Sexual rehabilitation after treatment for gynaecological cancer

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Summary

Sexual functioning is an important aspect of quality of life that can be severely affected by gynaecological cancer and its treatment. Treatment options include radical surgery, primary or postoperative radiotherapy with or without brachytherapy and chemotherapy, and often involves combinations of these. Attention to sexual problems caused by side effects, such as vaginal shortening and/or tightening, vaginal dryness, pain during sexual contact, or negative emotions resulting from changes in their sexual relationships, is essential in survivorship care of gynaecological cancer survivors. However, survivors and their partners with sexual concerns often do not receive the information or professional help that they desire or need. Also, no proven effective psychological interventions exist to support survivors with sexual problems after treatment.

In this thesis, quantitative and qualitative evidence was gathered in an attempt to improve and extend the current sexual health care of gynaecological cancer survivors. Although surgery has a major impact on sexual functioning, vaginal changes and symptoms have been shown to be more profound after intensive radiotherapy. Therefore, the studies in this thesis were especially focused on gynaecological cancer survivors who received radiotherapy, and mainly concerned cervical cancer patients; a relatively young patient population often treated with intensive external-beam radiation therapy (EBRT) in combination concurrent chemotherapy, and intrauterine and vaginal brachytherapy (BT), although the results are equally relevant to other gynaecological cancer patients treated with EBRT with or without BT.

In order to assess what type of patient education and/or support would be needed to minimise the impact of gynaecological cancer treatment on sexual functioning, and to improve the survivors' sexual recovery we followed several approaches: (i) assessment of survivors' experience with sexual distress after treatment, and unmet needs for psychosexual counselling and support; (ii) it was explored how survivors and professionals could best deal with treatment-induced vaginal changes; and, partly based on the previous findings, (iii) a sexual rehabilitation intervention was developed and evaluated in a pilot study.

Sexual distress and related needs after gynaecological cancer treatment

Gynaecological cancer survivors may experience sexual distress and health care needs related to recovery of their sexual functioning after completion of treatment. In **chapter 2** we conducted a cross-sectional questionnaire study showing that, in con-

cordance with previous results, about one-third (33%) of the sexually active cervical cancer survivors reported clinically relevant levels of sexual distress. Among survivors that were of comparable age but sexually inactive, possibly due to problems after cancer treatment, this rate was even higher (54%). Furthermore, the findings in **chapter 2 and 3** confirmed previous reports that sexual problems and sexual distress were more profound when treatment included radiotherapy as compared to treatment with surgery alone, especially regarding treatment-induced vaginal changes, and both vaginal symptom-related and overall cancer-related sexual problems.

Thus far, empirical research had rarely focused on the extent to which sexual distress can be attributed to the vaginal symptoms or other changes due to gynaecological cancer treatment. **Chapter 2** demonstrated that sexual distress among cervical cancer survivors was related to different kinds of biopsychosocial concerns. Higher levels of sexual distress were associated with physical treatment consequences, namely the higher levels of vaginal symptoms, possibly due to radiation-induced atrophy and fibrosis or anatomical changes. But higher levels of sexual distress were also related with psychological and interpersonal concerns that are frequently reported after treatment, such as sexual pain worry, body image concerns, and relationship dissatisfaction. In **chapter 3** an interview study was conducted among cervical cancer survivors and their partners. These qualitative findings confirmed that sexual distress had multidimensional determinants. Confirming the findings of **chapter 2**, in **chapter 3** we concluded that professional support should not only take vaginal symptoms as a consequence of treatment into account, but also psychosocial factors, such as anxiety related to pain or penetration while resuming sexual activity during recovery, and the level of relationship satisfaction and communication.

In **chapter 2** we found that the relationship between vaginal symptoms and higher levels of sexual distress was partly mediated by the degree to which survivors worried about sexual pain. Furthermore, as was hypothesized in **chapter 2**, and further discussed based on patient interviews in **chapter 3**, (worry about) sexual pain among gynaecological cancer survivors and their partners may lead to avoidance of sexual activity as a coping strategy, or to feeling inhibited during intercourse, and subsequent feelings of sexual distress such as guilt, grief, or feeling lonely in the sexual relationship.

In order to develop and provide appropriate measures, there was a need for more clear information regarding the psychosexual supportive care needs among gynaecological cancer survivors. Cervical cancer survivors and partners that were interviewed in **chapter 3** reported a need for more extensive, and less medically oriented, information and practical psychosexual counselling and support after treatment. Participants considered written and online information a useful first resource of information. Also, their oncologists were perceived as the primary professional to consult in case of sexual distress, and nurses were specifically appreciated because of their empathy and accessibility. Sexologists were perceived to be suitable for more complex sexual problems.

The study results described in **part II** of this thesis complemented the first chapters in search for what psychosexual counselling and support was needed. In **chapter 5** the results were reported of an online Delphi-study that was conducted among radiation oncologists, gynaecological oncologists and oncology nurses from all Dutch gynaecological cancer centres. In this study, the professional experts reached consensus and agreed that, amongst others, it is part of their responsibility to provide information about treatment-induced changes and practical advice on how to cope with sexual problems. Additionally, corresponding with survivors' suggestions, the professionals also decided that more extensive psychosexual support should preferably be initiated and given by specifically trained oncology nurses.

Gynaecological cancer survivors, their partners and professionals that were assessed in **chapter 3, 5 and 6**, generally thought that it was important to involve partners during psychosexual support. In **chapter 7** we described the feasibility study of a newly developed intervention among a pilot-sample of survivors and their partners after radiotherapy. During the exit-interviews participating women stated to value their partners' social support during sexual rehabilitation and/or vaginal dilator use. Some women added, however, that their partners' presence or engagement was not needed with regard to dilator use, only in case of sexual concerns. Therefore, the suggestion made by the experts in **chapter 5** to provide the opportunity the include partners, but to let the patient ultimately decide, seemed most appropriate.

Reducing treatment-induced vaginal consequences

In **part II** of this thesis it was explored whether vaginal changes due to treatment can be targeted, since these may precede sexual distress and related needs for support (**chapter 2 and 3**). Therefore, in **chapter 4** we conducted a psychophysiological controlled study among early-stage cervical cancer survivors treated with surgery with or without postoperative pelvic radiotherapy. It was found that treatment with conventional radical hysterectomy resulted in a lower vaginal blood flow response during sexual, while treatment with a nerve-sparing modification resulted in a vaginal blood flow response comparable to the response of healthy women. We concluded that nerve-sparing surgery could preserve the vaginal blood flow response. The vaginal blood flow among women treated with nerve-sparing surgery and postoperative EBRT did not significantly differ from the other treatment groups, although this should be interpreted with caution since this treatment group was small. The levels of subjective arousal and sexual dysfunction, however, were comparable between all treatment groups. Therefore, the results indicated that in the current sample, a lower vaginal blood flow did not necessarily induce sexual problems. This seemed to be in line with part I of this thesis showing 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. Thus, the provision of psychosexual patient support should not only depend on the type of treatment that survivors received, but it should rather be tailored to the survivors' self-reported sexual (dys)functioning.

Reducing vaginal treatment consequences of more advanced cervical tumours treated with radiotherapy largely focuses on vaginal dilator use to prevent vaginal

adhesions, tightening and shortening. As a starting point, the Delphi-study results that were described in **chapter 5** added to previous literature that consensus was reached, not only on the roles of the multidisciplinary health care providers, but also on the required patient information and support after radiotherapy. The panel agreed that information about sexual rehabilitation using vaginal dilators should be provided by radiation oncologists prior to treatment, and should always be provided to sexually active cervical and vaginal cancer patients, younger than 70. Patients with vulvar and endometrial cancer, patients older than 70 and/or patients that were sexually inactive before treatment, should receive tailored information depending on their age, wish to retain sexual activity, personal and medical situation. The panel advised to start dilation around 4 weeks after treatment once the epithelia is heeled, to perform dilation 2-3 times a week, for 1-3 minutes, and to continue dilation for 9-12 months. Therefore, the panel offered clear consensus-based recommendations for the content of the aftercare of gynaecological cancer patients treated with pelvic radiotherapy.

According to the qualitative reports in **chapter 6** and in line with previous research, however, only one-fourth of the survivors were able to use dilators according to the instructions that were summarised in **chapter 5**. Almost all survivors intended and attempted to perform long-term regular vaginal dilator use because of the expectation that it would prevent the development of vaginal stenosis. Only about a quarter of the survivors were able to maintain long-term regular dilator use, because they were planning dilator use and making it part of a routine, e.g., using dilators while taking a shower, and using lubricants, a smaller dilator size or vibrators. Factors that negatively influenced survivors' dilator use were a lack of instrumental, informational and social support, negative associations with BT, the dilators' hard plastic design, and (being anxious for) pain or blood loss. We suggested that survivors could benefit from planning and preparing for situations in which they might tend to stop using dilators. Therefore, interventions should help these women change their routine, counteract negative emotions about dilator use or enlarge their perceived self-efficacy, by dealing with behavioural skills and motivational issues.

The development of a sexual rehabilitation intervention

The findings described in the preceding chapters, **chapter 5 and 6** in particular, were used to develop a sexual rehabilitation intervention in combination with a patient information booklet in collaboration with radiation oncologists, gynaecologic oncologists, oncology nurses and sexologists from all gynaecological oncology centres in the Netherlands.

The specific information booklet was evaluated by means of short questionnaires and semi-structured interviews among radiotherapy patients, independent specialists, healthy lower educated women and a patient organization. Participants found the booklet very relevant, informative and of good length (**chapter 7**). The intervention was directed at increasing the patients' knowledge on sexual problems and benefits of dilator use, offering coping strategies to both patients (and their possible partners) regarding sexual issues and increasing long-term compliance with dilator use, after gynaecological cancer treatment with external and internal radiotherapy. Dedicated radiation oncology and gynaecology nurses and an advanced practitio-

ner brachytherapy conducted the intervention after a 50-hour skills training covering the basic principles of gynaecological cancer treatment (consequences), sexology, cognitive behavioural interventions relevant for fear & avoidance behaviour, motivational interviewing and the treatment protocol. Three psychologist-sexologists designed and conducted the training among the nurses.

A prospective multicentre pilot-study was conducted to assess the feasibility of the intervention among patients treated with EBRT in combination with BT, and their partners in **chapter 7**. The trained nurses reported to have obtained sufficient expertise and counselling skills to conduct the intervention. In contrast to the moderate and short-term compliance rates that were achieved in previous intervention studies, the results showed that the current intervention helped most of the participating gynaecological cancer survivors to maintain long-term regular vaginal dilation or resuming sexual activity after radiotherapy. Also, although this was a non-randomised feasibility study, the results were promising with regard to the recovery of their long-term sexual functioning. The intervention was received as feasible and supportive during sexual rehabilitation and regular dilator use.

General discussion and concluding remarks

It was established what education and/or support was needed according to health care professionals, patients and their partners to minimise the impact of gynaecological cancer treatment on sexual functioning, and to improve the survivors' sexual recovery and wellbeing. Both the findings and variety of research methods that this thesis brought forward successfully involved both health care professionals, including radiation oncologists, gynaecological oncologists, oncology nurses, sexologists, and patients and their partners. Therefore, the promising sexual rehabilitation strategies that were developed and integrated in the sexual rehabilitation intervention have enjoyed wide support from the start. The methodological challenges that we encountered and should be considered in future sex research among gynaecological cancer survivors were related to the inability to obtain prospective baseline data, difficulties with recruiting eligible participants, and possibly unintentionally investigating an eloquent and relatively open-minded sample with regard to talking about sexual health issues. Furthermore, to follow-up on the promising nurse-led sexual rehabilitation intervention, the (cost-)effectiveness of the four-session dedicated rehabilitation intervention will be investigated in a national randomized trial. Its effectiveness on sexual functioning will be compared to standard care consisting of information provided by the radiation oncologist, the patient information booklet, and a set of vaginal dilators. If proven cost-effective, the intervention can be easily generally implemented and complement the standard gynaecological cancer care. Future studies should also develop a tailor-made protocol of the sexual rehabilitation intervention for minority groups who have limited access to sexual health support and/or with different cultural backgrounds, and explore a less extensive version of the intervention to be used for gynaecological cancer survivors who received EBRT alone or were treated with surgery only, and for patients treated for other pelvic cancers. The developed information booklet and the practical and policy recommendations that were made, provide valuable guidelines to improve current clinical care for gynaecological cancer patients.