The Psychosexual Care of Women affected by Gynaecological Cancers:
A learning resource for healthcare professionals

Module 2: Understanding the experience

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Learning outcomes

- Identify the common psychosexual effects of diagnosis and treatment for gynaecological cancer.
- Describe the social and emotional experience of psychosexual changes associated with gynaecological cancer for women and their partners.
- Identify factors affecting sexual adjustment in women with gynaecological cancer and their partners.

Rationale

- Diagnosis and treatment for a gynaecological cancer can alter a woman's sexual function and her behaviour, attitudes and feelings towards sexuality and intimacy.
- These changes can have wide-ranging effects on the lives of women and their partners.
- Effective care needs health care professionals to appreciate the woman and her partner's changed sexuality and what this means for their roles, relationships and quality of life.

Activities & examples

Video

- Jane's story (full)
- Jane's story part 1: Meet Jane
- Jane's story part 2: Discussing dilators
- Jane's story part 3: Post treatment concerns
- Joan's story part 2: Understanding concerns
- Joan's story part 3: Assessing psychosexual concerns
- Joan's story (full)
- Joan's story part 1: Meet Joan
- Maria's story (full)
- Maria's story part 1: Meet Maria
- Maria's story part 2: Understanding past history
- Maria's story part 3: Treatment effects
- Maria's story part 4: Responding to psychosexual concerns
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- Norma's story part 1: Meet Norma
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2.1. Effects of gynaecological cancer & treatment on a woman's sexuality

The term 'gynaecological cancer' encompasses a disparate group of diseases with varied risk factors, clinical features, prognoses, treatment strategies and side-effects.

Gynaecological cancers affect women at all stages of their lifespan - from adolescents, women in their reproductive years, women at mid-life through to older women.

As a result of advances in managing gynaecological cancers, many women experience improved:

- prognosis
- survival rates
- living with the sequelae of the disease treatment.

A gynaecological cancer diagnosis challenges how a woman sees herself and can threaten her body image, sexuality, femininity, relationships and various roles.

Many aspects of sexual function are affected by gynaecological cancer. These changes can be experienced during different times:

- In the months before a definitive diagnosis, due to the onset of disease-related symptoms, including vaginal bleeding and discharge and pain and fatigue.
- During treatments resulting from the functional and physiological effects of surgery, radiotherapy, chemotherapy or other treatment. This can also happen from the psychological and social effects of a diagnosis and bodily changes.
- After finishing treatment, due to the longer term physiological, psychological and social sequelae of the disease and treatments.

Objectives

 Describe the effects of gynaecological cancers and their various treatments on physical, psychological, social and sexual functioning.

Activities & examples

Activity 1: Understanding diagnosis and treatment experiences

Listen to Kath's story (#7) and Common sexual problems (#4) on the Cancer Council Western Australia 'Life Now Cancer and Sexuality' CD. These audio recordings include women's diagnosis and treatment experiences.

Then, complete the activity.

1. Make a list of the major health and quality-of-life concerns for a woman who's:
   - newly diagnosed with gynaecological cancer
   - undergoing treatment for gynaecological cancer
   - completed treatment for gynaecological cancer.
2. How do these health and quality-of-life concerns influence a woman's sexuality?
3. How do changes to a woman's sexuality from gynaecological cancer affect her partner?

2.1.1. Endometrial cancer

Endometrial cancer is the most common uterine cancer and the most common gynaecological malignancy in Australia. In 2020, an estimated 2,830 Australian women are expected to be diagnosed with uterine cancer [1]

Although largely a disease of postmenopausal women, approximately one-quarter diagnosed with the disease are premenopausal women. [2]

The prognosis for women with endometrial cancer is good, because 75% of all diagnosed women present with early-stage endometrial cancer. [3]

Treatments

- The standard treatment for endometrial cancer is total abdominal hysterectomy with bilateral salpingo-oopherectomy.
- All women undergo pelvic lymphadenectomy, except those with confirmed early stage, low-grade tumours and those with very advanced, incurable disease at presentation.
- Radiotherapy is most commonly used post operative in women at high risk of the disease recurring.
- Vaginal vault brachytherapy and / or external beam radiation may be undertaken, either on its own or combined with another treatment.
- Chemotherapy may be recommended in advanced disease or for particular pathological sub-types. [4]

Effects of treatments

These treatments can lead to a number of changes, which can affect a woman's sexuality, including:

- anatomical changes to the vagina, resulting in vaginal stenosis, or decreased lubrication
- altered bowel and bladder function, raising concerns about incontinence
- functional limitations, resulting from treatment-related fatigue or lymphodema
- psychosocial effects, for example concerns about body image, fear of pain and altered roles and relationships.

References

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Australia, 2011-2020 Authors: Australian Institute of

Health and Welfare, (2012).

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From: Canberra: AIHW. 2

Endometrial cancer and fertility

Authors: Rackow, BW & Arici, A (2006).

In: Current Opinion in Obstetrics and Gynecology, 18: 245-252.

3 NCCN Clinical Practice Guidelines in Oncology

In: Uterine Neoplasms Vol 2010.1

Activities & examples

Activity 2: Looking at endometrial cancer

Review the following webpage(s) and watch the case study vignette. Answer the related questions in this activity.

Endometrial cancer (Cancer Australia, 2014)

For a more comprehensive summary of evidence on the treatment of cervical cancer:

Clinical Practice Guidelines for Oncology: Uterine Cancers (free article, but you must register and login to access it)

1. List the major treatment modalities for endometrial cancer.

Meet Jane - Part 1 Radiation Oncology Nurse

Watch the video

Jane is a 58 year old post menopausal woman who lives with her second husband of 6 years.

She underwent a total abdominal hysterectomy, bilateral salpingo-oopherectomy and pelvic lymph node dissection for a stage 2 endometrial cancer.

Due to her stage, she needed high dose brachytherapy to reduce her risk of recurrence.

1. Using the information in this section, list the potential effects of endometrial cancer and its treatment on Jane's sexuality:
    - during treatment
    - when treatment is completed.

2.1.2. Ovarian cancer

Ovarian cancer has a projected incidence rate of 1,640 cases in Australia in 2020. [1]

Around two-thirds of women are diagnosed with advanced stage cancer. Only 4 out of 10 survive for 5 years or longer. [2]

Ovarian cancer is the most common cause of death from gynaecological cancer in Australia - it accounts for 55% of gynaecological cancer deaths.[2]

Types of ovarian cancer

There are 3 main types of ovarian cancers, each beginning in a different type of cell in the ovary.

- **Epithelial ovarian cancers** are the most common and begin in the outer layer of cells of the ovary.
- **Germ cell ovarian cancers** begin in the cells inside the ovary and mature into the eggs (ova).
- **Sex cord-stromal ovarian cancers** develop from the cells that release the hormones oestrogen and progesterone. [1] [2]

Treatments

Treatment for ovarian cancer can include:

- debulking surgery, typically involving total abdominal hysterectomy, bilateral salpingo-oopherectomy and omentectomy
- resection of the small and large bowel
- appendicectomy
- splenectomy
- removal of diaphragmatic implants.

Except for women with low-grade, early stage disease, chemotherapy will also be needed. [3]

Despite recent advances in the treatment of ovarian cancer, 70 to 80% of women will relapse.

There are numerous treatment options. Many women live for several years with palliative chemotherapy controlling their disease. [3]

Germ cell tumour treatment

Germ cell tumours of the ovary are uncommon, but usually affect women of childbearing age. Over 70% of women present with stage one disease. [4]

In this case, treatment for early stage and selected advanced stage disease includes fertility-sparing surgery followed by chemotherapy. This is because the contralateral ovary is rarely involved.

Effective chemotherapy has made conservative surgery possible and virtually all women with germ cell tumours will receive platinum-based adjuvant chemotherapy. [4]

With such chemosensitive tumours, most women can expect to be cured and preserve their fertility, although there remains a significant risk of premature menopause for those receiving chemotherapy. [5]

Although diagnosing and managing ovarian cancer significantly affects sexuality, many women are sexually active during treatment. This helps them cope and preserving their self-esteem, feelings of femininity and confidence. [6]

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6 Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues Authors: Stead, ML, Brown, JM, Fallowfield, L et al (2003).

In: British Journal of Cancer, 88(5): 666-671.

Activities & examples

Activity 3: Looking at ovarian cancer

Review the information sheet and watch the case study. Answer the related questions in this activity.

Ovarian cancer information sheet

Ovarian cancer information sheet

1. Read 'Summary of Guidelines' on pages x to xvi in the ovarian cancer information sheet. List the major treatment modalities that may be considered for different stages of ovarian cancer.

Meet Joan - Part 1 Ovarian cancer

Watch the video

Joan is a 65-year-old woman who's been married to George for 40 years.

Joan presented to the emergency department with symptoms of a bowel obstruction. She underwent an emergency laparotomy for the ovarian cancer. Because it adhered to the bowel, Joan underwent a temporary colostomy formation and adjuvant chemotherapy.

1. Using the information you've reviewed in this section, list the potential effects of ovarian cancer and its treatment on Joan's sexuality:
   - during treatment
   - when treatment is completed
     - if her disease progressed.

2.1.3. Cervical cancer

Cervical cancer has a projected incidence rate of 915 cases in Australia in 2020. [1]

The recent development and introduction of a prophylactic vaccine against one of the major factors contributing to cervical cancer, Human Papilloma Virus (HPV), represent significant progress towards reducing the incidence of cervical cancer. [2]

The widespread use of cervical cancer screening (Pap Test) also means it's more possible to diagnose younger women and women at an early stage in the disease.

Around half of the surgically treated stage 1 cancers happen in women under 40 years of age. [3]

Treatment guidelines [4]

Stage	Treatment
IAI	Cone biopsy Total abdominal hysterectomy
IA2-IB	Radical hysterectomy with bilateral pelvic lymphadenectomy Radical trachelectomy with bilateral pelvic lymphadenectomy Concurrent chemo-radiation (external beam radiotherapy, brachytherapy & cisplatin)
IIA	Radical hysterectomy with bilateral pelvic lymphadenectomy Concurrent chemo-radiation (external beam radiotherapy, brachytherapy & cisplatin)
IIB-IVA	Concurrent chemo-radiation (external beam radiotherapy, brachytherapy & cisplatin)
IVB	Local treatment with radiotherapy to symptomatic metastases Systemic chemotherapy

In younger women, when it's feasible, surgery is generally preferred over concurrent chemo-radiation. This aims to preserve fertility and ovarian function.

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Authors: Australian Institute of Health and Welfare (2012).

In: Cancer series no. 66. Cat. no. CAN 62.

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3 Surgery Insight: radical vaginal trachelectomy as a method for fertility preservation for cervical cancer Authors: Beiner, ME & Covens, A (2007).

In: Nature Clinical Practice Oncology, 4(6): 353-361.

4 American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients

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In: Journal of Clinical Oncology, 24(18): 2917-2931.

Activities & examples

Activity 4: Looking at cervical cancer

Review the following webpage(s) and watch the case studies. Answer the related questions in this activity.

Cervical Cancer (Cancer Australia, 2014)

1. List the major treatment modalities for cervical cancer by stage of disease at diagnosis.

Meet Maria - Part 1 General Practitioner

Watch the video

Maria is a 29-year-old, who's never had a child and isn't in a relationship. She's never had a Pap Test.

She presents to her GP with inter-menstrual bleeding.

Note: To help you answer the questions, see:

National Cervical Screening Program

1. What signs and symptoms does Maria present with that would indicate she may have cervical cancer?
2. What are the current recommendations for cervical cancer screening in Australia?

Meet Maria - Part 3 Gynaecological Oncologist

Watch the video

Maria is 2 days post-op.

After meeting with the multidisciplinary team, her gynae-oncologist visits her to discuss treatment options in more detail.

1. Provide a rationale for the treatment plan proposed by the gynae-oncologist.
2. Using the information you've reviewed in this section, list the potential effects of cervical cancer and its treatment on Maria's sexuality:
    - during treatment
    - when treatment is completed.

Activity 5: Case studies - cervical cancer

Meet Karen

Karen is a 29-year-old, who's never given birth, and has undergone radical hysterectomy and pelvic lymph node dissection for stage 1B cervical cancer.

She doesn't need any further / adjuvant treatment.

She doesn't currently have a partner. She does have supportive friends and family.

Meet Joanna

Joanna is a 36-year-old divorced mother of a 6-year-old boy and has just started a new relationship.

She has just completed chemo-radiation for a stage 2B cervical cancer.

Questions

1. Consider what you'd discuss with these 2 women on the effect the diagnosis and treatment has had on their sexual function.
2. Identify patient resources you could provide to support your discussion.

2.1.4. Vulval cancer

Vulval cancer affects a woman's external genitalia.

It accounts for 1% of all malignancies in women and 4% of all gynaecological malignancies. [1]

It's most commonly diagnosed in older women. However, the incidence of vulval cancer is increasing in younger women because of its link to the Human Papilloma Virus (HPV). [2]

Treatments

Surgery is the most common treatment for vulval cancer.

Treatment decisions are based on the extent and depth of the tumour. The aim is to perform the most conservative procedure needed to cure the woman.

The treatment of choice for early stage vulval cancer is radical local excision with or without inguinofemoral lymhadenectomy. [2]

If the disease is more advanced, then multimodal treatment is required. This may include:

- radical vulvectomy and bilateral inguinofemoral lymph node dissection

- neoadjuvant chemo-radiation, or
- post operative radiotherapy to pelvis and groin. [2]

Women with vulval cancer experience significant sexual dysfunction and altered body image, regardless of the extent or type of surgery.

Older age and diminished physical functioning all decrease the likelihood of a woman resuming sexual activity after surgery. [3]

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In: International Journal of Gynaecologic Cancer, 13(4): 522-527.

2 Best Practice Gynaecological Clinical Practice Guidelines (PDF, 966kb) Author: NSW Department of Health (2009). 3 Sexual dysfunction following vulvectomy

Authors: Green, MS, Naumann, RW, Elliot, M, Hall, JB, Higgins, RV & Grigsby, JH (2000).

In: Gynecologic Oncology, 77(1): 73-77.

Activities & examples

Activity 6: Looking at vulval cancer

Review the following webpage(s) and watch the case study. Answer the related questions in this activity.

Vulval Cancer (Cancer Australia, 2015)

For a more comprehensive summary of evidence on the treatment of vulval cancer:

Vulval cancer: Best Practice Gynaecological Clinical Practice Guidelines (2009)

1. Read pages 1-8 of Section 4 'Vulval cancer: Best Practice Gynaecological Clinical Practice Guidelines' and list the major treatment modalities for vulval cancer.

Meet Norma - Part 1 Vulval Cancer

Watch the video

Norma is a 78-year-old who has been widowed for 15 years.

She lives alone and is independent. She has 4 adult children and several grandchildren who all live locally and are supportive.

She's very active in her community, church, bowls and senior citizens' centre.

Norma has had a wide local excision and bilateral groin node dissection for stage 1 squamous cell cancer of the vulva. Norma doesn't need adjuvant therapy, but will be closely monitored by the gynae-oncology team.

1. Using the information you've reviewed in this section, list the potential effects of vulval cancer and its treatment on Norma's sexuality:
    - during treatment
    - when treatment is completed.

2.1.5. Gestational trophoblastic disease

Gestational trophoblastic disease affects young women during their reproductive years.

It's a group of interrelated conditions that arise from the chorionic portion of the placenta.

It consists of:

- two premalignant diseases: complete and partial hydatidiform mole, and
- three malignant diseases: invasive mole, gestational choriocarcinoma and placental site trophoblastic tumour.

Treatments

Managing the premalignant disease involves suction curettage.

Because of the potential for malignant sequelae, all women need to be closely monitored while hCG levels remain elevated. Women with malignant disease need chemotherapy. [1]

Before starting chemotherapy, it's important to decide on the risk category the woman fits into (low / high risk) using a prognostic scoring system.

The scoring system means women will get the most appropriate treatment. They won't be exposed to unnecessary combination chemotherapy that can lead to an increased risk of premature menopause. [2]

Motherhood carries many social expectations. A woman's self esteem can be negatively affected if she feels her pregnancy is 'imperfect'. This can leave the woman feeling unattractive, lacking in femininity and flawed. [3]

The woman's sexual relations and desire can be affected by her fear of pregnancy, feelings of guilt, self blame or blame of her spouse.

References

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trophoblastic disease

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Authors: Seckl, MJ & Newlands, ES (2004).

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Philadelphia: Elsevier Ltd.

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3 Psychosocial consequences of gestational trophoblastic disease Editors: Hancock, BW, Newlands, ES, Berkowitz, RS & Cole, LA.

Authors: Wenzel, LB (2003).

In: Gestational Trophoblastic Diseases, 2nd edition

From: Sheffield: International Society for the Study of Trophoblastic Diseases.

Activities & examples

Activity 7: Looking at gestational trophoblastic disease

Review the following webpage(s) on gestational trophoblastic disease. Then complete the activity.

Gestational trophoblastic disease. (Cancer Australia, 2014)

1. List the major treatment modalities for gestational trophoblastic disease.
2. Using this information, list the potential effects of gestational trophoblastic disease and its treatment on a woman's sexuality.

2.1.6. Women with special needs

Pelvic exenteration

Pelvic exenteration is a radical operation that controls the local recurrence of cervical and endometrial cancers.

It involves resection of bladder, bowel, uterus and vagina and may include formation of 2 stomas and vaginal reconstruction.

It has a significant effect on a woman's quality of life and body image.

One study has reported that more than 50% of women don't resume sexual activity following pelvic exenteration. [1]

Palliative care

Advanced disease can have a significant effect on a woman's sexual function because of:

- unrelieved symptoms
- fatigue
- medication
- psychological distress loss of dignity.

Sexuality continues to be important for many women and their partners at the end of life.

Studies show that even terminally ill patients continue to have sexual feelings and value freedom for sexual expression.[2]

Women whose cancer is in an advanced stage may have an even stronger need for intimacy than they did before they had cancer. Physical closeness, sharing feelings and touching may become increasingly important.

Sexual activity in these circumstances is often described as life affirming and poignant by women and their partners.

Lack of privacy, shared rooms, staff intrusion and single beds are considered barriers to expressing sexuality in hospital and hospice settings. [2]

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2 Sexuality in palliative care: patient perspectives

Authors: Lemieux, L, Kaiser, S, Pereira J & Meadows, LM (2004).

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Activities & examples

Activity 8: Looking at pelvic exenteration

1. Identify additional burdens associated with pelvic extenteration that may affect a woman's sexuality.

Activity 9: Looking at advanced gynaecological cancer

1. Identify additional burdens associated with having advanced gynaecological cancer that may affect a woman's sexuality.

2.3. Supporting learning resources

Stage of adoption of the human papillomavirus vaccine among college women

Authors: Allen, JD, Mohllajee, AP, Shelton, RC, Othus, MK, Fontenot, HB & Hanna, R (2009).

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