

Oncosexology: A Multidisciplinary Approach to Sexuality and Cancer

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Abstract

Aim

Expose the theoretical references related to oncosexology, to propose the creation of oncosexology units, as a mechanism to improve the quality of life of patients.

Methodology

A search for articles was carried out in the Medical Literature Analysis and Retrieval System Online (MEDLINE), Scientific Electronic Library Online (SciELO), and PubMed

Results

Oncosexology is an autonomous multidisciplinary discipline since its origin in the Netherlands in 1998; however, despite many isolated experiences worldwide, its clinical value is not recognized and there are few oncosexology units. Studies show that including sexuality in diagnosis and advising decision-making on medical and surgical treatment can reduce the risk of sexuality, morbidity and help mitigate the negative effects of cancer on sexual function.


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Conclusions

Oncosexology is an autonomous discipline that aims to increase awareness of sexual issues in cancer care and stresses the importance of addressing them in all phases of health care, including health promotion, prevention, problems, and rehabilitation.

Keywords

Oncosexology, Sexuality, Oncology, Cancer

Introduction

In recent years, there have been great advances in the management of cancer, which has increased the survival rate and made the disease chronic. As a result, attention to sexual health has emerged as an important aspect of the well-being and quality of life of cancer survivors and their partners [1]. Numerous studies and researchers have highlighted how cancer can hurt sexual health, intimacy, and the ability to have sex [2,3].

Multimodal therapy, including surgery, pelvic radiation therapy, chemotherapy, and endocrine-targeted therapies, is the mainstay of modern cancer treatment. However, this combination of treatment modalities can come at a cost in terms of the number of patients who experience side effects that affect their well-being and sexual function for months and even years after cancer treatment [4]. This positive evolution has led to a change of focus in oncology, moving from cure to survival and attention to quality of life [5]. This means that a growing number of women and men who receive a cancer diagnosis need information about long-term physical issues, emotional and sexual side effects of cancer, and other treatment-related side effects, as well as rehabilitation of sexual function.

Oncosexology is a relatively new discipline that focuses on addressing the sexual and intimacy needs of people living with cancer. The term was developed by Dr. Woet Gianotten at the Utrecht and Netherlands Medical Centers in 1998, a gynecologist and sexologist who dedicated himself to medical sexology, a branch of sexology that deals with sexual problems caused by chronic diseases, physical disabilities, cancer, and medical interventions [1]. Through his experience, Dr. Gianotten specialized in the subspecialties of rehabilitative sexology, gerontosexology, and oncosexology, with a special focus on terminal and palliative stage cancer [1].

Importantly, sexuality is often overlooked in the clinical area, which can result in unmet sexual needs in these areas. Oncosexology seeks to address this issue by treating sexuality and intimacy as important aspects of the health and well-being of cancer patients. Through oncosexology, healthcare professionals can help patients understand and address changes in their sexual function, manage the side effects of cancer treatment, and improve their overall quality of life [1].

This recognition has resulted in the emergence of this new discipline [1]. Dr. Woet Gianotten co-founded the International Society for Sexuality and Cancer (ISSC) based in the Netherlands in 2002. This society was created to serve as a forum for the research, treatment, care, and prevention of sexual problems in cancer, as well as to promote the highest standards of practice, education, and research in the field of sexuality and cancer. The ISSC is a multidisciplinary and international society that seeks to make visible and defend this important area of clinical care. In 2010, the ISSC organized a Symposium on "Cancer and Sexuality" in Rotterdam, Netherlands, with European speakers [6].

The International Society for Sexuality and Cancer (ISSC) carried out a series of initiatives to raise awareness among health professionals about the negative effects that cancer and its treatments can have on sexual function, sexual experience and fertility from the patients. One of the first activities of the ISSC was this annual global
campaign on "Intimacy and sexuality: the neglected aspects of quality of life after cancer", in collaboration with the British charity MacMillan [7]. The campaign called for spreading the idea and influencing local cancer societies to include sexuality and intimacy in their campaigns and programs, and to send messages to national, regional, and global sexology organizations to add the topic of cancer to his work on sexuality. The ISSC also developed audiovisual tools to help patients understand the effects of cancer treatment on their sexual function and fertility [8,9]. However, these initiatives lost interest and disappeared around 2012.

In 2007, the first outpatient oncosexology service was created at the Medical Center of Netanya, Israel, with a multidisciplinary perspective. The service team was made up of an oncology nurse specializing in sexual counseling, a gynecologist specializing in sexual therapy, a social worker specializing in sexual and couple’s therapy, and a urologist. In addition to personal consultation with cancer patients, they offered a psychosexual support program for the patient and her partner, providing information, emotional support, and counseling on specific problems of sexuality and self-esteem [6].

Numerous studies have exposed the urgency of developing care for sexual problems associated with oncological disease, to improve the quality of life of patients and their partners [10-22]. In 2011, professors Enzlin and De Clippeleir [23] from the Institute for Family and Sexuality Studies at the University of Leuven in Belgium raised the need to include sexologists and sexual therapists as part of oncology teams to fill the gaps in the attention of this dimension in oncological management. These authors insisted on the inclusion of oncosexology to increase sensitivity to the topic among professionals and patients. Furthermore, they were the first to draw attention to "Sexual Rehabilitation" during and after treatment to maintain and restore a satisfactory sexual life within the limitations that the oncological disease presents to patients and their partners.

In 2010, the LIVESTRONG Foundation published the results of an online study involving male and female cancer survivors who were at least six months after their last treatment. 43% of the participants expressed concern about sexual issues, and sexual problems were the third most frequent physical concern in this population [24]. Unfortunately, the sexual complications of cancer are often not adequately addressed, even though they can have a great positive impact on patients, their partners, and their environment.

Aim

Know oncosexology as a multidisciplinary approach to treating the effects of cancer in cancer patients.

Material and Method

To carry out this work, an investigation was carried out consisting of a bibliographic review of the existing scientific literature. In addition, a systematic search of books was carried out and articles were consulted in the main databases such as Google Scholar, PubMed, Medline, and Scielo. Scientific articles that come from reviewed academic publications have been selected.

Results

Effectively addressing sexual concerns can be challenging, due to the diversity of etiologies and the multifactorial nature of sexual function. However, it has been shown that including sexuality in diagnosis and advising medical and surgical treatment decision-making can reduce morbidity and help mitigate the negative effects of cancer on sexual function [25].


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It is important to note that sexual problems can affect both men and women who suffer from cancer. For example, women may experience vaginal dryness, pain during sexual intercourse, or a decrease in sexual desire due to cancer treatments [26,27]. On the other hand, men may also experience erectile dysfunction, decreased sexual desire, or ejaculation problems [28].

Although there are medical and surgical strategies to preserve sexual function in men after cancer treatment, as studies have shown [29-31], women who seek help to treat sexual problems during and after cancer treatment have few evidence-based options [32].

The need to develop treatment strategies to address the sexual problems of cancer survivors has been evident for decades. Studies conducted on the topic since 1989 have demonstrated the importance of addressing these concerns [26,33].

In the United States, a solution is beginning to be found for the lack of scientific material to treat sexuality in the context of cancer. For this reason, in 2007, nurse Anne Katz published the book "Breaking the Silence on Cancer and Sexuality: A Handbook for Healthcare Providers." This book proposes three key moments to address sexuality in cancer patients: diagnosis, treatment, and the period after treatment [34].

At the time of diagnosis, since newly diagnosed people often do not receive enough information or do not remember what they are told after hearing "You have cancer," it is crucial to help patients understand in advance what to expect, especially about the loss of sexual function. It is important to provide them with guidance on how to deal with this situation and what resources can help.

During treatment, it is necessary to inform capabilities and address the effects of the disease and treatment on sexual function, behavior, and capabilities, adapting to the specific type of cancer. In addition, sexual problems should be prevented and treated through both individual and couple interventions.

Finally, in the post-treatment stage, it is important to address consequences such as vaginal stenosis, erectile dysfunction, and other effects, and if necessary, provide sexual therapy. This text also includes chapters dedicated to adolescents, adults, individuals, and couples, both heterosexual and sexual minorities. This book is of great value as it is written from a nursing-counseling perspective. However, it is important to highlight that the care of physical problems must be in the hands of specialized professionals; however, the formation of interdisciplinary teams from the beginning of care in oncosexology is not proposed.

With this concern in mind, the University of Chicago and Memorial Sloan-Kettering Cancer Center convened the broader community of experts in August 2010 to hold the first national conference on cancer and female sexuality. The goal was to bring together clinicians and researchers active in the field of cancer and women's sexual health to discuss and share information about the sexual problem's women face after cancer treatment. This conference was an important step in addressing the problem of the lack of evidence-based treatment options for women with sexual problems after cancer treatment. Since this conference, more research has been conducted and specific interventions have been developed to address the sexual needs of women after cancer [35].

Based on these initiatives, the Scientific Network on Women's Sexual Health was created in the United States, a cooperative interdisciplinary group that brings together mental and behavioral health professionals, educators, nurses, patients, physical therapists, physicians, and surgeons (including medical oncologists, surgical, gynecologists, and radiologists) and other related professionals. This network is established based on oncologists who refer patients to sexual health services, as well as those who seek to support the development of specialized practice in cancer and female sexuality so that women can receive assistance and education in
these organizations. Network members have published tools aimed at promoting and implementing specialized practices capable of addressing sexual dysfunction among women affected by cancer [36].

Continuing to advance this discipline, in 2017, Drs. Reisman and Gianotten [1] wrote the book “Cancer, Intimacy, and Sexuality: A Practical Approach,” which provides a broad description of the sexual consequences of cancer and its treatment. The main objective of this book is to equip doctors and other health professionals with the awareness and knowledge necessary to provide effective treatment to patients. This text has become the main reference for professionals dedicated to this new discipline.

Based on these concerns, numerous studies have been carried out that demonstrate the importance of addressing sexuality as a way to improve the patient's quality of life. However, most of these studies have focused on patients with prostate cancer and breast cancer, along with their partners, as noted by Li et al [37]. The general results of these investigations show that sexual function, sexual self-concept, and intimate relationships are negatively affected by any type of cancer and its treatments.

Although there is extensive scientific evidence that supports the importance of addressing sexuality in cancer patients, there are few hospital programs that provide routine care in this regard [38-44].

When examining the existence of oncosexology clinics, there is only evidence of one clinic in Portugal, which has been in operation since 2009. This clinic has a medical team, nurses, psycho-oncologists, radiation therapists, endocrinologists, urologists, and gynecologists. For example, in 2017, this clinic treated nearly 500 patients of both sexes from the moment of cancer diagnosis [45].

However, oncosexology has promoted actions in the field of public health, as evidenced in the first roadmap (2017-2020) of the National Sexual Health Strategy of France (2017-2030). Specific interventions about oncosexology are developed through actions 18 and 21, which seek to give greater importance to relational and sexual issues in consultations with patients suffering from chronic diseases, as well as in therapeutic education programs for the patients. Furthermore, it is intended to adapt the planning of sexual and reproductive health provision for young people, taking into account the specific needs of overseas territories and the available resources [39].

**Impact of different types of cancer on sexual functioning**

Sexual function is the result of a complex interaction between physiological, psychological, physical, and interpersonal factors, which are reflected in the personal experience of sexuality. Furthermore, it is recognized as a fundamental right to be able to enjoy pleasurable sexuality, have control over it, and make free and responsible decisions, without suffering coercion, discrimination, or violence [46]. On the other hand, according to the World Health Organization, addressing the difficulties that adults may have in achieving satisfactory sexual activity involves detecting and managing sexual problems. Likewise, it is recommended to provide psychosexual guidance with support and specific information to address these sexual problems, which contributes to recovering and managing the various disorders in this aspect of comprehensive health care [46].

The incidence of sexual dysfunction in men and women undergoing cancer treatment ranges from 40% to 100%, with 59% and 79% of women and men, respectively, experiencing the absence or decreased frequency of sexual activity [47-49].

There are physical, psychological, and social factors that affect cancer patients and generate changes in the expression of their sexuality. These include anatomical changes, as in the case of colorectal, penile, testicular, breast, or cervicovaginal cancer; physiological changes, such as hormonal imbalances, urinary or fecal incontinence, weight changes, fistulas or stomas; and adverse effects of treatment, which can manifest through...
nausea, vomiting, diarrhea, fatigue, and alopecia. Furthermore, self-image, shame, fear, gender roles, and sexual roles also influence the experience of sexuality of people with cancer [50].

On the other hand, more than 60% of people treated for cancer experience prolonged sexual dysfunction, of various types and intensities, but less than 25% of them receive help from a health professional [51]. Although sexual problems related to cancer usually begin with the physical damage of the disease, they are also affected by the effects of cancer treatments, the patient's coping skills, and the quality of the patient's relationship.

Research on the topic of sexuality in patients with oncological disease has been mostly descriptive, and most studies have focused on breast, gynecological, and urological cancer [52,53]. These studies have mainly addressed psychological and sexual self-esteem effects, as well as sexual dysfunctions such as decreased sexual desire and lubrication difficulties in women and erectile dysfunction in men.

On the other hand, studies evaluate intervention models based mainly on counseling, such as the PLISSIT method [54-57].

The PLISSIT method is a behavioral approach to the treatment of sexual problems, developed by Annon in 1974. This intervention consists of several stages: the first, called "Permission", in which the counselor creates a safe and trusting environment that allows patients to talk about sexual issues and express their concerns and problems; the second, called "Limited delivery of information", in which the counselor provides limited, real and fact-based information in response to sexual questions or problems raised by the patient; the third stage is "Specific Suggestion," where the counselor offers specific suggestions to address the patient's sexual problem; The fourth stage is "Problem-Solving", which is developed through joint decision-making between the patient and the counselor, and the fifth stage is "Intensive Therapy", in which, if the problem persists, the patient is referred to a sex therapist or specialist [54].

This method is carried out over 7 60-minute sessions over four weeks [57]. However, this approach has limitations as it does not address prescribing medications for sexual symptoms or pelvic floor therapies. Furthermore, being an old method, it does not incorporate the use of information technologies. The fact that it is still used as an intervention model for cancer patients highlights the lack of studies that use new information methodologies. This leads to the conclusion that in the places where these interventions are carried out, there is a lack of a coordinated and collaborative approach that can contribute to the prevention and treatment of sexual problems.

Given this situation, in 2017 the American Society of Clinical Oncology (ASCO) published practice guidelines on sexuality and cancer. These guidelines address major sexual problems related to cancer and its treatment, as well as strategies for coping with them after cancer treatment [58]. Additionally, the following recommendations are included:

Cancer care professionals should ask about sexual health problems at diagnosis and during follow-up. Incorporating sexual health as a routine system check or standardized assessment is one way to raise these concerns.

Concerns about sexuality are not solely for the primary oncology provider to address. Given the many domains in which cancer and treatment can impact sexuality, a multidisciplinary team that includes urologists, urogynecologists, gynecologists, pelvic floor physical therapists, mental health providers, and sex therapists, among others, can best meet the needs of women who have concerns.
Sexual health issues are important for all women, including those in low- and middle-income countries. Tools used in these settings should take into account national standards to generate culturally appropriate screening and therapeutic approaches.

For sexual and gender minority women, concerns about sexuality should be part of their cancer care, which begins with recognizing their identity. Institutions should enable the collection of sexual orientation and gender identity data and work to become a friendly environment for all people they serve, including this population.

It is evident that oncological disease impacts the expression of sexuality and it is essential to address these issues promptly since sexual problems usually entail both psychosocial and physiological consequences that reduce the patient's quality of life. On the other hand, oncologists lack specific training to address these situations. Therefore, given the need to prevent, treat, and rehabilitate sexual problems associated with cancer, the ideal discipline to be able to do so in a comprehensive manner is oncosexology. This discipline, autonomous and supported by a body of its knowledge, has professionals in sexology duly trained and familiar with the physical, psychological, and sociocultural aspects of sexuality and sexual and reproductive health, specializing in the different manifestations of cancer.

**The oncosexology unit**

The creation of an oncosexology unit in oncology treatment clinics is a proposal to adequately treat patients, recognizing the importance of sexuality in the quality of life; In addition, it provides the opportunity to dedicate time to sexual health, an aspect that is often overlooked in these clinics, despite being one of the topics that concerns patients [59]. The main obstacles to addressing sexuality during routine follow-up are reluctance on the part of both the patient and the doctor to discuss the topic, lack of specialized knowledge or experience, and time limitations [60].

Considering everything mentioned above, specialized knowledge in both sexuality and oncology is necessary to adequately address the sexual repercussions of cancer treatment, as pointed out by Lindau et al (30). In addition, it is important to have the support of other professionals such as cancer psychologists and pelvic floor therapists, who can provide management of related problems.

One of the most innovative proposals is the one presented by Nho, Kim, and Kook [61] in Korea, which consists of an online sexual health program for gynecological cancers. This program includes modules on sexual response, the sexual response cycle, treatment-related sexual dysfunctions, and methods for treating these dysfunctions. While this program has been of great help to patients, it is important to note that it primarily focuses on addressing sexual dysfunctions and cannot be directly applied to sexual problems arising from oncological disease.

Having an oncosexology unit with sexologists and sexual therapists should be part of the patient's comprehensive care [62]. This unit can be useful in addressing issues related to problems in the dimension of sexuality and the gap between the needs of patients and the supply of professionals specialized in oncology care. Their presence will help raise awareness of this sensitive topic and may improve knowledge about the link between cancer, sexuality, and intimacy for both professionals and patients [63].

Additionally, it will be better for patients to gain a deeper understanding of the changes that may be occurring in the area of sexuality and intimacy, which helps reduce levels of uncertainty [64]. In addition, group activities can be carried out in which socio-sexual conceptions that promote normative ideals of beauty and the pressure to participate in certain sexual activities without the necessary preparation or care are questioned. Therefore, the integration of sexologists into oncology teams can be of great help in various ways, such as informing,
educating, and assisting clinical professionals on this topic [44]. If in the future oncology clinics organized specific consultation opportunities to address sexual dysfunction, patients' needs would be better served.

Recommendations

The evidence shows the great impact of sexuality on the quality of life, therefore, this topic must be addressed from the beginning of the treatments, to normalize it, and open the door for future conversations about possible doubts and problems that may arise. and thus, contribute to shared decision-making regarding therapeutic options; which will benefit both patients, their partners, and family.

There are online resources on sexuality in cancer patients such as Oncolink [65] or Cancer.gov [66] in which there are guides for women during and after cancer treatment, for the management of vaginal dryness and sexual painful relations and for the use of vaginal dilators for radiotherapy. In the case of men, for erectile dysfunction after treatment, for penile implantation, and the management of loss of libido. These guides are written in simple language and give valuable recommendations based on scientific knowledge.

Incorporating online resources is an action that recognizes the importance of sexuality and, they should be made known to patients from the beginning of treatment, they do not require specialized personnel to do so, and making them part of the therapeutic plan reduces the uncertainty that this issue raises. in patients, improving their quality of life.

The backbone of the humanization of oncology must be the active consideration of the integrality and complexity of patients, taking into account their biography and not only their biology; So creating a clinical space that addresses sexuality in oncology units is part of the comprehensive management of the patient based on respect and promotion of her autonomy.

Conclusions

Oncosexology is a branch of medical sexology that was created by Dr. Gianotten in 1998 to address the problem of affected sexuality in cancer patients, with extensive scientific support. Since then, the intervention proposal has included a multidisciplinary team led by a sexologist who addresses the physical problems derived from the disease and its treatment, as well as providing support to the patient and her partner, as an integral part of their quality of life.

The importance of oncosexology lies in the fact that sexuality is a fundamental aspect of an individual's emotional and physical well-being, and cancer and its treatment can negatively affect sexual function, intimacy, and quality of life. Therefore, it is crucial to address these aspects to improve the quality of life of cancer patients and their partners.

The multidisciplinary team in oncosexology may include health professionals such as urologists, gynecologists, radiation therapists, physiotherapists, psychologists, and cancer nurses. They all work together to provide comprehensive care to the cancer patient and his or her partner, addressing the different problems that may arise about sexuality.

It is important to highlight that the oncosexology approach not only takes into account the physical aspects of the disease and its treatment, but also the emotional and psychological aspects that can affect the sexuality of the patient and their partner. In this way, we seek to provide comprehensive care that considers all dimensions of the individual's well-being.
In conclusion, oncosexology is a fundamental discipline to improve the quality of life of cancer patients and their partners. The multidisciplinary approach and comprehensive care are essential to address the different problems that may arise about sexuality, and thus contribute to and improve the emotional and physical well-being of the patient.

**Conflict of interests**

The author declares that she has no conflicts of interest in this research.

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