PSYCHO-ONCOLOGY FACTSHEET

What is psycho-oncology?

ENGAGe

ESGO European Network of Gynaecological Cancer Advocacy Groups

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What is psycho-oncology?

Patients, their partners, and their relatives may react differently to the diagnosis of cancer and its treatment.

Emotions related to disease and therapy vary from person to person and from day to day. With this leaflet about psycho-oncological issues, we want to support you and your caretakers while coping with cancer and the side effects of treatment, in order to ease your distress and lead to better self-awareness.

Psycho-oncology is an interdisciplinary approach between psychology and oncology. It is concerned with the medical, psychological, and social aspects of cancer and factors that may affect the remission or progression of the disease.

Quality of Life (QoL)

What is Quality of Life?

The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being, not merely the absence of disease."

No current treatment can avoid damaging healthy cells to some extent, and this damage may have long-term physical and mental consequences. As the survival rates in people diagnosed with cancer continue to increase[1], the need to understand longer-term quality of life becomes increasingly important. Many people with cancer live with its long-term physical and mental consequences for many years after treatment[2], e.g., psychosocial issues and physical symptoms such as pain, fatigue, depression, anxiety, lymphoedema, neuropathy, cognitive impairment, and sexual dysfunction.

The term quality of life (QoL) is used to evaluate the general well-being of individuals and QoL is increasingly used as one of the primary endpoints in studies to evaluate how well the treatment has worked and is used together with other endpoints of importance to the patient, such as overall survival and progression-free survival.

How is Quality of Life measured?

The number of symptoms of distress experienced by an individual has been related to QoL in a number of people with cancer, and an increasingly important issue in oncology is to evaluate QoL in cancer patients.

For all types of cancer, general QoL instruments can be used to assess the overall impact of patients' health status on their QoL. These are often in the form of either paper or online questionnaires. Many types of QoL instruments exist, but the ones most commonly used are the European Organization of Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-c30) and the Functional Assessment of Cancer Therapy-Generic (FACT-G) and the distress thermometer.

However, several cancer-specific instruments are used to assess QoL and disease-specific symptoms in a particular disease (e.g., ovarian cancer). QoL has become an important endpoint for treatment comparisons in randomised controlled trials, which means that in these clinical studies QoL is increasingly incorporated as an endpoint.

Distress

Distress is a common concern among cancer patients, beginning at diagnosis and extending to the post-treatment phase of cancer and long-term survivorship. All cancer patients feel distress in one form or another; one third suffers from extensive symptoms.[4]

Distress may be caused by physical, psychological, emotional or social problems as a consequence of the disease and has a multifactorial nature. Numerous factors contribute to distress, including the physical burden of disease (symptoms), declining functional status that interferes with daily living, and the emotional and social changes caused by a cancer diagnosis. Feeling distressed is a continuous process, ranging from common normal feelings of vulnerability, sadness, and fear - to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. Elevated distress can result in worse outcomes in terms of worse health-related quality of life, less adherence to treatment, extensive side-effects from treatment, lower satisfaction with care, and possibly lower survival. Because of its importance, distress is now endorsed as the "sixth vital sign".

Several studies have shown distress is underrated. Therefore, cancer patients should routinely be screened for distress, as a minimum during times of vulnerability along the cancer journey - at the time of initial diagnosis, before treatment, during and after treatment, and at the transition to end-of-life or palliative care. Appropriate screening for distress helps ensure early identification of people in need of additional support, with targeted intervention by the clinical team and referral to psychosocial services for those at higher risk for negative health outcomes.

A woman who is diagnosed with gynaecological cancer faces not only the changes and fear of cancer itself but also changes to the substance of her identity, femininity, sexuality, and motherhood.

Changes in your body, changes in your hormones, maybe the inability to bear children due to hysterectomy and chemotherapy - sometimes at a young age - can bring up issues and distress that are hard to handle.

Am I distressed?

If you suffer from any of the symptoms described above, ask your health care providers for screening for distress and moreover for help in a challenging situation. If there is no such available service, look for a cancer support group that has a psychologist trained in psycho-oncology for distress screening.

Changed self

Women diagnosed with gynaecological cancer are facing changes in their bodies, their hormones, and their lives.
They might undergo hysterectomy and experience early surgical menopause.
Fear, shame, guilt, anger, sadness, sorrow for her "new self" are some of the feelings she might face.
In some cultures, these issues are not often discussed.

Patients ask themselves thoughtful questions about:
"Is our womb what defines us as women?"
"Is becoming a mother the only way to be productive and fertile?"
"How can I deal with those changes?"
"How do other patients like me feel after a gynaecological cancer diagnosis?"
"How can I continue to live my life, to love, to flirt?"
"Should I tell my friends, new acquaintances, a potential partner?—and, if so, when?"

A woman who feels this way should consider ask for help from her health care provider, from a support group or from other women that deal or have dealt with these issues in the past.

Sexuality and gynaecological cancer

Depending on the cancer condition for which you have been treated, you may experience physical side-effects that affect your sex life.

Women who have been treated for abdominal cancer will most likely have more physical discomfort after treatment than others due to the affected abdominal organs, e.g., the removal of the uterus and/or the ovaries will cause decreased levels of female hormones or side-effects from treatments to the genital areas.

Surgery of vulvar, vaginal, and cervical cancer is often associated with sexual dysfunction because of loss of normal anatomy, vaginal stricture, lymphedema, and loss of clitoral tissue.

Radiotherapy can also cause vaginal stricture and damage to the vaginal mucosa with resultant ulceration or closing of the vagina or it can make sexual intercourse challenging. Some of these side effects may develop many years after treatment.

Chemotherapy can cause menopause with loss of oestrogen, causing vaginal atrophy and decreased lubrication, and resulting in painful sexual intercourse[3].

If you get sore or irritated in the genital area, it is often a result of sensitive or dry mucous membranes. However, it may also be a sign of an infection that requires treatment.

Soreness can occur either because you are missing female sex hormones, as you may have entered menopause, are receiving antihormonal treatment or because the area is damaged by radiotherapy.

Changes in appearance and feeling less attractive

The body may change during and after treatment of cancer and it can react differently and unpredictably. This can be difficult to accept, and it can make you feel less sexually attractive.

Although it can be difficult to reconcile oneself with one's changed body, working to accept it can be crucial.

If you are comfortable with yourself, know your body well, and accept the way you look, you have the right conditions for a satisfying sex life with your partner.

On the contrary, if you feel less attractive than before your treatment, it can be difficult to initiate sex or to express desire for it.

Many gynaecologic cancer survivors report sexual dysfunction because of pain or discomfort or lack of sexual desire and sexual arousal.

How can you work to turn your body perception into something positive?

The first thing you need to do is to work to accept your changed body and understand it as something that can give you joy and pleasure again - not just connecting it with illness and symptoms.

You can learn to get positive experiences through your body by doing something nice for yourself, for instance getting a good massage. Be patient with yourself. Time might be your enemy before cancer, but it is your friend after cancer.

Pamper yourself; try to accept and to love your new body image. If you are in a relationship, talk to your partner about what it is that makes having sex difficult for you.

Medication has unfortunately not been successful in this clinical scenario.

Psychoeducational intervention using mindfulness-based stress reduction has shown significant improvements in sexual functioning and in decreasing sexual distress. Gynaecologic oncologists should consider referral to specialists in this area.

There are also tips and therapies that deal with sexual dysfunction due to vaginal dryness and atrophy, such as the use of vaginal lubricants, e.g., non-hormonal products with hyaluronic acid which are available over the counter (Replens sanol, Astroglide lubricant).

These products hydrate the vaginal wall but need to be used 3–5 times per week, preferably at bedtime, to help restore vaginal hydration. These same products can also be used prior to sexual intercourse to help prevent vaginal and vulvar tears and to potentially minimise pain during intercourse.

For some women, for whom oestrogen use is not advised against by the treating physician, vaginal oestrogen products (in pill or cream formulation) can also help alleviate symptoms when used regularly.

Local hormone treatment can often also help with urinary problems, including incontinence.

Vaginal stricture associated with surgery or by radiotherapy can be treated with the use of vaginal dilators. However, some patients find it difficult to use a vaginal dilator and feel intimidated (vaginal dilators exist in different sizes). On the other hand, the use of a vaginal dilator 2–3 times per week is associated with a decreased risk of vaginal stricture/stenosis, especially in women undergoing intravaginal radiation therapy[5] (radiation administered from a radiation source inside the vagina).

An excellent piece of advice will always be to talk to your doctor or psycho-oncologist if you experience a change in your body after treatment. There might also be an organisation in your country for women who have or have had gynaecological cancer. It is often good to talk to someone who has had similar experiences.

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Further Information

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