Sexual rehabilitation after treatment for gynaecological cancer

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General discussion

CHAPTER 8

Improved cancer screening, early detection and treatment have led to higher survival rates and a growing number of women living with a history of gynaecological cancers over recent decades.[11] Cancer and its treatment may have a strong negative impact on women's sexual functioning. Half of the gynaecological cancer survivors report at least one sexual problem.[18,21,22,31,32] When sexual problems cause survivors to personally experience significant sexual distress this may lead to the diagnosis of a sexual dysfunction.[45] The increasing awareness of sexual difficulties during and after treatment, and attention to sexual problems in survivorship care is therefore a welcome and much-needed trend.

According to the Dutch national guideline for treatment of cervical cancer, each patient and her partner should receive counselling about possible treatment consequences for sexual functioning, and referral for professional support if needed.[4] However, current survivorship care does not meet the informational or professional help needs of these women and their partners.[179-184] While survivors only occasionally initiate a conversation or seek help for their sexual difficulties, in many cases the health care providers fail to raise the topic as well.[55,180,182,185,186] Therefore, appropriate rehabilitation measures for prevention and/or treatment of sexual problems among gynaecological cancer survivors are urgently needed.

This thesis focused on assessing what kind of education and/or support is needed to minimise the impact of gynaecological cancer treatment on sexual functioning, and on developing measures to improve the survivors' sexual recovery and wellbeing. In this chapter our main findings are discussed and put into perspective. Finally, research considerations and implications for clinical cancer care for future reference are provided.

Developing sexual rehabilitation measures in response to current sexual health care needs

It was established that gynaecological cancer survivors desired more extensive, and less medically oriented, information and practical psychosexual counselling and support after treatment (**chapter 3**). We investigated these shortcomings from several different perspectives. First of all, numerable gynaecological cancer survivors experience sexual distress (**chapter 2**). When we examined survivors' and their partners' experience with sexual recovery it was made clear that the impact on sexual distress was not only related to physical changes after treatment (**chapter 2**

and 3). The psychosocial aspects of sexual functioning were also important in determining whether survivors experienced sexual distress. Furthermore, it is likely that physical symptoms can induce or aggravate the psychosocial aspects and that both elements are not only two separate entities but are in fact interrelated. If this is true solving or diminishing physical symptoms might favourably affect the psychosocial aspects of sexual dysfunction. It was suggested that psychosexual support should be aimed at reducing treatment-induced vaginal symptoms and problems, but also at concerns about sexual pain, body image and relationship issues (**chapter 2 and 3**).

In order to improve current psychosexual care with practical and policy recommendations, we investigated how professionals should target physical vaginal symptoms as a consequence of treatment. Performing a nerve-sparing radical hysterectomy for early-stage cervical cancer did preserve survivors' vaginal blood flow during sexual arousal, whereas a radical hysterectomy resulted in a lower vaginal blood flow, compared to healthy controls. However, the reported levels of sexual dysfunction did not differ between women in the nerve-sparing versus non-nerve-sparing radical hysterectomy groups. Therefore, support during rehabilitation should not solely depend on the type of surgery that was conducted and rather be tailored to survivors' experiences with their sexual recovery (**chapter 4**). This seemed to be in line with **chapter 2** and a previous psychophysiological study, indicating that the experience of sexual concerns is not only determined by physical changes, but is affected by other factors as well, such as the survivors' psychological and relationship functioning.[103]

Women who receive combined primary external beam radiation therapy (EBRT) with brachytherapy (BT) for more advanced stages of cervical cancer or vaginal cancer are especially in need of support since they run a higher risk of radiation-induced vaginal symptoms, and are prone to experience higher levels of sexual distress (**chapter 2**). Consequently, these women need timely information and specific support to address sexual health related issues, and promote vaginal dilator use in order to prevent vaginal stenosis and adhesions. It is advised that they use dilators with a frequency of at least twice a week during at least 9 months after radiotherapy (**chapter 5**). The survivors' low compliance with these instructions was suggested to be best targeted by planning, preparing and coping with situations in which they might tend to stop using dilators (**chapter 5 and 6**). Health care providers should counteract negative emotions about dilator use or enlarge their perceived self-efficacy, by dealing with behavioural skills and motivational issues (**chapter 6**).

The professionals in gynaecological cancer treatment who participated in the studies agreed that it is part of their responsibility to provide information and practical advice on how to cope with sexual problems after treatment, and provide specific information and support regarding dilator use issues (**chapter 5**). It is important to stress that gynaecological cancer survivors should be supported with sexual relationship adjustment after treatment and regaining pleasurable sexual contact, which should also include alternative ways besides focusing on coital sex only (**chapter 3 and 6**). Furthermore, it was agreed that patients' radiation oncologists and gynaecological oncologists serve as a useful first resource of information, and specifically

trained nurses should provide the more extensive psychosexual support, after dedicated training. In case of more complex sexual problems and sexual distress, physicians should refer patients to a clinical psychologist-sexologist (**chapter 3 and 5**).

However, it is known that health care providers encounter barriers to provide psychosexual support to survivors such as embarrassment, a lack of time, but also a perceived lack of appropriate skills-training and dedicated patient information.[180] Physicians felt this dedicated support should be integrated in standard gynaecological cancer care. Therefore, supplemental training, time and materials should be made available to professionals working with survivors during sexual rehabilitation (**chapter 3 and 5**).

In the past thirty years only a few randomized controlled studies have investigated psychosexual interventions aimed at supporting gynaecological cancer survivors during sexual rehabilitation.[73,74,82,102,103,187–191] The interventions only showed a moderate effect in supporting survivors and the trials were of limited methodological quality.[79,103,192] Providing psycho-education 'only' turned out to have a relatively small effect in supporting survivors and additional professional support improved this effect significantly.[73,74,189] Therefore, future interventions should focus on more than providing information alone, and target patients' motivational and self-efficacy skills.[74,78] Providing two supportive group sessions shortly after gynaecological cancer treatment did not seem to suffice.[73,74] Indications are that specifically trained nurses can successfully conduct a psychosexual intervention that positively affects sexual functioning among gynaecological cancer survivors shortly after treatment.[82,187]

Adding such extensive psychosexual rehabilitation support, provided by specifically trained nurses, to standard care in the recovery phase seemed appropriate and promising in the context of our findings (**chapter 7**): In response to the findings in this thesis and previous literature we developed a four-session sexual rehabilitation intervention together with a patient information booklet for gynaecological cancer patients treated with EBRT combined with BT. Dedicated nurses conducted the intervention, directed at increasing knowledge and coping strategies regarding sexual issues, and dilator use, after a skills training by our psychologist-sexologists. The nurses' skills training covered, amongst others, techniques that were known to enhance the effectiveness of psychosexual support; the basic principles of sex- and cognitive behavioural therapy interventions relevant for negative emotions and avoidance behaviour,[97,135,193,194] and motivational interviewing to explicitly address self-efficacy and compliance with dilator use.[74,159,163,195] In line with survivors' and professionals' suggestions (**chapter 3, 5, 6 and 7**), the patients' partners, if available, were invited to participate in order to further increase the intervention's effectiveness.[164] Our prospective multicentre pilot-study showed that the intervention was feasible and promising regarding gynaecological cancer survivors' support during sexual rehabilitation, and regular dilator use (**chapter 7**). Our intervention can be seen as a stepped care model, such as for example the PLISSIT model.[196] Consistent with a stepped care model, we expect that most survivor's sexual problems can be resolved by following several levels of intervention. Greater knowledge and training of the health care provider regarding the subject is required as one moves up each

level of intervention.

Challenges in sexual health research among gynaecological cancer survivors

A strength of this thesis is that it encompasses research that successfully involved both health care professionals, including radiation oncologists, gynaecological oncologists, oncology nurses, sexologists, and patients and their partners. Therefore, the results of the studies and the sexual rehabilitation intervention that was developed have enjoyed wide support from the start, and may be easily implemented in future gynaecological cancer care. Furthermore, the various research methods described throughout the chapters proved to be valuable. The self-report questionnaires and psycho-physiological assessments served to quantify sexual functioning issues and associated biopsychosocial factors that patients experienced after gynaecological cancer treatment. The qualitative research provided further insight in survivors', referring to patients and partners, experiences with and mechanisms behind these issues, and put the quantitative survey results into perspective. Also, the interviews served both as feedback with regard to the current psychosexual support practice and needs of survivors and their partners, and as input for the development of our sexual rehabilitation intervention using vaginal dilators. The Delphi-method we used can be seen as a form of a mixed methods research; participating experts were allowed to provide comments, which gave insight regarding their clinical considerations and recommendations. The response rate of our Delphi-panel was unusually high (100% versus the advised minimum response rate of 70%), showing that our panel was very committed, and the method we used proved to be highly efficacious.[150,197]

Nonetheless, several methodological challenges should be considered. It took longer than expected to include 20 gynaecological cancer patients eligible and willing to participate in the intervention's pilot-study. Besides the relative infrequency of women with advanced cervical cancer, recruitment problems were mostly related to language barriers, culture gaps or relocation, but also to metastatic disease or psychiatric problems. Participants' dropout rate of 40% was mostly due to somatic reasons (25%). Future studies should keep in mind that eligibility and dropout rates among cervical cancer patients treated with combined EBRT and BT may differ from other populations. However, the relatively high inclusion rate of 65% was satisfying, possibly being a reflection of the relatively young cervical cancer population's high need for more extensive support during sexual recovery.

Conducting prospective research to assess pre-treatment characteristics among gynaecological cancer survivors is complicated for apparent reasons. In an attempt to target individual variations, in our intervention's pilot-study participants were asked about their sexual functioning before diagnosis in retrospective, bringing along a possible recall bias while interpreting the findings (**chapter 7**). Perhaps more importantly, the measurements conducted among survivors could not always be compared to age-matched controls and no normative data was available (**chapter 2 and 7**). Therefore, we could not reliably establish that the reported levels of a variety of symptoms should only be attributed to the gynaecological cancer (treatment) and were significantly higher than in a normal population.

Another drawback of sexual functioning research among gynaecological cancer survivors is that recruiting participants can be difficult. In the current studies regarding long-term survivors (**chapter 2, 3, 4 and 6**), one-third to half of the eligible survivors declined participation, often stating reasons such as that the topic was too intimate, confronting, or reminded them of their cancer (treatment), or because they had a negative experience during sexual rehabilitation after treatment. Also, due to the conducted self-report methods, participants had to have sufficient knowledge of the Dutch language and to be willing to talk about the current topics. Consequently, current participants may have been relatively more eloquent and open regarding sexual problems. Also, only a limited number of the available questionnaires in sex research are validated to measure sexual concerns among gynaecological cancer survivors. Some of these questionnaires include items unintentionally excluding sexually inactive participants, or participants that do not focus on having sexual contact through coitus, possibly introducing a selection bias as well. The aforementioned matters urge us to develop more dedicated questionnaires.

Future considerations to further improve sexual health care after gynaecological cancer treatment

Central to our findings were the clinical recommendations that could be made in consultation with multidisciplinary health care professionals, patients and partners. Although the policy and practical recommendations serve as a valuable starting point in the improvement of gynaecological cancer care, it is important to first confirm the (cost-)effectiveness of several aspects. Several research directions regarding our developed patient information booklet and intervention, vaginal dilator use, the benefits of patient participation in this field of research, and also regarding support for minority groups and other pelvic cancer survivors, should be considered for future reference.

Developing an effective sexual rehabilitation intervention for survivors treated with radiotherapy

When gynaecological cancer survivors evaluated our patient information booklet during its development, most stated that the booklet was very useful and would have fulfilled the informational needs they experienced after radiotherapy. Therefore, in order to provide optimal care to current patients, Dutch gynaecological and radiation oncology centres are currently integrating the information booklet, together with standard instructions regarding sexual and medical treatment related issues, and vaginal dilator use, in their gynaecological cancer care. However, as was mentioned earlier, providing psycho-education 'only' may not be sufficiently effective in supporting patients during sexual recovery.

To follow-up on the promising nurse-led sexual rehabilitation intervention, its (cost-) effectiveness in improving sexual functioning among survivors after pelvic radiotherapy in comparison to standard care should be investigated. In order to do so, a national multicentre randomized trial should be initiated together with all Dutch gynaecological oncology centres. In every Dutch gynaecological oncology centre, two nurses should be specifically trained to be able to conduct this intervention. This trial should compare the intervention's effectiveness to optimal standard care

consisting of information provided by the patient's radiation oncologist, the patient information booklet, and a set of vaginal dilators. The intervention group would additionally receive four nurse-led rehabilitation consultation sessions during 12 months after treatment. It should also be investigated whether the intervention increases compliances with dilator use, reduces sexual distress, fear of penetration or sexual contact, and psychological distress, and improves body image, generic health-related quality of life and relationship satisfaction.

If proven effective, it would be possible to implement the findings in cancer care almost directly since (1) the intervention has been developed and evaluated in collaboration with all the end-users; (2) specialized nurses will be available with experience in conducting the intervention in all Dutch gynaecological oncology centres after the national trial; and (3) the personnel and material costs of implementing the intervention are relatively low.

Vaginal dilator use as a sexual rehabilitation strategy

Our sexual rehabilitation intervention uses, amongst others, vaginal dilator use as a sexual rehabilitation strategy. Although vaginal dilator use has been associated with less vaginal shortening and/or tightening after radiotherapy[39,62,63], no firm data exists on the effectiveness of regular dilator use in preventing these vaginal symptoms.[65] Also, although dilator use is advocated worldwide, data showing that regular dilator use improves sexual functioning among survivors is lacking. Therefore, vaginal treatment sequelae should be measured systematically, both in relation to vaginal symptoms and sexual functioning. Physician reporting is usually less accurate than patient reporting regarding, amongst others, vaginal symptoms.[198] Thus, patient-reported outcome measures are indispensable to evaluate type and severity of symptoms, and problems encountered. Also, investigators should agree on definitions or measurement tools to assess vaginal symptoms (varying from atrophic changes, bleeding from telangiectasia, vaginal dryness to tightening and shortening) since this probably caused the incidence of such symptoms after radiotherapy to vary in the literature.[65,67,199] Furthermore, the consequences of regular dilator use should be investigated during a longer follow-up period of at least 12 months, since the question remains whether it leads to long-lasting improvements of the patients' sexual functioning.

In response to the abovementioned lack of evidence, it is important to investigate the working mechanism of our developed sexual rehabilitation intervention. It should be analysed whether an improvement in vaginal symptoms, such as shortening and/or tightening, and in turn sexual functioning, is mediated by the reported frequency of vaginal dilator use. Other possible working mechanisms of the intervention, such as a reduction in worries about pain during sexual contact, will also be explored.

Patient participation in improving survivorship care

In the last decades, patient participation is increasingly recognized as an important component in patient cancer care. Patients' reported needs for information and support are considered as valuable directions regarding how to improve survivorship care.[200–202] Although in this thesis patients reported a need for more extensive infor-

mation, researchers and health care providers should not neglect to critically review this suggestion in light of the available evidence-based knowledge. Observational studies did show that cancer patients with a fulfilled need for, and satisfaction with, the received information and counselling are known to report a better quality of life, and experience less anxiety and depression.[202] However, although randomized controlled intervention studies providing more extensive information on disease and treatment consequences, and other support or rehabilitation options lead to satisfaction with the received information, the information did not necessarily lead to a better quality of life or less psychological distress.[202] One randomized controlled trial even showed no beneficial effect of information provision on satisfaction with the information and care, and worse psychosocial adjustment after cancer (treatment).[203] Although our pilot-study participants received additional nurse-led consultations to support them with sexual recovery, it should be investigated in a randomized trial whether survivors are satisfied with the information by itself.

The patients' and nurses' exit-interviews, and audio recordings, demonstrated that the patient-centred nurse-led consultations did not only address sexual, relational and dilator use issues. The consults were naturally directed at patients' other psychosocial concerns after treatment as well, such as their experiences with the cancer (treatment), physical concerns such as tiredness, or work reintegration. Thus, although cancer care providers are advised to address survivors' sexual recovery, they should address this besides, but not instead of, other needs for psychosocial support, since it is but one part of providing high quality survivorship care corresponding to the patients' needs. Nevertheless, it is the responsibility of the health care provider not to avoid targeting possible sexual concerns after treatment, being a burdensome and, to some patients, an embarrassing subject, particularly for those who need for regular dilator use after radiotherapy. During our future trial, the intervention's effectiveness should be controlled for how much time nurses spend on providing support for other psychosocial issues besides sexual recovery.

Sexual health care for minority groups and other pelvic cancer survivors

There is a paucity of data regarding certain minority groups who have limited access to support during sexual recovery in view of language or cultural barriers.[204,205] If proven effective, our intervention and clinical recommendations should be extended to these groups of women. Women with other cultural backgrounds or language problems may be in need of leaflets making more extensive use of drawings and culturally sensitive wording.[206,207] Such materials should be developed together with dedicated input from psychologists or health care workers from different cultural backgrounds and specialists in the field of low health literacy.

Studies into sexual problems among gynaecological cancer survivors have mainly addressed the needs of women treated for cervical cancer, as these are relatively often treated with extensive surgery or primary EBRT with BT, and are often young, pre-menopausal and sexually active. However, although in a less profound manner, other gynaecological cancer patients treated with pelvic EBRT also suffer from radiation-induced sexual problems. Less specific information is available with regard to vaginal and vulvar cancer survivors.[33,208] A less extensive and/or tailored version of

the sexual rehabilitation intervention may be supportive for these other groups of gynaecological cancer patients as well, but also for women treated with EBRT for other pelvic cancers, such as women treated for rectal, anal or bladder cancer. Ideally, our developed rehabilitation intervention should be made available to all female pelvic cancer survivors, with different modules tailored to specific situations. A treatment protocol for these patients could focus more on sexual functioning and rehabilitation in general, and less on vaginal dilation, being just one possible component among, for example, endometrial cancer patients treated with postoperative EBRT. All other issues during the recovery phase, such as reduced lubrication, reduced libido, menopausal symptoms, fatigue, and fear (for sexual contact), would be similar. We expect such a tailored protocol to be helpful to all female pelvic cancer survivors in need of sexual health support. Evidently, it would be worthwhile to address sexual dysfunction in male pelvic cancer survivors as well.[33]

Both the findings and multidisciplinary methods that this thesis brought forward will assist in providing the appropriate education and/or support to improve gynaecological cancer survivors' sexual recovery and wellbeing. It proved to be important for gynaecological cancer survivorship care to follow a biopsychosocial approach, taking not only treatment consequences but also psychosocial circumstances into account. We consider it necessary to continue gaining insight in the (cost-)effectiveness of our proposed sexual rehabilitation strategies in view of the favourable evaluations of our promising nurse-led sexual rehabilitation intervention for patients treated with radiotherapy. International colleagues may be inspired to deploy the methods that we used in order to tailor the recommendations to their possibly differing cultural settings and clinical infrastructures. Until we gain further knowledge regarding their (cost-)effectiveness, the practical and policy recommendations that were made, provide guidance to professionals, and policy-makers, and contribute to providing optimal clinical care for gynaecological cancer patients in the near future.