# Sexuality in Women Recovering from Gynaecological Cancer

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**Abstract:** *Objective*: The clinical radical treatment of gynecological cancer has been characterised as defeminising women, with ignoring impacts on sexual functioning in intimate relationships. This research examined the psychological factors regarding this disease and its treatment for women and their sexuality across four main cancer types two years after recovering from gynecological cancer. *Methods*: Seventy-five cancer patients with a mean age at diagnosis of 51 (SD=15.3) gave their consent. Of these, eighteen participants (24%) had experienced endometrial, 25(33%) ovarian, 11(15%) vulva and 21(28%) cervical cancer. Sexual and relationship satisfaction were assessed with Golombok Rust Inventory of Sexual Satisfaction (GRISS) and the Relationship Assessment Scale (RAS). *Results*: Of the 53 women in intimate relationships who completed full datasets, only 4 (8%) returned to normal sexual activity and were sexually satisfied, 49 (92%) were not. Nonetheless, 50 (86%) of participants reported their relationship as satisfactory. The cancer effecting sexual activity the most was endometrial, which effects have been reported as anorgasmia and vaginismus, however all groups were dissatisfied with the lack of frequency of sexual activity.

Although cancer needs urgent treatment with the most desirable outcome in terms of physical heath, more emphasis is needed on caring for women's sexuality in the recovering process.

**Keywords:** Sexuality, intimate relations, gynaecological cancer, psychological factors, quality of life.

## INTRODUCTION

Although many of the psychological problems of gynaecological cancer patients are similar to those of other cancer patients, research suggests that the nature of the diagnosis and treatment of gynaecological cancers provide an added stressful burden to women regarding their sexuality [1,2].

Primary gynaecological cancers occur in four main sites including the endometrium, cervix, vulva and ovaries. It is very difficult to predict accurately how cancer and its treatment will have an effect, but for most women there are changes which require adaptation and development of new ways of giving and receiving sexual pleasure, without sexuality being destroyed [3].

Four main ways that cancer or its treatment can affect sexuality has been described as the physical ability to give and receive sexual pleasure; thoughts and body image; feelings such as fear, sadness, anger and joy; and, roles and intimate relationships [4].

Gynaecological malignancies as a collective group are common. These account for approximately 20% of all cancers in women and about 11% of cancer deaths [5]. The most common gynaecological cancers are those of the endometrium, ovary and cervix. Less common types are cancers of the vulva and vagina.

The incidence of cervical cancer in the UK is approximately 4,000 new cases and about 2,200 deaths each year [6]. These overall figures have remained steady for many years despite the introduction of cervical screening, which enables earlier detection. Moreover, these figures have indicated an increase in morbidity and mortality among younger women in recent years, which seem to correspond with changes in sexual behaviour.

Treatment for gynaecological cancer entails integrated multi-modality therapy, with patients often receiving a combination of surgery, radiotherapy and/or chemotherapy. Cancer treatment that affects the genitals and breasts directly causes quite marked affects on an individual's sex life. A hysterectomy combined with removal of the ovaries (Oophorectomy) constitutes a common surgical procedure. This surgery can usually result in a slight shortening on the vagina, although this does not usually cause a problem for intercourse, a woman might prefer not to have penetrative intercourse [3]. Although women can still experience orgasm, those who have undergone this type of surgery report a different effect [2].

A vulvectomy, involves removal of the entire vulva including the clitoris and can permanently change the outward appearance of the body, and as a result can affect women's feelings's about sexuality and

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**E-ISSN: 2309-4400/15** 

womanhood. A woman may feel she has lost part of her female identity and may worry that this will affect her sexual relationships. However, with time and understanding there is no reason why sexual relationships cannot be resumed.

When a diagnosis of gynaecological cancer is made, both the patient and her physician usually focus their immediate attention on trying to enhance the woman's survival by eliminating potentially lethal cancer cells. Research on cancer therapy has tended to focus on survival rates and has neglected to fully address quality of life issues. Most quality of life models address concerns such as side effects of treatment. No consensus exists on quality of life distress of long-term cancer survivors or on the impact of psychological disturbances arising. During treatment, little attention is paid to the potential sexual side effects of treatment [3,7].

In summary, the organs involved in gynaecological malignancies are, by their very nature, integral to issues of sexuality, sexual functioning and femininity. It therefore comes as no surprise that developing a malignancy in this area can have a significant impact on these dimensions of a woman's well being. The research on treatments suggests that there are significant variations in the psychological consequences for women depending on the site of cancer and treatment method used [2]. Despite this, many psychological studies have grouped together patients with different gynaecological cancers and described them as one collective group.

The present study was interested in the less researched area of gynaecological cancers and examined the psychological factors regarding this disease and its treatment for women and their sexuality across the four main gynaecological cancer types: endometrial, ovarian, cervical cancer and cancer of the vulva.

## METHOD

This study employs a between group cross sectional design. Data were collected using quantitative methodologies in the form of self-report measures. Approval for the study was obtained through both the NHS and university ethics committees. Participants were recruited from a large public hospital in the North East of England, using the hospital's electronic patient database system, which contained details of all the women diagnosed with gynaecological cancer. To ensure that participants had completed their treatment, women were included only if a minimum of two years had passed since they received their initial diagnosis. Furthermore, participants had to be female and be able to read and write in English. Individuals who were known to be undergoing medical treatment for an illness where excluded from the study.

Seventy-five patients consented to the study and returned their questionnaires within the subsequent eight-week period. The mean age of participants at the time of diagnosis was 51 years (SD = 15.3). Eighteen participants (24%) had experienced endometrial cancer, 25 (33%) ovarian cancer, 11 (15%) cancer of the vulva and 21 (28%) cervical cancer.

Nineteen participants (25%) were single, whilst 56 (75%) were involved in a current relationship. Of those in a relationship the average length of relationship was 25.2 years (SD = 16.8). The sexual orientation of 93% (n=70) respondents was heterosexual, with 5% (n=4) homosexual in orientation. One woman responded as heterosexual and homosexual, which could identify as bisexual.

Apart from demographical variables, the questionnaire assessed perception of sexual functioning with the Golombok Rust Inventory of Sexual Satisfaction (GRISS) [8] and quality of the intimate relationship with the Relationship Assessment Scale (RAS) [9].

The Golombok Rust Inventory of Sexual Satisfaction (GRISS) was developed to provide objective assessments of the quality of sexual relationships and a person's function within it. It is a short questionnaire for assessing the existence and severity of sexual problems. The scale consists of 28 items with a five-point response format. This refers to the frequency of sexual interests and activities, on a scale from 'never' to 'always'. The GRISS provides an overall score for the quality of sexual functioning within a relationship. In addition it obtains seven subscale scores, and for women these are: Infrequency, Non-communication, Female dis-satisfaction, Female avoidance, Female non-sensuality, Vaginismus and Anorgasmia.

The Relationship Assessment Scale (RAS) was developed to measure a single construct, namely one's subjective evaluation of a close/intimate relationship [10] It is a brief, generic measure of relationship satisfaction based on an earlier five-item version for marital satisfaction [9]. It consists of a 7-item Likert scale with scores ranging from 1 (low satisfaction) to 5 (high satisfaction). Items 4 and 7 are reverse scored.

The RAS assesses general satisfaction, how well the partner meets one's needs, how well the relationship compares to others, regrets about the relationship, how well one's expectations have been met, love for partner and problems in the relationship. These items are specific enough to tap several relationship dimensions, yet general enough to be appropriate for married couples, couples who are living together, dating couples, gay couples, and, with minimal changes, even for friendships.

Statistical analysis was undertaken using the Statistical Package for the Social Sciences (SPSS) version 9. An alpha level of 0.05 was used to determine statistical significance.

## RESULTS

Analysis of the demographic variables suggested that the cancer groups did not differ on mean current age, age at diagnosis, sexual orientation, relationship status, duration of current relationship, employment status, and child status. This suggests that the demographic variables were comparable across the four cancer groups.

Of the 75 participants, only 53 (71%) returned the GRISS fully completed. Of the 22 ladies who did not complete the GRISS, the majority (n=16, 73%) were widowed, separated or not in a current relationship. The remaining six (27%) ladies were in a relationship but did not complete the GRISS.

Tables **1** and **2** show the mean scores for these scales across the four cancer groups (N=53).

**Table 1: Mean Overall Raw Scores for the Golombok Rust Inventory of Sexual Satisfaction (GRISS)**

| Cancer Type | n | Mean | SD | Range |
|---|---|---|---|---|
| Endometrial | 10 | 45.5 | 16.4 | 24-70 |
| Ovarian | 19 | 34.2 | 13.3 | 10-64 |
| Vulva | 6 | 35.5 | 7.0 | 27-44 |
| Cervical | 18 | 32.8 | 14.6 | 7-53 |
| Whole group | 53 | 36.0 | 14.3 | 7-70 |

Table **3** shows the mean scores for the RAS across the four cancer groups (N=58).

The cut-off scores for the GRISS, provided by Rust and Golombok (1986), suggest that it is 'normal' for the general population to report at least one subscale score of five or more. Table **4** illustrates that 92% of participants reported significant difficulties on more than one of the sexual functioning subscales.

**Table 2: Mean Transformed Subscale Scores for the Golombok Rust Inventory of Sexual Satisfaction (GRISS)**

| Cancer Type | n | Mean | SD | Range |
|---|---|---|---|---|
| Endometrial | 10 | 4.60 | 1.26 | 3-6 |
| Ovarian | 19 | 3.74 | 1.56 | 1-7 |
| Vulva | 6 | 3.83 | 1.17 | 3-6 |
| Cervical | 18 | 3.50 | 1.58 | 1-6 |
| Whole group | 53 | 3.83 | 1.49 | 1-7 |

**Table 3: Mean Scores for the Relationship Assessment Scale (RAS)**

| Cancer Type | n | Mean | SD | Range |
|---|---|---|---|---|
| Endometrial | 14 | 4.26 | 0.82 | 2.43-5 |
| Ovarian | 20 | 4.26 | 0.68 | 2.86-5 |
| Vulva | 7 | 4.73 | 0.39 | 4-5 |
| Cervical | 17 | 4.26 | 1.03 | 1-5 |
| Whole group | 58 | 4.32 | 0.80 | 1-5 |

**Table 4: Clinically Significant Cases for the Golombok Rust Inventory of Sexual Satisfaction (GRISS) according to Cancer Type**

| Cancer Type | Non- sign. / Normal (%) | Significant/ Problematic (%) | |
|---|---|---|---|
| Endometrial | | 10 (19) | |
| Ovarian | 1 (2) | 18 (34) | |
| Vulva | | 6 (11) | |
| Cervical | 3 (6) | 15 (28) | |
| Whole group | 4 (8) | 49 (92) | 53 |

These results suggest that despite receiving treatment for gynaecological cancer, four women (8% of respondents) were able to re-establish normal sexual functioning.

Participants' satisfaction with their relationship was measured using the Relationship Assessment Scale (RAS). The reference values for the RAS indicate that non-distressed partners are likely to score over 4.0, whereas scores between 3.5 and 3.0 for women would indicate greater relationship distress and possibly substantial relationship dissatisfaction [9]. The RAS scores from the current sample were compared to these cut off values and can be seen in Table **5**.

**Table 5: Clinically Significant Relationship Assessment Scale (RAS) Scores**

| Cancer Type | Problematic/ Significant (%) | Non problematic/ insignificant (%) | |
|---|---|---|---|
| Endometrial | 3 (5) | 11 (19) | |
| Ovarian | 3 (5) | 17 (29) | |
| Vulva | 0 | 7 (12) | |
| Cervical | 2 (4) | 15 (26) | |
| Whole group | 8 (14) | 50 (86) | Total = 58 |

The majority of participants (86%) reported overall satisfaction with their personal relationship. Only eight women (14%) reported dissatisfaction.

To examine differences in sexual functioning across cancer type the individual GRISS subscales of Infrequency, Non-communication, Female dissatisfaction, Female avoidance, Female non-sensuality, Vaginismus and Anorgasmia were compared.

Chi-squared analysis was conducted out to test for differences between the cancer groups, however this analysis violated the minimum cell frequency assumption and was therefore considered inappropriate. Instead, frequencies were examined to explore patterns within and between the cancer groups (see Tables **6a** and **b**).

The majority of participants reported infrequent sexual contact (85%) with their partner, and of those who reported frequent sexual contact, the majority (88%) were recovering from cervical cancer.

The majority of women (69%) reported significant problems with non-communication of their sexual feelings and preferences with their partner. Only 16 women (31%) expressed that they felt able to successfully discuss their sexual relationship openly. A significant proportion of women (70%) avoided sexual contact and this appeared to be consistent across all cancer groups. A similar proportion of women (67%) indicated that they had significant problems with non-sensuality.

On the two measures of sexual dysfunction: vaginismus and anorgasmia, the majority of women (64%) reported experiencing vaginismus, whereas only nine women (17%) indicated that they had an inability or difficulty experiencing an orgasm during sexual contact. Women who had cancer of the endometrium were more likely to experience vaginismus and they were also the group most affected by anorgasmia.

**Table 6a: Clinically Significant Subscale Scores for the Golombok Rust Inventory of Sexual Satisfaction (GRISS) according to Cancer Type**

| Cancer Type | n | Infrequency | | Non-communication | | Dissatisfaction | |
|---|---|---|---|---|---|---|---|
| | | No (%) | Yes (%) | No (%) | Yes (%) | No (%) | Yes (%) |
| Endometrial | 10 | 0 | 10 (100) | 1 (10) | 9 (90) | 8 (80) | 2 (20) |
| Ovarian | 19 | 0 | 19 (100) | 7 (39) | 11 (61) | 16 (84) | 3 (16) |
| Vulva | 6 | 1 (17) | 5 (83) | 3 (50) | 3 (50) | 5 (83) | 1 (17) |
| Cervical | 18 | 7 (39) | 11 (61) | 5 (28) | 13 (72) | 15 (83) | 3 (17) |
| Whole group | 53 | 8 (15) | 45 (85) | 16 (31) | 36 (69) | 44 (83) | 9 (17) |

**Table 6b: Clinically Significant Subscale Scores for the Golombok Rust Inventory of Sexual Satisfaction (GRISS) according to Cancer Type**

| Cancer Type | Avoidance | | Non-sensuality | | Vaginismus | | Anorgasmia | |
|---|---|---|---|---|---|---|---|---|
| | No (%) | Yes (%) | No (%) | Yes (%) | No (%) | Yes (%) | No (%) | Yes (%) |
| Endometrial | 5 (50) | 5 (50) | 2 (20) | 8 (80) | 2 (20) | 8 (80) | 6 (60) | 4 (40) |
| Ovarian | 6 (32) | 13 (68) | 6 (33) | 12 (67) | 6 (38) | 10 (62) | 16 (84) | 3 (16) |
| Vulva | 0 | 6 (100) | 4 (67) | 2 (33) | 2 (33) | 4 (67) | 4 (67) | 2 (33) |
| Cervical | 5 (28) | 13 (73) | 5 (28) | 13 (72) | 8 (44) | 10 (56) | 18 (100) | 0 |
| Whole group | 16 (30) | 37 (70) | 17 (33) | 35 (67) | 18 (36) | 32 (64) | 44(83) | 9 (17) |

Women who had experienced cancer of the cervix were least likely to experience vaginismus and all 18 women cervical had no significant difficulties experiencing orgasm. Despite the sexual difficulties expressed by participants, only a small proportion (n=9, 17%) reported significant dissatisfaction with their sexual relationship.

## DISCUSSION

The results leave significant questions to be answered in the way gynaecological cancers are treated, and opens up possible collaborations with health psychologists regarding assessment and care for patients and their sexuality.

The results obtained in this study on women' experience of their satisfaction with their sexual life, show devastating effects. Out of the 53 participants responded, only 4 women were able to re-establish normal levels of sexual activity with some levels of satisfaction. Current research shows that both sexual activity and sexual satisfaction play an important role in creating and maintaining relationships [11]. It is therefore important to take this into account in the treatment of gynaecological cancers. Although it is vital to treat the illness, most physicians will choose more radical treatments to lower chances of reoccurrences, but do not take into account quality of life after treatment. It should also be noted that psychological care for both the women and her partner should be offered as a coping mechanism, as well as to learn alternative ways to satisfy the sexual relationship [12].

Using the relationship assessment scale, the results showed that 50 (86%) participants reported a satisfactory relationship following the treatment of gynaecological cancer. Only 8 reported dissatisfaction. This would suggest that women are happy within the relationship, even though sexual satisfaction is reported as poor.

When looking at these results, it is interesting to find that 45 (85%) women reported the biggest problem being infrequences of sexual activity across all cancer groups. This would suggest, that despite problems and discomfort, women still seek and desire sexual intimacy from their partner. However, avoidance was a large issue across all cancer groups. This would suggest that despite women enjoying sexual activity, 37 (70%) females still avoid it, therefore, it is important to examine sexual activity more carefully.

Vaginismus affected 32 (64%) of females over all cancer sites, however this was more prominent for women who recovered from endometrial cancer (80%). Results were similar for anorgasmia, with women who have recovered from endometrial cancer, reported continuous occurrence (40%), whereas other cancer groups reported this problems as being infrequent (0-17%). This would allow that conclusion that, women who recover from endometrial cancer have greater problems with anorgasmia and vaginismus; however reported the infrequency of sex as the biggest problem.

With the research in mind, it is important to look at the quality of life aspect. Sexual activity is important in a person's relationship, and is fundamental at creating and maintain a relationship due to the level of intimacy. Therefore is it essential that physicians take into account patients' views in the treatment of gynaecological cancers.

Psychological care is important and beneficial to both the partner and the patient in understanding the consequences to sexual activity after treatment, and therefore preparation and acceptance in key to psychological, physical and emotional recovery.

## CONFLICT OF INTEREST

None.

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Received on 24-12-2014 Accepted on 06-01-2015 Published on 15-02-2015

DOI: http://dx.doi.org/10.14205/2309-4400.2015.03.01.1