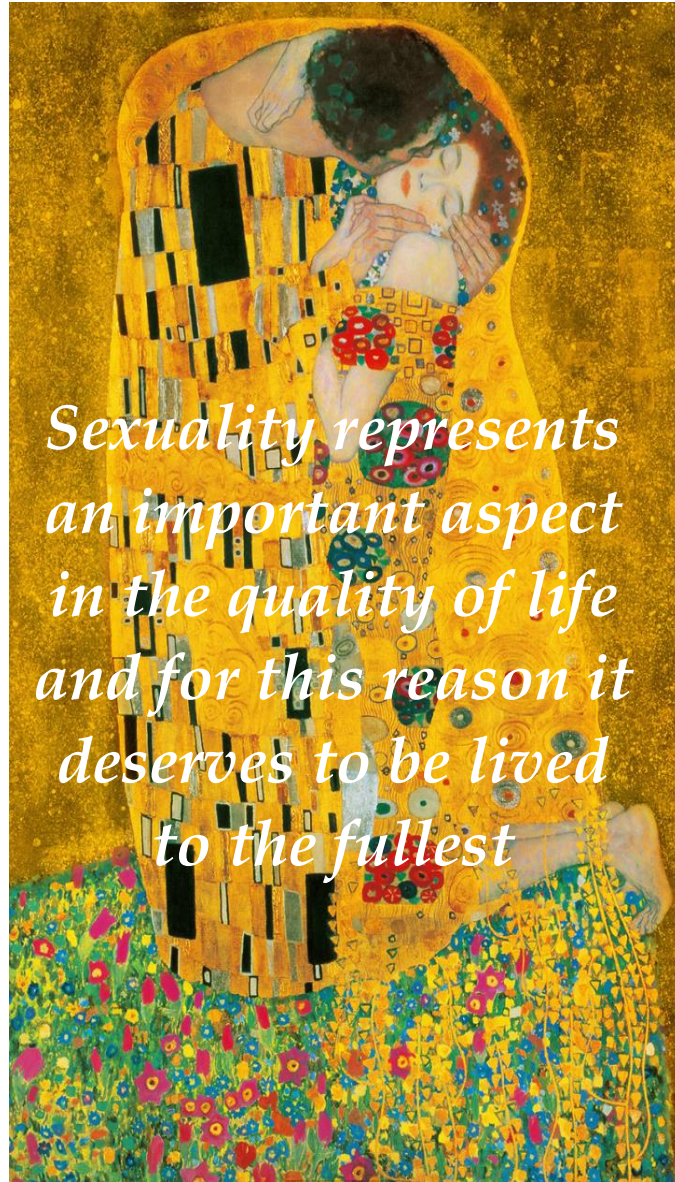


SEXUALITY AND CANCER



*Sexuality represents
an important aspect
in the quality of life
and for this reason it
deserves to be lived
to the fullest*

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Introduction

When the diagnosis of cancer bursts into a person's life, it determines a series of very important changes that are not only physical but also psychological. These can heavily affect the sexual sphere, thus determining a further deterioration in the quality of life.

As a result of the diagnosis, first of all there is a state of anxiety linked to the threat that the disease represents for one's life, the fear of not succeeding in fighting it, of not making it through. Once the appropriate treatment is found, the necessary therapy is undertaken and the fear of imminent death has overcome, the patient wants to return to his/her normality, take back his/her life and even sexuality has a new importance. However, often, due to cancer-related diagnosis and therapies, physical and psychological scars remain such as not to allow a serene sexual life.

The disorders of the sexual sphere related to cancer can sometimes directly depend on the disease or on the treatment that is being carried out for it, but they are often related to psychological causes: the fear of not pleasing, the fear of feeling pain, the fear to have lost a fundamental functional aspect for one's existence, the loss of one's sexual connotation, the modification of one's body image, the devaluation of oneself and the shame of being seen by one's partner, the experience of disability, the sense of guilt of feeling pleasure despite the tumor.

Therefore it is important to evaluate and understand what lies behind these problems in order to find the best solution and live one's sexuality with serenity despite the disease.

First of all, it is necessary to understand that changes in the sexual sphere do not concern all patients in the same way, but are individually experienced differently, since sexuality represents an intimate aspect of one's life to which a different value is attributed in relation to various psychological but also cultural aspects.

The sphere of sexuality is already extremely complex in itself, presenting a cognitive, a bodily and an emotional component. The disease can impact on each of these three factors causing an interruption of sexual response. Distracting thoughts, physical and emotional pain, relationship with the partner, sense of shame, can adversely affect the person's sexual activity.

Sexuality is activated only in situations of safety for the person and therefore the oncological disease, as a moment of total uncertainty, can damage the mechanism that is at the basis of sexual life.

The topic of sexuality in cancer patients is not much treated: some studies have shown that even today health professionals talk little about problems related to sexuality with their patients. This trend could be related to the fact that the operators themselves, with cancer patients, focus more on aspects related to survival and therapy responses, thus putting sexual activity in the background. Perhaps little is said about it because even health workers do not know how to communicate certain information, embarrassment and lack of time can have a great role in such a delicate topic, and maybe they do not have a specific preparation in this sphere.

However, we must consider that sexual life is an integral part of the patient's quality of life and therefore it is essential to take it into account in the care relationship. In fact, a patient who feels completely taken in charge, who considers the quality of his new life adequate with the disease, because he is also satisfied from a sexual point of view, participates more actively in the treatment process.

The crucial point of the comparison about sexual sphere dysfunctions after an oncological disease is to distinguish the symptom (anorgasmia) from the problem/cause. This symptom in fact can hide a great variety of problems that require a thorough assessment of the physical and psychological causes of the dysfunction. Of course, the identification of the problem brings to the best solution for the patient.

The patient must also be helped to adapt to the physical and psychological changes related to the disease that interfere with his/her sexuality in order to find a new normality in the relationship with the partner. The interview between patient and doctor/psychologist must work on expectations, meanings, relationships, communication and the new normality after the diagnosis of cancer.

In this work of analysis and problem understanding it is also useful to involve the partner who can help the patient to overcome all psychological aspects of the new situation.

This booklet is just a simple way to reflect on the problem, giving the chance of opening to a topic so difficult for everyone. Hopefully some useful advices will help to face the situation in a serene way.

"A special thanks to Eleonora Preti, Ludovica Scotto and Dirier Florace of the European Institute of Oncology who, thanks to their interesting conference of 9th March 2019 at the Hospital of Borgomanero, allowed us to go into the details of such an important topic for our patients, giving us the possibility to carry out this project"

Definition of sexuality

Treccani Dictionary (2019)

Sexuality is the complex of sexual characteristics and phenomena concerning sex. In mankind, the complex of behavioral psychological phenomena relating to sex. These behaviors are directed to the search for physical pleasure and psychological satisfaction through the activation of the physiological functions of male and female genital organs, as well as the set of perceptions, instincts, desires linked to the awareness of one's own sex. Sexuality reaches maturity together with the fulfillment of the reproductive function of the genital organs, at the time of puberty, when the hormonal mechanisms determine the appearance of secondary sexual characteristics. In this age of life, even the sexual instincts become particularly intense and are corroborated by the attraction to people of the same opposite sex.

Medicine Dictionary (2010)

Sexuality is the complex of psychological behavioral phenomena related to sex. These behaviors concern the set of perceptions, instincts and desires linked to the awareness of one's own sex and are directed towards the pursuit of physical pleasure and psychological satisfaction through the activation of one's genital organs.

World Health Organization

The modern concept of Sexual Health, derived from the basic definition of the World Health Organization (OMS), includes not only the absence of disease, dysfunction or infirmity but also the acquisition and maintenance of a state of physical, emotional and social well-being. From this also derives a right to sexual well-being, both for the single person and for the couple.



The sexual sphere involves biology, psychology and culture of each person: it conditions their growth and their relationship as a couple. A regular and satisfying sexual activity undoubtedly represents an essential nourishment for the couple's well-being. For people who love each other, the sexual intercourse is a unique way to show one's own love, favor the complicity and intimacy of the couple: feel the presence of the partner with all his/her diversity within us, with love and respect, managing to express one's needs and understand those of the other. Healthy sexual activity promotes complicity, gives meaning to life and is good for health.

*Sexuality is much richer and more complex
since it has the ability of being
as rich and complex
as human beings.
Julian Fernández de Quero*

Sexuality, complexity, diversity

Sexuality is necessary to procreation for the maintenance of the species, but it also has a relational and playful function.

It is therefore a very complex sphere of life that is conditioned by multiple factors: familiar, social, psychological, experiential already in normal situations (absence of oncological disease) and which can further complicate after a cancer diagnosis. Sexuality is divided into three main categories: biological, psychological and social, all three related to each other. It is not possible to consider these three fundamental aspects of sexuality individually because, at that point, it would not make any sense. The psychosocial unity of sexuality implies a certain sexual configuration which favors the development of the personality.

The World Health Organization gives this definition of human sexuality: sexuality is influenced by the interaction of biological, psychological, social, economical,

political, ethical, legal, historical, religious and spiritual factors that enrich and strengthen communion and love between people.

Sexuality from the biological point of view

The biological aspect is the one that has been most taken into consideration when formulating the concept of sexuality. However, it is a very reductionist point of view which does not take into account the body scheme as a unity. The integration of the body into sexuality allows us to understand that we are sexual individuals from birth until death. This implies that both children and adolescents, as well as adults and the elderly have sexuality. If one refers only to the biological part of sexuality, then one focuses on sex, through the genital organs, and on reproduction as a goal. The biological aspect of sexuality can be expanded and acquires greater significance when related to the other factors mentioned. It is our body that understands and that can accomplish this task only through a complete body scheme. Dividing the body and considering only certain functions of it involves denying the pleasure of knowing and communicating correctly with others.

Sexuality from the social point of view

This dimension of sexuality has to do with eroticism, through acquired behaviors and the internalization of different uses and customs: this is why in every culture there are different beliefs about sexuality, which depend on the historical context that is able to influence people's behavior. Our political, religious, cultural beliefs in a sense regulate what is right and what is not. What is considered normal has given rise to a series of limitations from the sexual point of view. As social beings as we are, our fears are a way of not feeling rejected, isolated or considered strange. For this reason we respect and transmit through communication the messages we have internalized, making them become values and rules of behavior. The way in which a community experiences sexuality is the fruit of socialization. However, being aware of what behaviors and attitudes we have internalized, without questioning them, can help us to adapt and modify them according to the development of our own personality. This implies breaking the limits and false beliefs that have been imposed through the socialization process, in order to experience sexuality as something positive and different for each person. For this reason it would be more correct to speak of sexuality in the plural. Thus sexual education, has a lot to say because, through knowledge, the process of awareness is activated so that each individual is free to decide and choose how to live and enjoy his/her sexuality.

Sexuality from the psychological point of view

The psychological dimension takes birth by the biological dimension, that is the integration of the body scheme with the way you live it and by the social dimension, that is the way you have to act within socialization

The psychological factor implicit in sexuality is characterized by thoughts, fantasies, attitudes and tendencies. The psychological aspect of sexuality has to do with how we feel, both with ourselves and others, taking into account emotions, feelings, pleasure, thoughts, experience and the acquisition of knowledge. During the development of our personality, since we came into the world, we have acquired an individual view about our experience of sexuality. This view changes according to the stages of life we are living. That's why we refer to sexuality with a plural form. We feel different and our emotions are different, even if the situation is the same. Everyone experiences pleasure in his/her own way, as what causes pleasure to some, perhaps does not to others. The respect for this aspect implies a profound knowledge of what we feel and desire. We take responsibility for it, to share it or not, based on relationships with other people.

Sexuality is implicit in every stage of life, as we are sexed beings from birth to death. It is not a static concept, but something dynamic that changes according to our personal modifications. The informations we acquire from the outer world with regards to the sexual sphere, influence our way of thinking, of knowing ourselves and of living relationships with other people. There is no single sexuality for all people that establishes how to experience pleasure, but there are as many sexualities as there are people, each with their own peculiarities that depend on personality, knowledge and experience itself.

Once we understand this, we can put aside what is considered normal and learn to know for ourselves what we like, without fear nor guilt, enjoying our sexuality.

*Sexuality is not what we believe,
it is not how we were told.
There is no single sexuality:
there are many.
Albert Rams*

Sexuality, desire, arousal, orgasm, pleasure

Sexuality plays a fundamental role in the well-being of the person and in the quality of life led. Anxiety and sadness, as well as feelings of inadequacy, frustration and anger are common outcomes of the discomfort or difficulty that people may experience with their sexuality. Sexuality is also a very important

component of the couple bond as it should be an expression of care and attention towards one's partner and oneself, as well as a factor of consolidation of the intimate relationship.

Unfortunately, as a result of social, cultural and religious conditioning and / or an inadequate sexual education, sexuality is experienced with discomfort, frequent emotions of shame and guilt that threaten the psychophysical well-being necessary for both personal and couple balance.

The oncological disease is part of such a delicate sphere, impacting on sexual function. Obviously this influence can be extremely different between patients as the impact depends on:

- meaning and value attributed by the patient to sexual life before the disease;
- patient's stage of life at the time of diagnosis;
- organ affected by the tumor;
- kind of treatments received;
- quality and importance of the couple's relationship before the disease;
- fear of not being desirable;
- non-acceptance of body modifications after illness;
- beliefs about cancer.

It is therefore important to face any discomfort or difficulty in the sex sphere as soon as possible as a competent and appropriate intervention will help to take your own sexuality back consciously, respecting both personal and partner's time. A significant improvement in psychophysical well-being will be the consequent result leading to a better quality of life.

In fact, sexology pays particular attention to the psychophysical and relational aspects of sexuality than to the simple reproductive "functionality". From this point of view we speak more properly of erotic functioning rather than of sexual functioning in which fantasies, emotions, neurovegetative and somatic reactions that produce "sexual pleasure" take on greater importance.

Erotic functioning is composed of four main phases or moments:

- Desire
- Arousal
- Orgasm
- Erotic pleasure

Desire

Sexual desire is an emotion characterized by the presence of sexual thoughts and fantasies and by the desire to engage in sexual activity. The phase of desire foreshadows sexual pleasure as on one side it triggers arousal and, on the other, because usually the more the act is desired the more pleasant will be.

Desire varies from person to person and can also depend on circumstances such as phases of the menstrual cycle, pregnancy, menopause, quality of the couple's relationship, dissatisfaction with one's body, etc. Desire, like pleasure, is mostly a mental (psychic) phenomenon.

Arousal

Arousal is a subsequent emotion similar to that of desire, but, unlike it which is a mental and psychic phenomenon, arousal is mostly physical, linked to the body. It therefore arises from desire and prepares for the next phase of orgasm, producing a general activation of the organism, which corresponds to a subjective experience of sexual pleasure.

Men come to arousal only through the stimulation of genitals or nipples, while in most women this is obtained through clitoral stimulation. Through this it is possible to reach orgasm. However, even the stimulation of other body areas can be very arousing to women. This diversity allows women to adapt more easily to possible changes in their most familiar sexual patterns, caused by the disease, while it is more difficult for men to experience sexual pleasure if the genital function is compromised in some way.

Orgasm

It is an extreme emotion, comparable to a discharge of energy and tension followed by a deep state of relaxation called resolution phase. Orgasm is in fact reached at the peak of arousal and puts an end to the sexual reaction, momentarily extinguishing the desire. It is followed by a pause characterized by a momentary erotic and male-only numbness called refractory period. The orgasm phase consists in reaching the peak of physical and mental pleasure which, as already mentioned, is followed by a decrease in sexual tension until total relaxation, which is caused by rhythmic contractions of the perineal muscles and the reproductive organs.

The strong sensations that are felt on a mental level together with physical

modifications make orgasm a gratifying, unique and easily recognizable experience. Female descriptions of orgasm are more accurate than male ones; these therefore suggest that women have a better knowledge of their complex anatomy or, more simply, that they are less reticent in describing their sensations.

For men orgasm is functional to procreation and is always followed by a refractory phase of rest.

In women things are very different: ovulation is a cyclical process independent of orgasm. During intercourse they may feel a peak of orgasm, none or multiple ones.

Erotic pleasure

Erotic pleasure is a particular subjective experience that generally accompanies, nourishes and increases the other phases of erotic functioning (desire, arousal, orgasm and resolution). It acquires specific characteristics in each phase: the subtle pleasure of desire, the pleasure of satisfaction during the resolution phase, the shocking pleasure of orgasm. Pleasure, like desire, is mostly a mental (psychic) phenomenon.

Sexual dysfunctions

In women sexual dysfunctions can be related to desire disorders (reduction of testosterone), disturbances of arousal (reduction of estrogen and progesterone, but also to psychological aspects), the orgasm phase, pain during penetration (related to dryness of vulvo-vaginal mucous membranes).

In men major problems may be related to the arousal phase with interference in erection related to reduced testosterone, alteration of the nerve structures that regulate the blood supply to the penis during erection.

Normally also states of anxiety, depression, fear, worries can interfere with the sexual cycle and these aspects are often more accentuated in the case of oncological disease.

Impact of oncological treatments on the sexual sphere

Many cancer treatments can cause changes in sexual functioning, even if they do not directly affect the genital organs. The quadrantectomy or mastectomy in fact determine an alteration of the body perception in women which can lead to an important psychological impact: the fear of not being desirable, the feeling of permanent disability can in fact interfere with the phase of desire and sexual arousal. Surgical, radiotherapy or oncological interventions on the genitals in the

presence of gynecological, prostate, bladder and testicular cancers are very different depending on the patient's sex.

In women

In case of hysterectomy or oophorectomy the surgeon closes the apical end of the vagina with stitches, reducing slightly its length. The reduction of vaginal length is not in itself a problem for sexual activity, however, as long as the surgical scars are not perfectly healed, it may be useful not to have full intercourse or to ask the partner to be very delicate.

Surgical treatment does not affect women's ability to reach orgasm through clitoral stimulation. Despite this, some women declare that after the operation they are no longer able to have sexual activity as before. Many of them complain about painful penetration.

In the case of tumors of the vulva, surgery makes it necessary to ablate the large and small labia, the clitoris and the regional lymph nodes: this operation radically changes not only the perception that a woman has of herself and her body, but also the sensations which can be felt at genital level.

After ovariectomy, pelvic radiotherapy or chemotherapy, it is possible that women experience premature menopause, characterized by heat fluctuations, sweating, sleep disturbances, fatigue, irritability and mood swings, vaginal dryness and decreased libido. These are the same symptoms of natural menopause, but its sudden and early appearance can cause important disturbances on the patient's quality of life from a physical, psychological and social point of view. Often the patient hardly tolerates these disorders since they are long-lasting and constantly related to the disease. Early menopause is usually associated to the loss of health and well-being, to the loss of reproductive capacity, to the loss of peculiar planning in young women. Moreover, when the treated neoplasm is hormone-dependent, there is not even the possibility of using hormone replacement therapy (TOS) which could solve the symptoms described.

Chemo-induced menopause can be temporary or permanent, and the menstrual cycle may not completely stop allowing a pregnancy. It is therefore important to discuss the necessity of suitable birth control methods with the referring physician.

In breast cancers the activation of preventive hormonal therapies (adjuvants) with tamoxifen, aromatase inhibitors and/or similar LHRH can determine a substantial

interference with sexual functionality, that is reduced libido, vaginal dryness, vaginal discharge, reduced elasticity of the vagina, mood swings.

Genito urinary syndrome is defined as the set of symptoms and signs associated with the reduction of estrogen and other sex hormones which determine changes in sexual organs. Genito urinary syndrome affects between 15-70% of women and about two thirds of female patients treated for cancer.

In men

In men, the removal of the prostate, the removal of a portion of the bladder and abdominal-perineal surgery for rectal cancer can cause erectile dysfunction and dry ejaculations. Although modern surgical techniques aim to respect the nerves of this body part, many men will still have erectile problems. This may be due to the inability to guarantee surgery that spares both nerves for sexuality, the patient's age and age-related sexual changes as well as psychological issues that contribute to sexual difficulties. The fear of losing one's sexuality can lead to high levels of performance anxiety in some men leading to sexual failure or avoidance of sexual activity. A psychologically similar situation can characterize young patients suffering from testicular cancer after orchiectomy.

Chemotherapy in men interferes with sexual function less than in women, although some men report that fatigue and nausea during therapy affect sexual desire.

Radiotherapy treatments for prostate, rectal and bladder cancer could also affect sexual function with an effect proportionate to the dose taken.

The hormonal treatment that is activated in prostate tumors can cause gynecomastia, hair loss, hot flashes and reduced libido with possible impact on erection.

Resume sexual activity

After diagnosis and start of disease-specific treatments, most patients want to resume regular sex. Times and methods for the reactivation of sexual activity are highly variable and change from individual to individual. If sexual problems related to the phase of tumor diagnosis are temporary, the difficulty inherent to the permanent effects of the treatments performed often remains. It is important to give yourself time sharing these difficulties with your partner.

Some useful tips to better face the resumption of sexual life

1. Clarify in the pre-treatment phase what problems could arise in the sexual sphere. Information allows the patient to understand, reduces his/her anxiety, gives the opportunity to face what will happen with greater serenity. If the doctor does not bring it up, the patient can and must ask for more information.
2. Reassure the patient that he/she can have a regular sex life during and after a tumor. The only advice is to use condoms during sexual intercourse to avoid vaginal irritation due to drugs which can damage the mucous membranes, the presence of drugs precipitates in the seminal fluid or the onset of pregnancy. It is important to dispel some myths indicating that cancers are not sexually transmitted. Sexual activity can promote the transmission of pathogenic viruses that can develop cancer without however being its direct cause. Sexual activity in addition cannot lead to a worsening of the cancer but on the contrary a serene sex life even during the illness can help the patient to better deal with the treatment path. Only in case of pelvic surgery it is useful to avoid full intercourse in the period immediately following the operation.
3. Try to gradually accept the changes related to the disease through a progressive knowledge of the body (looking, touching, caressing), first on one's own and then with the partner. It is important to find an emotional intimacy first and then a sexual one. In this process the support of a psychologist can also be very useful to help the patient adapt to bodily changes that make him/her feel less attractive (mastectomy, ostomy).
4. Talk with your partner openly about the changes caused by the disease, the difficulty of experiencing certain sensations or achieving an erection or pleasure, about your fears (to be rejected, no longer desirable, about the fear of pain). It is important to discuss it together in an atmosphere of mutual comparison, which can lead to a new intimacy. It is fundamental that the resumption of sexual life is progressive, foreseeing a longer phase of foreplay, the search and sharing of new ways of stimulating pleasure trying to create moments of tranquility to understand the cause of sexual dysfunction. There are dysfunctions mainly related to psychological factors that can either be solved through the discussion with the partner and the psychologist, but some situations require specific treatments.
In men: in case of persistent erectile dysfunction, medical therapies (phosphodiesterase inhibitors) or local therapies such as intracavernous injections of prostaglandins or vasodilators such as papaverine can be

carried out (andrologist). In case of lack of response, it is possible to think about the implantation of rigid or flexible penile prostheses.

In women: in case of persistence of pain on penetration and vaginal dryness it is possible to use vaginal dilators, lubricating gels, local specific therapies such as MonnaLisa Touch * (gynecologist). Prevention is certainly important: it is useful to have adequate intimate hygiene (wash little, no more than once or twice a day with a mild detergent without menthol and dissolved in water), keep hydrated using emollient creams daily, especially on the vulvar intake (almond oil is very useful), use pessaries once/twice a week to hydrate the vaginal mucosa. It is also possible to use hyaluronic acid with topical action on the advice of the gynecologist. Some Centers propose the use of topical phytoestrogens while others prefer topical estrogens for short periods. Anyway this should be discussed and decided always with the gynecologist. Scented creams should be avoided.

* MonnaLisa Touch TM: it is a functional vaginal rejuvenation laser treatment based on a special fractional CO2 laser system, specifically made for the vaginal mucosa. MonnaLisa Touch TM prevents and solves the effects of estrogenic decline on vaginal tissues (typical of menopause and postpartum) by reactivating the production of new collagen and restoring the conditions of the vaginal mucosa characteristic of fertile age.

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