Cancer and sexual health: The continuum of care

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PART V

FUTURE DIRECTIONS

Chapter 10: Summary and general discussion

The main purpose of this thesis was (1) to evaluate the needs and preferences of information and support regarding sexual health in cancer care and (2) to investigate the best way of providing information regarding sexuality to patients. In addition, (3) strategies to enhance communication about sexuality were explored.

Over the last decades, it has been well studied that cancer and its treatment have a negative impact on sexuality and intimacy of patients with cancer and their partners. A negative impact on sexuality might occur regardless of age, cancer type or treatment(1). Problems with sexuality might arise at time of diagnosis, during treatment or follow-up. Sexual health problems are likely to remain into long-term survivorship(1-5). Patients do report a need for information and support with these problems(6-13). However, patients, as well as healthcare providers, experience several barriers to discuss sexual health in medical practice. This thesis adds new insights about preferences of patients and partners regarding information and support for cancer induced sexual concerns (**Chapter 2, 4, 5, 7**). Additionally, in **Chapter 3** factors which are related to sexual satisfaction after cancer treatment were discussed, in particular for patients after radical prostatectomy for prostate cancer. In **Chapter 6, 7** and **8** perspectives of healthcare professionals were described. **Chapter 9** provided insights in the effectiveness of education for healthcare professionals to enhance communication about sexuality and describes other factors to optimize the delivery of sexual healthcare. Finally, a summary of the results and future directions are described in this chapter (**Chapter 10).**

The patient
Not all patients with cancer may have the same need for information regarding sexual health(14). According to the survey described in **Chapter 2**, 35% of the cancer patient did not report a direct need for information. To deliver patient-centered care, it would be helpful to explore which patients are more in need of information. In **Chapter 2** was found that younger age, more self-reported negative impact of cancer on sexuality and time since diagnosis were associated with a higher need. These factors can be seen as guiding factors, not to exclude patients from information or support. Younger patients, for example, reported a higher information need. However, sexual activity continues to an old age. Older adults stated their sexual life as important. Therefore, sexuality in older patients cannot be neglected (1, 6, 15-18). Though research in the elderly cancer patient is limited. In **Chapter 2,** a higher need for support and information was found in patients diagnosed less than two years ago. This finding may indicate that information should be provided actively to patients during this period. In **Chapter 5,** investigating the preferences of breast cancer patients, was again highlighted that information should be offered at the appropriate time during the treatment process. AYAs (**Chapter 7)** agreed with the importance of timing of information, preferably at start of treatment. Timely information provision may contribute to realistic expectations of the impact of cancer treatment on sexuality and may reduce distress(21). Nevertheless, in **Chapter 2** was described that 57% of the respondents who were diagnosed with cancer more than 10 years ago still reported a need for information. This indicates the importance of the availability of information regarding sexuality during long time follow-up. Sexual issues are known to remain into long-term survivorship(2). It is recommended to embed information regarding sexuality not only in standard care and follow-up but also make it is available and easily accessible online without healthcare professionals needing to be the gatekeepers to that information.

Chapter 2 further explored what kind of information cancer patients preferred. Practical advice, practical information and experiences from others were considered as most useful. **Chapter 7** and **Chapter 5** suggested that information can be offered during a conversation with a healthcare professional as well as in written form via brochures or websites. Given the distribution of preferences regarding kind of information, the availability of information in multiple forms would be helpful. In **Chapter 7** and **Chapter 5** most patients reported to feel most comfortable to discuss sexuality with a nurse practitioner. In the Netherlands, the nurse practitioner plays a coordination role in cancer care and supports patients during treatment and follow up. Previous research reveals that nurses do feel responsible for discussing treatment related sexual problems with patients, but experience some barriers to discuss sexual health(19, 20). There is ongoing research to develop interventions which try to support healthcare providers.

Chapter 3 demonstrated that sexual satisfaction of prostate cancer patients is not exclusively dependent on erectile function. Sexual satisfaction before cancer treatment is more important to sexual satisfaction than the erectile function itself. Moreover, no improvement nor decrease in sexual satisfaction between 6-months and 36-months follow-up in patients with erectile dysfunction were found. Psychological interventions focusing on adjustment to changes in sexual functioning after surgery might improve sexual satisfaction; especially for those men who remain suffering from erectile dysfunction(21). It can be argued that these findings might also be true for other cancer types. In a study among survivors of testicular cancer (TC) and their spouses was found that older TC survivors had a greater sexual satisfaction, although a younger age was predicted a better sexual functioning in TC survivors. Sexual satisfaction was strongly related to marital satisfaction(22). This supports our findings that sexual satisfaction and sexual function are not perfectly matched. It is recommended not only to ask about sexual function but also about sexual satisfaction and relationship to deliver good sexual healthcare. More research is needed to implement and optimize this care.

The partner

Previous literature revealed that partners of patients with cancer report a negative impact on their sexuality and relationship due to disease and treatment(7, 23-27). In **Chapter 4** and **Chapter 5**, partners reported the need to be involved in communication and information regarding sexual health. These chapters further investigated which partners are more in need as well as their preferences. In contrast to the findings in **Chapter 2** and the existing literature, in **Chapter 4** (a survey among partners of patients with cancer) was found that age and time since diagnosis were not associated with a higher need for information(6, 7, 18). Patients' treatment or stage of disease were neither related. In concordance with findings in **Chapter 2**, self-reported negative impact of cancer on sexuality and intimacy was associated with a higher information need. Given these findings, it might be difficult to identify partners who are likely to be more in need of information. Moreover, it can be argued that partners are less likely to directly report their need for support and information regarding treatment induced sexuality problems. Some partners may consider their sexual needs are inappropriate(24). In time, people want life to return to as normal as possible again and may have more attention for sexuality and intimacy. During this phase, information regarding sexual health might be more important. Though, partners in **Chapter 5** reported to prefer to receive information regarding sexual health before treatment. Suitable information with respect to sexuality and intimacy for partners can be helpful to create realistic expectations about sexual function during treatment and after cancer(28). Additionally, open communication may result in better coping with sexual concerns(29-31). Partners in **Chapter 4**, suggest that information should be easily accessible and actively provided to partners. To optimize information and support, future research could include a longitudinal prospective study to evaluate information for partners per type of cancer including qualitative data.

The healthcare professional

As described in **Chapter 2, 4, 5** and **7**, in current medical practice, communication about treatment induced sexual concerns between patient, partners and healthcare professional is not routine of care. Literature reveals several difficulties and mismatches in expectations in discussing sexual health in cancer care(7, 8, 16, 24, 32). Best timing of providing information and the responsibility for discussing sexual side effects within a medical team was point of discussion. Regarding best timing, healthcare professionals working with AYAs (**Chapter 8)** tended to discuss more urgent side effects of cancer treatment first. Some did consider sexual side effects not as a priority. Further, in **Chapter 6,** Dutch oncologists stated to rarely bring up sexual side-effects during the informed consent conversation before the start of treatment. Informed consent is seen as a crucial component of medical practice and authenticates patients‘ autonomy(23). Given the high prevalence and additional burden of sexual dysfunction after cancer treatment, these sexual side-effects of treatment may considered to be part of informed consent conversation(1, 33-38). Lack of clarity about sexual side-effects in existing guidelines may result in ambiguity regarding timing for discussing sexual health(39).

Concerning the responsibility of bringing up the subject, members of the multidisciplinary oncological team seem to count on each other to tackle the conversation about sexual health(19, 20, 40). **Chapter 6** and **8** emphasized the importance of defining responsibilities within the oncology treatment team. De Vocht et al. described a Stepped-Skills-model, which could be of help to define responsibilities(39). In this team-approach-model, there are team members who are “spotters”. These spotters, most likely the oncologist, discuss sexual side-effects of treatment, check whether patients need help and refer them when necessary. Other members are called “skilled companions”. They have the responsibility to support patients in their sexuality issues. This task fits probably best to specialized nurses given their frequent contact with the patient and their available time, as reported in **Chapter 8.** Consequently, these members require training to improve their communication skills and their knowledge.

As facilitating tools to enhance communication about sexual health in medical practice, healthcare professionals, interviewed in **Chapter 8,** suggested a self-report questionnaire for the patients, a checklist for healthcare professionals and material to hand. The availability of written material was also emphasized by the patients who participated in the surveys in **Chapter 2, 5** and **7**. However, with the increasing pressure on daily practice of healthcare professionals, and taking the major barrier – lack of time - into consideration, there is also a need for alternative ways of providing sexual healthcare.

The organization & future directions

There has been a call within cancer care organizations to improve patient reported outcomes by improving the delivery of sexual healthcare for cancer patients. Suitable sexual healthcare includes psychosocial support, attention for the partner and information about treatment options(41). Current literature is lacking an optimal format of sexual health in oncology care. However, some models of providing sexual healthcare are described in literature(42, 43). These models are described as a pyramid of care; at the bottom general, straight-forward services that are of benefit for all patients. Services more toward the top are more intensive and specialized, for complex problems (**Figure 1**). For a part of the patients, and partners, queries can be solved with (online) educational materials only, as displayed in the bottom of the pyramid in **Figure 1**(43). Others may in need of a step up in the pyramid and prefer to discuss the topic with a healthcare professional. However, in concordance with previous research, the survey among oncologist in **Chapter 6** reported important reasons for the lack of frequency in discussing sexual health to be a 'lack of training' and a 'lack of knowledge'(19, 20, 40, 44). Education for healthcare professionals is highlighted in **Figure 1,** as well as in **Chapter 8** and **Chapter 6** of this thesis. **Chapter 9** focussed on the effectiveness of educational interventions for oncology healthcare professionals to improve communication about sexual health with patients. The amount of studies and quality were limited. Therefore an overall recommendation could not be provided. Nevertheless, an increase in having enough knowledge, practice items, frequency of discussing, comfort levels and less perceived barriers due to an intervention for healthcare professionals were seen in these studies. On the base of the review, it can be argued that face-to-face education with practice exercises are more effective than online interventions. However, the effectiveness of education for healthcare providers cannot be proven based on the existing literature. More longitudinal research is needed to optimized a format for educational interventions.

Attention regarding sexual healthcare should not only be focused on knowledge and training of the healthcare professionals, but also on organization of sexual healthcare within medical practice. Sexual health concerns are typically not prioritized in busy follow-up clinics focusing on cancer status. Helpful organizational factors concerning providing sexual healthcare by healthcare professional to patients were explored in **Chapter 8.** Healthcare professionals suggested it would be easier initiating the conversation if they had the opportunity to discuss patients' problems in a multidisciplinary team meeting to get advice. They considered the possibility to refer patients to a sexologist within their hospital as important. A recent evaluation within a Canadian cancer center showed that the introduction of specialized sexual health services within the hospital increased the frequency of healthcare professionals initiating a conversation about sexuality with their patients(43). The guideline 'interventions to address sexual problems in people with cancer' of the American Society of Clinical Oncology (ASCO) recommends clinicians to conduct an overview of experts and resources to address sexual health within their practice in order to deliver optimal sexual care to patients(38).

To treat specific sexuality issues caused by cancer, expertise in the complexity of cancer treatment and psychological support is fundamental. A trend is the formation of specialized cancer-related sexual health clinics(43, 45-47). Advantages include the availability of specialized knowledge, protected time to prioritize sexual health concerns within cancer care and provision of integrated biopsychosocial care. Studies which investigated specialized multidisciplinary sexuality programs within their hospitals faced different challenges, like lack of sustainable funding, lack of staff and excessive wait times due to heave usage of the clinic(42, 43, 45, 46). However, a specialized sexuality clinic would tackle some frequently reported barriers like lack of time and lack of knowledge. More research is needed on the implementation of sexual healthcare in oncology practice to deliver continuum of care, which will ultimately improve patient care.

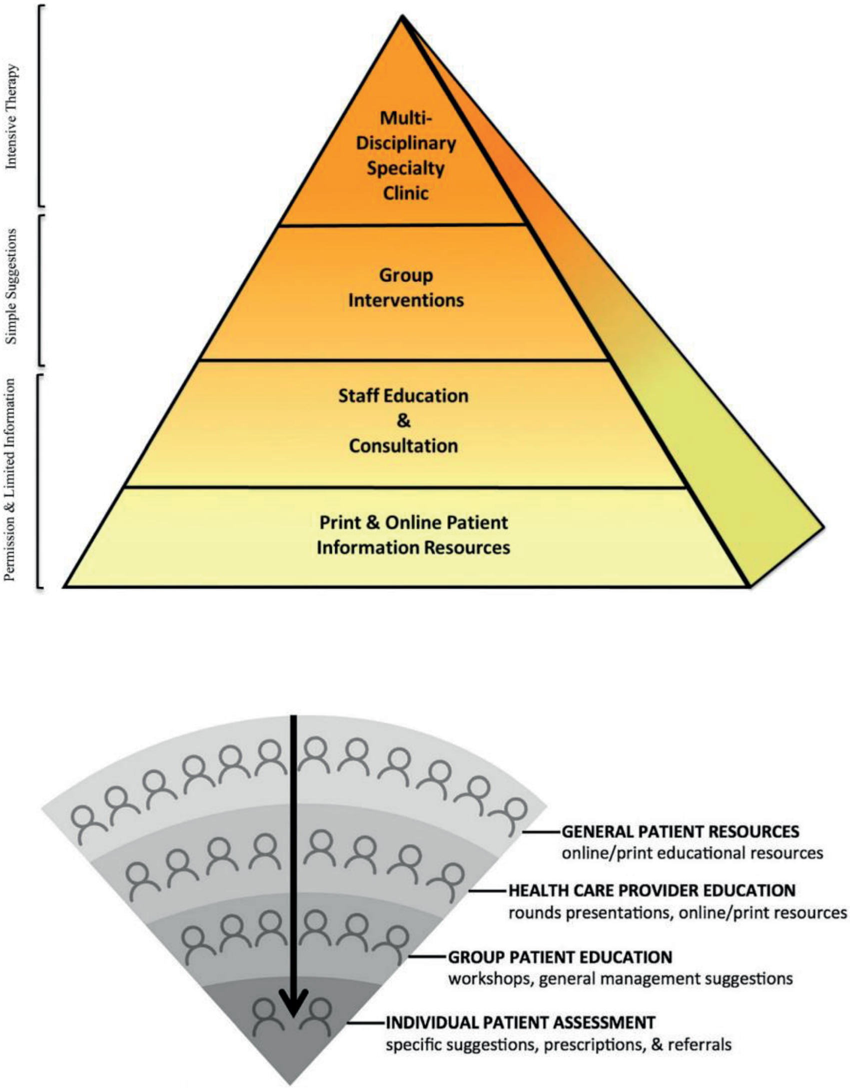

Figure 1: OASIS program model of sexual health care provision
Source: Duimering et al. *Support Care Cancer* (2019) and Walker et al. *J Canc Educ (2019)*.

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