The emerging field of 'oncosexology': recognising the importance of addressing sexuality in oncology

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Due to the increased survival rate of cancer treatment several types of cancer have gradually evolved from an acute to a chronic illness. This progress has introduced a shift in focus from survival to improving quality of life in oncology care. The reverse of this evolution is that oncologists and other healthcare professionals in oncology are more often confronted with patient's reports of long-term physical, emotional and sexual side-effects. While physical and – to some extent also – emotional comorbidity are mostly being addressed in standard care, there is less attention for the fact that cancer, its treatment(s) and its psychosocial and relational impact may be deleterious for fertility, sexual functioning and sexual experience. Nevertheless, patients and their partners express the need to be informed about the effects of the disease and its treatment(s) on sexuality. Increasing awareness about the gap between the patient's needs for information and the neglect of sexuality in care has been the inspiration for developing a new discipline: oncosexology. Oncosexology aims at increasing the awareness of sexual issues in oncology care and stresses the importance of addressing these issues to prevent the development of (chronic) sexual dysfunctions, problems or worries.
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Introduction

Multimodal cancer therapy including surgery, radiotherapy, chemotherapy or targeted therapies has become the mainstay of modern cancer treatment. With the emergence of these advanced treatment options the survival rate of cancer patients has significantly increased, often leading to long-term survival. Yet, this combination of treatment modalities may come at a price in terms of the number of patients experiencing late treatment effects that have an impact on their well-being and sexual function months and, in some cases, even years after cancer treatment. This positive evolution has introduced a shift in focus in oncology from cure leading to survival to care leading to improving quality of life.[1-6] This implies that an increasing number of men and women confronted with a cancer diagnosis receive extended cure and care based on which cancer gradually evolved from an acute to a chronic illness.[2,5,6] The reverse of this positive evolution in the outcome of cancer treatment is that healthcare professionals are increasingly confronted with - previously non-existent - questions regarding long-term physical, emotional and sexual side-effects of cancer and cancer treatment.[1,2] The recognition of the importance of addressing these new side-effects is clearly

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reflected in the emergence of the fast growing field of psycho-oncology and in the (financial) support of psychosocial care in oncology by policy makers (e.g. National Cancerplan).[7,8] However, while attention for the psycho-social impact of cancer is generally accepted, the fact that discussing sexual side-effects of cancer and/or its treatments in oncology care is warranted, has only recently been recognised. This recognition has resulted in the emergence of a new discipline called oncosexology and the foundation of the International Society for Sexuality and Cancer (ISSC), a new multidisciplinary international society founded to advocate this important area of clinical care.[9] Healthcare professionals should be aware that cancer and its treatment(s) may have deleterious effects on sexual functioning, sexual experience and fertility. These effects frequently extend beyond the acute phase and may be precipitated and/or maintained by both the type of cancer and its treatment(s).[2,4,5,6] Furthermore, according to many patients, these changes occurring in the field of sexual functioning and sexual experience may be one of the most dramatic outcomes affecting general and social well-being of cancer survivors and their partners.[1] Hence, sexuality is believed to be an important contributor to the maintenance and quality of relationships. Despite the life-threatening nature of cancer that might result in the assumption that sexuality is not important to patients and their partners, listening to the experiences of patients suggests the opposite.[5]

Moreover, it has been shown that sexual side-effects are not uncommon: several studies show that 35%-50% of cancer survivors may experience sexual dysfunction as a consequence of cancer or its treatment.[4,7,9,10] This high prevalence contrasts with the lack of attention for sexuality in care for patients with a chronic disease.[11] When asked about this matter, cancer patients clearly report that they would welcome information about sexual matters; however, several barriers seem to prevent this.[10] This means that patients and their partners often report feelings of abandonment, of not being taken seriously, and to be minimally informed or even uninformed about this sensitive topic. The fact that sexual side-effects are not addressed in care often leads to unnecessary chronic sexual problems that could have been prevented by a simple and empathic discussion about this topic.[5,7,10,11]

Impact of cancer on sexual functioning, sexual experience and intimacy of men and women with different types of cancer

Different types of cancer and their treatment may have different effects on sexual functioning and sexual experience as shown in the vignettes underneath:

Michael, a 37- year old homosexual patient has had a jawbone removal: "I am so afraid to kiss my boyfriend. I feel unattractive with the big scar in my face and after the removal of my jawbone I produce a lot of saliva. I am also not sure if my partner still finds me attractive."

Maggy, a 34-year old woman who survived breast cancer: "where previously I felt pleasure when my breasts and nipples where touched, I now feel pain and a numb sensation when being touched there. My partner is not allowed anymore to touch this area. For me, this part of my body has become a 'forbidden' area. I also became postmenopausal which means that my vagina feels dry, I have hot flashes, I cannot sleep very well … and this all clearly affects my sexual life."

Heidi, a 54-year old woman with lung cancer: "I am too tired to think about sex. Sex has been off the menu from the time of diagnosis and has been ever since."

The primary aim of cancer treatment is to cure the patient or to reduce the worst symptoms of the disease in an attempt to improve the quality of life of patients.[12] As for medical practice in general, this means that certain side-effects are inevitable.[13] For all cancer treatment options it is true that they can potentially affect sexuality in a negative way with their impact ranging from relatively mild to extremely debilitating.[2] The impact on sexuality may stem from biological as well as from psychological and relational consequences of cancer and more often a combination of bio-psycho-social factors is involved.[11,14]

From a biological perspective, a wide variety of physical changes occurring as a result of specific cancer processes may affect the physiology of sexual functioning due to hormonal imbalances (e.g. pituitary adenoma), vascular or nerve damage (e.g. paraneoplastic syndromes).[2] Several cancer treatment options may also affect the physiology of sexuality (e.g. chemotherapy-induced premature menopause, surgery-induced mutilation (e.g. vulvectomy, penectomy), radiotherapy-induced stenosis). Men were often shown to suffer from erectile dysfunction related to nerve damage,

blood flow to the penis, dry and retrograde ejaculations and loss of sexual desire.[13] In women, sexual dysfunction is frequently associated with the sudden failure of the ovaries and its associated menopausal symptoms such as decreased sexual desire, sterility, anovulation, hot flashes, mood swings, vaginal atrophy, fibrosis, stenosis, vaginal dryness, irritation, itching and dyspareunia.[2,4,16] Moreover, ovarian failure has a serious impact on fertility and is consequently extremely distressing for those diagnosed in their reproductive years.[4] Difficulty to reach orgasm may occur but is mostly secondary to a lack of desire and pleasure during sexual activities. Loss of sexual desire is often a consequence of the side-effects of chemotherapy such as hair loss, lack of energy, nausea, fatigue, diarrhoea, constipation, dry mouth and insomnia.[1,2,4,5,13] Thus, chemotherapy, radiation and surgical cancer treatments may affect sexual activity by making it either difficult or undesirable.[2] It is important to note that in the context of chronic illnesses, there is a tendency to overestimate the importance of somatic factors in the aetiology of sexual dysfunctions and sexual problems.[11] Awareness of this skewed attention bias should help healthcare professionals not to restrict their way of addressing sexual side-effects to this topic.

Indeed, apart from physiology, psychological and relational issues related to cancer and/or its treatment(s) may also affect sexual functioning and sexual experience. Cancer is more than a somatic disease as it also introduces existential uncertainty and consequently has been characterised by a high psychological burden, comprising feelings such as e.g. shame, low self-esteem, stress, depression and communication problems which may lead to an aggravation of symptoms.[1,11,13] Similarly, sexuality is also more than sexual functioning per se, it also concerns body-image, confidence levels and self-esteem which all have their impact on intimacy and relationships.[10] In most cancer patients, their psychosocial well-being is affected. [1,11,13] But cancer not only affects patients; it affects their partners as well. Partners often feel inadequate and unprepared about their (in)ability to cope with their partner's illness. [2,15,16] The often prolonged stress around the cancer and its treatment has an impact on both the partner's physical and emotional well-being.[15] On the one hand, differences in coping with emotions, feelings of disappointment and grief can lead to anxiety or distance which, in their turn, can lead to sexual concerns. On the other hand, the shared distress can lead to an intensification of the relationship.[13] Sexuality and intimacy may help to pass cancer treatment because intimacy may be a source of comfort during treatment and recovery from cancer. Very often, intimacy becomes more important than sexuality itself.[7] Hence, human sexuality in the context of cancer is much more than the ability to have intercourse, it may also be helpful in coping with the many challenges related to a cancer diagnosis: being intimate with a partner helps people to feel loved, supported and accepted.[1,7,10]

Why is it so difficult to talk about sexuality?

The impact of cancer on sexuality thus often requires an adjustment from both the patient and the partner. In comparison to other areas of adjustment after illness, the recovery of sexuality may be hampered by the fact that most patients and partners find it difficult to talk openly about sex. Furthermore, there is a lack of professional attention for this topic which is partially based on the general taboo surrounding sexuality.[3,10] Nevertheless, it has been shown that patients and their partners, need and want information regarding the effects of illness, the treatment, and the effects on sexuality.[7,10,17] For many patients sexuality is an important subject that adds to their quality of life.[10] Hordern and Street (2007) showed that many patients were disappointed by the lack of information, support and practical suggestions in living with the sexual and intimate changes they experienced in the face of cancer, provided by healthcare professionals .[18]

Patients have many questions and concerns about their sexuality, but they find it difficult to initiate a conversation with a healthcare provider. They do not feel comfortable bringing up such a sensitive topic and they hope/expect that healthcare professionals will start this conversation.[9,17,19] But even when a patient starts a dialogue about sexual issues, most, often well-trained professionals do not know how to deal with the sexuality issue. Professionals often do not regard discussing sexual dysfunctions and sexual problems with their patients as their responsibility. Frequently, they do not feel skilled or confident enough to address sexual issues and they are often worried about offending patients by asking too intimate questions.[9,20] They assume that, if a

patient has a specific concern about sexuality, he or she will raise the topic himself or herself.[19] Unfortunately, research has shown that patients - in their turn - are not sure whether asking sexual questions would be appropriate, and if so, they are unaware whether anything could be done.[9] Consequently, avoidance of discussing sexuality – by patients, partners and healthcare professionals – is more rule than exception.[10,19]

What could be done in this respect in oncology ?

An open dialogue about sexuality must be initiated soon after the diagnosis of cancer has been confirmed and must continue throughout the whole course of treatment.[2,11] Research has shown that, if sexuality is mentioned in the early stages of treatment, the sexual outcome may be better.[10]

Key factors for the improvement of communication about sexuality in oncology care are education of professionals, healthcare professionals and the general public.[5,10] The responsibility of ensuring this sensitive topic could be taken up by trained professionals such as e.g. sexologists or sex therapists who may educate both healthcare professionals and patients about the impact of cancer and its treatment(s) on sexuality and intimacy.[9] In this way, addressing sexual side-effects of cancer and its treatments could become an integral part of training courses for professionals working in an oncology setting. Indeed, healthcare professionals' work should be based on a holistic view, which includes ensuring that patients have the knowledge they need about the effects of cancer treatment on their sexuality.[10,20] Sexuality must be discussed with the patient and if needed, patients and their partners should be referred to a trained specialist.

The PLISSIT model of Jack Annon (1976)[21]

Annon developed a model in 1976 illustrating the fact that most people with sexual problems do not need an intensive course of therapy (see *Figure 1*).[16] He used the acronym PLISSIT to describe 4 levels of sex counselling: Permission giving, Limited Information, Specific Suggestions and Intensive Therapy.[2,13,20,21] Permission giving to the individual (or couple) to ask questions and discuss sexuality, providing Limited Information about sexual concerns or questions, giving Specific Suggestions in response to questions about sexuality, providing Intensive Therapy for sexual issues of the individual (couple).[16] Each level of the PLISSIT model provides increasingly deeper or more complex levels of treatment for which more training is necessary. The first 3 levels can easily be performed by healthcare professionals such as nurses and physicians that have invested in some personal and professional training in this field.[2,16] The last level, intensive therapy, should be performed by sex therapists and only when the first 3 levels were not sufficient to bring a solution. [2,16] Thus, nurses, physicians and other healthcare professionals are responsible for what could be called the basis.[16] Indeed, the nurse routinely caring for the patient is in an ideal position to provide information because of frequent patient contact, often involving hygienic and personal care, as well as emotional support.[17] A good analysis of the specificity of sexual problems can lead to practical interventions which can be as simple as advising a lubricant, vaginal moisturisers, discussing the possibilities of other sexual positions or having sex in the morning without fatigue. All these recommendations, when discussed in an understanding and empathic manner, can make a big difference in the life of cancer survivors and their partners.[11,20] Patients also need to be reassured that the changes they are experiencing are normal. For many patients, just giving them the permission to discuss sexuality will suffice.[5, 10] For others, this is insufficient, which means that healthcare professionals should search for the right level in terms of the PLISSIT-model to address their patients.

According to Chamberlain et al, we can distinguish 4 key processes needing to be addressed by health-

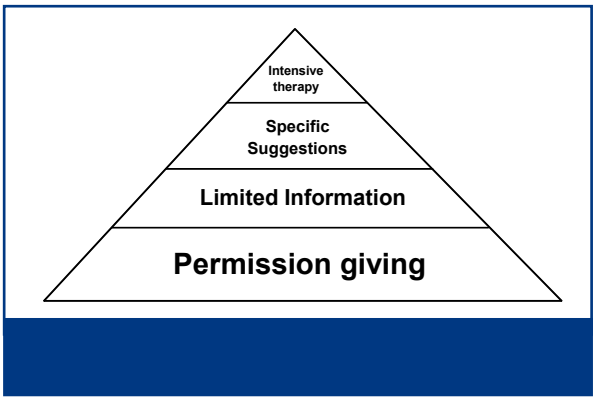

Figure 1. The PLISSIT Model of Sex Therapy

Key messages for clinical practice

1. Overall, 35%-50% of all cancer patients suffer from sexual problems due to cancer and/or its multimodal treatment.
2. Sexual dysfunction, problems and worries are amongst the most common and long-term side-effects of cancer treatment.
3. Both patients and healthcare professionals are reluctant to discuss the sexual side-effects of cancer and its treatments.
4. Patients and their partners express a need for more information about sexual side-effects of cancer and its treatments.
5. Healthcare professionals are responsible for initiating a discussion on sexuality in the context of oncology care.
6. The PLISSIT-model is a useful framework for the analysis of patients' needs and choosing the level on which a professional feels him/herself comfortable to address sexual issues in clinical care.
7. A multidisciplinary approach is needed, in which professionals with expertise in the field of sexual healthcare or sex therapy are integrated.

care professionals in order to be able to grow in the responsibility to discuss sexuality with their patients: (a) achieving comfort with their own sexuality and with talking about sexuality; (b) gaining sufficient knowledge about sexuality, illnesses, and treatments and how these affect sexuality; (c) to hone effective communication skills; and (d) identifying practitioners (with more experience) who can help to incorporate sexual healthcare into their practice.[20]

The need for sexologists in oncology care

Sexologists and sex therapists that are part of oncology teams may be helpful in closing the above described and currently existing gap between what patients need and professionals offer in oncology care. Their presence will be helpful to increase awareness about this sensitive topic and they can improve the knowledge on the link between cancer, sexuality and intimacy for both professionals and patients. Apart from being the dog in the bowling game in teams of professionals, sexologists may help patients with sexual adaptation - also called sexual rehabilitation - during and after cancer treatment. It is important that people feel themselves accepted and supported in their sexual needs and that they can re-establish a feasible and satisfactory sexual life within the possibilities that still exist. Talking to a (sexual) healthcare provider with an open, warm and accepting attitude can be liberating. Using a bio-psycho-social framework of the patient's problem could be helpful in this respect. One of the tasks of a sex therapist could be helping to shape sexuality in a creative way, paying attention to the existing limitations and helping to overcome or cope with these. The emphasis in this approach is focussed on sexual pleasure rather than on sexual performance.[11] Sexologists and sex therapists are trained to formulate several hypotheses when looking at sexuality in the context of cancer care, and are capable of looking beyond physiological problems.[11] It may be useful to inform patients preventively about the effects of cancer and its treatments on sexuality and intimacy. By doing so, patients and their partners will be better prepared

for any dysfunction, problems or worries that may occur. It may also be helpful for patients to have a more clear understanding of the changes in the area of sexuality and intimacy that may be taking place. Ignoring sexuality during cancer treatment can, as such, be an important factor in the development of - often preventable - chronic sexual problems.[19] While discussing sexuality and intimacy, attention should also be paid to socio-sexual cognitions that put forward seemingly normative beauty ideals and pressure to perform (e.g. reach an orgasm, have penetration) because these seem to have a large impact on patients and couples with cancer.[11] Thus, although sexologists are still only rarely integrated in oncology teams, they can be very helpful in different ways such as e.g. informing, educating and assisting healthcare professionals on this link between cancer, sexuality and intimacy and address the needs of patients.[11] If, in future, cancer clinics would organise specific consultation opportunities for addressing sexual dysfunction, the needs of patients would be better served in oncology care.[5,10]

Conclusion

It is clear that all cancer types and all cancer treatments may potentially negatively affect the bio-psycho-social basis of sexuality. It is possible to continue a healthy and satisfying relationship and maintain a healthy sexual image even after these have changed as a consequence of cancer or its treatments. It may require adaptation of the patient's current sexual patterns but with the right information, support and encouragement from well-informed and trained healthcare professionals and acceptance and support of their partners, it should be possible for those interested. Sexual dysfunction and sexual problems are potential long-term complications of cancer treatments and these should therefore be addressed with adequate sexual information and, if necessary, sex therapeutic interventions.[4]

The desirability of a multidisciplinary approach on cancer has long been recognised. The number of specialised teams in hospitals has increased; however, sexological and/or sex therapeutic expertise is mostly lacking. It is important that a full integration of sexual rehabilitation becomes a reality of supportive care in oncology. It has been advocated that oncology must pay attention to all areas of quality of life; this means that sexuality and intimacy should be included in this too. Let this new sexual (r)evolution soon begin!

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