



# HHS Public Access

Author manuscript

*Support Care Cancer*. Author manuscript; available in PMC 2019 February 05.

Published in final edited form as:

*Support Care Cancer*. 2013 October ; 21(10): 2889–2898. doi:10.1007/s00520-013-1893-5.

## Issues of ovarian cancer survivors in the USA: a literature review

**Katrina F. Trivers,**

Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, 4770 Buford Highway, NE, MS F76, Atlanta, GA 30341, USA

**Jennifer Rees Patterson,**

SciMetrika, LLC, Durham, NC, USA

**Katherine B. Roland,** and

Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, 4770 Buford Highway, NE, MS F76, Atlanta, GA 30341, USA

**Juan L. Rodriguez**

Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, 4770 Buford Highway, NE, MS F76, Atlanta, GA 30341, USA

### Abstract

**Purpose**—As the number of ovarian cancer survivors increases, so does the need for appropriate intervention and care. A literature review was conducted to assess the issues affecting ovarian cancer survivors in the USA, including the needs of younger survivors.

**Methods**—Articles on six topics (finances/employment, reproductive and sexual health, treatment effects, information needs, genomics, and end-of-life/palliative care) among ovarian cancer survivors were identified through comprehensive database searches. Abstracts for all citations were reviewed to determine relevancy. Data from relevant articles, defined as including a sample size of  $\geq 20$ , published in English, involving human subjects in the USA, and published between 2000 and 2010, were abstracted.

**Results**—Thirty-four articles were relevant. Common, but often unaddressed, treatment side effects included infertility and issues with sexual health. Survivors reported not receiving adequate information about their disease. Hereditary cancer can lead to concern for family members. End-of-life/palliative care was often not addressed by physicians. Most of the studies used a cross-sectional design and lacked control groups. Participants were primarily recruited from academic medical centers or clinical trials and tended to be White. Few studies specifically addressed young survivors; however, reproductive health issues are common.

---

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

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

**Conclusions**—Ovarian cancer has wide-ranging impacts. This review emphasizes the need for more research among ovarian cancer survivors, particularly related to finances, reproductive and sexual health, information, genomics, and end-of-life care. Issues specific to young survivors also deserve more attention. Direction for future research and clinical implications are discussed.

### Keywords

Ovarian neoplasms; Survival; Treatment; Financial; End of life; Fertility; Sexual health

---

### Introduction

Over 21,000 women are diagnosed with and 14,000 women die from ovarian cancer annually [1]. The 5-year survival rate for ovarian cancer (43.2 % for those diagnosed between 2002 and 2008) is substantially lower than for breast cancer (90.2 %) [2]. Ovarian cancer also has a high risk of recurrence; most survivors can expect to have at least one recurrence [3]. The 5-year survival rate significantly improved from 36.1 % for those diagnosed between 1975 and 1977 to 43.2 % for those diagnosed between 2002 and 2008 [2], leading to an increase in the absolute number of survivors. Since there is no effective or approved screening test for ovarian cancer [4] and there are increasing numbers of women with ovarian cancer, one way to mitigate its effects is to address survivorship concerns. For example, ovarian cancer brings an array of unpleasant treatment side effects from surgical procedures and repeated doses of chemotherapy [5–8] and brings unanticipated changes in areas including finances and sexual health [9].

There is a need to understand what is already known about ovarian cancer survivorship, where the research gaps are, and where the possibilities for intervention lie, particularly for younger survivors. Younger ovarian cancer survivors, an especially vulnerable population [10], may face unique challenges (e.g., fertility concerns, impact to family life) given their stage of life and the type of tumor they are more likely to be diagnosed with (e.g., germ cell tumors). No review has comprehensively reviewed the literature on a variety of ovarian cancer survivorship topics since 2006 [11], and no reviews have described the issues specific to young survivors.

The aim of this paper is to conduct a literature review on issues affecting ovarian cancer survivors in order to highlight gaps in the literature and guide future Centers for Disease Control and Prevention (CDC) research and initiatives. Finances, reproductive and sexual health, treatment effects, information needs, genomics, and end-of-life/palliative care are included as relevant topics. Psychosocial needs were not included in this review. A secondary focus was to explore and describe the differences between younger (<45 years of age) and older survivors within each of these six topics. Throughout the paper, we will use the term survivor to mean any woman diagnosed with ovarian cancer, from diagnosis through the end of her life, consistent with the National Cancer Institute and CDC definitions (<http://www.cancer.gov/dictionary?Cdrid=450125>; [http://www.cdc.gov/cancer/survivorship/basic\\_info/index.htm](http://www.cdc.gov/cancer/survivorship/basic_info/index.htm)). However, it should be noted that most women do not survive long-term.

## Methods

A comprehensive literature search was conducted using the following databases: PubMed, PsycINFO, CINAHL, Cochrane, and Web of Knowledge. Articles from English peer-reviewed publications, involving human subjects conducted in the USA, and published between December 2000 and December 2010 were included. Seven searches were conducted; one for ovarian cancer survivors and the remaining six combining the ovarian cancer survivors search with each topic. Example keywords used in the general ovarian cancer survivorship search included: ovarian neoplasm; disease-free survival; and survivor(ship). Example keywords for each of the topics are noted in quotes: (1) finances and employment: “bankruptcy,” “(un)employment”; (2) reproductive and sexual health: “reproduction,” “fertility”; (3) treatment effects: “treatment decisions,” “long (late) term effects”; (4) information needs: “consumer health information,” “information seeking behavior”; (5) genomics: “BRCA1,” “genetic counseling (testing)”; and (6) end-of-life/palliative care: “end of life care,” “palliative care.”

Abstracts for all identified citations were reviewed and classified as relevant, somewhat relevant, or not relevant. Papers that had a sample size of <20, were not specific to ovarian cancer survivors (e.g., breast cancer survivors that are now at higher risk of ovarian cancer), reported on the efficacy of treatment or drug therapies exclusively, or were conducted outside of the USA were excluded. Non-US studies were excluded due to differences in health care systems, insurance coverage, and access to care and because this review may guide US federal research and programmatic initiatives. To ensure quality, a secondary reviewer was randomly assigned 25 % of all abstracts. The reviews were initially 99 % concordant on relevance classification; discrepancies were discussed by the primary and secondary reviewers. The primary reviewer made a final decision regarding classification. The full texts of papers classified as somewhat relevant were reviewed to give a final classification of relevant or not relevant.

As a second search strategy, the reference list of citations identified from relevant articles was reviewed and those that addressed the research questions and met the inclusion criteria were retrieved and reviewed for relevance.

While one citation could provide information on multiple topics (e.g., reproductive health and information needs), individual data elements were abstracted and captured under one of the seven topics. Information abstracted for young ovarian cancer survivors included data (1) specifically addressing young survivors (<45 years of age) or (2) from germ cell tumor studies. Germ cell tumor studies predominately, but not exclusively, included women <45 years of age. The goal of this paper was to describe the literature and not to systematically evaluate the quality of the literature; however, we provide a discussion of methodological considerations (e.g., sample size, sample design).

## Results

Our initial search identified 1,634 papers, 56 of which were definitely or somewhat relevant. A review of the reference list of identified citations uncovered an additional 20 definitely or

somewhat relevant papers. Of those 76 papers, 34 articles were determined to be definitely relevant and were included in the review (Table 1). Findings unique to young survivors are highlighted within each section, if addressed in the studies.

### Treatment effects

Ovarian cancer often includes a prolonged course of intensive treatment, primarily surgery (possibly including hysterectomy, bilateral salpingo-oophorectomy with omentectomy) and multiple rounds of chemotherapy [12]. Radiation is not commonly used as a treatment modality [12]. All of these treatments have numerous side effects [13]. Twenty-four of the 34 studies examined the impact of treatment [5, 6, 8, 9, 11, 13–31]. The literature generally fell into two subtopics: (1) side effects [6, 8, 9, 11, 13, 16–24, 30, 31] and (2) options for nonstandard treatments, including the use of alternative/complementary therapy [13, 18, 20, 25–28].

Initial treatment for ovarian cancer typically involves surgery to remove as much of the tumor as possible [11, 17, 26, 28, 30, 32]. Chemotherapy causes side effects to the neurological system, gastrointestinal tract, and sexual health [11], leading to a wide variety of self-reported symptoms [9, 13, 14, 18, 21]. Pain, fatigue, and peripheral neuropathy were the most frequently reported side effects [13, 14, 21], followed by nausea, decreased libido, hair loss, and anorexia [6, 9, 14, 15, 18, 21]. Symptom prevalence was substantial; fatigue was reported by 70 % of survivors and 30 % experienced nausea, difficulty eating, constipation, and sexual concerns [21].

Women currently receiving chemotherapy, radiation, or surgery report more physical symptoms and lower functioning than those not currently receiving those modalities [6, 24, 28, 31]. Most survivors undergo multiple chemotherapy rounds due to recurrences or disease progression [8, 11, 25]. The number of treatments was positively correlated with the number of side effects experienced [25]. In one study, 28 % of long-term (5+years post-diagnosis) survivors met the criteria for cognitive impairment, significantly higher than the 15 % impairment reported in noncancer populations [17], and there was an inverse association between prior number of chemotherapy treatments and performance on tests of executive function [17]. Some articles report a relatively low amount of symptom issues and associated psychological dysfunction [14, 20, 22]. These contradictory results possibly reflect differences in study populations, number and types of treatments received, and time since diagnosis.

Seven studies addressed nonstandard treatment [13, 18, 20, 25–28]. A number of complementary therapies are used by ovarian cancer survivors, including osteopathy, herbs and vitamins, acupuncture, prayer, yoga, meditation, and massage [20, 26, 28]. von Gruenigen et al. found that 62 % of survivors used at least one type of complementary therapy and use increased after initial therapy was completed [28]. Survivors used complementary therapies to attempt to cure their disease, provide symptom relief, and improve quality of life (QoL) [25, 28], despite the lack of evidence of a direct benefit [25]. Survivors were interested in exploring all treatment possibilities and wanted more control over their treatment modalities [13, 27].

**Young survivors**—In a study of germ cell tumor survivors, more gynecological symptoms were associated with worse neurotoxicity; fewer gynecological symptoms and younger age at diagnosis were associated with better physical functioning [16]. Survivors were significantly more likely than controls to report a diagnosis of hypertension, hypercholesterolemia, or hearing loss [19].

### Reproductive and sexual health

Eleven of the 34 articles discussed survivors' concerns about reproductive and sexual health, loss of fertility from treatment, or the onset of surgically induced menopause [6, 13, 15, 16, 24, 25, 27, 30, 33–35]. In one study, 25 % of survivors reported entering menopause as a result of treatment and 27 % reported distress related to this transition [24], which is lower than similar estimates in young women with breast cancer [36], but the ovarian cancer study included older women (mean age, 56 years) and did not stratify results by menopausal status at diagnosis. Ovary removal causes rapid decreases in estrogen and testosterone [15], and low levels of these hormones are associated with hot flashes, vaginal dryness, and diminished libido [15, 30, 37]. One study observed that 50 % of survivors were sexually active, and of sexually active survivors, 47 % reported no or little sexual desire, 80 % had vaginal dryness, and 62 % experienced pain or discomfort during sex [6]. Increasing time since diagnosis also correlated with increased sexual activity [6].

**Young survivors**—Most of the reproductive/sexual health and fertility literature discussed young survivors' concerns [13, 15, 16, 25, 27, 30, 33–35]. Young survivors had greater reproductive concerns than matched controls, and infertile survivors reported more reproductive concerns than fertile survivors [33, 34]. Infertility was particularly distressing for young survivors who desired children [13, 27, 30]; many found this more traumatic than the initial diagnosis [30]. Anger and regret were common among survivors due to not having time and information to explore fertility preservation options [30]. Many survivors were still interested in parenthood either through treatments that increase the likelihood of pregnancy or through adoption [13].

Posttreatment, sexual pleasure was higher for women who had fewer gynecological symptoms, were married, and had less reproductive concerns [16]. Survivors reported less sexual pleasure and lower sexual activity than women without cancer [33, 34].

Approximately one quarter of young survivors experienced decreased sexual interest or desire which impacted intimate relationships [35].

### Information needs

Ten of 34 articles discussed the information needs of survivors [5, 8, 9, 11, 13, 16, 21, 27, 30, 32]. Data from these ten studies primarily addressed (1) lack of ovarian cancer information available [5, 8, 9, 11, 21, 27, 30, 32] and (2) patient–provider communication [11, 13, 16, 30].

Survivors reported a lack of information on the basics about ovarian cancer, prognosis, and treatment decision making; 34 % of survivors did not receive any written information about their disease and 31 % had only a few of their questions answered [11]. Survivors want as

much information as possible about the disease and are frustrated by the lack of ovarian cancer information compared to more prevalent diseases such as breast cancer [8, 9]. Specific unmet information needs include fertility preservation among young survivors and exploring complementary/alternative treatment options [27, 30]. Increased knowledge about ovarian cancer and CA125 testing is associated with lower depression levels and anxiety [5, 32].

The other subtopic addressed was how the survivor–provider relationship impacts the acquisition of information. Many survivors reported symptoms to their doctors long before receiving their ovarian cancer diagnosis; self-reported pre-diagnosis symptom prevalence was upwards of 24 % [13], leading to anger and a perception of a delayed diagnosis. This led to frustrations with and low opinions of their providers [13]. Survivors treated by a gynecologic oncologist reported more positive relationships, as well as increased trust in their physician [13]. Effective survivor–provider communication, including feeling satisfied with the information received and having their disease experiences validated, benefits overall well-being and QoL [11, 16].

Alternative/complementary therapies [13] and sexual dysfunction [30] were difficult for survivors to discuss with physicians. Alternative/complementary therapies may not be viewed by physicians as valid forms of treatment [13]. Barriers to discussing sexual dysfunction include its sensitive nature, beliefs that discussions should focus on treatment-related issues, time constraints during clinic appointments, and a physician’s reluctance to discuss the topic [30].

### Finances and employment

Seven articles discussed the impact of ovarian cancer on finances or employment, most of which focused on survivors’ ability to work [9, 11, 19, 20, 23, 26, 33]. Survivors reported taking time off from work for cancer-related treatment [9, 23]; 43 % of ovarian cancer survivors reported working full-time post-diagnosis, compared to 67 % prediagnosis; however, this resulted in minimal impact on overall socioeconomic status [20]. Retirement was common after an ovarian cancer diagnosis [20].

Survivors cited economic factors (e.g., need for insurance to pay for care, lost money from not working) as one reason for wanting to return to work [9]. Employment is also a symbol for overcoming cancer and returning to “normal” and provided feelings of achievement and validation [9]. Employed survivors or those with incomes above \$50,000 had significantly higher overall and social QoL scores compared to unemployed survivors or those making less than \$50,000 [26], consistent with another study that observed that survivors with the lowest QoL scores were significantly less likely to be able to work [23].

**Young survivors**—Young ovarian cancer survivors had lower mean incomes than age-matched controls [19, 33]; however, this was not significant after adjusting for partnership status [33]. Changes in occupation as a result of cancer occur among younger survivors; 14 % of survivors reported a change in occupation because ovarian cancer impacted their ability to work [19]. Survivors were more afraid to change jobs for fear of losing health insurance compared to the controls (22 vs. 11 %) [19]. However, there were no differences

in unemployment 10 years post-diagnosis between survivors and controls, suggesting that most survivors remained in the workforce [19].

### Genomics

A large risk factor for ovarian cancer is a family history of the disease [30]. Seven studies addressed the genomic aspect of ovarian cancer [9, 18, 26, 27, 30, 38, 39]. Survivors who had watched older relatives face the disease [9] felt compassion for their own daughters, knowing the agony of watching a loved one battle ovarian cancer [27]. Guilt and fear that their daughters may develop ovarian cancer [27] or may have inherited a genetic predisposition for cancer [9, 18] was common. Similarly, survivors with known BRCA1/2 mutations may have concerns about passing on a mutation or choosing whether to pursue fertility preservation [30].

Survivors wanted female relatives to be screened for ovarian cancer; however, the lack of effective screening measures aggravated the fear and uncertainty felt for relatives [27]. Few studies investigated the prevalence of, and barriers to, genetic testing among survivors, but in one study, 21 % of survivors had a family history of ovarian cancer but only 14 % had undergone genetic testing [26].

### End-of-life/palliative care

Six studies discussed end-of-life and palliative care needs of survivors [11, 18, 30, 40–42]. Literature fell into two subtopics: (1) palliative care decision making and (2) end-of-life experiences.

Advanced stage ovarian cancer often requires making difficult decisions regarding curative vs. palliative care [11]. Some survivors may not be willing to transition to palliative care despite an unfavorable prognosis [30]. Physicians may not know when to initiate a conversation about shifting to palliative care; some address palliation at a recurrence of ovarian cancer, while others wait until the terminal stage [30]. Good survivor–provider communication during palliative chemotherapy increases survivor’s understanding of the goal of palliation; several planned conversations between the provider, survivor, and family may be required [30].

Five articles described survivors’ experiences at the end of life [18, 40–43]. Herrinton et al. found no record of treatment for many complications that may contribute to a difficult death and concluded that end-of-life care may be inadequate [40]. For example, 67 % of survivors with ascites, 50 % of survivors with pleural effusion, and 33 % of survivors with a bowel obstruction were not treated [40]. In another study, 85 % of survivor’s charts included documented complaints of pain [42] but little evidence of systematic pain assessment or management [42]. Barriers to appropriate pain management include survivor’s failing to communicate their pain to their provider, possibly due to addiction fears or side effects from pain medications or because they do not want to complain [42]. Pain medication use increased as death neared, with 9 % of women on high intensity pain medication drugs 5–6 months before death vs. 22 and 54 % at 3–4 and 1–2 months before death, respectively [42].

In a qualitative study, survivors reported coming to terms with their mortality by living life to the fullest, spending time with loved ones, and working with advocacy and support groups [18]. Planning their memorial services and making final arrangements provided a sense of control and comfort [18]. Survivors wanted a “good death,” one in which they receive competent care, are aware of what is going on, have effective symptom management, and are not a burden to a spouse or caretaker [41].

### Methodological considerations

The relevant studies in this review had an average sample size of 210 participants, included ovarian cancer survivors who were younger than the median age of survivors (50 vs. 63 years of age) and were, on average, 7 years from their diagnosis. Most studies were cross-sectional and descriptive in nature; few contained control groups and, among those that did, the control groups were predominately acquaintance controls. Study samples were largely recruited from academic medical centers (e.g., MD Anderson Cancer Center) or included participants from clinical trials (e.g., Gynecologic Oncology Group) and, as such, were not population-based. Most studies predominately included White women.

### Discussion

This comprehensive review summarizes the major issues and concerns of ovarian cancer survivors, with particular focus on young survivors, an understudied group. Ovarian cancer affects many facets of a survivor’s life. Overall, this review suggests that debilitating treatment side effects were common. Survivors experience changes to their reproductive and sexual health due to treatment, including infertility and the onset of menopausal symptoms. Survivors report frustration with the lack of ovarian cancer-specific information available; CAM use and sexual health were difficult topics to discuss with health care providers. Survivors experience deleterious financial effects, at least in the short term. Many survivors recall their female relatives dealing with the disease and they feel guilt, worry, and concern about their younger female relatives developing ovarian cancer. End-of-life and palliative care options need to be discussed and addressed by physicians when appropriate; more could be done to help survivors navigate end of life.

For all survivors, financial and employment matters, reproductive and sexual health, information needs, genomics, and end-of-life care received less attention than treatment side effects. The literature on young survivors primarily focuses on fertility and sexual health, and even in these domains, more study is needed. Additional domains of research should address whether and how the needs of young survivors are unique. Given the lack of data specifically on young survivors, it is difficult to determine whether their needs truly are distinctive, but considering their life stage, some issues will be more salient and prevalent, including reproductive and sexual health and financial issues. The reasons for differences in results in younger vs. older survivors is unclear and was not directly addressed in any article, but could be due to the differences between the types of ovarian cancer prevalent at each age; germ cell tumors are more common in younger patients vs. epithelial cancers in older patients. Younger survivors are difficult to study given the rarity of ovarian cancer in this age group.



The methodological considerations described in the results could have affected the reported results in a number of ways. In general, because studies included survivors who were younger than the median age of all survivors and, on average, 7 years post-diagnosis, they may be healthier. Thus, the literature may paint a more optimistic and skewed view of the ovarian cancer survivorship experience. Since studies typically recruit patients from academic medical centers or clinical trials, the published literature may include potentially biased samples that are more affluent, have better access to care, and be more likely to live in an urban area than the ovarian cancer survivor population as a whole. Based on this literature review, several recommendations for the improvement of clinical care and research to address current gaps can be made.

### **Recommendations for clinical care**

Because women with ovarian cancer are often diagnosed in advanced stages, symptom burden is significant. Health care providers should be aware of, screen for, and manage common symptoms, including pain, fatigue, neuropathy, and gynecological symptoms, as better symptom control may improve QoL. Health professionals should initiate discussions about the effects of treatment on sexual function and fertility prior to treatment initiation, including education and possible referral. Sexual health should continue to be addressed after treatment.

Ovarian cancer-specific information should be provided, including available treatments (e.g., typical experiences and mitigation of side effects) and the likelihood of cure. Tailored information should be provided based on the survivor's prognosis, needs, and desires, consistent with the Institute of Medicine recommendations that survivors receive care plans which include information on the long-term effects of cancer and its treatment and provide guidance on follow-up care [44].

The use of appropriate genetic services among survivors is low and could be improved; ascertaining BRCA1/2 mutation carriers could allow the identification of high-risk family members who could take various actions to prevent cancer.

Given the high fatality rate of ovarian cancer, survivor's fears and concerns about dying and losing hope should be acknowledged by clinicians. A willingness to discuss end-of-life issues is an important sign of support, and regular assessments and treatment of pain are recommended for terminal cases as interventions are available to address these issues.

### **Recommendations for research**

Ovarian cancer survivorship research could benefit from study design improvements, like the inclusion of more diverse and population-based samples of survivors who are not recruited just from academic medical centers and clinical trials groups. More rigorous study design is needed; studies should be less descriptive/cross-sectional in nature and include population-based control samples (either other cancer survivors or age-matched noncancer controls). Without such comparison groups, it is difficult to determine what issues are unique to ovarian cancers. Prospective studies are needed to examine health throughout the disease trajectory. Cross-sectional studies do not allow for a detailed and systematic description of changes over time (e.g., whether treatment side effects are transitory or permanent or

whether side effects differ by type of chemotherapy) or permit valid comparisons between groups of survivors. Studies should attempt to recruit ovarian cancer survivors as soon as possible after diagnosis so as not to bias results towards healthier and long-term survivors.

For all survivors, more research on the use and safety of complementary/alternative therapies would be helpful, given survivors' interest in the topic. Hereditary ovarian cancer is an understudied area, particularly survivor's knowledge of inherited cancer risk and subsequent medical decision making.

More research in young survivors is needed, particularly for topics of specific interest to them including reproductive and sexual health and fertility. Since younger survivors are usually still in the workforce, research on the financial effects of cancer would be of tremendous interest to this group.

These recommendations for clinical care and research are not unique to ovarian cancer survivorship, but could be true for other cancers, particularly those that are rare or rapidly fatal (e.g., lung or esophageal cancers), but this is one of the first times these considerations are comprehensively described for ovarian cancer.

This review has limitations. In order to be as comprehensive as possible, both original research and review articles were included; some research findings were potentially included more than once. Therefore, the number of articles should not be viewed as a true estimate of the proportion of literature devoted to that topic. It is difficult to completely separate data into mutually exclusive topics, given the interdisciplinary and cross-cutting nature of the research. Also, our results are not generalizable to non-US populations.

The strengths of this review are that it was comprehensive; we reviewed the literature on a variety of topics. We were particularly interested in stratifying our results by age; issues specific to younger survivors have received little attention. This review highlights existing gaps emphasizing the need for more research in order to identify the unmet needs of survivors. Additional research is particularly needed for finances, reproductive and sexual health, information, genomics, and end-of-life care. The concerns of young survivors deserve more attention. This review can be used to inform future research which will assist CDC and others to address the needs of ovarian cancer survivors.

## Acknowledgments

This work was funded by the Centers for Disease Control and Prevention.

## References

1. United States Cancer Statistics: 1999–2008 Incidence, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute 2011 Available at <http://wonder.cdc.gov/cancer-v2008.html>. Accessed 15 May 2012
2. Howlader N, Noone A, Krapcho M, Neyman N, Aminou R, Waldron W, Altekruse S, Kosary C, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Eisner M, Lewis D, Chen H, Feuer E, Cronin KA (2012) SEER cancer statistics review, 1975–2009 (vintage 2009 populations). National Cancer Institute,

Bethesda. Based on November 2011 SEER data submission, posted to the SEER web site, April. Available at [http://seer.cancer.gov/csr/1975\\_2009\\_pops09/](http://seer.cancer.gov/csr/1975_2009_pops09/)

3. Cannistra SA (2004) Cancer of the ovary. *N Engl J Med* 351(24):2519–2529. doi: 10.1056/NEJMra041842 [PubMed: 15590954]
4. Buys SS, Partridge E, Black A, Johnson CC, Lamerato L, Isaacs C, Reding DJ, Greenlee RT, Yokochi LA, Kessel B, Crawford ED, Church TR, Andriole GL, Weissfeld JL, Fouad MN, Chia D, O'Brien B, Ragard LR, Clapp JD, Rathmell JM, Riley TL, Hartge P, Pinsky PF, Zhu CS, Izmirlian G, Kramer BS, Miller AB, Xu JL, Prorok PC, Gohagan JK, Berg CD, Team PP (2011) Effect of screening on ovarian cancer mortality: the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Randomized Controlled Trial. *JAMA: J Am Med Assoc* 305(22):2295–2303. doi: 10.1001/jama.2011.766
5. Arden-Close E, Gidron Y, Moss-Morris R (2008) Psychological distress and its correlates in ovarian cancer: a systematic review. *Psychooncology* 17(11):1061–1072. doi:10.1002/pon.1363 [PubMed: 18561287]
6. Carmack Taylor CL, Basen-Engquist K, Shinn EH, Bodurka DC (2004) Predictors of sexual functioning in ovarian cancer patients. *J Clin Oncol: Off J Am Soc Clin Oncol* 22(5):881–889. doi: 10.1200/jco.2004.08.150
7. de Moor JS, de Moor CA, Basen-Engquist K, Kudelka A, Bevers MW, Cohen L (2006) Optimism, distress, health-related quality of life, and change in cancer antigen 125 among patients with ovarian cancer undergoing chemotherapy. *Psychosom Med* 68(4):555–562. doi:10.1097/01.psy.0000222379.71389.91 [PubMed: 16868264]
8. McCorkle R, Pasacreta J, Tang ST (2003) The silent killer: psychological issues in ovarian cancer. *Holist Nurs Pract* 17(6):300–308 [PubMed: 14650572]
9. Ferrell BR, Smith SL, Ervin KS, Itano J, Melancon C (2003) A qualitative analysis of social concerns of women with ovarian cancer. *Psychooncology* 12(7):647–663 [PubMed: 14502590]
10. Forsythe LP, Kent EE, Weaver KE, Buchanan N, Hawkins NA, Rodriguez JL, Ryerson AB, Rowland JH (2013) Receipt of psychosocial care among cancer survivors in the United States. *J Clin Oncol: Off J Am Soc Clin Oncol*. doi:10.1200/jco.2012.46.2101
11. Lockwood-Rayermann S (2006) Survivorship issues in ovarian cancer: a review. *Oncol Nurs Forum* 33(3):553–562. doi:10.1188/06.onf.553-562 [PubMed: 16676012]
12. Cannistra SA, Gershenson DM, Recht A (2011) Ovarian cancer, fallopian tube carcinoma, and peritoneal carcinoma In: DeVita VT, Lawrence TS, Rosenberg SA (eds) DeVita, Hellman, and Rosenberg's cancer: principles and practice of oncology, 9th edn. Lippincott Williams & Wilkins, Philadelphia
13. Ferrell B, Smith S, Cullinane C, Melancon C (2003) Symptom concerns of women with ovarian cancer. *J Pain Symptom Manage* 25(6):528–538 [PubMed: 12782433]
14. Badr H, Basen-Engquist K, Carmack Taylor CL, de Moor C (2006) Mood states associated with transitory physical symptoms among breast and ovarian cancer survivors. *J Behav Med* 29(5):461–475. doi:10.1007/s10865-006-9052-9 [PubMed: 16705484]
15. Bodurka DC, Sun CC (2006) Sexual function after gynecologic cancer. *Obstet Gynecol Clin North Am* 33(4):621–630. doi:10.1016/j.ogc.2006.09.006, ix [PubMed: 17116505]
16. Champion V, Williams SD, Miller A, Reuille KM, Wagler-Ziner K, Monahan PO, Zhao Q, Gershenson D, Cella D (2007) Quality of life in long-term survivors of ovarian germ cell tumors: a Gynecologic Oncology Group study. *Gynecol Oncol* 105(3):687–694. doi:10.1016/j.ygyno.2007.01.042 [PubMed: 17355890]
17. Correa DD, Zhou Q, Thaler HT, Maziarz M, Hurley K, Hensley ML (2010) Cognitive functions in long-term survivors of ovarian cancer. *Gynecol Oncol* 119(2):366–369. doi:10.1016/j.ygyno.2010.06.023 [PubMed: 20630576]
18. Ferrell B, Smith SL, Cullinane CA, Melancon C (2003) Psychological well being and quality of life in ovarian cancer survivors. *Cancer* 98(5):1061–1071. doi:10.1002/cncr.11291 [PubMed: 12942576]
19. Matei D, Miller AM, Monahan P, Gershenson D, Zhao Q, Cella D, Champion VL, Williams SD (2009) Chronic physical effects and health care utilization in long-term ovarian germ cell tumor

- survivors: a Gynecologic Oncology Group study. *J Clin Oncol: Off J Am Soc Clin Oncol* 27(25): 4142–4149. doi:10.1200/jco.2008.20.9189
20. 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(6): 1183–1193. doi:10.1111/j.1525-1438.2007.01167.x [PubMed: 18217977]
  21. Otis-Green S, Ferrell B, Sun V, Spolum M, Morgan R, Macdonald D (2008) Feasibility of an ovarian cancer quality-of-life psychoeducational intervention. *J Cancer Educ* 23(4):214–221. doi: 10.1080/08858190802188784 [PubMed: 19058068]
  22. Shinn EH, Taylor CL, Kilgore K, Valentine A, Bodurka DC, Kavanagh J, Sood A, Li Y, Basen-Engquist K (2009) Associations with worry about dying and hopelessness in ambulatory ovarian cancer patients. *Palliat Support Care* 7(3):299–306. doi:10.1017/s1478951509990228 [PubMed: 19788771]
  23. von Gruenigen VE, Huang HQ, Gil KM, Gibbons HE, Monk BJ, Rose PG, Armstrong DK, Cella D, Wenzel L (2009) Assessment of factors that contribute to decreased quality of life in Gynecologic Oncology Group ovarian cancer trials. *Cancer* 115(20):4857–4864. doi:10.1002/cncr.24520 [PubMed: 19691091]
  24. Wenzel LB, Donnelly JP, Fowler JM, Habbal R, Taylor TH, Aziz N, Cella D (2002) Resilience, reflection, and residual stress in ovarian cancer survivorship: a gynecologic oncology group study. *Psychooncology* 11(2):142–153 [PubMed: 11921330]
  25. Arriba LN, Fader AN, Frasure HE, von Gruenigen VE (2010) A review of issues surrounding quality of life among women with ovarian cancer. *Gynecol Oncol* 119(2):390–396. doi: 10.1016/j.ygyno.2010.05.014 [PubMed: 20594586]
  26. Ferrell B, Cullinane CA, Ervine K, Melancon C, Uman GC, Juarez G (2005) Perspectives on the impact of ovarian cancer: women's views of quality of life. *Oncol Nurs Forum* 32(6):1143–1149. doi:10.1188/04.onf.1143-1149 [PubMed: 16270110]
  27. Ferrell BR, Smith SL, Juarez G, Melancon C (2003) Meaning of illness and spirituality in ovarian cancer survivors. *Oncol Nurs Forum* 30(2):249–257. doi:10.1188/03.onf.249-257 [PubMed: 12692659]
  28. von Gruenigen VE, Frasure HE, Jenison EL, Hopkins MP, Gil KM (2006) Longitudinal assessment of quality of life and lifestyle in newly diagnosed ovarian cancer patients: the roles of surgery and chemotherapy. *Gynecol Oncol* 103(1):120–126. doi:10.1016/j.ygyno.2006.01.059 [PubMed: 16556458]
  29. Ponto JA, Ellington L, Mellon S, Beck SL (2010) Predictors of adjustment and growth in women with recurrent ovarian cancer. *Oncol Nurs Forum* 37(3):357–364. doi:10.1188/10.onf.357-364 [PubMed: 20439220]
  30. Sun CC, Ramirez PT, Bodurka DC (2007) Quality of life for patients with epithelial ovarian cancer. *Nat Clin Pract Oncol* 4(1):18–29 [PubMed: 17183353]
  31. Norton TR, Manne SL, Rubin S, Hernandez E, Carlson J, Bergman C, Rosenblum N (2005) Ovarian cancer patients' psychological distress: the role of physical impairment, perceived unsupportive family and friend behaviors, perceived control, and self-esteem. *Health Psychol* 24(2):143–152. doi:10.1037/0278-6133.24.2.143 [PubMed: 15755228]
  32. Parker PA, Kudelka A, Basen-Engquist K, Kavanagh J, de Moor J, Cohen L (2006) The associations between knowledge, CA125 preoccupation, and distress in women with epithelial ovarian cancer. *Gynecol Oncol* 100(3):495–500. doi:10.1016/j.ygyno.2005.08.057 [PubMed: 16242759]
  33. Monahan PO, Champion VL, Zhao Q, Miller AM, Gershenson D, Williams SD, Cella D (2008) Case-control comparison of quality of life in long-term ovarian germ cell tumor survivors: a gynecologic oncology group study. *J Psychosoc Oncol* 26(3):19–42 [PubMed: 19042263]
  34. Gershenson DM, Miller AM, Champion VL, Monahan PO, Zhao Q, Cella D, Williams SD (2007) Reproductive and sexual function after platinum-based chemotherapy in long-term ovarian germ cell tumor survivors: a Gynecologic Oncology Group Study. *J Clin Oncol: Off J Am Soc Clin Oncol* 25(19):2792–2797. doi:10.1200/jco.2006.08.4590

35. Swenson MM, MacLeod JS, Williams SD, Miller AM, Champion VL (2003) Quality of life after among ovarian germ cell cancer survivors: a narrative analysis. *Oncol Nurs Forum* 30(3):380. doi: 10.1188/03.onf.e48-e54 [PubMed: 12719752]
36. Howard-Anderson J, Ganz PA, Bower JE, Stanton AL (2012) Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *J Natl Cancer Inst* 104(5):386–405. doi:10.1093/jnci/djr541 [PubMed: 22271773]
37. Bodurka DC, Levenback C, Wolf JK, Gano J, Wharton JT, Kavanagh JJ, Gershenson DM (2003) Phase II trial of irinotecan in patients with metastatic epithelial ovarian cancer or peritoneal cancer. *J Clin Oncol: Off J Am Soc Clin Oncol* 21(2):291–297
38. Mellon S, Gold R, Janisse J, Cichon M, Tainsky MA, Simon MS, Korczak J (2008) Risk perception and cancer worries in families at increased risk of familial breast/ovarian cancer. *Psychooncology* 17(8):756–766. doi:10.1002/pon.1370 [PubMed: 18613300]
39. Mellon S, Janisse J, Gold R, Cichon M, Berry-Bobovski L, Tainsky MA, Simon MS (2009) Predictors of decision making in families at risk for inherited breast/ovarian cancer. *Health Psychol* 28(1):38–47. doi:10.1037/a0012714 [PubMed: 19210016]
40. Herrinton LJ, Neslund-Dudas C, Rolnick SJ, Hornbrook MC, Bachman DJ, Darbinian JA, Jackson JM, Coughlin SS (2007) Complications at the end of life in ovarian cancer. *J Pain Symptom Manage* 34(3):237–243. doi:10.1016/j.jpainsymman.2006.11.011 [PubMed: 17606360]
41. Penson R, Cella D, Wenzel L (2005) Quality of life in ovarian cancer. *J Reprod Med* 50(6):407–416 [PubMed: 16050565]
42. Rolnick SJ, Jackson J, Nelson WW, Butani A, Herrinton LJ, Hornbrook M, Neslund-Dudas C, Bachman DJ, Coughlin SS (2007) Pain management in the last six months of life among women who died of ovarian cancer. *J Pain Symptom Manage* 33(1):24–31. doi:10.1016/j.jpainsymman.2006.06.010 [PubMed: 17196904]
43. Jackson JM, Rolnick SJ, Coughlin SS, Neslund-Dudas C, Hornbrook MC, Darbinian J, Bachman DJ, Herrinton LJ (2007) Social support among women who died of ovarian cancer. *Support Care Cancer* 15(5):547–556. doi:10.1007/s00520-006-0197-4 [PubMed: 17177041]
44. Institute of Medicine (2007) Implementing cancer survivorship care planning: workshop summary. Available at <http://www.iom.edu/Reports/2006/Implementing-Cancer-Survivorship-Care-Planning-Workshop-Summary.aspx>

Table 1

Summary table of published ovarian cancer studies on survivorship issues

First author (year), reference number	Study design	Sample size (non-review articles)	Average time since diagnosis (years) (non-review articles)	Average age at diagnosis (years) (non-review articles)	Year of data collection	Recruitment strategy (non-review articles)	Percent non-White (non-review articles)	Topic: finances	Topic: reproductive and sexual health	Topic: treatment effects	Topic: information needs	Topic: genomics	Topic: end-of-life/palliative care	Topic: young survivors
Arden-Close (2008) [5]	Review	N/A	N/A	N/A	1/1994–5/2007	N/A	N/A			X	X			
Arriba (2010) [25]	Review	N/A	N/A	N/A	2010	N/A	N/A	X		X				X
Badt (2006) [14]	Prospective study	33	Not found	Not found	Not found	MD Anderson or Gynecologic Oncology of Houston	27 %			X				
Bodurka (2006) [15]	Review	N/A	N/A	N/A	Not found	N/A	N/A	X	X	X				X
Carmack Taylor (2004) [6]	Cross-sectional	232	4.3	52.3	Not found	MD Anderson	15 %	X	X	X				X
Champion (2007) [16]	Cross-sectional	132	10.2	25.7	Not found	GOG or MD Anderson	20 %	X	X	X	X			
Correa (2010) [17]	Cross-sectional	48	6.5	54.5	Not found	Memorial Sloan-Kettering Cancer Center	Not found			X				
Ferrell (2003) [9]	Qualitative study	21,806 pieces of correspondence	Not found	Not found	1/1994–12/2000	US and international recipients of "Conversions!: The newsletter for those fighting ovarian cancer"	Not found	X		X	X			
Ferrell (2003) [18]	Qualitative study	21,806 pieces of correspondence	Not found	Not found	1/1994–12/2000	US and international recipients of "Conversions!: The newsletter for those fighting ovarian cancer"	Not found			X		X		X
Ferrell (2003) [27]	Qualitative study	21,806 pieces of correspondence	Not found	Not found	1/1994–12/2000	US and international recipients of "Conversions!: The newsletter for those fighting ovarian cancer"	Not found		X	X	X	X		
Ferrell (2005) [26]	Cross-sectional	1,383	4	53	11/2002–2/2003	US and international recipients of "Conversions!: The newsletter for those fighting ovarian cancer"	5 %	X		X		X		
Ferrell (2003) [13]	Qualitative study	21,806	Not found	Not found	1993–2000	US and international recipients of "Conversions!: The newsletter for those fighting ovarian cancer"	Not found		X	X	X			X
Gershenson (2007) [34]	Case-control	132	10.2	25.7	Not found	GOG or MD Anderson and acquaintance controls	20 %		X					X
Herrinton (2007) [40]	Retrospective	421	Not found	Not found	1995–2000	Three managed care organizations	17 %						X	

First author (year), reference number	Study design	Sample size (non-review articles)	Average time since diagnosis (years) (non-review articles)	Average age at diagnosis (years) (non-review articles)	Year of data collection	Recruitment strategy (non-review articles)	Percent non-White (non-review articles)	Topic: finances	Topic: reproductive and sexual health	Topic: treatment effects	Topic: information needs	Topic: genomics	Topic: end-of-life/palliative care	Topic: young survivors
Jackson (2007) [43]	Retrospective	421	Not found	Not found	1995–2000	Participants of three managed care organizations	17 %						X	
Lockwood-Rayermann (2006) [11]	Review	N/A	N/A	N/A	Not found	N/A	N/A	X		X	X		X	
Matei (2009) [19]	Case-control	132	10.2	25.8	Not found	Participants in 4 GOG trials or MD Anderson and acquaintance controls	20 %	X		X				X
Matulonis (2008) [20]	Cross-sectional	58	5.8	48.3	Not found	Dana-Farber Cancer Institute, Massachusetts General Hospital, and Brigham and Women's Hospital	3 %	X		X				
McCorkle (2003) [8]	Review	N/A	N/A	N/A	Not found	N/A	N/A			X	X			
Mellon (2009) [39]	Cross-sectional	50	2 to 6	Not found	1999–2002	Participants in the Metropolitan Detroit Cancer Surveillance System	47 %					X		
Mellon (2008) [38]	Cross-sectional	50	Not found	Not found	1999–2002	Participants in the Metropolitan Detroit Cancer Surveillance System	47 %					X		
Monahan (2008) [33]	Case-control	132	10.2	25.7	Not found	GOG or MD Anderson Cancer Center	20 %	X						X
Norton (2005) [31]	Cross-sectional	143	1.6	53.6	Not found	Outpatient clinics of 3 cancer centers and 2 community hospitals	11 %			X				
Otis-Green (2008) [21]	Intervention	33	Not found	Not found	Not found	Outpatient clinic of a comprehensive cancer center	23 %			X	X			
Parker (2006) [32]	Cross-sectional	126	2.7	56	Not found	MD Anderson Cancer Center	14 %				X			
Penson (2005) [41]	Review	N/A	N/A	N/A	Not found	N/A	N/A						X	
Ponto (2010) [29]	Cross-sectional	60	5.4	Not found	Not found	National advocacy groups	3 %			X				
Rolnick (2007) [42]	Retrospective	421	Not found	Not found	1995–2000	Participants of three managed care organizations	17 %						X	
Shinn (2009) [22]	Cross-sectional	254	Not found	Not found	Not found	MD Anderson and Gynecologic Oncology of Houston	14 %			X				
Sun (2007) [30]	Review	N/A	N/A	N/A	2006	N/A	N/A		X	X	X		X	X
Swenson (2003) [35]	Qualitative study	109	9.9	26.1	Not found	GOG or MD Anderson Cancer Center	19 %		X					X
von Gruenigen (2009) [23]	Cross-sectional	361	Not found	Not found	6/1994–1/2001	GOG	12 %	X		X				

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

First author (year), reference number	Study design	Sample size (non-review articles)	Average time since diagnosis (years) (non- review articles)	Average age at diagnosis (years) (non- review articles)	Year of data collection	Recruitment strategy (non-review articles)	Percent non- White (non- review articles)	Topic: finances	Topic: reproductive and sexual health	Topic: treatment effects	Topic: information needs	Topic: genomics	Topic: end-of- life/ palliative care	Topic: young survivors
Wenzel (2002) [24]	Cross-sectional	49	8.7	55.9	Not found	GOG	10 %		X	X				
von Gruenigen (2006)[28]	Prospective	42	Not found	Not found	12/2000–6/2004	Two gynecologic oncology offices in OH	Not found			X				