Sexuality and cancer: Sexual problems and communication with patients. By Joanna Tsatsou, Cancer nurse, Msc, PhDc

WHO defines sexuality as "a central aspect of human life which encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" [1,2]. Sexuality is a core component of quality of life and it is expressed in thoughts, fantasies, desires, beliefs, attitudes, values, practices, roles and relationships. While sexuality can embrace all of these dimensions, it is not always experienced or expressed. Sexuality is influenced by the interaction between biological, psychological, social, economic, political, cultural, moral, legal, historical, religious and spiritual factors [1,2]. Sexuality has also been defined as "the process of giving and receiving sexual pleasure and is associated with a sense of belonging or being accepted by another" [3]. Intimacy on the other hand is "the sharing of identity, closeness, and reciprocal rapport, more closely linked to communication issues rather than sexual function" [4].

In the cancer care context, sexuality is characterized as a high priority issue by one to three quarters of cancer survivors and is classified as a major unmet need. Sexual dysfunction after cancer is consistently associated with poor QoL [5]. The incidence of long-term, severe sexual dysfunction is as high as 50% among cancer survivors in the United States [6]. Sexual dysfunction rates of childhood cancer survivors are close to 33%, with women having double the chances of dysfunction than men the United States [7]. In the United Kingdom, 43% of cancer patients reported that their sex lives were adversely affected by anti-cancer therapies. After breast cancer and cancer of the cervix, prostate and rectum, sexual difficulties reach the 70-80% [5].

Most sexual problems are not caused by the cancer itself, but by the toxicities of the various cancer treatments. In particular, the damage caused by various therapies to the pelvic nerves, blood vessels and organ structures leads to higher rates of sexual dysfunction. Both men and women can have interruptions in sexual activity due to the side effects of treatments such as fatigue, nausea, urinary or fecal incontinence. Sexuality remains important even for many older survivors. Sexual problems are more unpleasant for those under the age of 65 and those who are sexually active at the time of the diagnosis of cancer [5].

Men with cancer experience common sexual problems such as erectile dysfunction and loss of desire. Less common are changes in the quality of orgasm, difficulties in achieving orgasm and painful erection ^[6]. Men who have undergone surgery in the bladder or rectum have higher rates of erectile dysfunction. Sexual problems (as a result of hypogonadism and pelvic nerve damage) also occur in men who have received intensive chemotherapy, pelvic radiotherapy or total body irradiation. Testicular or lymphoma cancer survivors report high rates of sexual inactivity and low sexual desire ^[8]. Causes of problems can be multifactorial, including hypogonadism, fatigue, negative mood and stress ^[9].

In women, the most common sexual problems are vaginal dryness, pain during sexual activity and loss of sexual desire, and these are usually accompanied by difficulty in arousal and pleasure during sexual intercourse^[5,6]. Cancer treatments increase the risk of sexual dysfunction for women because they cause sudden, premature ovarian failure in women who have not yet entered menopause ^[10]. Alkyliating agents, pelvic radiotherapy (which causes ovarian failure and immediate damage to genital tissues), ovariectomy or hysterectomy and those under the age of 35 are at higher risk for sexual problems. The use of gonadotropin agonists or antagonists to create a temporary state of ovarian failure also causes sexual problems, although the dysfunction can be resolved when they are stopped. Oestrogen replacement helps with vaginal dryness but does not restore normal sexual function. Hormone therapy can also cause sexual problems. Women taking tamoxifen have minimal changes in sexual function while aromatase inhibitors can cause severe vaginal dryness and discomfort ^[11].

Psychological effects

Sexuality is not only affected by the physical effects of cancer and therapies but also by the psychological ones. The diagnosis causes fear, anxiety and panic thus affecting the sexuality of the person. Sexual desire and activity are significantly inhibited in this phase. In addition, with the

implementation of various treatments, stress, uncertainty, losses and sadness increase. There is a change in body image from alopecia, mastectomy, ostomy, hysterectomy, amputation and change in self-perception (loss of fertility, femininity or masculinity). These not only reduce sexual desire but also the feeling that the person is not sexually desirable to their partner. Thus, psychological and biological problems interact and contribute to sexual dysfunction. Inevitably, the quality of a couples' intimate and sexual relationship changes after cancer diagnosis and treatment.

How cancer nurses can help

Cancer nurses, who are a consistent presence for their patients during treatment, most often become the person to whom patients confide their concerns and problems, including sexual ones. Nurses are therefore the ones who must educate their patient about the sexual alterations following cancer treatments, assess sexual problems and provide possible ways of resolving them or liaise with appropriate sexual services. When we educate our patients on the treatment toxicities, we include fertility issues but sexual health is often a neglected issue.

Communicating with patients about sexuality includes numerous concerns by patients and healthcare professionals alike. Unfortunately, healthcare professionals are often reluctant to raise the topic of sexuality. This can be due to inadequate education, a fear of personal or patient embarrassment or overstepping professional boundaries, lack of knowledge about appropriate resources for problems identified or because other cancer care issues take precedence during brief patient encounters [12]. On the other hand, patients are often unwilling to ask about sexual issues, also fearing embarrassment or that their feelings must be unimportant or taboo since providers did not mention them [12,13]. However, patients feel that sexual health is a priority, and they are willing to discuss sexual issues when given the opportunity [12], even though many would prefer that a healthcare professional instigate the discussion [14]. It has also been noted, that patients' and healthcare professionals' views and expectations differ around sexual health discussions, contributing to patients' unmet sexual needs [15].

A sensitive approach

So, when nurses or other healthcare professional, discuss sexuality with patients a sensitive approach is essential. When nurses implement sexual assessment and follow-up at their routine assessments they feel more comfortable with the discussion. First of all, nurses should find appropriate timing for each patient and ask permission to discuss and then provide non-judgmental, accurate information that moves from less to more sensitive issues over time and avoiding use of medical jargon. Sexuality discussions should be neutral to sexual orientation and gender, avoid cultural stereotyping and move from one topic to another with a normal flow. Then, assessments and interventions should be individually tailored to the specific age, gender, developmental level, sexual orientation, and disease type, stage, and treatment plan as well as the identified concerns and issues raised by the patient. The goal is to build a trusting and supportive relationship with the patient, in order to enhance the communication about sexual problems, support sexual self-esteem and provide appropriate resources and referrals [16].

To facilitate the communication between patients and healthcare professionals, models for sexual assessment have been created, but few have been developed specifically for cancer patients. The most frequently used model is the PLISSIT model described by Annon in 1974 [17]. Another commonly used model in cancer care is the BETTER [18]. These assessment models may assist healthcare professionals to assess and attend to their patients' sexual health needs.

In summary, sexuality in cancer patients is negatively affected by many factors both physical and psychosocial. Patients require specific sexual care to overcome the physical and emotional sexual problems resulting from cancer and its treatments. In order to ensure better care, cancer nurses must learn and address sexual issues. Education is the key to ensuring adequate guidance and advice is given to cancer patients and that this highly unmet need of sexuality is addressed. There is a significant correlation between sexuality and quality of life. Sexual health should therefore be systematically monitored by multidisciplinary teams and interventions implemented through integrated care to improve it.

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