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## **Cancer and sexual health: The continuum of care**

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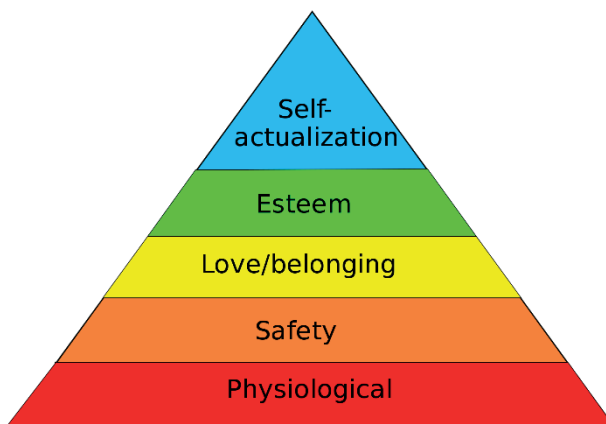
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## **Chapter 1:** General introduction

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*“There is a need for reduction of impact on sexual life of medical and surgical conditions or treatments.” – World Health Organization(1).*

In his hierarchy of needs consisting of five stages (**Figure 1**), the American psychologist Maslow classified sex under the physiological needs, indicating the most basic needs that have to be met by humans(2). Although the place of sex in the hierarchy of needs has been criticized, sexual health is known to be a fundamental part of life. Sexual health is a multidimensional concept with a lack of consensus in literature regarding the definition. For the purpose of this thesis, sexual health is composed of sexual self-concept, sexual functioning, sexual relationships and intimacy(3-5). The World Health Organization (WHO) defined sexual health as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships(6).”



**Figure 1:** Maslow's hierarchy of needs

*Source: Maslow, A.H, A theory of human motivation. Psychological Review 1943. 50 (4): 370–96.*

## **Cancer and sexual health**

Advances in cancer diagnosis and treatment have led to rising survival rates. As a consequence, more people are living with and beyond cancer(7-9). There is expanding recognition of problems following cancer treatment and growing attention for improving patients' wellbeing and quality of life. Sexual health is considered as an important quality of life issue(10, 11). Sexual concerns are common consequences of cancer treatment. The prevalence rates of side effects affecting sexuality varies between cancer site and treatment, up to 100%. More than half of patients treated for malignancies in the pelvic and over twenty-five percent of people with other malignancies are affected(12). The diagnosis itself and treatment can affect different domains of sexuality, both physical and psychological. Issues with sexual health may start at the beginning of treatment and are likely to continue during the follow-up and survivorship. Consequently, it can be a persistent reminder of malignancy, often far beyond end of treatment(12). As a result, cancer patients and survivors with sexual health concerns are more likely to have distress and a poorer quality of life(13, 14). Sexual problems can affect patients regardless of age, cancer site, gender or treatment.

### *Age*

In particular, younger cancer patients experience more distress with sexual functioning in comparison to older patients(15-17). However, sexuality remains important during life, even for geriatric cancer survivors(12). A study on the prevalence of sexual activity among 10,000 European adults showed that sexual desire and activity persist through old age. Half the male participants and a quarter of the female participants between 70 and 80 years old reported to be sexually active(18). Nevertheless, sexual problems following cancer treatment of older and younger patients may differ. In case cancer occurs during adolescence or young adulthood (AYA), cancer can interfere with normal sexual development, psychosexual formation and the evolvement of romantic relationships(16, 17, 19-21).

### *Cancer site*

Research focussed mainly on sexual concerns in 'sexual/reproductive cancers'; prostate and testicular cancer in men and gynaecological and breast cancer in women(10). However, sexual problems are not only a concern in those with a reproductive cancer, but irrespective of cancer site(10, 22-24). Other cancer site and their treatment, like hematologic, colorectal or head and neck cancer, may also cause sexual side effects(25-27).

### *Treatment modalities*

Both men and women may suffer from sexual health problems due to cancer treatment(10, 22). Most sexual problems are not caused by the cancer itself, but by the toxicity of treatment. Damage to nerves, blood vessels and organs may cause sexual problems. All treatment modalities, as surgery, chemotherapy, hormonal therapy or radiotherapy, cause specific physical or psychological sexual problems(22). The most common sexual problems in men are erectile dysfunction and loss of sexual desire. Surgery or radiation therapy to the pelvic organs are well-known to cause erectile dysfunction due to damage to pelvic nerves and blood vessels. Besides, intensive chemotherapy or hormonal therapy may lead to hypogonadism causing sexual dysfunction(23). In women, the most common sexual problems are loss of desire, pain during intercourse and vaginal dryness.

Chemotherapy and hormonal therapy can cause (permanent) ovarian failure. Hormonal therapy and pelvic radiotherapy lead to dryness and pain during sexual intercourse. Surgery, for example a mastectomy, may cause change in nipple sensation, body image and self-esteem. Bone marrow transplantation causes scarring of the vulva and the vagina(10, 12, 28). Moreover, in both men and women, general side effects of treatment like fatigue, nausea, urinary and bowel incontinence cause problems with sexuality(12).

#### *The partner*

Most intimate partners of patients with cancer report a negative impact of the disease on their sexuality and intimacy(24, 29-33). Physical changes, adverse effects of the treatment and repositioning of their partner as asexual contribute to changes in sexual relationship between the person with cancer and the partner(24, 30, 34). Partners report to experience feelings of frustration and sadness due to these changes(34, 35). An intimate relationship during cancer treatment and survivorship is important since it is associated with better psychosocial outcomes in both cancer patients and partners(36, 37).

#### **Discussing sexual health in medical practice**

Sexual health is rated as an important unmet need during cancer survivorship(10, 12). Patient reported outcomes show poor satisfaction with support for cancer-related sexual problems(38). Most patients are not informed about sexual concerns, for example how treatment may affect sexuality, what the common problems are and what can be done(7). The majority of cancer patients believes that communication about sexuality with their healthcare provider is important and half of the patients report to be not satisfied with the communication and information received(39). Sexual health is a challenging topic to discuss in medical practice. Patients might face barriers like feelings of shame or lack of privacy to bring up the topic(10, 26, 40-43). Most healthcare professionals do feel responsible for bringing up the topic(44). They consider sexual health as important but experience barriers to discuss sexuality as well, like lack of knowledge and training, lack of time, feeling of shame, presence of a third party and illness of the patient(45-47). Literature reveals that sexual health is least likely to be discussed unless asked by the healthcare professional. Patients report they want that their healthcare professionals to provide information and help with sexual consequences of cancer treatment, as do their partners(24, 32, 34, 35). According to the literature, there is a need for improvement of information about sexuality for cancer patients and if applicable their partners(26, 32, 40, 42, 48-51).

#### **Aim and outline of this thesis - Cancer and sexual health: the continuum of care**

This thesis aims to evaluate the need and preferences of information and support regarding sexual health throughout patients' treatment process, follow-up and during survivorship. Since sexual problems can arise during each stage of treatment, follow-up and survivorship, it is an admirable goal to achieve integration of sexual health in the continuum of care for patients. Continuum of care is a concept involving an integrated system of care that maintains continuity of the medical care delivered to the patient from the diagnosis onwards(52).

In this thesis a distinction is made between patients, partners, healthcare professionals and the organization of health care - stakeholders which are involved in sexual health. In **Part I**, patients are evaluated regarding their preferences in sexual healthcare. **Part II and III**, aims to explore the view of the partner and healthcare provider. In **Part IV**, effectiveness of educational interventions for healthcare providers and recommendations for the organization of sexual health care will be explored. By involving different stakeholders, recommendations can be provided for patient-centered sexual healthcare while considering the role of healthcare professionals and the challenges within the healthcare system.

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