

Quality of Life and Sexuality of Patients after Treatment for Gynaecological Malignancies: Results of a Prospective Study in 55 Patients

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Abstract. *Aim: To assess the sexuality and quality of life (QoL) of women with gynaecological malignancies after multimodal therapy. Materials and Methods: This is a prospective analysis of the sexual status among women after treatment for gynaecological malignancies. Validated questionnaires-female sexual function index (FSFI-d), a semi-structured questionnaire and the quality of life score SF12, were applied. Results: Overall, 55 patients (median age=61, range=22-74 years) were enrolled. The cancer diagnoses were 54% ovarian, 26% breast, 13% cervical, 6% vulvar and 2% endometrial cancer. Twenty patients (55.6%) claimed experiencing changes in their sexuality after cancer treatment. The main reasons for this impairment were distortion of their self image (45%; n=9), dry vaginal mucosa (25%; n=5), fear of physical harm (20%; n=4) and pain during sexual intercourse (20%; n=4). Forty percent of the patients gave no information about their sexuality after cancer therapy. Patients with cervical, endometrial or vulvar cancer had significantly higher changes in their sexuality compared to patients with ovarian cancer even after adjusting for age, recurrence rate and partnership status. The evaluation of SF12 revealed significantly higher psychological functional scores with increasing age. Patients who reported changes of their sexuality were also shown to have a lower overall SF12 score. Conclusion: Evaluation of sexuality and self image perception after cancer treatment is an unmet need and needs to be addressed in women with gynaecological malignancies. Further studies are warranted to assess the influence of the various types of cancer therapies in regard to their effect on sexuality and quality of life.*

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Key Words: SF-12 questionnaire, sexual activity gynaecological cancer, quality of life.

During the past decades, survival rates have improved for various gynaecological malignant tumours on account of better surgical techniques and adjuvant therapies (1).

Apart from the tumour control rates, quality of life aspects are an equally important objective for cancer therapies influencing patient's satisfaction and should, therefore, be considered and incorporated in the treatment decision making process (2, 3). Although various studies have shown that sexual setbacks also have negative effects on the quality of life of the patients (4-6), up to date only few aspects of sexuality have been examined extensively among cancer patients. The treatment of gynaecological malignancies may induce significant changes in the physical, psychological and social aspects of a woman's life, potentially strongly influencing her sexuality and self perception (7-12).

Changes of body functions, as well as changes of the hormone status and loss of the sexual organs and anatomic structures, can have a tremendous impact on sexuality (10-13). Moreover, the inevitable and necessary adjuvant therapies such as radiotherapy or anti-hormonal agents, may cause additional negative impacts on the sexual capacity of the affected women (14, 15). The considerable psychological influence on self-esteem and one's own self image and perception is of additional relevance. Current data clearly show that the issue of sexuality and self image is still insufficiently addressed in the literature, with patients with rare vulvar and ovarian cancer being especially underrepresented (16). On this regard, we conducted the present study among patients with various gynaecological malignancies after the end of their primary treatment.

Materials and Methods

Questioning period and study population. The interviews were performed from November 2011 until January 2012 at the Gynaecological Clinic of the Charité University at the Virchow Campus Medical Center of Berlin. Based on an interdisciplinary (gynecological, psychosomatic) and interprofessional (nurses, psychologists, and self-help initiatives) workup, the study design

and the applied questionnaires were defined. The questionnaires were handed out to the patients during the routine tumour aftercare consulting hour in an outpatient setting. Patients with the following inclusion criteria were questioned: histologically-continued gynaecological malignancy, end of primary therapy at least three months before study entry; age ≥ 18 years; sufficient ability to read and answer the German questionnaires. As an exclusion criteria, we considered current active cancer, current radiotherapy and chemotherapy.

Questionnaires. SF-12 is 12-item validated questionnaire and based on a shortened and more practicable form of the SF-36 (17), without any significant loss of information.

The following items and dimensions are included in SF-12: physical function, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and emotional well-being (5 items) (17, 18). For the present study, the validated female sexual function index (FSFI-d) was also applied. The letter 'd' in FSFI-d stands for the German-speaking version of the questionnaire which was used throughout the present study (20). The FSFI-d is a multiple choice questionnaire consisting of 19 items. The patients are questioned according to six categories regarding their genital function (genital desire, excitation, lubrication, orgasm, sexual satisfaction, and pain) (19). To collect additional information about the patients demographics and further information about their dealing with the topic of sexuality, an additional semi-structured questionnaire was applied. This Charité questionnaire (CQ) includes 20 items, including demographic features and questions about symptoms, frequency of sexual activities, sources of information about sexuality, and barriers of communication about sexual problems.

Patient interviews. Initially 10 patients were questioned in a setting of personal interviews, as a pilot project. The interviews were carried out by one person (AP) who was not primarily involved in the therapeutic management. During the period of personal interviews, the practicability and comprehensiveness of the questionnaires was tested. The total average time frame to answer all three questionnaires was 15 min (range=10-20 min). The questionnaires were always questioned in the same order (CQ, FSFI-d, SF-12). After a short introduction of the study's objective and the patients commitment for participation, the patient received an envelope with the questionnaires. If patients indicated in the CQ document that they had experienced changes in their sexuality after the treatment, then they were invited to answer an additional eight questions. The questionnaires were filled out by the patients-only and were handed in a sealed envelope to a nurse.

Statistics. SF-12 was summarised according to the instructions for the physical and a psychological global sum scale. By using the method of statistical weighting, the scales were standardized based on an average value of 50 and a standard deviation of 10 for the general population to allow for an indirect comparison of cancer and non-cancer patients (18).

For the FSFI, the total scale and six sub-scales were formed according to the official guidelines (21). Over the entire scale, a value of less than 26 was evaluated as a sexual dysfunction (22).

Differences from nominal variables were analysed by means of the chi-square test or Fisher's exact test, from ordinal variables by

the Kendalls tau b-test, and from continuous variables such as that of the SF-12 scale, by the t-test. In multivariate models, predictors of SF-12 and FSFI total scores were analysed using linear regressions; alterations in sexuality and dysfunction were analysed using logistic regressions.

All analyses were carried out using PASW 19 (SPSS Inc., Chicago, USA). A two-sided p -value of <0.05 was considered to be statistically significant.

Results

Study population. Overall, 64 women were screened for the present study, while only 55 were actually enrolled. Nine patients did not fulfil the inclusion criteria due to engering radiotherapy. The median age of the patients was 61 years (range=22-74 years). The most common cancer type was ovarian carcinoma, with 54%, followed by breast cancer in 26%, cervical cancer 13%, vulvar cancer 6% and endometrial cancer 2%. (see Table I). Forty-one patients (74.5%) lived in a partnership.

SF-12. Forty-nine (89%) out of the 55 patients answered the SF-12 questionnaire. The mean psychological sum scale was 47.95 (SD ± 12.53), and was not significantly different from the equivalent values of the general population ($p=0.258$). Moreover, the evaluation showed that the psychological functionality of the patients rose significantly with increasing age ($p=0.011$). Patients with ovarian cancer were, in comparison to those with other malignancies, in a more dismal physical condition, even though the difference was not significant ($p=0.391$). We did not identify any significant relation of the psychological functionality and the number of previous operations or form of adjuvant therapy. No association was observed between the psychological functionality and the partnership state. The mean physical sum score was 46.2 (SD ± 10.91) and thus significantly lower than that of the general population ($p=0.015$). We did not identify any independent prognostic value of any of the examined variables for the overall outcome, apart the question regarding sexuality impairment. Cancer-related changes of the sexuality were associated with a significantly lower total SF-12 score and also with a lower quality of life of the patients compared to those who had no changes in their sexuality after treatment of their malignant tumour ($p=0.047$).

FSFI questionnaires. The mean score was 18.48 (SD ± 10.08). The highest values were obtained for satisfaction 3.71 (SD ± 1.84) and pain 3.31 (SD ± 2.40). The lowest values were observed for desire, with a mean score of 2.74 (SD 1.07), and for excitation, with a mean value of 2.88 (SD ± 1.87). No significant differences were identified among the different tumour entities. Patients who lived in a

Table I. *Patients' characteristics.*

Variable	n (%) or median (range)
Age (years)	61 (22-74)
Partnership	
Yes	41 (74.5)
No	14 (25.5)
Primary carcinoma	
Ovarian carcinoma	29 (52.7)
Breast carcinoma	14 (25.5)
Cervix carcinoma	7 (12.7)
Vulva carcinoma	3 (5.5)
Corpus carcinoma	1 (1.8)
Missing data	1 (1.8)
Previous operation	55 (100)
Previous chemotherapy	
Yes	30 (54.5)
No	25 (45.5)
Hormonal therapy	
Yes	8 (14.5)
No	47 (85.5)
Recurrence	
Yes	15 (27.8)
Non	39 (72.2)

partnership had a slightly higher FSFI score, however, without this reaching a statistical significance ($p=0.137$). Thirty-two out of the 41 patients (78%) reported genital dysfunctions according to a score of <26 (22). No differences were observed in regard to tumour entity, age and partnership. All 18 patients with sexuality disorders had significantly more frequent sexual dysfunctions in comparison with 13 out of the 21 (62%) patients who had no changes ($p=0.004$).

Charité - Questionnaire (CQ). When asking patients directly about possible cancer treatment-related changes of their sexuality using the CQ, only 20 women (36.4%) were identified as having a problem. The frequency of sexual intimacy was once weekly in 20% ($n=4$), in a further 20% ($n=4$) one to two times a month, whereas 55% of the patients ($n=11$) reported having sexual intercourse at a frequency of less than one to two times a month. Eight patients even claimed experiencing positive changes in their sexuality, such as "more closeness to their partner". In total 75% ($n=15$) reported that the problems started "immediately" after end of the treatment whereas 15% ($n=3$) identified this initiation in a time period of 56 months after the treatment onset. Moreover, 65% ($n=13$) of the patients complained of continuous problems, while 15% ($n=3$) experienced sexual problems more rarely. The main reason for impaired sexuality was a distorted self image (see Table II). Under the heading "Miscellaneous" the

Table II. *Making use of information sources about sexuality after treatment of gynaecological malignancies (more than one answer possible).*

No inquiries made	40% ($n=8$)
Doctor	25% ($n=5$)
Information pamphlets	15% ($n=3$)
Family relatives	5% ($n=1$)
Friends	5% ($n=1$)
Other patients	5% ($n=1$)
Partner	5% ($n=1$)
Internet	5% ($n=1$)
Miscellaneous	5% ($n=1$)
No answers	10% ($n=2$)

patients gave the following causes as being responsible for their limited sexuality: missing libido ($n=4$), fear of infections ($n=2$), fears of the partner ($n=2$) and old age ($n=1$). Sexual activity of the patients was described by using a scale ranging from 1 (very little) and 10 (very active). The average score was 3, with a range from 0 -7. A total of 40% of the patients provided no information about sexual activity after treatment of their malignant tumour, whereas 25% of them had discussed this with their doctor (see Table II).

Multivariate analysis of FSFI, SF-12 and changes of the sexuality. Patients living in a partnership showed a trend for higher FSFI scores compared to those without partners, by 7.6 points ($p=0.097$). Patients who reported any changes of their sexuality had a total FSFI score 5.3 points lower than those patients who reported no changes ($p=0.139$). According to the multivariate analysis, cervical, endometrial or vulvacancer had a significant negative-impact on the sexuality in contrast to ovarian cancer, regardless of age, recurrence status and partnership status (odds ratio=6.8, 95% confidence interval=1.0-45.2; $p=0.049$). SF-12 physical scores: The patients' age, the tumour entity and the type of treatment had no influence on the overall physical scores. Those patients who indicated changes of their sexuality had mean physical functionality scores of less than 7 points ($p=0.045$), while patients living in a partnership were in only a slightly better physical condition ($p=0.058$).

SF-12 psychological scores: Increasing age was the only independent factor associated with higher psychological scores ($p=0.033$). Patients with ovarian carcinomas had on average, scores 11 points lower compared to patients with other pelvic tumours ($p=0.064$). Patients who indicated changes of their sexuality had on average 5 points less than those who experienced no change of their sexuality ($p=0.182$).

Discussion

Sexual dysfunction in women is mainly characterised by decreasing desire, lower interest in any sexual activities, loss of excitation and dyspareunia, but also difficulties in reaching an orgasm (7). Despite the high relevance of this issue, only limited information is so far available on the incidence of sexual dysfunction after gynaecological cancer treatment with reported rates ranging from 30 to 100% (2, 23-25). The reason for this broadly-varying data may be due to the methodical limitations of the different studies, such as non-homogeneous patient populations, varying time points of the interview within a multimodal therapy, types of the applied questionnaires, but also strongly varying control groups (26-28). Harter *et al.* recently presented their data including 79 patients with ovarian or endometrial cancer showing a higher rate of sexual activity impairment in cancer patients, without this however being projected into a lower global quality of life, as assessed by a validated European Organisation for Research and Treatment of Cancer questionnaire (EORTC- questionnaire). This is in contrast to our study which demonstrates a clear association between impairment of sexuality and quality of life. A strong limitation of the study of Harter is the control group of non-cancer patients, being from a department of Prosthodontics. A control group should consider both the surgical and non-surgical interventions independently of the cancer status in order to better-understand the global effects of the multimodal therapies (29). Therefore we decided to use no control group for this pilot study.

Only 55.6% of the patients in our study claimed, upon direct questioning, experiencing any change of their sexuality. The multidimensional FSFI questionnaire assessed 78% of the patients as having some sexual disorder. Graham *et al.* also described the existing discrepancy between the presence of genital disorders and the communication of this by the patients to their doctors (30). Various studies have shown that patients rarely use their physicians as a primary source of information for sexuality aspects. This is also confirmed by our study. Based on our study, many patients do not actively seek information about sexuality and cancer. These problems should also be more strongly considered in the clinical routine to build up an adequate environment to discuss these intimate topics. Physicians should address this theme actively and should be supported by an inter-professional team. Further information using classical and modern materials, including the internet may also stimulate the patient-physician dialogue. In our study, a large number of the women presented the loss of their attractiveness as a reason for their altered sexuality. In a comparative manner, Bourgeois-Law *et al.* described as early as in 1999 that the change of a patient's body and their own perception of their self image was the most significant impairment after they had survived the treatment of their cancer (26). In various studies, cancer patients report of their

fear towards anatomical damages during the sexual intercourse (27). In our study 20% of the patients also reported this problem. Therefore, all physician should discuss this relevant topic with their patients. The trend described in the literature, which indicates young women having more sexual problems than post-menopausal women (31, 32) was not confirmed by our study, with all the limitations of the study design. The changes in sexuality among the questioned patients were all independent of age. Whether or not any relevant differences between the individual gynaecological malignancies exist remains completely unclear (8). In our investigation, patients with vulvar, endometrial and cervical carcinomas reported sexual problems more often than patients with ovarian cancer. Further prospective studies should be performed in order to more precisely characterise the influence of the surgical, systemic and radiological therapies for these specific tumour entities. In addition, the influence of co-morbidities, for example hypertension and obesity, often associated with endometrial cancer should be analyzed to discriminate cancer from non-cancer effects.

Conclusion

The present study demonstrates the high impact of sexual disorders on the quality of life in patients with gynaecological malignancies. Future prospective studies are warranted to better understand the influence of various cancer therapies on the sexuality, self image and quality of life of these women with the aim of improving the situation of patients with gynaecological malignancies.

Conflicts of Interest

The Authors declare that there are no conflicts of interest.

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Received July 7, 2012
Revised September 29, 2012
Accepted October 2, 2012