Cancer and sexual health: The continuum of care

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Chapter 1: General introduction

"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)."

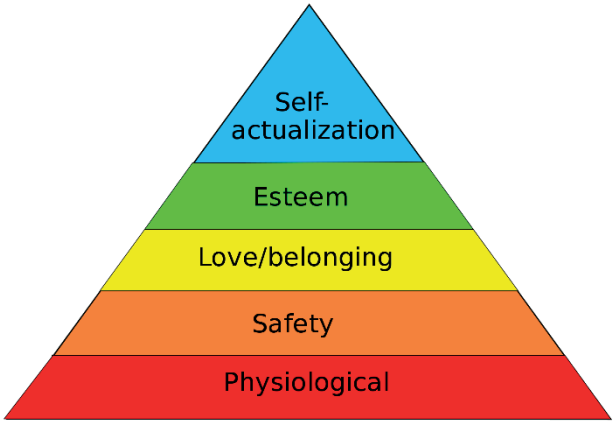

Figure 1: Maslow's hierarchy of needs
Source: Maslow, A.H, A theory of human motivation. Psychological Review 1943. 50 (4): 370–96.

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**, effectives 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.

REFERENCES

1. World Health Organization, Sexual health issues [2 april 2020]. Available from: https://www.who.int/sexual-and-reproductive-health/sexual-health-issues/ [
2. Maslow A. A Theory of Human Motivation Psychological Psychological Review. 1943;40(4): 370-96.
3. Cleary V, Hegarty J. Understanding sexuality in women with gynaecological cancer. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2011;15(1):38-45.
4. Woods NF. Toward a holistic perspective of human sexuality: alterations in sexual health and nursing diagnoses. Holistic nursing practice. 1987;1(4):1-11.
5. de Vocht H, Hordern A, Notter J, van de Wiel H. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. The Australasian medical journal. 2011;4(11):610-9.
6. World Health Organization. Defining sexual health 2006 [1 april 2020]. Available from: https://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/.
7. C Foster LC, A Richardson, H Pimperton, R Nash. Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice. Journal of Cancer Policy. 2018;15:92-5.
8. Maddams J, Utley M, Moller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. British journal of cancer. 2012;107(7):1195-202.
9. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2019. CA: a cancer journal for clinicians. 2019;69(1):7-34.
10. Ben Charif A, Bouhnik AD, Courbiere B, Rey D, Preau M, Bendiane MK, et al. Sexual health problems in French cancer survivors 2 years after diagnosis-the national VICAN survey. J Cancer Surviv. 2016;10(3):600-9.
11. Sun V, Grant M, Wendel CS, McMullen CK, Bulkley JE, Herrinton LJ, et al. Sexual Function and Health-Related Quality of Life in Long-Term Rectal Cancer Survivors. The journal of sexual medicine. 2016;13(7):1071-9.
12. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. EJC supplements : EJC : official journal of EORTC, European Organization for Research and Treatment of Cancer [et al]. 2014;12(1):41-53.
13. Andersen BL, DeRubeis RJ, Berman BS, Gruman J, Champion VL, Massie MJ, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2014;32(15):1605-19.
14. Weaver KE, Forsythe LP, Reeve BB, Alfano CM, Rodriguez JL, Sabatino SA, et al. Mental and physical health-related quality of life among U.S. cancer survivors: population estimates from the 2010 National Health Interview Survey. Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology. 2012;21(11):2108-17.
15. Chang YC, Hu WY, Chang YM, Chiu SC. Changes in sexual life experienced by women in Taiwan after receiving treatment for breast cancer. International journal of qualitative studies on health and well-being. 2019;14(1):1654343.
16. Acquati C, Zebrack BJ, Faul AC, Embry L, Aguilar C, Block R, et al. Sexual functioning among young adult cancer patients: A 2-year longitudinal study. Cancer. 2018;124(2):398-405.
17. Wettergren L, Kent EE, Mitchell SA, Zebrack B, Lynch CF, Rubenstein MB, et al. Cancer negatively impacts on sexual function in adolescents and young adults: The AYA HOPE study. Psychooncology. 2017;26(10):1632-9.
18. Nicolosi A, Buvat J, Glasser DB, Hartmann U, Laumann EO, Gingell C. Sexual behaviour, sexual dysfunctions and related help seeking patterns in middle-aged and elderly Europeans: the global study of sexual attitudes and behaviors. World journal of urology. 2006;24(4):423-8.

19. Dobinson KA, Hoyt MA, Seidler ZE, Beaumont AL, Hullmann SE, Lawsin CR. A Grounded Theory Investigation into the Psychosexual Unmet Needs of Adolescent and Young Adult Cancer Survivors. Journal of adolescent and young adult oncology. 2016;5(2):135-45.
20. Olsson M, Steineck G, Enskar K, Wilderang U, Jarfelt M. Sexual function in adolescent and young adult cancer survivors-a population-based study. J Cancer Surviv. 2018;12(4):450-9.
21. Szalda D, Schapira MM, Jacobs LA, Palmer SC, Vachani C, Metz J, et al. Survivorship Care Planning for Young Adults After Cancer Treatment: Understanding Care Patterns and Patient-Reported Outcomes. Journal of adolescent and young adult oncology. 2018;7(4):430-7.
22. Ussher JM, Perz J, Gilbert E. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC cancer. 2015;15:268.
23. Sadovsky R, Basson R, Krychman M, Morales AM, Schover L, Wang R, et al. Cancer and sexual problems. The journal of sexual medicine. 2010;7(1 Pt 2):349-73.
24. Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. Cancer Nurs. 2009;32(4):271-80.
25. Chatterjee R, Andrews HO, McGarrigle HH, Kottaridis PD, Lees WR, Mackinnon S, et al. Cavernosal arterial insufficiency is a major component of erectile dysfunction in some recipients of high-dose chemotherapy/chemo-radiotherapy for haematological malignancies. Bone marrow transplantation. 2000;25(11):1185-9.
26. Wendt C. Perception and Assessment of Verbal and Written Information on Sex and Relationships after Hematopoietic Stem Cell Transplantation. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017;32(4):681-9.
27. Reese JB, Haythornthwaite JA. Importance of sexuality in colorectal cancer: predictors, changes, and response to an intimacy enhancement intervention. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2016;24(10):4309-17.
28. Reisman Y, Gianotten W. Cancer, Intimacy and Sexuality. 1 ed: Springer International Publishing; 2017.
29. Lehto US, Aromaa A, Tammela TL. Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. European journal of cancer care. 2018;27(1).
30. Oldertroen Solli K, de Boer M, Nyheim Solbraekke K, Thoresen L. Male partners' experiences of caregiving for women with cervical cancer-a qualitative study. Journal of clinical nursing. 2019;28(5-6):987-96.
31. Miaja M, Platas A, Martinez-Cannon BA. Psychological Impact of Alterations in Sexuality, Fertility, and Body Image in Young Breast Cancer Patients and Their Partners. Revista de investigacion clinica; organo del Hospital de Enfermedades de la Nutricion. 2017;69(4):204-9.
32. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. European journal of cancer care. 2016;25(2):280-93.
33. Garos S, Kluck A, Aronoff D. Prostate cancer patients and their partners: differences in satisfaction indices and psychological variables. The journal of sexual medicine. 2007;4(5):1394-403.
34. Gilbert E, Ussher JM, Hawkins Y. Accounts of disruptions to sexuality following cancer: the perspective of informal carers who are partners of a person with cancer. Health (London, England : 1997). 2009;13(5):523-41.
35. Mehta A, Pollack CE, Gillespie TW, Duby A, Carter C, Thelen-Perry S, et al. What Patients and Partners Want in Interventions That Support Sexual Recovery After Prostate Cancer Treatment: An Exploratory Convergent Mixed Methods Study. Sexual medicine. 2019;7(2):184-91.
36. Rottmann N, Gilsa Hansen D, dePont Christensen R, Hagedoorn M, Frisch M, Nicolaisen A, et al. Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study. Acta oncologica (Stockholm, Sweden). 2017:1-8.
37. Kroenke CH, Michael YL, Poole EM, Kwan ML, Nechuta S, Leas E, et al. Postdiagnosis social networks and breast cancer mortality in the After Breast Cancer Pooling Project. Cancer. 2017;123(7):1228-37.

38. Walker LM, Wiebe E, Turner J, Driga A, Andrews-Lepine E, Ayume A, et al. The Oncology and Sexuality, Intimacy, and Survivorship Program Model: An Integrated, Multi-disciplinary Model of Sexual Health Care within Oncology. Journal of cancer education : the official journal of the American Association for Cancer Education. 2019.
39. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology. 2012;21(6):594-601.
40. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Medical journal of Australia. 2007;186(5):224-7.
41. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. Psychology & health. 2013;28(12):1370-90.
42. Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. Social science & medicine (1982). 2007;64(8):1704-18.
43. Crowley SA, Foley SM, Wittmann D, Jagielski CH, Dunn RL, Clark PM, et al. Sexual Health Concerns Among Cancer Survivors: Testing a Novel Information-Need Measure Among Breast and Prostate Cancer Patients. Journal of cancer education : the official journal of the American Association for Cancer Education. 2016;31(3):588-94.
44. Hautamaki K, Miettinen M, Kellokumpu-Lehtinen PL, Aalto P, Lehto J. Opening communication with cancer patients about sexuality-related issues. Cancer nursing. 2007;30(5):399-404.
45. Krouwel EM, Nicolai MP, van der Wielen GJ, Putter H, Krol AD, Pelger RC, et al. Sexual Concerns after (Pelvic) Radiotherapy: Is There Any Role for the Radiation Oncologist? The journal of sexual medicine. 2015;12(9):1927-39.
46. Krouwel EM, Hagen JH, Nicolai MP, Vahrmeijer AL, Putter H, Pelger RC, et al. Management of sexual side effects in the surgical oncology practice: A nationwide survey of Dutch surgical oncologists. European journal of surgical oncology : the journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology. 2015;41(9):1179-87.
47. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2015;19(6):707-15.
48. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? Psycho-oncology. 2015;24(9):1167-73.
49. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. Patient education and counseling. 2016;99(11):1814-20.
50. Jonker-Pool G, Hoekstra HJ, van Imhoff GW, Sonneveld DJ, Sleijfer DT, van Driel MF, et al. Male sexuality after cancer treatment--needs for information and support: testicular cancer compared to malignant lymphoma. Patient education and counseling. 2004;52(2):143-50.
51. Almont T, Couteau C, Etienne H, Bondil P, Guimbaud R, Schover L, et al. Sexual health and needs for sexology care in digestive cancer patients undergoing chemotherapy: a 4-month cross-sectional study in a French University Hospital. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2018.
52. Evashwick C. Creating the continuum of care. Health matrix. 1989;7(1):30-9