

APPENDIX

Table 1 Summary of the literature search findings according to the key themes.

Theme	Key findings
Age	<ul style="list-style-type: none"><li>• Heterogeneously recorded.</li><li>• Age thresholds varied for younger versus older patients.</li><li>• History of premenopausal hysterectomy unclear.</li><li>• Reduced sexual functioning found in younger ages alongside diminished sexual pleasure.<sup>16 19 24 34</sup></li></ul>
Comorbidities	<ul style="list-style-type: none"><li>• Comorbidities associated with psychosexual morbidity: increased cardiovascular risk; sedentary lifestyle; physical problems; anxiety and depression.<sup>16 23 25 28-30</sup></li><li>• Effects of treatment of such co-morbidities not investigated.</li><li>• Diabetes not included despite potential role in sexual symptoms of autonomic neuropathy.</li><li>• Pre-cancerous comorbidities not reported.</li><li>• Depression rates higher in women with epithelial ovarian cancer versus general population and correlated with sexual problems in patients and partners.<sup>25 37</sup></li></ul>

- Younger women with epithelial ovarian cancer with relationship concerns were particularly vulnerable to anxiety (p<0.05).<sup>29</sup>
- Anxiety and fear are associated with pain during sex (dyspareunia) leading to reduced intimate touching.<sup>25</sup>
- Treatment**
  - Primary surgery precedes worsened body image, attitude toward the disease and chemotherapy-associated symptoms (p<0.05).<sup>34</sup>
  - Women after lymphadenectomy reported impaired orgasm at 12 months compared to baseline, whilst women without lymphadenectomy reported improved orgasm at 12 months (p=0.02).<sup>21</sup>
  - More chemotherapy cycles are associated with psychosexual morbidity (p<0.001).<sup>17</sup>
- Stage**
  - Unclear relationship between stage of disease and psychosexual dysfunction.
  - Several confounding factors: age (younger patients usually have earlier stage disease); menopausal symptoms; and differences in treatment.
  - Tolerance of side effects can vary depending on aim of treatment: 61% of women willing to tolerate sexual side effects if curative goal but 55% if aiming for disease stabilisation (p=0.070).<sup>33</sup>
- Reduced sexual activity**
  - Fewer women with epithelial ovarian cancer were sexually active compared to age-adjusted healthy controls (47% vs 53%, respectively).<sup>16</sup>
  - Women with ovarian cancer who were sexually active reported lower levels of sexual pleasure (p < 0.001) and higher

levels of sexual discomfort ( $p < 0.001$ ).<sup>16</sup>

- 63-75% of women reported negative changes in their sex life following diagnosis, especially after multiple recurrences.<sup>18 19</sup>
- Possible explanations include: vaginal dryness (87%); reported dyspareunia (77%); reduced sexual interest (51%); physical problems preventing sex (36%); and fatigue (18%).<sup>19</sup>
- Often reported together.
- Vaginal dryness affected 81-87% of sexually active women with epithelial ovarian cancer, with significant intensity in up to a quarter.<sup>19 20</sup>
- Dyspareunia affected up to 77% of women with ovarian cancer,<sup>19</sup> worsening from diagnosis and with longer survival.<sup>12 21 24 25</sup>
- Women after premenopausal oophorectomy had higher levels of sexual discomfort ( $p < 0.001$ ).<sup>16</sup>
- Greater sexual discomfort in sexually active women with ovarian cancer was associated with both lower serum levels of oestradiol ( $p = 0.02$ ) and higher levels of sex hormone binding globulin ( $p = 0.04$ ).<sup>16</sup>
- Lack of sexual interest increased with epithelial ovarian cancer diagnosis from 33% to 61% (54% attributed to epithelial ovarian cancer).<sup>24</sup>
- Reduced sexual interest ranged widely (31-90%).<sup>6 16 19 20</sup>

### **Vaginal**

### **dryness and dyspareunia**

### **Reduced sexual desire, interest and**

- arousal**
  - A lack of interest or desire for sex affected over a third of women with epithelial ovarian cancer (36-43%), more commonly than age-adjusted controls.<sup>16 19</sup>
  - Lack of satisfaction was described in 21% of women with epithelial ovarian cancer.<sup>19</sup>
- Reduced sexual enjoyment and ability to orgasm**
  - Orgasm is worse in long-term survivors and at one year post lymph-node resection.<sup>12 21</sup>
  - Up to two thirds of women with epithelial ovarian cancer described reduced sexual satisfaction (21-66.7%)<sup>18 19</sup> and nearly half (29-47%) felt less satisfied since treatment.<sup>41</sup>
  - Chemotherapy-induced autonomic neuropathy was not mentioned despite theoretic potential to impaired orgasm.
- Body image**
  - Difficulties with altered body image affected between a third to over half of women with epithelial ovarian cancer.<sup>22 41</sup>
  - Up to two thirds of women with epithelial ovarian cancer feel less sexually attractive since diagnosis.<sup>22 24</sup>
  - Body image changes were associated with psychosexual morbidity, sedentary behaviour, younger age, and more time since chemotherapy ended.<sup>6 16 20 28 34</sup>
- Intimate relationships**
  - Overall evidence suggested impaired relationships or reduced enjoyment of intimacy in women with epithelial ovarian cancer.<sup>22 25 36</sup>
  - Two thirds of women with epithelial ovarian cancer were dissatisfied with their sex life.<sup>18</sup>
  - Common reasons reported for sexual inactivity included: lack of interest in sex (51%); having no partner (35%); and

- Most women (75-81.5%) reported feeling close to their partners.<sup>18</sup>

Paper	6	12	13	14	15	17	18	19	20	21	22	23	28	29	30	31	32	33	34	37	41	38		16	24	25	35	36	39	40
reports on:																														
Age	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓
Marital status					✓	✓											✓													
Ethnicity	✓																													
																							Mixed methods							

Co-morbidities			✓					✓											
Treatments received		✓	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓		✓		✓	✓
Aim of treatment		✓	✓	✓		✓	✓	✓				✓		✓	✓				
Early/Advanced cancer	✓			✓	✓				✓	✓	✓	✓	✓	✓	✓	✓		✓	
Vaginal dryness/dyspareunia		✓	✓	✓	✓	✓	✓	✓	✓				✓	✓		✓	✓	✓	✓
Reduced desire/arousal/orgasm	✓	✓	✓		✓	✓	✓									✓	✓	✓	

Body image	✓					✓	✓	✓		✓	✓	✓			✓	✓	✓
Anxiety & Depression	✓					✓			✓			✓			✓	✓	✓
Partner/relationship impact			✓	✓	✓	✓	✓		✓		✓	✓	✓			✓	✓
Patient preference/ QoL	✓	✓	✓		✓		✓	✓	✓	✓	✓	✓		✓		✓	✓
FSFI		✓	✓				✓	✓				✓					✓
FSDS												✓				✓	
EORTC QLQ-OV28	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓		✓		✓	
EORTC QLQ-C30	✓	✓	✓			✓	✓	✓		✓	✓	✓				✓	

SAQ			✓																
Other questionnaire*	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 3 Results: Primary research papers investigating the sexual dysfunction of women with ovarian cancer specifically (n=29). \* EOC = epithelial ovarian cancer.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
Questionnaire studies				
17	One questionnaire (EORTC) QLQ-OV 28 Single institute prospective study. Aim: assess sexual health in patients treated for OC, disease free at the time of analysis.	47% had sex in past 3 months. Lower median score for sexual function than other	Symptoms Sexual score affected by Co-morbidities (p=0.007) Vaginal dryness & pain	Strengths= Large sample, prospective, significant results.



No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	n=72 age=45y (median) Women with EOC disease free and married.	domains.	(p<0.04) More chemo cycles (p<0.001) Fear of recurrence (p<0.02)	Limitations= Could only access abstract. No control. Single centre. One questionnaire
38	Symptoms Representation Questionnaire Functional Assessment of Cancer Therapy - Ovarian. Aim: elicit priority rankings of 28 symptoms: prevalence, severity, top 3, association with functional wellbeing. n=497 age=? Patients with recurrent OC/fallopian/peritoneal cancer.	Sexual concerns 19th of 28 symptoms ranked in top 10.		Strengths=large sample. Limitations=retrospective.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
18	Multiple surveys  Quality of life (FACT-O), mood (CESD), social support (SPS), physical activity (IPAQ-SF), diet, and clinical characteristics.  Five sites  Aim: to identify if survivors with multiple recurrences would have poorer QOL, more survivorship concerns, higher levels of distress, poorer well-being and relationships, and be less physically active than those with 0–1 recurrence	Sexual health changes were  prevalent (0–1: 65% vs. multiple: 75%).  The majority of survivors (0–1: 58.9% vs. multiple: 62.5%) reported being in a relationship that could involve sex; however only about half of these women (0–1: 52.2% vs. multiple: 50.0%) reported being sexually active in the last	Symptoms  Predominant concerns being decreased or absent desire, dyspareunia, and reduced quality of orgasms.  A majority of women (0–1: 81.5% vs. multiple: 75%) reported feeling close to their partners. These proportions did not differ by group (n.s.).	Strengths=comparator group (0-1 recurrence).  Limitations=not a validated questionnaire re sexual health, was designed for this study. Possibly no external validity.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
		month.  n=56 (16 multiple recurrences, 40 with 0-1 recurrences).  Age=62.2y (mean, multiple recurrences), 66.9y (0-1 recurrence).  Patients with multiple recurrence vs patients with 0-1 recurrence.		
33	Online survey 30 questions about treatment side effects developed by investigators.	61% (n=201) of survivors were willing to tolerate sexual side effects for the		Strengths=large sample size, prospective.
	Online – patients from different treatment centres.	goal of cure, 59% (n=193) if aiming for remission,		Limitations=no mention of their own limitations

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	Aim: To determine whether survivors' acceptance of treatment side effects also changes over the disease continuum.  n=328.  Age=51-60years (mode, 43 years).  Included women with OC, on or off treatment, completed treatment and in remission.	55% (n=179) if aiming for stable disease.		
29	A validated 25-item questionnaire measuring level of concern over 5 domains: emotional	Relationship concerns predict anxiety risk, esp.	55% at risk of clinically significant anxiety, 37%	Strengths=large sample size.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	concerns, symptom burden, body/healthy lifestyle, health care team communication (HCTC), and relationships. Patients invited from cancer support registry.	with younger ages (p<0.05).	depression. Relationship, body/healthy lifestyle, symptom burden, and healthcare team communication concerns	Limitations= (Poster session). No control. Only conference abstract published.
	Aim: To explore predictors of psychosocial distress among a community-based sample of women with ovarian cancer.		were bivariately associated with anxiety and depression risk (P < 0.001).	
	n=128 Age=57.3y (mean) 86% white. 4.5y (mean) since diagnosis. 34% metastatic, 45 chemo, 22% XRT, 11% hormonal.			

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
34	Multiple questionnaires:  EORTC QLQ-OV28,  FSFI,  Female Sexual Distress Scale (FSDS).  Single site  Aim: to evaluate the quality of life and sexual function of EOC patients during chemotherapy (CT).  n=49  Age= <=48 or >48y.	No comment	Age:  Sexual outcomes resulted in better scores in younger patients in all questionnaires  Younger women scored higher on body image, indicating they were worse affected. Scores concerning body image, attitude toward the disease and CT-associated symptoms resulted worse in patients after the	Strengths=multiple validated questionnaires used.  Limitations=conclusion states that younger women worse affected when actually score better.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	OC type= Results stratified into: single surgery versus multiple surgeries, and first-line CT versus multiple lines of CT.		first surgery (p = 0.017, p = 0.002 and p = 0.012, respectively).	
			Symptoms: Menopause-related symptoms, body image and attitude toward the disease were significantly worse during first-line CT (p = 0.018, p = 0.029 and p = 0.006, respectively).	

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
19	Internet-based evaluation.  Paper and online questionnaire:  Fallowfield Sexual Activity Questionnaire (SAQ)  Charity website, online – patients from different centres. Or invited from outpatient clinic  Aim: To investigate sexual functioning in women with ovarian cancer.  n=102 (23 from clinic, 79 online).	63% of women reported their ovarian cancer diagnosis had negatively changed their sex life.  46% sexually active, no age difference (t-test, p=0.97).  49% reported less sex since diagnosis (median 1-2 times per month).  58% ranked sex as very or	Age:  Negative impact on sexual lives reported more by younger patients (ANOVA, p=0.018).  Symptoms:  Most common reasons for absent sexual activity: lack of interest in sex (51%), physical problems that prevented sex (36%), no partner (35%), too tired	Strengths=large sample size.  Limitations=no control group.  Used data from Atkins et al. for healthy non-study cohort and EOC screening population for comparisons.  Did not collect info on sexual orientation



No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	Age=51.3y (mean) Median 4y from diagnosis.	somewhat important to them, although 43% had little or no desire for sex.	(18%), partner not interested in sex (16%).  Of the 46% of responders who stated they were sexually active, 77% reported dyspareunia (pain or discomfort during intercourse) 87% described vaginal dryness.	
28	Multiple questionnaires EORTC QLQ-C30,	PSM prevalence not reported.	Sedentary behaviour was associated with poorer	Strengths= two centre study, validated

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	QLQ-OV28	35% of women overweight,	quality of life scores	questionnaires, BMI at
	The Godin Leisure Time Exercise questionnaire	18% obese, only 21% met recommendations for PA.	including sexual functioning (p=0.001) and body image (p=0.018). Obesity associated with poorer body image (p=0.023)	time of surgery not dx, 71.3% response rate. Women dx at stage I/II perhaps representing the surviving population.
	Two centre cross-sectional study.			
	Aim: To evaluate the association between body mass index (BMI), physical activity (PA) and the quality of life (QoL) of ovarian cancer survivors.			Limitations= Non-responders had higher BMIs. Most women stage III/IV at dx. Self-reported measures of height, weight, PA -risking
	n=204			
	age=63y at diagnosis			

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
				inaccuracy/reporting bias.
	49% stage I/II disease at diagnosis. 97% had surgery, 84% had chemo.			
12	Questionnaire, FSFI	LTS showed lower rates Desire (1.2 vs. 3.3), Arousal (1.0 vs. 4.2), Lubrication (0.5 vs. 5.4). Orgasm (0.0 vs. 5.0).	Pain more commonly reported by LTS (0.0 vs. 5.2) Shows lasting effect of EOC on sexuality (8y+ post diagnosis).	Strengths=healthy women control group  Limitations=insufficient data for p values? Insufficiently powered?
	Aim: To evaluate the impact of sexuality in longterm survivors with ovarian cancer	Overall sexuality score for n=20 LTS (long term survivors), 28 healthy controls.		
	Age=LTS 68y median, control 49y median.	LTS was 5.2 compared to 28.2 for healthy women.		

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	Healthy vs EOC long-term survivors (>=8y since diagnosis)			
30	Multiple Questionnaires: EORTC QLQ-C30 EORTC QLQ OV28 Investigator questionnaire  Single centre  Aim: Pilot study re quality of life in ovarian cancer.	Global quality of life did not vary by clinico-pathologic parameters.  Cardiovascular comorbidities were associated with the EORTC scores of sexual health (P =. 0.025).	Demographics:  Clinical factors such as age, stage, and histology did not have a significant impact on QoL.  Symptoms:  Psychosocial factors have a larger impact on global quality of life than physical	Strengths=sample size calculation number met.  Limitations= small number. Mixed methods of collecting data before/after clinic,  No Control group.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
	n=102  All women with OC, 80% EOC of which  66% HGSOC. 47% stage III, 46% under surveillance.  Age=58 mean		symptoms.	
31	Multiple questionnaires  EORTC QLQ-C30  EORTC QLQ- OV28   Single site   Aim: evaluate longitudinally the quality of life (QOL) in women treated for ovarian	Prevalence of PSM was not documented, rather a downward trend of symptoms from treatment.	Symptoms:  Decrease of symptoms concerning body image and sexual worries observed between and 3 and 6 months (p=0.0052).	Strengths=validated questionnaire.  Limitations=no control group, patients not surveyed on chemotherapy type, only stage IC-III.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
	cancer, pre-operatively, three and six months postoperatively.  n=93 FIGO IC-III Age=56 mean (28-89)			
32	Single questionnaire:  Supportive Care Needs Survey-Short Form  measured 34 needs across five domains (3 of which comprised sexuality).  Aim:  To determine changes in supportive care	Unmet sexuality needs  decreased over 2 years from baseline (6-12/12 post dx)  versus up to 2y post dx (p < 0.05).  On average, sexuality needs		Strengths=country-wide assessment, validated tool.  Limitations=baseline survey completed over wide interval (6-12/12).

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	needs after first-line treatment for ovarian cancer and identify risk factors for future unmet needs.  n=219  Age=59 median.  76% married/in partnership.	were either non-existent or completely met by 12 and 24 months after baseline, respectively (p < 0.001 and p = 0.011 for change over time, respectively).		Limited sample for multi-variable modelling.
6	Multiple questionnaires  EORTC QLQ-C30  EORTC QLQ-OV28  Sexual problems due to cancer (CALGB).	Decreased sexual interest and activity attributed to cancer affected 31–54% of survivors.	Demographics:  Early staged ov ca  demonstrated a correlation between sexual dysfunction	Strengths=advanced vs early stage.  Limitations=no normal

<u>No.</u>	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	MHI-17 (anxiety, depression and global well-being) FACT Fatigue Beck's Hopelessness Scale, Fear of Recurrence, PCL-C post-traumatic stress disorder (PTSD), Unmet Needs FACT-Spirituality, Complementary therapy Use. MOS Social Support Survey.  Single site.	Decreased sexual interest attributed to cancer and anxiety when getting CA-125 testing were of concern for both groups.	and global QoL ?due to younger age or different expectations  Symptoms: Sexual problems were significantly correlated to worse body image (early P < 0.0001, advanced P<0.01). .	control group, higher proportion of those with early disease refused participation – selection bias. Age difference between groups. Mostly white, educated, married.



No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	<p>Aim: to compare the long-term adjustment and quality of life of early and advanced stage ovarian cancer survivors.</p> <p>n=58 early and 42 advanced</p> <p>Predominantly ovarian (also fallopian and primary peritoneal.)</p> <p>Age (mean)= 48.3y early (SD 8.8), 55.1y advanced (SD 11.3)</p>			
41	Four-part Questionnaire compiled by investigators.	>69% in each group  satisfied with sex life pre-	Symptoms  Large proportion found	Strengths=considers many  aspects of sexual

<u>No.</u>	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	Multiple sites	treatment. 29-47% felt sex life worsened after treatment (more advanced	partners had same (33-45%) or better (26-37%) attitude towards them.	functioning. Large sample size.
	Aim: to compare treatment modalities' effects on ovarian ca: surgery, surgery + chemo, chemo. Completed 2-6 months post treatment.	being most affected, p<0.05).	Over half experienced a change in body image (not statistically significant P > 0.05). Women with advanced disease or treated with combination or chemotherapy were worse affected than women with early stage disease or surgery	Limitations=No control group. Not a validated questionnaire. Assumes partner male.
	n=483			
	N=156 = early stage, surgery only.			
	N=238, advanced, surgery +chemo.			
	N=89 advanced inoperable/metastatic,			

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	chemo alone.		alone.	
	Age=?		<10% thought they would be unable to have intercourse after treatment.	
			Problems in sexual functioning appear to be related to the consequence of artificial menopause symptoms and the extent of disease.	
20	Multiple questionnaires.	The majority of women	Symptoms:	Strengths=all patients had

<u>No.</u>	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	EORTC QLQ-C30, EORTC QLQ-OV28 Wellbeing thermometer.  Single site.	surveyed experienced persistent psychological and physical symptoms following ovarian cancer treatment incl: sexual inactivity.	Vaginal dryness was reported by 81% of participants but was of significant intensity in 25%.  Greater time since end of chemotherapy was a	had surgery and some platinum-based chemotherapy. No-one with actively progressing/recurring disease.
	Aim: to evaluate physical and psychological symptoms of patients following completion of treatment for ovarian cancer, compared to symptoms documented in their hospital notes.	90% reported none or “a little” interest in sex within the preceding 4 weeks, 22% had been sexually active to some extent.	predictive factor for deterioration in body image perception (odds ratio: 1.001, p: 0.04).	Limitations=includes patients treated with primary or recurrent disease – heterogenous sample. Recall bias. Age categorised as < or > 62y.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
	n=100			No age-matched control.
	Age= 62.8y mean (categorised <62y, >62y).			
21	Multiple Questionnaires:  Sexual Activity Questionnaire (SAQ)  FSFI.  EORTC QLQ-C30   Multiple sites   Aim: to investigate the effect of lymphadenectomy (pelvic and para-aortic)  with subsequent chemotherapy on sexual	Prevalence of PSM not reported.	55 sexually active, 182 inactive, 17 NA.   Symptoms:  Discomfort evaluated as dryness of the vagina and dyspareunia was significantly worse at 12 months compared to baseline (p < 0.001) but the surgical	Strengths=prospective.   Limitations=51% response rate, 72% sexually inactive, no healthy control.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	activity. Pre-surgery then at 6, 12, 24 months.		variable LNE did not show any impact on this.	
	n=254.		Orgasm subscale showed diverging results with a deterioration from baseline to 12 months in the LNE group, but slightly improving in the no-LNE group (p=0.02).	
	Age=60.5y (21.4-75.8).			
22	Pts and partners questionnaires EORTC-QLQC30, EORTC-QLQ-OV-28, Female Sexual Function Index (FSFI) and	65% couples sexually active. 27% EOC survivors and 9% partners found physical	Symptoms: 31% EOC survivors felt body negatively changed by OC.	Strengths=involves partners also. Limitations=no control

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	self-developed questions.  Single site  Aim: to investigate the effects of EOC and its treatment on the survivor's body image and her feelings of attractiveness as reported by EOC survivors and their partners.  n=130 couples. Age 39y (Relationship duration median, 5-60y).	contact less enjoyable.	62% survivors felt less attractive.  Partners rarely felt like this (6% and 3% respectively).  Global FSFI 19 (6.8-30) and on body image subscale 21 (0-100).	group, work supported by industry. Only abstract available.
23	Single Questionnaire	Prevalence of PSM not	Symptoms:	Strengths=validated

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	EORTC QLQ-OV28.  Single site.  Aim: to compare quality of life outcomes for women post-surgery and chemo in early vs advanced OC.  n=47 EOC, last chemo >6/12 ago. n=26 advanced and 21 early.  Age=56.5, 58.3 (18-70).	reported.	No significant difference between early and advanced groups in sexual function (p=0.789), menopausal symptoms (p=0.763), body image (p=0.342).	questionnaire.  Limitations=only includes sexually active women, no control.
37	Multiple Questionnaires Patient and partner	Prevalence of PSM not	Symptoms:	Strengths=involves



No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	HR-QoL, HADS Sexual Function.	reported.	For women with ovarian cancer, depression seems to correlate with sexual function and sexual function in partners is mediated by depression.	partners and multiple questionnaires. Limitations= only abstract available. Ambiguous results presentation in abstract.
	Aim: To give an insight to the extent of impact that ovarian cancer, treatment and/or side effects may have had on the sexual function of both partners and longterm survivors.			
	N=? (not published)			
	Mean 6y post diagnosis.			
	Correlation and regression analyses.			

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
13	<p>Cross-sectional, case-control.</p> <p>Questionnaires</p> <p>EORTC QLQ-30,</p> <p>EORTC QLQ-OV28,</p> <p>FSFI.</p> <p>Aim: To compare quality of life (QoL) and sexual functioning between sexually active ovarian cancer survivors and healthy women.</p> <p>n=146: 73=OC, 73=Healthy</p> <p>Age=mean 50.7-52.0.</p> <p>Predominantly FIGO stage I and III. 78%</p>	<p>Sexuality, both in terms of desire, arousal, lubrication, orgasm, satisfaction, and pain and in terms of interest in sex, sexual activity, and enjoyment of sex (EORTC QLQ-OV28) were similar between the groups.</p>	<p>Symptoms:</p> <p>Vaginal dryness was more problematic in ovarian cancer survivors, with borderline statistical significance (p=0.081).</p>	<p>Strengths= ov ca vs healthy control.</p> <p>Limitations=only incl. women sexually active in past 3/12. Selection bias from study design, reporting bias from self-reported questionnaires.</p>

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	had surgery and chemotherapy.			
14	Semi-structured qualitative interviews comparing adult women having had chemotherapy for ovarian cancer and adult caregivers for women with ovarian cancer.  n=55 patient (23 care-givers)  Age=53 patient, 54 care-givers.  Mean 4y since dx.	Prevalence of PSM not documented.	Patients reported dyspareunia.	Strengths=control group  Limitations=only abstract (oral). 44% carers husbands, 22% daughters – not always sexual relationship and assumes caregivers healthy?
15	Multiple Questionnaires:  HR-QoL and sex function: EORTC-QLQC30, OV-28.  Norm data for age-matched controls from	OC survivors:  median sexual function 83 (17-100), 36% undisturbed sex function. Partners: 43	-	Strengths=compares to normal control. Linearly transformed questionnaire scores, differences and

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	PROFILES registry.	and 1.5%, respectively.  15% partners scored 0.		correlations calculated.
	Aim: to compare sexual function after ovarian cancer for survivors and partners with normdata in age-matched controls. n=275 EOC survivors, n=137 partners. Mean 6y post diagnosis.	Normdata:  score of 17 and 50 for female and male age- matched controls, respectively.		Limitations=confusing results when compared with age-matched controls. Only conference abstract published.
	Age=?	Sexual function between survivors and partners correlated strongly (Spearman's rho .617, p<0.01). Did not correlate		

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
		strongly with age matched controls, effect seems limited.		
Mixed methods				
24	Questionnaires & Interviews EORTC QLQ-OV28 CALGB (Cancer and Leukemia Group B) Sexual Functioning Scale)  Multiple sites.  Aim: to describe the quality of life, consequences of treatment, and factors	<10% of survivors reported either an interest in sex or were sexually active.  61% states sex was not at all or a little enjoyable,  10% reported sexual interest,	Demographics:  Age was negatively correlated with sexual problems (more sexual problems in younger women) and with comorbidities.  Symptoms:	Strengths=validated measurement tools.  Limitations=high proportion of unanswered questions – up to 1/3.  Recall bias.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	correlating with psychologic state in early-stage ovarian cancer.	9% sexually active.	Menopausal symptoms and negative impact on sexuality were reported.	
	n=58	33% decreased sexual interest 1yr pre-dx then	Increased dyspareunia and feeling sexually unattractive since dx.	
	Age (mean)= 48.3 at dx, 56.2 at interview.	61% as survivor, 54% due to cancer.		
	97% White.			
	Predominantly IA or IC.			
25	Questionnaires and focus group	Women with OC: poorer	Symptoms	Strengths=validated
	EORTC-QLQ-C30	QoL, sexual distress, lower	Themes from focus groups:	measurement tools; in-
	DAS	relationship satisfaction and	Pain and loss of desire	depth focus group;
	SFQ	increased depression rates	Changes to Orgasm	multisite.
	FSDS	vs published general	Body image	

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	BDI  SF-36   Multiple sites   Aim: To evaluate how women with ovarian cancer (OC) experience and express sexuality, in the context of their illness.   n=64 completed questionnaires n=3 Focus group	population values.		Limitations=no control.
39	Interviews and multiple questionnaires  FSFI to measure sexual dysfunction.	Sexual dysfunction was the  second most commonly	No comment.	Strengths: Large sample  size.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	Principal component analysis with a varimax.  Single site	reported symptom (99%)  following chemotherapy-induced peripheral neuropathy.		Limitations sexual function not included in symptom cluster.
	Aim: to investigate the symptom clusters and effects of symptom clusters on the quality of life of patients with Ovarian cancer.  n=210  Age: Median 55 years.	Symptoms arranged into 2 clusters but sexual dysfunction not included in either cluster because its Spearman rank correlation coefficient value was lower than 0.30.		



<u>No.</u>	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
36	Qualitative descriptive methods.  Individual interviews and focus group.  Single site.  Aim: To understand treatment induced changes in sexuality from the patient perspective.  n=8, (individual interviews)  Age: 33-69y	Regardless of age or relationship status, sexuality is altered by the diagnosis (62%) and treatment of ovarian cancer.  Women defined sexuality broadly from their physical appearance to how they relate to their partners.	Symptoms:  Mechanical changes caused by surgery coupled with hormonal changes added to the intensity and dimension of the symptom experience.  Physiologic (incl. post-surgical hormonal changes and scarring, chemotherapy-induced cognitive changes, peripheral neuropathy,	Strengths: wide range of ages and point in treatment included.  Limitations: no control group, Possible selection bias for who goes into interviews vs focus group, heterogenous sample, recall bias.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	1 <sup>st</sup> line treatment, 6-24 months from diagnosis.  n=5 (focus group)  Age: 40-75y, 6/12-8y from diagnosis.		weight change, menopausal symptoms), psychological (loss of fertility, perceptions of scars, ports, alopecia), and social factors (incl. partner relationships) also impacted how this symptom was experienced.	
35	Principal component analyses, structured interviews of older (>=65y) and younger (21-65y) women.	PCA components for values incl: length of life and sexual function: 3 items,	Demographics:  While worry during EOC treatment decision-making	Strengths= High number of respondents. Structured phone interviews

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
		proportion of variance explained 20.1%.	may differ across age groups, values do not.	consistent approach.
	Multiple sites			Limitations= No response
	Aim: To understand the differences in value and worries of older and younger women with ovarian cancer, diagnosed in past 2 years.			rate discussed. Unclear results presentation.
	n=170			Potential interview bias.
	Age=42.3% 65y+			Measured using own questionnaire but not correlated.

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of PSM (comment on what prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
16	Mixed Methods:  Questionnaire and sex hormone blood tests  Single site.  Aim: To explore sexual activity and functioning in epithelial ovarian cancer survivors (EOCSs) compared to age-adjusted controls from the general population (NORM).  n=189 (66%) OC, 98 NORM  age=51y at dx, 56,58y at survey	47% EOCs sexually active vs 53% NORM. The sexually active EOCSs reported lower levels sexual pleasure (p < 0.001) and higher levels of sexual discomfort than NORM (p < 0.001).	Symptoms:  In sexually active EOCSs an association between higher level of sexual discomfort and both lower serum levels of estradiol (p = 0.02) and higher levels of SHBG (p = 0.04) was observed.  Lack of interest (36%) and physical problems (23%) were significantly more common in sexually inactive	Strengths=Compared to age-adjusted controls, powered. 2 controls per EOC patient randomly selected form 988.  Limitations=low participation rate of NORM sample, EOC pts incl. pts treated from 1979.

No.	Study type, Tools, Demographic	Prevalence indicators of PSM (comment on what prevalence includes)	Risk Factors Identified	Intervention / Action
			EOCSs compared to NORM.	
			In multivariable analyses of sexually active EOCSs premenopausal oophorectomy, having had chemotherapy, age at survey, mental health and body image were significantly associated with sexual functioning.	
40	Retrospective review of patients Data from	Clinicians never reported		Strengths=aims to

No.	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u> <u>PSM (comment on what</u> <u>prevalence includes)</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
	an RCT.	sexuality concerns or hot		improve patient-clinician
	Questionnaire: Symptom Representation	flashes (both priority		communication.
	Questionnaire for 28 symptoms and selected	symptoms for 6%). Over		
	3 priority symptoms (PS)	half (52%) reported		Limitations=retrospective,
		abdominal/pelvic		no control reported,
	Single site	pain/bloating.		?selection bias – one site
				completed this
	Aim: Compared patient-reported PS to	Discordance between		questionnaire in RCT.
	clinician documentation of symptoms and	symptoms reported by		
	interventions over the time period	patients and those		
	corresponding to study WRITE Symptoms	documented. If not		
	Study (GOG 259), a randomized controlled	documented, less likely to		
	trial of internet-based recurrent ovarian	receive intervention.		

<u>No.</u>	<u>Study type, Tools, Demographic</u>	<u>Prevalence indicators of</u>	<u>Risk Factors Identified</u>	<u>Intervention / Action</u>
		<u>PSM (comment on what</u>		
		<u>prevalence includes)</u>		

cancer symptom management.

n=50

Age=58y (28-77).

All with recurrent/persistent disease.