INQUIRY INTO GYNAECOLOGICAL HEALTH IN AUSTRALIA

COMMUNITY AFFAIRS

REFERENCES COMMITTEE

PARLIAMENT HOUSE
CANBERRA ACT 2600
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Mr. Elton Humphery
Committee Secretary

Thank you for the opportunity to submit a response to the "Inquiry into gynaecological cancer in Australia".

I am pleased to submit the following submission relating to Issues (b) (c) and (e) that will assist the Community Affairs references Committee in its inquiry. I also refer the committee to supporting documents as separate attachments:

1]"Gynaecological Cancer – Sexuality issues" GCS brochure
2] Patients' experiences of intracavity brachytherapy treatment for gynaecological cancer" by Warnock (2005)
3]"The impact of molar pregnancy on psychological symptomology, sexual function and quality of life" by Petersen et al (2005)
4] The role of the clinical psychologist in gynaecological cancer" by Rieger et al (1998)
5] "Women's experiences of information, psychological distress and worry after treatment for gynaecological cancer" by Booth et al (2005)

Please do not hesitate to contact me if you require further details.

Yours sincerely,

(By email) [Margaret Heffernan on behalf of A Rosengarten]

Ms Alexa Rosengarten

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SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO GYNAECOLOGICAL HEALTH IN AUSTRALIA

This submission is relevant to the following inquiry issues:

(b) Extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;

(c) Capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;

(e) Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and

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HEALTH CARE MODELS IN GYNAECOLOGICAL CANCER MANAGEMENT OF PSYCHOSEXUAL NEEDS OF WOMEN WITH A GYNAECOLOGICAL CANCER AND THEIR PARTNERS

To progress to a more holistic and comprehensive model of health care in gynaecological cancer, sexuality and sexual expression options need to become a legitimate issue within health care practice to improve women's quality of life.
Understanding and addressing sexual changes, difficulties and sexual dysfunctions warrants immediate attention by health care professionals and government alike, as it is generally ignored.

Sexual dysfunction due to gynaecological cancer is underestimated. However sexual changes, difficulties, or dysfunctions are common sequelae, significantly affecting the ability for sexual and relationship satisfaction. These can occur due to the actual cancer itself or be as a consequence of treatment/s to eradicate or palliate the cancer. Treatments which impact on sexual function include: surgery, invasive
procedures, chemotherapy, radiotherapy (both external beam radiotherapy and brachytherapy) and prescribed medications.

An estimated 20 -90% of gynaecological cancer patients experience significant sexual difficulties (Rieger 1998). Davidson, et al, 2003, (Radiation Oncology), and Jensen et al, 2003, (IJRO BP) found 30 percent of women with gynaecological cancer experience sexual dysfunction, with 50 percent experiencing dyspareunia (painful sex), and only 50 percent of women remain sexually active after treatment. Many women fear pain with sex and relapse of cancer. Some struggle with urine and/or faecal incontinence with sexual activity. These changes may continue for years post treatment or may be permanent.

To understand the sexual changes and dysfunctions that may occur due to gynaecological cancer, one needs to consider the non-genital impacts, both physical and emotionally, as well as the direct genital impacts.

Physical non-genital factors affecting sexual expression function and include:
- Pain
- Fatigue - both short term and long term
- Depression
- Interruption to hormone levels with early/abrupt onset menopause
- Incontinence - bladder, bowel or both

- Sleep disturbances
- Skin inflammation or burns due to radiotherapy sites
- Scarring
- Altered sensations - numbness/hypersensitivity
- Lymphoedema
- Metastases
- Constipation or diarrhoea
- Hair loss
- Nausea and vomiting

Prescribed medications can impact on sexual functioning in many ways due to their effect on the central nervous system, smooth muscle or alteration to hormones levels. Possible sexual changes due to medications may include reduced sex drive and interest, impaired sexual reflex responses, diminished vaginal lubrication and
engorgement, impaired orgasmic ability and/or pain with sex (vulval, vaginally or anally).

Other non-genital factors are due to psychological influences to the woman with gynaecological cancer and/or their partner.
Such as:
- Fear, stress, anxiety, tension and guilt
- Grief and loss due to changes in ones' body, health, lifestyle and sexual interactions or expression
- Fear of rejection and abandonment
- Dealing with immortality and the fear of relapse and death
- Coping with the diagnosis of cancer and managing with the associated therapies
- Shame and embarrassment and feeling less of a woman due to both changes both internally as well as externally, for example to gender imbued anatomy such as the vulval and the vagina
- Fear of "contamination" - by either the woman or her partner
- Fear of pain with sex and managing pain with sex
- Depression
- Irritability and emotionally lability due to hormone changes, depression and stress
- Altered appearance and identity as a woman
- Financial concerns as the woman may need to give up work or work part-time
- altered roles in the home or at work
- The "invisibility" to others and therefore the lack of understanding of what one is struggling with during and post treatment
- Altered sexual roles in the relationship
- Loss of fertility and parenthood
- Feeling mutilated
- Loss of femininity and womanhood

This can be very confusing and distressing for women and their partners. For couples this can add enormous pressure on relationships. "Feelings of self-worth and attractiveness are threatened at a time when the need for intimacy and belonging is the greatest, causing a sense of loneliness and isolation" (Glass and Padrone, 1986).
People often feel isolated due to fear, anxiety, uncertainty, grief, anger, frustration, resentment and potential for loss of life etc. Communication can breakdown and/or become reactive creating emotional distress. Hugging, kissing and physical closeness and sexual interaction may diminish or cease completely, leaving women and their partners starved for affection. Misunderstandings and distance

result because couples may start to avoid each other in order to protect themselves, causing further interruption to intimacy and exacerbating loss of connection.

Women dealing with gynaecological cancer and its consequence often find they experience low sexual esteem, low levels or loss of sexual satisfaction, negative feelings as a sexual being and with a sexual partner, frustration when managing sexual activity, and if they are single difficulty establishing sexual partnerships.

Sexual expression is important as it supports the need to feel loved, to belong, to release tension, to cope with stress, to give and receive pleasure, to be intimate with oneself or with another. Furthermore, it promotes the feeling of wholeness and celebrates life.

Partners can also be significantly affected due to gynaecological cancer. Many fear they will hurt their partner if they are sexual with them. They are also dealing with their own stress, grief, tension, guilt and isolation. They are adjusting to the multiple changes to their lifestyle as well as the changes to their partner's body. They may experience rejection from their partner with cancer. Due to changes
in roles at role and the potential for added responsibilities, partners may themselves be experiencing depression, fatigue and irritability. Finally, due to the stress they may develop their own sexual dysfunction, such as loss of libido or erectile dysfunction if they are male.

Desire discrepancy may develop in the relationship. This is where one person in a relationship desires the need for sex more than other person. This can create a "pursuer/distancer" dynamic (King, K, 1997, Good Loving Great Sex). This is where the person who does not want sex becomes a "distancer" in order to protect themselves from the advances of their sexual partner. They tend to withdraw from and close off from sexual contact, including affection to prevent the any sexual advances from their partner. On the other hand, the "pursuer" finds themselves in the position of the chaser in an effort to intimate sexual contact and interaction.
The "distancer" feels pressured, while the "pursuer" feels rejected. This dynamic that develops becomes a vicious cycle in the relationship. Both the woman with the gynaecological cancer and their partner feel distressed, unloved and frustrated.
Each person in this dynamic are struggling and missing out.

Women with gynaecological cancer have the right to be sexual and have sex.
Consequently, woman and their partners should be provided with proper information and counselling to manage sexual changes and the impact on their self-esteem, sexual-esteem and their relationships. There are some therapeutic options now available for women to access and a multidisciplinary approach with sexologists is needed.

BIBLIOGRAPHY

Full references can be supplied by Ms Rosengarten on her return from overseas, and on request.

ATTACHMENTS RELEVANT TO THIS DOCUMENT:

1]"Gynaecological Cancer – Sexuality issues" GCS brochure
2] Patients' experiences of intracavity brachytherapy treatment for gynaecological cancer" by Warnock (2005)
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