

ORIGINAL ARTICLE

Sexual activity and functioning in women treated for gynaecological cancers

Ragnhild Johanne Tveit Sekse, Karl Ove Hufthammer and Margrethe Elin Vika

Aims and objectives. A description and comparison of sexual activity and function in relation to various gynaecological cancer diagnoses, treatment modalities, age groups, psychological distress and health-related quality of life.

Background. Various forms of gynaecological cancer have the potential to negatively influence sexual functioning, but there are few studies that describe and compare sexual activity and functioning according to diagnosis.

Design. A descriptive cross-sectional study.

Methods. The study includes 129 women from an intervention study. The questionnaires addressed sexuality, psychological distress, health-related quality of life and demographics. Disease and treatment characteristics were extracted from medical records.

Results. Close to two-thirds of the women were sexually active. However, 54% of the sexually active women reported that they were not satisfied or little satisfied with their sexual activity. About half of the women reported dryness in the vagina, and 41% reported pain and discomfort during penetration. There were no significant differences concerning pleasure and discomfort related to treatment modality, diagnoses or FIGO stage.

Conclusion. Health personnel should make a priority of sexuality throughout a patient's cancer treatment and in the follow-up, as sexuality is a vital part of a good life.

Relevance to clinical practice. Since the patients experience relatively low satisfaction with their sexual activity and many report pain during penetration, health personnel need to be sensitive to the woman, her questions, and her needs. Of importance are also the personnel's ability to communicate and their expertise in diagnosing and treating difficulties relating to sexuality.

Key words: follow-up, gynaecological cancer, quality of life, sexual activity, sexual functioning

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What does this paper contribute to the wider global clinical community?

- More than 50% of the women are not satisfied with their sexual activity after treatment for gynecological cancer
- About half of the women report dryness in vagina
- The women have a high score on pain and discomfort related to sexual activity

Introduction

Background

Improved treatment methods, in addition to a higher incidence of cancer and an ageing population, have resulted in an increase in the number of gynaecological cancer survivors. Consequently, there is also an increasing population of survivors suffering from side-effects of cancer treatment (Juraskova *et al.* 2003, Jensen *et al.*, 2003; Frumovitz *et al.* 2005, Mercadante *et al.* 2010, Lind *et al.* 2011, Lammerink *et al.* 2012).

The adverse effects on women's sexuality caused by the cancer treatment have been a focus of attention lately (Bergmark *et al.* 1999, Liavaag *et al.* 2008, Greimel *et al.* 2009, Hersch *et al.* 2009, Grover *et al.* 2012, Vaidakis *et al.* 2014). Ovarian, cervical, endometrial and vulvar cancers all have the potential to negatively influence sexual functioning, but there are few studies that describe and compare sexual activity and functioning according to diagnosis. The ongoing debate, however, is the discussion of different treatment options on sexual functioning outcomes, particularly after radiation and/or chemotherapy (Greimel *et al.* 2009, Korfage *et al.* 2009, Cleary & Hegarty 2011). Regardless of diagnosis and treatment of cancer in the female genital organs, each stage of the sexual response cycle may be affected: sexual desire, arousal and orgasm (Audette & Waterman 2010, Lammerink *et al.* 2012). For instance, 33 of the 34 studies in a review (Abbott-Anderson & Kwekkeboom 2012) identified physical concerns among the gynaecological cancer survivors, for example, concerns of pain during intercourse, lubrication, vaginal dryness and vaginal atrophy.

Despite the connection between physical changes and sexuality, research on gynaecological cancer and sexuality has been criticised for its unilateral focus on physical aspects (Cleary & Hegarty 2011) and its lack of a holistic perspective. Sexuality is an integral part of human life and, as such, fundamental to a person's health. Sexuality and sexual well-being are thus complex phenomena, involving all aspects of a person's life (Hordern 2008, Sekse *et al.* 2010, Cleary *et al.* 2011, Gilbert *et al.* 2011, Abbott-Anderson & Kwekkeboom 2012). In addition to the physical sequelae following gynaecological cancer, the women's sexuality may also be negatively affected, due to psychological factors. Their QoL and well-being may be negatively affected by anxiety, depression, psychological distress, changes in femininity and body-image (Juraskova *et al.* 2003, Reis *et al.* 2010, Cleary & Hegarty 2011, Gilbert

et al. 2011, Abbott-Anderson & Kwekkeboom 2012, Sekse *et al.* 2012).

Moreover, side-effects like fatigue and poor QoL may affect the ability and desire for sexual activity (Stead *et al.* 2007, Greimel *et al.* 2009, Grover *et al.* 2012, McCallum *et al.* 2012, Carter *et al.* 2013). Not surprisingly, the effects of cancer and its treatment also had an adverse effect on intimacy and physical relationships (Ratner *et al.* 2010, Abbott-Anderson & Kwekkeboom 2012). Many women, for example, fear that intercourse may be painful (Abbott-Anderson & Kwekkeboom 2012).

Summing up, gynaecological cancer and its treatment might affect women both physically, psychologically, socially and existentially, and, by that, their quality of life and sexual life. This study's purpose was a description and comparison of sexual activity and functioning of the various gynaecological cancers according to diagnosis, treatment modality and age. Secondly, we wanted to investigate the relationship between sexual activity and functioning according to psychological distress and health-related quality of life.

Methods

Participants

This study was part of a larger randomised controlled study with two test groups (educational and a physical training group), carried out between 2009 and 2012. The women were contacted mainly by mailed letters, from three different hospitals in Norway. The participants were selected based on the following criteria: female; having completed curative treatment, independent of type of gynaecological cancer and FIGO stage; age >18 years; able to walk on a treadmill; and agreement to participate, as specified by informed written consent. Exclusion criteria: significant amnesic symptoms. A total of 129 women were included in the study.

Data collection

Psychometric instruments that measure sexuality, anxiety, depression, fatigue and health-related quality of life were used to assess the women. A questionnaire specifically made for the main study was used for demographic data (age, level of education, marital status and employment status). Diagnostic and treatment information was gathered from the respondents' medical records.

The Sexual Activity Questionnaire (SAQ) is a self-report questionnaire consisting of three sections covering (1)

relational status, (2) reasons for sexual inactivity and (3) sexual functioning (SAQ-F) (Thirlaway *et al.* 1996).

The first section, relational status, assess whether women are sexually active or not. The sexually inactive have to complete section 2 and omit section 3. The second section contains eight possible reasons for being sexually inactive. Sexually active women complete section 3, which assesses sexual functioning that may be influenced by hormonal status: desire, frequency, satisfaction, dryness of vagina and penetration pain. The sexual functioning (SAQ-F) has a time frame of last month, and consists of 10 items. Items 1–7 of the SAQ-F are rated on a four-point scale from ‘very much’ to ‘not at all’. We used a modified version of a Norwegian translation of the SAQ, where these seven items were instead rated ‘yes’ or ‘no’. The SAQ discomfort items concerns ‘dryness of the vagina’ and ‘pain and discomfort at penetration.’ The SAQ pleasure items comprised the items “Was ‘having sex’ an important part of your life this month?”, ‘Did you enjoy having sex this month?’, ‘Did you desire to have sex with your partner last month?’, ‘In general, were you satisfied with your sexual activity last month?’, ‘How often did you engage in sexual activity last month?’, and ‘Were you satisfied with the frequency of sexual activity last month?’. Note that some of the questions differ somewhat in meaning from the questions in the original SAQ in Thirlaway *et al.* (1996).

The Hospital Anxiety and Depression Scale (HADS) is a 14-item, 4-point ordinal response questionnaire for measuring symptoms of anxiety and depression in a nonpsychiatric context. Seven items measure anxiety, and seven items measure depression, with higher scores reflecting higher symptom loads. The questionnaire has shown good reliability and validity in primary care and in clinical populations (Bjelland *et al.* 2002), and has also been used in relation to gynaecological cancer (Liavaag *et al.* 2009).

The Fatigue Questionnaire (FQ) (Chalder *et al.* 1993) contains 11-items measuring fatigue intensity during the preceding month. We used a modified version, translated into Norwegian. (Cella & Chalder 2010). The translation has previously been used in a large population survey in Norwegian (Loge *et al.* 1998a).

SF-36 is multidomain questionnaire measuring general health, and is not age, disease or treatment specific (Ware & Sherbourne 1992). The response options vary from yes/no to answers on ordinal response scales. The measure contains eight individual subscales: physical functioning (10 items), physical role limitations (4 items), bodily pain (2 items), general health (5 items), energy/vitality (4 items), social functioning (2 items), emotional role limitations (3 items) and mental health (5 items). The eight dimension

scores were transformed into scales from 0 (poorest/worst health) to 100 (best health). The psychometric properties are well recognised, also in Norwegian studies (Loge *et al.* 1998a,b).

Ethical considerations

The regional Committee for Medical Research Ethics (2009/895) approved the study, and all participants gave their written consent.

Data analysis

Data were stored in an SPSS data file (IBM Corp., Armonk, NY, USA), and analysed using R version 3.1.1 (R Core Team 2013). Categorical data were analysed using cross-tabulation and Fisher’s exact test. Continuous data were compared using Welch’s two-sample *t*-test. Ordinal data were compared using the exact Mann–Whitney–Wilcoxon test. The results are reported as means, 95% confidence intervals, counts and percentages, along with *p*-values. In all analyses, *p*-values ≤ 0.05 are considered statistically significant.

Results

Patient characteristics

Of the 129 women (mean age 57, SD 13, range 28–81), 76% were married or lived in a paired relationship. Forty-four per cent had attended college/university. Half the women (52%) were employed and a quarter (26%) were retired (Table 1).

Diagnosis and treatment characteristics

The mean follow-up time since diagnosis was 16 months (SD 9, range 1–38). The cancer diagnoses were uterine cancer 45%, ovarian cancer 28%, cervical cancer 24% and vulvar cancer 3% (Table 1). The FIGO stages were stage I (69%), stage II (11%), stage III (17%) and stage IV (3%) (Table 1). Most of the women (94%) were treated with surgery, and 47% were treated with surgery only, while 49% also received adjuvant chemotherapy. A total of 15% received radiation treatment.

Sexually active vs. sexually inactive

Of the 129 women, 78 were in a sexual relationship, 42 were not and 9 chose not to respond to this question. The

Table 1 Distribution of patient characteristics and treatment-related factors of sexually active and inactive cancers survivors

	<i>n</i>	Sexually active (<i>n</i> = 78)		Not sexually active (<i>n</i> = 42)		<i>p</i> -value	Total sample (<i>n</i> = 120)	
		Mean or count	SD or perc.	Mean or count	SD or perc.		Mean or count	SD or perc.
Age at survey	78/41	53	12	61	13	0.001	56	13
Civil status								
Paired relation	78/40	72	92%	18	45%	<0.001	90	76%
Single		2	3%	8	20%		10	8%
Divorced		4	5%	7	18%		11	9%
Widowed		0	0%	7	18%		7	6%
Living with children under 18 years	78/41	27	35%	7	17%	0.06	34	29%
Educational level								
Elementary school	78/41	5	6%	5	12%	0.06*	10	8%
Secondary school		33	42%	22	54%		55	46%
College/university		40	51%	14	34%		54	45%
Employment status								
Employed	78/42	51	65%	15	36%	<0.001	66	55%
Unemployed		9	12%	5	12%		14	12%
Retired		8	10%	20	48%		28	23%
Disability pension		3	4%	2	5%		5	4%
Homemaker		5	6%	0	0%		5	4%
Other		2	3%	0	0%		2	2%
Regular physical activity								
7 times a week or more	78/38	3	4%	2	5%	0.85*	5	4%
4–6 times a week		16	21%	9	24%		25	22%
2–3 times a week		29	38%	12	32%		41	36%
Once a week		21	27%	7	18%		28	24%
Once a month		3	4%	2	5%		5	4%
Less than once a month		2	3%	5	13%		7	6%
Never		3	4%	1	3%		4	3%
Time from diagnosis to survey (months)	78/48	16.6	8.6	16.1	10	0.77	16.5	9.1
Diagnosis								
Uterine cancer	78/42	35	45%	18	43%	0.99	53	44%
Ovarian cancer		22	28%	13	31%		35	29%
Cervical cancer		19	24%	10	24%		29	24%
Vulvar cancer		2	3%	1	2%		3	2%
FIGO stage								
I	74/41	50	68%	29	71%	0.52*	79	69%
II		7	9%	6	15%		13	11%
III		13	18%	6	15%		19	17%
IV		4	5%	0	0%		4	3%
Treatment modality								
Surgery only	76/42	37	49%	19	45%	0.98	56	47%
Surgery and chemotherapy		26	34%	17	40%		43	36%
Surgery, chemotherapy and radiation		5	7%	3	7%		8	7%
Chemotherapy and radiation		4	5%	2	5%		6	5%
Surgery and radiation		2	3%	1	2%		3	3%
Chemotherapy only		2	3%	0	0%		2	2%
Fatigue (bimodal sum score)	75/36	4.1	3.4	4.1	3.6	0.91	4.1	3.5
Anxiety (HADS score)	76/41	4.8	3.6	5.4	3.5	0.26	5	3.6
Depression (HADS score)	77/42	2.9	2.9	3.8	4	0.15	3.2	3.4
Recidivism	75/39	8	11%	8	21%	0.17	16	14%

**P*-value based on the exact Mann–Whitney–Wilcoxon test.

most frequent reason for being sexual inactive were ‘no partner’ (50%), ‘not interested in sex’ (19%) and ‘partner not interested in sex’ (12%) (Fig. 1). One fourth of the women (24%) had multiple reasons for being sexual inactive, while 14% did not state any reason.

Marital status and education

The differences in marital status between sexually active and inactive women are shown in Table 1. Of the sexually active women 92% were married or lived in a paired relation, compared to 45% of the sexually inactive women.

The sexually active women were on average younger (53 years compared to 61 years; $p = 0.002$) than the inactive women (Table 1, Fig. 4). Sexually active women had higher education (although not statistically significant, $p = 0.06$). There was also a positive association between having high(er) education and enjoying having sex ($p = 0.02$), and with feeling satisfied with one’s sexual activity ($p = 0.04$), but not for the other SAQ pleasure questions.

Diagnosis, quality of life and psychological distress

There were no differences in the proportion of sexually active women with different diagnoses (all proportions between 62% and 67%, $p = 0.95$), and no association between being sexually active and FIGO stage, time since diagnosis (16.1 months vs. 16.6 months), treatment modalities, anxiety or depression (HADS), fatigue (FQ) or frequency of physical activity per week.

There was little difference in quality of life as measured by SF-36 between sexually active and inactive women (Fig. 2). The only statistical significant difference was on the subscale *Physical functioning*, where sexually active women reported better quality of life (mean scores of 87 and 81, respectively, $p = 0.02$). Most of this difference was due to a greater proportion of sexually active women with the very highest scores of 95 and 100 (52% of the sexually active women vs. 24% of the not sexually active women).

SAQ-functioning (SAQ-F)

Sexual habit/frequency

Of the sexually active women 89% (64/72) were engaged in sexual activity at least once in the preceding month, 1–2 times (36%), 3–4 times (25%) and 5 or more times (28%). There were no differences in frequency of sexual activity according to age, diagnosis, FIGO stage or treatment method (Table 2). In women reporting being sexually active, nearly 51% reported the frequency of sexual activity the preceding month to be about the same as was usual, while 35% reported a lower frequency.

Sexual pleasure and activity

Of the sexually active women 24% (17/71) were not satisfied with their sexual activity, 30% were a little satisfied, 38% somewhat satisfied and 8% very much satisfied. There were no differences related to the items measuring pleasure according to age group, diagnosis, FIGO stage or treatment.

Dryness, pain and discomfort during sexual activity

Half of the sexually active women reported vaginal dryness, 70%, 50%, 33% and 0% of the women treated for ovarian, uterine, cervical and vulvar cancer respectively ($p = 0.06$).

About 41% of the sexually active women reported pain or discomfort during penetration (Fig. 3), 50, 41, 27 and 50% of the women treated for ovarian, uterine, cervical and vulvar cancer respectively. The differences were not statistically significant ($p = 0.52$).

There were no significant differences in mean age for the proportion responding ‘yes’ on the seven yes/no items. However, there was a higher proportion responding that they had noticed dryness in vagina for the middle age group (age 50–65), 72%, compared to 20% in the older group and 43% in the younger group ($p = 0.01$). The women in the middle age group also reported more pain and discomfort during penetration, 60%, compared to 9% in the older group and 35% in the younger group ($p = 0.009$). There

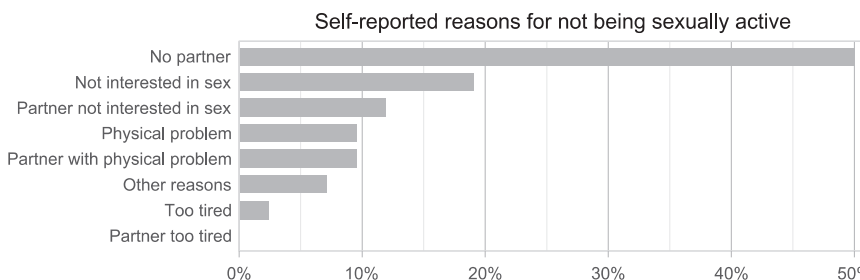


Figure 1 Women’s self-reported reasons for not being sexually active ($n = 142$) (It was possible to state more than one reason).

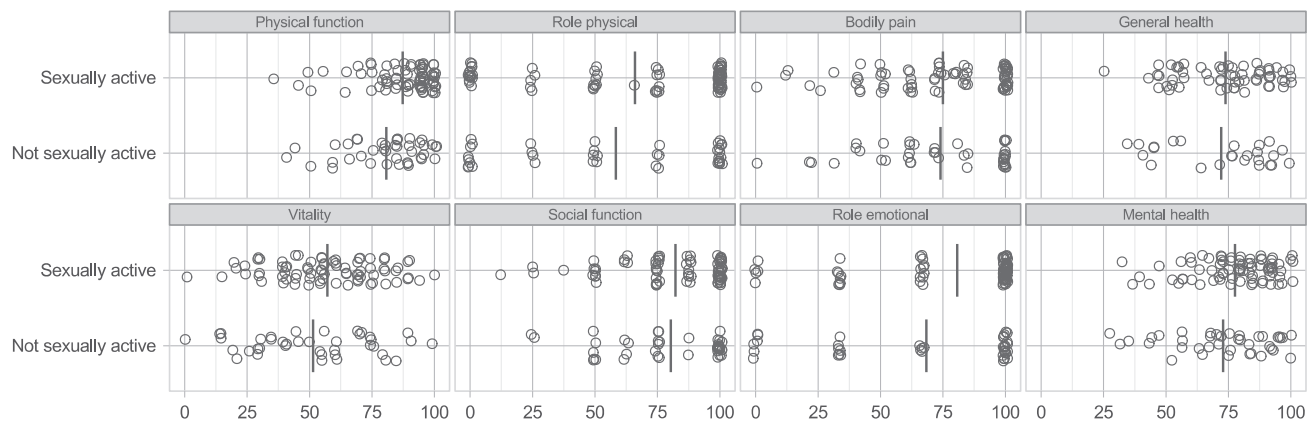


Figure 2 Scores on the eight quality of life domains of the self-report scale SF-36 in sexually active ($n = 61\text{--}78$) and not sexually active ($n = 25\text{--}42$) women. Higher values indicate better quality of life. The dots have been jittered to reduce the effect of overplotting. The mean values are shown as vertical lines.

Table 2 Distribution of engagement in sexual activity according to age, diagnosis, FIGO stage and treatment modality

	<i>n</i>	Engagement in sexual activity the preceding month							<i>p</i> -value	
		Not at all	1–2 times	3–4 times	5 times or more					
Age										
≤50	72	3	9%	14	40%	8	23%	10	29%	0.89
50–65		3	12%	7	28%	8	32%	7	28%	
>65		2	17%	5	42%	2	17%	3	25%	
Diagnosis										
Uterine cancer	72	6	19%	11	34%	8	25%	7	22%	0.38
Ovarian cancer		1	5%	7	35%	5	25%	7	35%	
Cervical cancer		0	0%	8	44%	5	28%	5	28%	
Vulvar cancer		1	50%	0	0%	0	0%	1	50%	
FIGO stage										
I	68	4	9%	18	38%	13	28%	12	26%	0.38
II		0	0%	2	33%	3	50%	1	17%	
III		2	18%	4	36%	0	0%	5	45%	
IV		0	0%	1	25%	1	25%	2	50%	
Treatment modality										
Surgery only	71	3	8%	15	42%	6	17%	12	33%	0.24
Surgery and chemotherapy		3	13%	8	35%	6	26%	6	26%	
Surgery, chemotherapy and radiation		0	0%	1	20%	4	80%	0	0%	
Chemotherapy and radiation		0	0%	1	33%	1	33%	1	33%	
Surgery and radiation		1	50%	0	0%	0	0%	1	50%	
Chemotherapy only		1	50%	1	50%	0	0%	0	0%	

were no significant differences in reports of discomfort associated with treatment or FIGO stage.

Discussion

As far as we know, no other study offers a detailed description of sexual functioning and activity in women treated

for different kinds of gynaecological cancers. Our results indicate that sexual activity decreases with age. This is in line with Vistad *et al.* (2007a), who reported a decrease in sexual activity with increasing age. Furthermore, women in our study are less sexually active compared to the normative sample in Vistad's study (2007a). Still, nearly two-thirds of the women had participated in sexual activity the

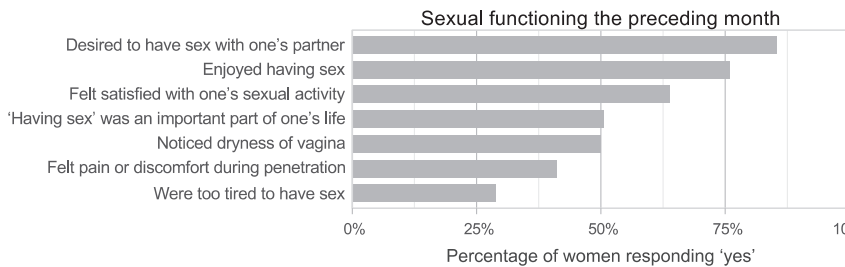


Figure 3 Sexually active women's self-reported sexual functioning the preceding month ($n = 70-75$).

month before, more than in other similar samples. For example, in a study by Liavaag *et al.* (2008) approximately one in two ovarian cancer survivors ($n = 189$) were sexually active, and Vistad *et al.* (2007b) showed that 30% of the cervical cancer survivors were sexually active during the last month.

The women in this study reported a lower level of sexual pleasure and a higher level of discomfort compared to a normative sample (Vistad *et al.* 2007a). Over half of the sexually active women were not satisfied or little satisfied with their sexual activity. Also, about half of the women reported vaginal dryness. The percentage varied among women with ovarian cancer (70%), uterine cancer (50%) and cervical cancer (33%). Overall 41% of the sexually active women reported pain or discomfort during penetration. A negative impact on sexual functioning over time in women who have had gynaecological cancer is also well documented (Bergmark *et al.* 1999, Stewart *et al.* 2001, Park *et al.* 2007, Sekse *et al.* 2010). Lack of sexual interest, physical problems and fear of pain during intercourse are some of the difficulties mentioned. For example, in a study of disease-free long-term survivors ($n = 860$) with a history of cervical cancer, participants reported reduced sexual functioning and performance compared to healthy controls (Park *et al.* 2007). In a review (Abbott-Anderson & Kwekkeboom 2012), physical concerns, vaginal dryness and pain was a deterrent to participating in sexual activity. However, despite findings in our study and some other studies that reveal pain and discomfort (which comprise sexual activity), women's sexual activity appears to be very similar to healthy controls', even in a long-term perspective (Bergmark *et al.* 1999). How are we to understand this? One perspective might be that the women have a desire to maintain their sexual lives, and to have the same level of intimacy with their partners as before cancer diagnosis and treatment. This might be explained by their wish to maintain their sexual life primarily to satisfy their partners rather than themselves (Bergmark *et al.* 1999). In a qualitative study by Juraskova *et al.* (2003) the findings revealed that intimacy rather than physical acts of sexual intercourse

was desired by the women, but was not sufficient to satisfy their partners. Some women may thus set aside their own needs to resume their normal lives. Nevertheless, it is reasonable to assume that pain during sex reduces the women's pleasure. The somewhat low frequencies of sexual activity in our study should thus be seen in the light of the women's challenges following gynaecological cancers.

Even though there is debate and conflicting opinion with regard to what treatment options are more detrimental to sexuality following gynaecological cancer, several studies have found that sexual problems are particularly related to adjuvant radiotherapy and chemotherapy (Hawighorst-Knapstein *et al.* 2004, Korfage *et al.* 2009, Lind *et al.* 2011, Lammerink *et al.* 2012). One might expect that women treated with radiation and/or chemotherapy would report lower levels of 'pleasure' and higher levels of 'discomfort'. Surprisingly, this study found no significant differences on pleasure and discomfort related to treatment modality, diagnosis or FIGO stage. Our results correspond with recent studies that have found no significant differences in sexual functioning related to adjuvant therapy compared to those with main treatment (Becker *et al.* 2011, Nout *et al.* 2011, Onujiogu *et al.* 2011). For example, Nout *et al.* (2011) reported that there was no significant difference in sexual morbidity between the ($n = 246$) endometrial cancer survivors who received external beam radiotherapy and those who received no adjuvant therapy.

Many of the sexually inactive women were older (Fig. 4). This is also in line with other studies (Carmack Taylor *et al.* 2004, Lai *et al.* 2009). In contrast, Bifulco *et al.* (2012) found that out of ($n = 263$) early stage gynaecological cancer survivors (divided into two groups, older and younger than 45 years) younger women were significantly more affected by impaired sexuality. The study showed that the younger women had less sexual activity than midlife adults, suffered more from poor body image, perceived poorer sexual vaginal functioning and had more severe menopausal symptoms. Although the age groups are not directly comparable, this seems to be in contrast with Vistad *et al.* (2007b) study, where a higher proportion of the

women in the middle age group (age 50–65) reported dryness in vagina and more pain and discomfort during penetration. In the normative study by Vistad *et al.* (2007a,b) the oldest age group reported significantly less pleasure and more discomfort compared to the younger women. The oldest age group (age 56–69) in Vistad's study was younger than in our study (age 66–81), which may indicate even greater differences in discomfort when comparing the two studies. One explanation may be that the oldest women in the present study have been through a normal menopause and become accustomed to dryness and other ailments before treatment for gynaecological cancer, while the middle age group may have experienced being thrown into a more severe menopause because of the cancer treatment.

We found that a majority of survivors after various types of gynaecological cancer and treatment modalities reported a relatively satisfactory quality of life, despite bodily ailments, discomforts and changes in sexual life. This finding is also echoed in other studies on gynaecological cancer (Harter *et al.* 2013), also in a long-term perspective (Stewart *et al.* 2001). To understand this, researchers have interpreted it partly in light of 'response shift' (Sprangers & Schwartz 1999). Sprangers and Schwartz (1999) states that a person's values will most likely be affected following a serious illness. The response shift involves a shift in personal standards, values and perception of quality of life. What is regarded as important in life may change after surviving a life-threatening illness. According to many studies, women seem to experience a positive shift in their perspectives on life, side-effects notwithstanding, after gynaecological cancer, and feel enriched. (Ponto *et al.* 2010, Sekse *et al.* 2010, Stewart *et al.* 2001). The women may have

experienced a change in priorities that partially compensates for other, more negative, changes. As such, the women's sense of loss concerning sexual functioning may change after cancer illness (Stewart *et al.* 2001, Harter *et al.* 2013).

Study limitations

The study had a relatively small sample ($N = 129$), with even fewer participants qualified to complete all sections of the questionnaire. There were only three women diagnosed with vulvar cancer, and the study is thus not representative of all women facing type of cancer. Since we have no data related to the sexuality of the women prior to cancer diagnosis and treatment, we cannot draw strong conclusions on the longitudinal effect of gynaecological cancer and cancer treatment on sexual activity and functioning.

Furthermore, the results may not apply to the general population of survivors of gynaecological cancer, as the sample consisted of women who had already agreed to take part in an extensive intervention study.

The focus of the questionnaire used in this study was sexual function and activity. Sexuality is certainly a more complex phenomenon than what is reflected through those aspects, and a study would benefit from a broader approach. The negative effects of gynaecological cancer and its treatment are likely to be recognised also in the psychological and social aspects of sexuality and quality of life. A broader perspective by adding a qualitative element, for example, open-ended questions, to the survey, may be one way to explore the phenomenon to a wider extent. This could also lead to improved nursing care and practice.

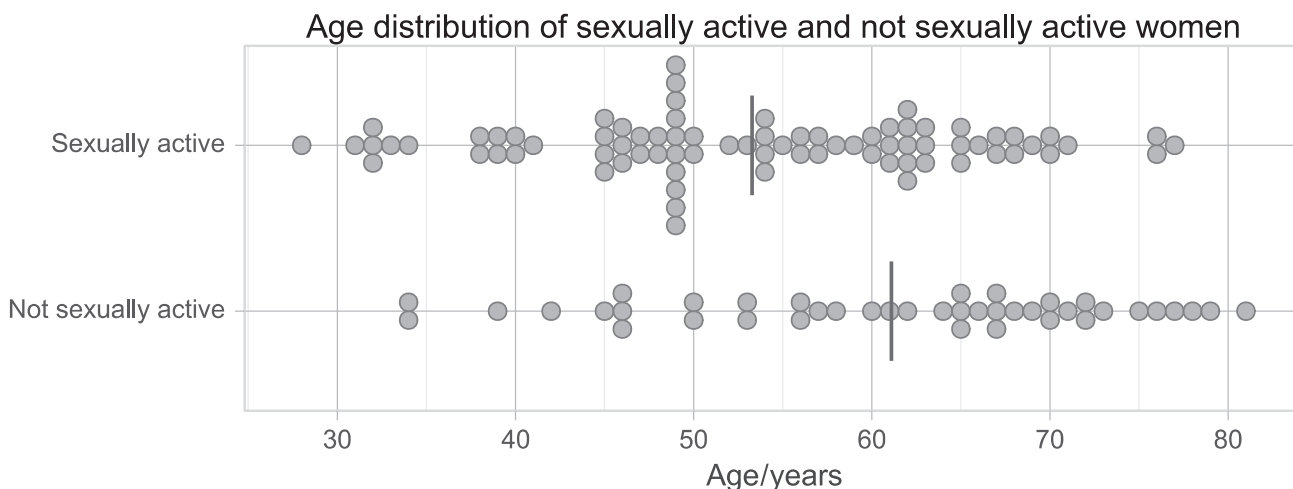


Figure 4 Dot plot showing age distribution of the sexually and not sexually active women ($n = 119$). The mean ages are shown as vertical lines.

Conclusion

This study shows that although women after gynaecological cancer are sexually active, more than 50% are not satisfied or little satisfied with this part of their life. They also report high scores on pain and discomfort related to sexual activity. Sexuality is a significant part of a woman's life, and health personnel should address the issue during treatment and follow-up.

Relevance to clinical practice

Health personnel should develop a greater understanding of the challenges cancer poses to a woman's sexuality, and should address these in any interaction with the patients, considering sexual function, response cycle, body image and sexual relationships. The personnel's ability to communicate and their expertise in diagnosing and treating difficulties relating to sexuality are important. Furthermore, any counselling consultation on the issue should also be accompanied by written information to ensure that the information is received by the patient.

References

- Abbott-Anderson K & Kwekkeboom KL (2012) A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecologic Oncology* **124**, 477–489.
- Audette C & Waterman J (2010) The sexual health of women after gynecologic malignancy. *Journal of Midwifery & Women's Health* **55**, 357–362.
- Becker M, Malafy T, Bossart M, Henne K, Gitsch G & Denschlag D (2011) Quality of life and sexual functioning in endometrial cancer survivors. *Gynecologic Oncology* **121**, 169–173.
- Bergmark K, Åvall-Lundqvist E, Dickman PW, Henningsohn L & Steineck G (1999) Vaginal changes and sexuality in women with a history of cervical cancer. *New England Journal of Medicine* **340**, 1383–1389.
- Bifulco G, De Rosa N, Tornesello ML, Piccoli R, Bertrando A, Lavitola G, Lavitola G, Morra I, Di Spiezio Sardo A, Buonaguro FM & Nappi C (2012) Quality of life, lifestyle behavior and employment experience: a comparison between young and mid-life survivors of gynecology early stage cancers. *Gynecologic Oncology* **124**, 444–451.
- Bjelland I, Dahl AA, Haug TT & Neckelmann D (2002) The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *Journal of Psychosomatic Research* **52**, 69–77.
- Carmack Taylor CL, Basen-Engquist K, Shinn EH & Bodurka DC (2004) Predictors of sexual functioning in ovarian cancer patients [Comparative Study Research Support, Non-U.S. Gov't Research Support, U.S. Gov't, P.H.S.]. *Journal of Clinical Oncology* **22**, 881–889.
- Carter J, Stabile C, Gunn A & Sonoda Y (2013) The physical consequences of gynecologic cancer surgery and their impact on sexual, emotional, and quality of life issues. *J Sex Med* **10**, 21–34.
- Cella M & Chalder T (2010) Measuring fatigue in clinical and community settings. *Journal of Psychosomatic Research* **69**, 17–22.
- Chalder T, Berelowitz G, Pawlikowska T, Watts L, Wessely S, Wright D & Wallace EP (1993) Development of a fatigue scale. *Journal of Psychosomatic Research* **37**, 147–153.
- Cleary V & Hegarty J (2011) Understanding sexuality in women with gynaecological cancer. *European Journal of Oncology Nursing* **15**, 38–45.
- Cleary V, Hegarty J & McCarthy G (2011) Sexuality in Irish women with gynecologic cancer. *Oncology Nursing Forum* **38**, E87–E96.
- Frumovitz M, Sun CC, Schover LR, Munsell MF, Jhingran A, Wharton JT, Eifel P, Bevers TB, Levenback CF, Gershenson DM & Bodurka DC (2005) Quality of life and sexual functioning in cervical cancer survivors. *Journal of Clinical Oncology* **23**, 7428–7436.
- Gilbert E, Ussher JM & Perz J (2011) Sexuality after gynaecological cancer: a review of the material, intrapsychic, and discursive aspects of treatment on women's sexual-wellbeing. *Maturitas* **70**, 42–57.
- Greimel ER, Winter R, Kapp KS & Haas J (2009) Quality of life and sexual functioning after cervical cancer treatment: a long-term follow-up study. *Psycho-Oncology* **18**, 476–482.

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Study conception and design, and drafting of the manuscript: MEV and RJTS; data analysis: MEV and KOH; critical revisions for intellectual content: KOH.

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Conflict of interest

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- Grover S, Hill-Kayser CE, Vachani C, Hampshire MK, DiLullo GA & Metz JM (2012) Patient reported late effects of gynecological cancer treatment. *Gynecologic Oncology* **124**, 399–403.
- Harter P, Schrof I, Karl LM, Hils R, Kullmann V, Traut A, Scheller H & du Bois A (2013) Sexual function, sexual activity and quality of life in women with ovarian and endometrial cancer. [Sexuelle Funktion, sexuelle Aktivität und Lebensqualität bei Frauen mit Ovarial- und Endometriumkarzinom]. *Geburtshilfe und Frauenheilkunde* **73**, 428–432.
- Hawighorst-Knapstein S, Fusshoeller C, Franz C, Trautmann K, Schmidt M, Pilch H, Schoenefuss G, Knapstein PG, Koelbl H, Kelleher DK & Vaupel P (2004) The impact of treatment for genital cancer on quality of life and body image—results of a prospective longitudinal 10-year study. *Gynecologic Oncology* **94**, 398–403.
- Hersch J, Juraskova I, Price M & Mullan B (2009) Psychosocial interventions and quality of life in gynaecological cancer patients: a systematic review. *Psycho-Oncology* **18**, 795–810.
- Hordern A (2008) Intimacy and sexuality after cancer: a critical review of the literature. [Review]. *Cancer Nursing* **31**, E9–E17.
- Jensen PT, Groenvold M, Klee MC, Thranov I, Petersen MA & Machin D (2003) Longitudinal study of sexual function and vaginal changes after radiotherapy for cervical cancer. *International Journal of Radiation Oncology*Biophysics* **56**, 937–949.
- Juraskova I, Butow P, Robertson R, Sharpe L, McLeod C & Hacker N (2003) Post-treatment sexual adjustment following cervical and endometrial cancer: a qualitative insight. *Psycho-Oncology* **12**, 267–279.
- Korfage IJ, Essink-Bot M-L, Mols F, van de Poll-Franse L, Kruitwagen R & van Ballegooijen M (2009) Health-related quality of life in cervical cancer survivors: a population-based survey. *International Journal of Radiation Oncology Biology Physics* **73**, 1501–1509.
- Lai BY, Tang C-K & Chung TH (2009) Age-specific correlates of quality of life in Chinese women with cervical cancer. *Supportive Care in Cancer* **17**, 271–278.
- Lammerink EAG, de Bock GH, Pras E, Reyners AKL & Mourits MJE (2012) Sexual functioning of cervical cancer survivors: a review with a female perspective. *Maturitas* **72**, 296–304.
- Liavaag AH, Dørum A, Bjørø T, Oksefjell H, Fosså SD, Tropé C & Dahl AA (2008) A controlled study of sexual activity and functioning in epithelial ovarian cancer survivors. A therapeutic approach. *Gynecologic Oncology* **108**, 348–354.
- Liavaag A, Dørum A, Fosså S, Tropé C & Dahl A (2009) Morbidity associated with “self-rated health” in epithelial ovarian cancer survivors. *BMC Cancer* **9**, 1–11.
- Lind H, Waldenstrom AC, Dunberger G, Al-Abany M, Alevronta E, Johansson KA, Olsson C, Nyberg T, Wilderäng U, Steineck G & Avall-Lundqvist E (2011) Late symptoms in long-term gynaecological cancer survivors after radiation therapy: a population-based cohort study. *British Journal of Cancer* **105**, 737–745.
- Loge JH, Ekeberg Ø & Kaasa S (1998a) Fatigue in the general norwegian population: Normative data and associations. *Journal of Psychosomatic Research* **45**, 53–65.
- Loge JH, Kaasa S, Hjerstad MJ & Kvien TK (1998b) Translation and performance of the Norwegian SF-36 Health Survey in patients with rheumatoid arthritis. I. Data quality, scaling assumptions, reliability, and construct validity. *Journal of Clinical Epidemiology* **51**, 1069–1076.
- McCallum M, Lefebvre M, Jolicoeur L, Maheu C & Lebel S (2012) Sexual health and gynecological cancer: conceptualizing patient needs and overcoming barriers to seeking and accessing services. *Journal of Psychosomatic Obstetrics & Gynecology* **33**, 135–142.
- Mercadante S, Vitranò V & Catania V (2010) Sexual issues in early and late stage cancer: a review. *Supportive Care in Cancer* **18**, 659–665.
- Nout RA, van de Poll-Franse LV, Lybeert MLM, Wárlám-Rodenhuis CC, Jobsen JJ, Mens JWM, Lutgens LC, Pras B, van Putten WL & Creutzberg CL (2011) Long-term outcome and quality of life of patients with endometrial carcinoma treated with or without pelvic radiotherapy in the post operative radiation therapy in endometrial carcinoma 1 (PORTEC-1) trial. *Journal of Clinical Oncology* **29**, 1692–1700.
- Onujiogu N, Johnson T, Seo S, Mijal K, Rash J, Seaborne L, Rose S & Kushner DM (2011) Survivors of endometrial cancer: who is at risk for sexual dysfunction? *Gynecologic Oncology* **123**, 356–359.
- Park SY, Bae D-S, Nam JH, Park CT, Cho C-H, Lee JM, Kim SH, Park SM & Yun YH (2007) Quality of life and sexual problems in disease-free survivors of cervical cancer compared with the general population. *Cancer* **110**, 2716–2725.
- Ponto JA, Ellington L, Mellon S & Beck S (2010) Predictors of adjustment and growth in women with recurrent ovarian cancer. *Oncology Nursing Forum* **37**, 357–364.
- R Core Team (2013). *R: A Language and Environment for Statistical Computing*. R Foundation for Statistical Computing, Vienna, Austria. URL <http://www.R-project.org/>.
- Ratner ES, Foran KA, Schwartz PE & Minkin MJ (2010) Sexuality and intimacy after gynecological cancer. *Maturitas* **66**, 23–26.
- Reis N, Beji NK & Coskun A (2010) Quality of life and sexual functioning in gynecological cancer patients: results from quantitative and qualitative data. *European Journal of Oncology Nursing* **14**, 137–146.
- Sekse RJT, Raaheim M, Blaaka G & Gjengedal E (2010) Life beyond cancer: women’s experiences 5 years after treatment for gynaecological cancer. *Scandinavian Journal of Caring Sciences* **24**, 799–807.
- Sekse RJT, Gjengedal E & Råheim M (2012) Living in a changed female body after gynecological cancer. *Health Care for Women International* **34**, 14–33.
- Sprangers MAG & Schwartz CE (1999) Integrating response shift into health-related quality of life research: a theoretical model. *Social Science and Medicine* **48**, 1507–1515.
- Stead ML, Fallowfield L, Selby P & Brown JM (2007) Psychosexual function and

- impact of gynaecological cancer. *Best Practice & Research Clinical Obstetrics & Gynaecology* 21, 309–320.
- Stewart DE, Wong F, Duff S, Melancon CH & Cheung AM (2001) “What Doesn’t Kill You Makes You Stronger”: an ovarian cancer survivor survey. *Gynecologic Oncology* 83, 537–542.
- Thirlaway K, Fallowfield L & Cuzick J (1996) The sexual activity questionnaire: a measure of women’s sexual functioning. *Quality of Life Research* 5, 81–90.
- Vaidakis D, Panoskaltis T, Poulakaki N, Kouloura A, Papadimitriou G & Salamalekis E (2014) Female sexuality after female cancer treatment: a clinical issue. *European Journal of Gynaecological Oncology* 35, 635–640.
- Vistad I, Fosså SD, Kristensen GB, Mykletun A & Dahl AA (2007a) The Sexual Activity Questionnaire: psychometric properties and normative data in a Norwegian population sample. *Journal of Women’s Health (15409996)* 16, 139–148.
- Vistad I, Fosså SD, Kristensen GB & Dahl AA (2007b) Chronic fatigue and its correlates in long-term survivors of cervical cancer treated with radiotherapy. *BJOG: An International Journal of Obstetrics & Gynaecology* 114, 1150–1158.
- Ware JE Jr & Sherbourne CD (1992) The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 30, 473–483.