illness Therapy (FACIT)	Champion *et al.* [19]; Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]; Monahan *et al.* [40]; von Gruenigen, *et al.* [29]
Fatigue (FACIT-F) [53]	
Spirituality (FACIT-Sp) [54]	
Gynecologic Symptoms Scale [55]	Champion *et al.* [19]; Gershenson *et al.* [35]; Monahan *et al.* [40]
Illness Intrusiveness Scale [56]	Wenzel *et al.* [22]
Medical Outcomes Study (MOS) 36 Item Short Form Survey [57] (SF-36)	Champion *et al.* [19]; Fox *et al.* [21]; Monahan *et al.* [40]; von Gruenigen, *et al.* [29]; Wenzel *et al.* [22]
Memorial Symptom Assessment Scale [58]	Carmack-Taylor *et al.* [41]
Quality of Life-Cancer Survivorship (QOL-CS) Inventory [59]	Wenzel *et al.* [22]
Quality of Life (QOL) Ovarian Cancer Tool [60]	Ferrell, B. *et al.* [26]; Otis-Green *et al.* [25]
Social support and relationships	
Duke-UNC Functional Social Support questionnaire (DUFSS) [61]	Champion *et al.* [19]; Monahan *et al.* [40]; Wenzel *et al.* [22]
Dyadic Adjustment Scale (DAS) [62]	Champion *et al.* [19]; Gershenson *et al.* [35]; Matulonis *et al.* [42]; Monahan *et al.* [40]
Family Adaptability, Partnership, Growth, Affection and Resolve (APGAR) scale [63]	Champion *et al.* [19]; Monahan *et al.* [40]

Instruments	Study
Medical Outcomes Study (MOS) Social Support Survey [64]	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Perceived Negative Behaviors Scale [65]	Norton *et al.* [32]
Self-image and sexual functioning	
Cancer and Leukemia Group B (CALGB) Sexual Functioning Scale [66]	Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Reproductive Concerns Scale [67]	Champion *et al.* [19]; Gershenson *et al.* [35]; Monahan *et al.* [40]
Rosenberg Self-Esteem Scale [68]	Norton *et al.* [32]
Sexual Activity Questionnaire (SAQ) [69]	Carmack-Taylor *et al.* [41]; Champion *et al.* [19]; Gershenson *et al.* [35]; Monahan *et al.* [40]; Wenzel *et al.* [22]
Sexual Problems Related to Cancer [70]	Kornblith *et al.* [20]
Sexual Self-Schema Scale [71]	Champion *et al.* [19]; Gershenson *et al.* [35]; Monahan *et al.* [40]
Gynecologic concerns scale^{d}	Wenzel *et al.* [22]
Psychological distress and functioning	
Beck Depression Inventory (BDI) [72]	Norton *et al.* [33]
Beck's Hopelessness Scale [73]	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Center for Epidemiologic Studies-Depression (CES-D) Scale [74]	Bodurka-Bevers *et al.* [23]; Carmack-Taylor *et al.* [41]; Champion *et al.* [19]; de Moor *et al.* [28]; Monahan *et al.* [40]; Parker *et al.* [43]; Wenzel *et al.* [22]
Impact of Events Scale (IES) and Revised Impact of Event Scale (R-IES) [75]	Monahan *et al.* [40]; Norton *et al.* [33]; Wenzel *et al.* [22]
Life Event List [76]	Matulonis *et al.* [42]
Life Orientation Test-Revised (LOT-R) [77]	de Moor *et al.* [28]
Mental Health Inventory [78]; MHI-17 [79]	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]; Norton *et al.* [33]; Norton *et al.* [32]
Mishel Uncertainty in Illness Scale (MUIS) [80]	Otis-Green *et al.* [25]
Physician's Health Questionnaire (PHQ-9) [81]	Shinn *et al.* [44]
Perceived Stress Scale (PSS) [82]	de Moor *et al.* [28]
Positive and Negative Affect Scale (PANAS) [83]	Champion *et al.* [19]; Monahan *et al.* [40]
Post-Traumatic Stress Disorder (PTSD) Checklist-Civilian (PCL-C) [84]	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Psychological Distress Thermometer [85]	Otis-Green *et al.* [25]
Spielberger State-Trait Anxiety Inventory [74]	Bodurka-Bevers *et al.* [23]; Carmack-Taylor *et al.* [41]; de Moor *et al.* [28]; Parker *et al.* [43]
Stressful Life Events Instrument [87]	Monahan *et al.* [40]; Matulonis *et al.* [42]
Symptom Distress Scale [88]	Ponto *et al.* [38]
Treatment-Specific Optimism Scale (TSOS) [89]	de Moor *et al.* [28]
Zubrod Score [90]	Bodurka-Bevers *et al.* [23]; Carmack-Taylor *et al.* [41]

Instruments	Study
CA125 preoccupation[d]	Parker *et al.* [43]
Fear of death/recurrence	
Fear of Relapse/Recurrence Scale [91]	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Personal growth and coping	
Confidence Adjusting to Illness Scale (CAIS) (adapted from [92])	Champion *et al.* [19]; Wenzel *et al.* [22]
Constructed Meaning Scale [93]	Ponto *et al.* [38]
Impact of Cancer Scale [94]	Kornblith *et al.* [20]
Integrative Cancer Experience Scale (ICES) (no citation available)	Champion *et al.* [19]; Wenzel *et al.* [22]
Post Traumatic Growth Inventory (PTGI) [95]	Champion *et al.* [19]; Matulonis *et al.* [42]; Monahan *et al.* [40]; Ponto *et al.* [38]; Wenzel *et al.* [22]
Psychological Adjustment to illness Scale – Self-Report (PAIS-SR) [96]	Ponto *et al.*,[38]
Other	
Unmet Needs [97]	Kornblith *et al.* [20]; Matulonis *et al.* [42]; Mirabeau-Beale *et al.* [31]
Ovarian cancer knowledge[d]	Parker *et al.* [43]
Perceived control[d]	Norton *et al.* [32]

[a] Ferrell, *et al.* [39] (*Symptom concerns of women with ovarian cancer; Psychological well being and quality of life in ovarian cancer survivors; A qualitative analysis of social concerns of women with ovarian cancer*; and *Meaning of illness and spirituality in ovarian cancer survivors*) and Jackson *et al.*. [36] did not use scales in their studies.

[b] Von Gruenigen *et al.* [29] included the Eating Pattern Assessment Tool, but that tool is not reported in this table.

[c] Seven unidentified quality of life (QoL) scales used in Swenson *et al.* are not included in this table.

[d] Scale developed for study