Sexual health and wellbeing among female pelvic cancer survivors following individualized interventions in a nurse-led clinic

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Abstract

Purpose  Treatment-induced sexual and intestinal dysfunctions coexist among women after pelvic radiotherapy. We aimed to explore if sexual health and wellbeing may be improved after radiotherapy following nurse-led interventions and if an association exists between improved intestinal health and sexual health.

Methods  A population-based cohort of women treated with pelvic radiotherapy underwent interventions at a nurse-led clinic at Sahlgrenska University Hospital, Sweden, from 2011 to 2017. Self-reported questionnaires were used, pre- and post-intervention, to compare self-reported changes in sexual health and wellbeing. A regression model was performed to explore the association between intestinal and wellbeing variables.

Results  Among the 260 female pelvic cancer survivors included in the study, more women reported increased than decreased satisfaction with overall sexual health post-intervention (26.0% vs. 15.3%, \(p=0.035\)). They also reported significantly reduced superficial genital pain (25.8% vs. 13.1%, \(p \leq 0.025\)), reduced deep genital pain (23.1% vs. 8.0%, \(p \leq 0.001\)), increased QoL (42.7% vs. 22.4%, \(p < 0.001\)), and reduced levels of depression (43.1% vs. 28.0%, \(p=0.003\)) or anxiety (45.9% vs. 24.4%, \(p < 0.001\)) post-intervention. We found a significant association between reduced urgency to defecate and improved satisfaction with overall sexual health (RR 3.12, CI 1.27–7.68, \(p=0.004\)) and between reduced anxiety mode (RR 1.56, CI 1.04–2.33, \(p=0.021\)).

Conclusion  Sexual health and wellbeing can be improved by interventions provided in a nurse-led clinic focusing on physical treatment-induced late effects. Further research to optimize treatment strategies in female pelvic cancer survivors is needed.

Keywords  Nurse · Cancer survivors · Physical side effects · Rehabilitation · Sexual dysfunction · Radiotherapy

Introduction

Sexual dysfunction is highly prevalent among female cancer survivors treated with pelvic radiotherapy [1–3] which, not infrequently, leads to chronic problems affecting their quality of life [4, 5]. With an estimated 4700 new pelvic cancer diagnoses every year in Sweden, pelvic cancer survivorship care needs to be strengthened [6]. For women treated with pelvic radiotherapy, long-term sexual dysfunction is a common and distressing problem regardless of specific pelvic cancer diagnosis [7–9]. In recent decades, efforts have been made when planning radiotherapy to avoid and treat radiotherapy-induced late effects, including sexual dysfunction, intestinal- and urinary tract dysfunctions, and lymphedema [3, 10–12]. Commonly, cancer and cancer treatment negatively affect sexual function and satisfaction due to direct and indirect physiological, psychological, and interpersonal factors [4, 5, 13]. Previous studies have suggested a broad...
scope of interventions and simple strategies addressing sexual health concerns to enable sexual rehabilitation after cancer treatment [14–17].

The importance of sexual health may vary with age and sexual activity, and relates to general health. For many women with chronic illnesses, sexual health remains important despite other symptoms [13]. Since radiotherapy comprises a wide range of physical problems, multidimensional interventions directed at female pelvic cancer survivors are considered to offer a solution to the widespread issue of decreased health after completion of pelvic radiotherapy [18]. However, it is not known whether sexual health problems could improve in female pelvic cancer survivors following a biopsychosocial-approached nurse-led intervention.

Previous research in women with non-malignant diseases reports associations between impaired intestinal function and sexual health [19, 20]. In women with a history of gynecological cancer, the presence of intestinal late effects, such as fecal leakage and loose stools, is reported to severely impair quality of life [21, 22]. Living with fecal incontinence may lead to the avoidance of being in or embarking on relationships that might lead to sexual intimacy [23]. Studies focusing on interventions aimed at improving female pelvic cancer survivors’ sexual health have been mainly limited to small prospective studies and pilot randomized controlled trials [24, 25]. There are therefore calls for studies with an intervention focus to fill the gaps [26–28].

In this paper, we use data from a population-based cohort of female cancer survivors treated with pelvic radiotherapy who had completed interventions in a nurse-led clinic, as previously described [29]. We aim to study whether sexual health and wellbeing improves among women treated with radiotherapy following a nurse-led intervention and to explore associations between improved sexual and intestinal health.

Methods

The cohort profile, the data collection, the questionnaire, and interventions for the current study can be found outlined elsewhere [29]. This section provides a brief summary.

Setting and study participants

All women receiving radiotherapy to the pelvic region with curative intent during 2007–2016 at Sahlgrenska University Hospital in Sweden, and pelvic cancer survivors referred to the nurse-led clinic, were invited for inclusion in the study. The women included in the analysis for this study had participated in a nurse-led clinic intervention and completed baseline and follow-up questionnaires.

Data collection

Eligible study participants responded to a baseline questionnaire. Three months after the completed intervention, the study participants were sent a follow-up questionnaire (Fig. 1).

Study-specific questionnaire

The validated study-specific questionnaire consisted of 175 questions including items concerning demographic details, aspects of wellbeing, body image, childbirth, intestinal-, and urinary tract health, sexual function, sexual abuse, and lymphedema. Some questions served to rank the patient’s most distressing symptoms. A self-reported evaluation was included in the follow-up questionnaire. Detailed information on the questionnaire can be found in a previous paper [29].

Nurse-led interventions

The nurse-led clinic, established in 2011 at Sahlgrenska University Hospital, was based on the national strategy proposals financed by the Regional Cancer Centre in Western Sweden. Currently, the team consists of three clinical oncology nurses, specialized in understanding and addressing pelvic cancer survivorship late effects, and one gynecologic oncologist. The overall goal with the interventions is to provide treatment and support for radiotherapy-induced late effects and chronic states in order to improve quality of life.

The follow-up consisted of visits and/or phone calls or digital meetings focusing on communication to support both physical and psychosocial health challenges. The duration of contact varied from 3 months to several years due to the individualized care and the severity of symptoms that could require varying content and extended interventions. In some cases, a partner was involved. Referrals were sent to experts if necessary. Intestinal health interventions followed an algorithm based on research by our and other research groups [18, 30], further developed and adopted by the Swedish national pelvic cancer healthcare rehabilitation program [31].

Sexual health interventions consisted of both psychoeducational efforts and efforts to provide a broader perspective of sexuality and sexual experiences. Using the PLIS-SIT model [32], information was provided about common radiotherapy-induced vaginal changes and menopausal symptoms, the consequences of the lack of estrogen that may affect the patient, and infertility. Counseling concerning vaginal dilator therapy, topical estrogen, guidance, and
suggestions regarding lack of desire and barriers to intimacy and partner communication were also given.

**Data processing**

Data from the questionnaires were coded and transferred to EpiData Software V.3.1 (EpiData Association) and then exported to Microsoft Excel. The first analyses focused on whether there was a change of at least one step along the scale of the baseline questionnaire compared to the follow-up questionnaire, e.g., from “a little” to “moderate” or from “moderate” to “a lot.” Any changes in a positive direction were recognized as clinically meaningful improvement. A sequence of univariate analyses was conducted to explore associations between improvement in intestinal health and improvement in satisfaction with overall sexual health, quality of life, depressed, or anxious mood. To ensure that no misrepresentation regarding respondents versus non-respondents was present, a random sample of 20 non-respondents was selected for a dropout analysis (Fig. 1). According to medical records, six people had died, two could not be reached, and two declined to attend. The remaining ten non-respondents were contacted through first a letter. For ethical reasons, they were requested to send a text message if they declined participation. The participating respondents were contacted by phone and asked to answer eight questions to assess the level of physical and psychosocial health problems at the time of the 3-month follow-up.

**Statistical analysis**

Frequency and percentages were used for descriptive statistics. The Wilcoxon signed-rank test was used to assess changes in the variables for sexual health and wellbeing aspects included in the analysis at follow-up compared to baseline. Changes were trichotomized into three categories: increase, no change, and decrease (see Table 2). Subsequently, to assess the associations between change in overall satisfaction with sexual life and wellbeing aspects on the one hand, and changes in bowel symptom intensities at follow-up compared to baseline on the other hand, changes in both classes in the categories “improvement” and “no improvement” were dichotomized. A log-binomial regression model was performed to assess the association between each pair of dichotomized changes in overall sexual health or the wellbeing aspects and dichotomized changes in bowel symptom intensities. Likelihood ratio test p values were calculated to assess the level of statistical significance for the estimated effect measures, i.e., relative risks. The level of significance (p value) was set to 0.05. All calculations were performed in R version 4.0.0.
Ethical considerations

The study was approved by the Regional Ethical Committee (EPN) in Gothenburg (D 686–10). Informed consent was obtained from all participants included in the study.

Results

Characteristics

A total of 260 female pelvic cancer survivors who had completed both the baseline questionnaire and the 3-month follow-up questionnaire, pre- and post-intervention between 2011 and 2017, were eligible for inclusion in the analysis. Baseline characteristics of the participants are shown in Table 1. The most common diagnosis was endometrial cancer (32.7%), followed by rectal- (25.8%), cervical- (20.8%), anal- (16.9%), and vulvar cancer (2.3%). The majority of the study participants had undergone surgery as a part of their cancer treatment (73.1%). The mean age was 62.5 years, 71.5% of the women were married or living with a partner.

Sexual health and wellbeing aspects

We studied changes in levels of satisfaction with overall sexuality and sexual life at baseline vs. 3-month follow-up. As shown in Table 2, a higher proportion of women reported increased rather than decreased satisfaction with overall sexual health and sexual life (26.0% vs. 15.3%, \( p = 0.035 \)). Reduced superficial genital pain (25.8% vs. 13.1%, \( p \leq 0.025 \)) and reduced deep genital pain during vaginal sex (23.1% vs. 8.0%, \( p \leq 0.001 \)) were reported post-intervention. More women reported a decrease than an increase in their ability to have an orgasm (19.4% vs. 14.8%, \( p = 0.041 \)), while the majority (65.7%) reported no change in this sexual function following the nurse-led interventions.

In the analysis of wellbeing aspects, almost twice as many women reported an increased rather than a decreased level of quality of life (42.7% vs. 22.4%, \( p \leq 0.001 \)) post-intervention (Table 2). A statistically significantly higher proportion of the women reported reduced depressed (43.1% vs. 28.0%, \( p = 0.003 \)) or anxious mood (45.9% vs. 24.4%, \( p \leq 0.001 \)).

Improvement in intestinal health

According to the univariable analysis (Table 3), statistically significant associations were found between reduced urgency to defecate and improved satisfaction with overall sexual health (RR 3.12, CI 1.27–7.68, \( p = 0.004 \)) and between reduced urgency to defecate with fecal leakage

| Table 1 | Demographics and clinical characteristics of study participants |
|----------|---------------------------------------------------------------|
| Characteristics | Total study group of female pelvic cancer survivors, \( N=260 \) |
| Cancer type | \( N (%) \) |
| Endometrial cancer | 85 (32.7) |
| Cervical cancer | 54 (20.8) |
| Vulvar cancer | 6 (2.3) |
| Rectal cancer | 67 (25.8) |
| Anal cancer | 44 (16.9) |
| Other | 4 (1.5) |
| Age in years | \( \text{Mean} \pm \text{SD} \) |
| 29–39 | 62.5 ± 11.7 |
| Age, grouped | \( N (%) \) |
| 29–39 | 12 (4.6) |
| 40–49 | 17 (6.5) |
| 50–59 | 70 (26.9) |
| 60–69 | 85 (32.7) |
| 70–79 | 60 (23.1) |
| 80– | 13 (5.0) |
| Years since radiotherapy | \( \text{Mean} \pm \text{SD} \) |
| 0.5 | 2.9 ± 4.2 |
| Years since radiotherapy, grouped | \( N (%) \) |
| 0.5 | 16 (6.2) |
| 1 | 90 (34.6) |
| 2 | 39 (15.0) |
| 3 | 68 (26.2) |
| > 4 | 46 (17.6) |
| Cancer treatment | \( N (%) \) |
| External radiotherapy with and without brachytherapy | 70 (26.9) |
| Surgery and external radiotherapy with and without brachytherapy | 190 (73.1) |
| Marital status | \( N (%) \) |
| Married or living with a partner | 186 (71.5) |
| Widow | 22 (8.5) |
| Has a partner but lives alone | 13 (5.0) |
| Single | 39 (15.0) |
| Education level | \( N=259 \) |
| Elementary school | 55 (21.2) |
| Secondary school | 111 (42.7) |
| College/university | 93 (35.8) |
| Employment status | \( N=259 \) |
| Student | 2 (0.8) |
| Unemployed job-seeker | 5 (1.9) |
| Employed | 96 (36.9) |
| Housewife | 1 (0.4) |
| On sick leave | 20 (7.7) |
| Disability pension | 17 (6.5) |
| Retired | 118 (45.4) |
and reduced anxiety (RR 1.56, CI 1.04–2.33, \( p = 0.021 \)). Although not statistically significant, the following factors seemed slightly associated with improved quality of life: reduced frequency of defecation, defecation urgency, defecation urgency with fecal leakage, leakage volume, and leakage without forewarning. As shown in Table 4, severe intestinal symptoms reduced following the interventions, for example, high frequency (5 times per day or more often) of defecation (6.4% vs. 4.1%), high frequency (at least every day) of loose stool (17.4% vs. 11.3%), unable to hold gas (at least every day) (18.4% vs. 11.3%), urgency (at least every day) to defecation (21.1% vs. 13.4%), unable to hold stool <1 min (18.6% vs. 11.4%), and defecation urgency with fecal leakage (at least once per week, 3 times per week, at least every day) (summed up, 16.6% vs. 8%).

Proportions of symptoms pre- and post-intervention

Although no statistically significant comparisons were made when analyzing proportions of answers pre- and post-interventions, we found reports of slightly decreased symptoms of genital pain, depression, anxiety, and almost all intestinal health variables post-intervention (Table 4). Women with a high degree of distress from persistent vaginal shortness and inelasticity were lower post-intervention.

Evaluation of interventions

The majority of the respondents (88.6%) reported that they were moderately to very satisfied with help offered regarding sexual health issues and intestinal symptoms (Fig. 2). Advice received for late effects had been moderately to very beneficial to the majority of women.

Discussion

The findings from this study suggest that sexual health and wellbeing can improve in women treated with pelvic radiotherapy through interventions provided in a nurse-led clinic focusing on a wide range of physical treatment-induced late effects. Specifically, quality of life, satisfaction with overall sexual health, and decrease in pain during vaginal sex were statistically significantly improved. Regarding intestinal health, reduced episodes of defecation were statistically significantly associated with improved satisfaction with overall sexual health. Moreover, we found reduced urgency to defecate associated with reduced degree of anxiety. Regarding sexual function, improvement was not found in all aspects. For the majority of the women, vaginal shortness and inelasticity did not improve, nor did lubrication, genital swelling, or the ability to achieve orgasm.

To the best of our knowledge, no other studies have taken a similar approach that is studying sexual health in women with a wide range of problems, providing multidimensional individualized interventions directed at women with a history of pelvic radiotherapy, and mainly focusing on physical treatment-induced late effects but with a psychosocial approach. In a recent study among elderly individuals, an increase was observed in the number of physical illnesses, which associated with a decrease in satisfaction with sexual life [33], a finding similar to the results in the current study. In previous research, gynecological cancer survivors with fecal incontinence reported low quality of life [10]. A recent study reported that fecal incontinence entails a constant uncertainty regarding leakage and dealing with shame and degradation in social situations [23]. We found that improvements in intestinal symptoms could increase women’s quality of life and sexual wellbeing, and lead to lower levels of anxiety. Thus, it seems important to prioritize individuals’ physical illness in parallel with the initiation of sensitive and individualized discussions both early and later in the rehabilitation process, since questions about sexuality may arise when other troublesome symptoms have been successfully treated. While depression and anxiety are previously shown to be more prevalent among women with a history of sexual abuse [7, 34], this also needs to be considered in counseling.

A high prevalence of genital pain and vaginal shortness among women treated with pelvic radiotherapy has been previously reported [7, 8, 16]. Since interventions provided in the current study could explain the decrease in genital pain, we suggest that available guidelines [14, 35], including local estrogen, lubricants, discussing how to carry out vaginal dilator therapy, and alternative ways...
Table 2  Analysis of changes in aspects of sexual health and wellbeing among female pelvic cancer survivors who completed both the baseline and the 3-month follow-up questionnaire post-intervention

| Aspects assessed                                      | N (%)        | p value |
|-------------------------------------------------------|--------------|---------|
| **Satisfaction with overall sexual life—baseline versus follow-up** |              |         |
| No change                                             | 126 (58.6)   |         |
| Increased satisfaction with overall sexuality          | 56 (26.0)    |         |
| Decreased satisfaction with overall sexuality          | 33 (15.3)    |         |
| **Sexual thoughts—baseline versus follow-up**         |              |         |
| No change                                             | 127 (58.5)   |         |
| Increase in frequency of sexual thoughts               | 32 (14.7)    |         |
| Decrease in frequency of sexual thoughts               | 58 (26.7)    |         |
| **Level of sexual thoughts and fantasies—baseline versus follow-up** |              |         |
| No change                                             | 138 (64.8)   |         |
| Increase in frequency of sexual fantasy                | 36 (16.9)    |         |
| Decrease in frequency of sexual fantasy                | 39 (18.3)    |         |
| **Arousal in sexual situations—baseline versus follow-up** |              |         |
| No change                                             | 127 (59.3)   |         |
| Increase in frequency of arousal when in sexual situations | 39 (18.2)  |         |
| Decrease in frequency of arousal when in sexual situations | 48 (22.4) |         |
| **Lubrication in sexual situations—baseline versus follow-up** |              |         |
| No change                                             | 133 (62.1)   |         |
| Increase in frequency of lubrication when in sexual situations | 35 (16.3)  |         |
| Decrease in frequency of lubrication when in sexual situations | 46 (21.5) |         |
| **Noticed genital swelling during sexual arousal—baseline versus follow-up** |              |         |
| No change                                             | 149 (72.3)   |         |
| Increase in frequency of genital swelling when in sexual situations | 27 (13.1) |         |
| Decrease in frequency of genital swelling when in sexual situations | 30 (14.6) |         |
| **Orgasm frequency—baseline versus follow-up**        |              |         |
| No change                                             | 121 (55.8)   |         |
| Increase in frequency of orgasm                       | 39 (18.0)    |         |
| Decrease in frequency of orgasm                       | 57 (26.3)    |         |
| **Ability to have an orgasm during sexual stimulation or vaginal sex—baseline versus follow-up** |              | 0.041 |
| No change                                             | 142 (65.7)   |         |
| Increase in the ability to have an orgasm             | 32 (14.8)    |         |
| Decrease in the ability to have an orgasm             | 42 (19.4)    |         |
| **Noticed vaginal shortness during vaginal sex—baseline versus follow-up** |              | 0.559 |
| No change                                             | 147 (66.8)   |         |
| Increased vaginal length when in vaginal sex situations | 26 (11.8)  |         |
| Decreased vaginal length when in vaginal sex situations | 47 (21.4) |         |
| **Noticed vaginal inelasticity during vaginal sex—baseline versus follow-up** |              | 0.769 |
| No change                                             | 144 (67.6)   |         |
| Increased vaginal elasticity when in vaginal sex situations | 28 (13.1)  |         |
| Decreased vaginal elasticity when in vaginal sex situations | 41 (19.2) |         |
| **Numbness in labia or inside of thighs—baseline versus follow-up** |              | 0.338 |
| No change                                             | 124 (66.7)   |         |
| Decrease in numbness in labia/inside of thighs         | 32 (17.2)    |         |
| Increase in numbness in labia/inside of thighs         | 30 (16.1)    |         |
| **Superficial genital pain during vaginal sex—baseline versus follow-up** |              | 0.025 |
| No change                                             | 130 (61.0)   |         |
| Decreased level of superficial genital pain during vaginal sex | 55 (25.8) |         |
| Increased level of superficial genital pain during vaginal sex | 28 (13.1) |         |
| **Deep genital pain during vaginal sex—baseline versus follow-up** |              | < 0.001 |
| No change                                             | 146 (68.9)   |         |
to practice sex, could be more frequently used in clinical practice. However, it is known that genital pain may include underlying causes, such as decreased sexual desire and experiencing pain instead of pleasure. One study reported that some (young) women prioritize their partner’s enjoyment before their own, despite pain [36], which may also be relevant for cancer survivors and needs to be taken into account in the support of female pelvic cancer survivors as well. Furthermore, in the light of the previously reported relationship between genital pain and experience of sexual abuse [7, 34], this also needs to be discussed in counseling, however not further explored in the current paper. As previously mentioned, time spent educating, discussing, and supporting are vital parts of counseling given in addition to medication or devices [24, 25, 28]. When it comes to vaginal changes, the irreversible effect of radiotherapy on vaginal epithelial tissue [8, 37], nerves, and vessels [38, 39] probably explains the lack of improvement in vaginal changes and sexual function in our study. These late effects could be addressed, not only by vaginal dilator therapy and individual counseling, but also by preventative planning of organ-sparing radiotherapy.

Previous research reports that patients want healthcare professionals to raise the topic of sexuality [40]. Although the balance between providing too much or too little information before cancer treatment is challenging, early information could improve women’s preparedness for possible sexual side effects. In a previous study, low preparedness for sexual side effects post-surgery in prostate cancer survivors was reported to negatively influence the bother of sexual side effects and negatively affect self-esteem [41], which may also apply to female pelvic cancer survivors. In our opinion and as previously suggested, oncology nurses are well-placed to implement and develop cancer prehabilitation interventions [42] and could offer a solution to the widespread issue of late effects following pelvic radiotherapy.

**Strengths and limitations**

Strengths of this study include the large population-based cohort, the longitudinal design, the novelty of the comprehensive nurse-led interventions targeting female pelvic cancer survivors, and the use of a validated pelvic cancer-specific questionnaire. However, the questionnaire was validated for female pelvic survivors but not for survivors invited to undergo interventions. Hence, one could argue that the reliability may be limited since the participants were not anonymous, which could bias the responses. The fact that the women were recruited from only the western region in Sweden might induce generalization problems. Nevertheless, we do not know if the results in this study are applicable to other populations. We consider data prior to pelvic radiation would have facilitated comparisons of health aspects pre- and post-cancer treatment. The diverse treatment schedules due to the various cancer diagnoses and

| Table 2 (continued) | Aspects assessed | N (%) | p value |
|---------------------|----------------|-------|--------|
| Decreased level of deep genital pain during vaginal sex | 49 (23.1) | | |
| Increased level of deep genital pain during vaginal sex | 17 (8.0) | | |
| **Frequency of vaginal sex—baseline versus follow up** | | | 0.476 |
| No change | 133 (64.6) | | |
| Increase in frequency of vaginal sex | 36 (17.5) | | |
| Decrease in frequency of vaginal sex | 37 (18.0) | | |
| **Level of quality of life—baseline versus follow-up** | | | <0.001 |
| No change | 86 (35.0) | | |
| Increase in level of quality of life | 105 (42.7) | | |
| Decrease in level of quality of life | 55 (22.4) | | |
| **How often feeling depressed—baseline versus follow-up** | | | 0.003 |
| No change | 71 (28.9) | | |
| Decrease in how often feeling depressed | 106 (43.1) | | |
| Increase in how often feeling depressed | 69 (28.0) | | |
| **How often feeling worried or anxious—baseline versus follow-up** | | | <0.001 |
| No change | 73 (29.7) | | |
| Decrease in how often feeling worried or anxious | 113 (45.9) | | |
| Increase in how often feeling worried or anxious | 60 (24.4) | | |

Number (n) and proportion (%) of women is presented. p values in bold font indicate statistical significance (≤0.05). A change of at least one step along the scale in the baseline questionnaire, compared to the follow-up questionnaire was recognized as a clinically meaningful improvement. N delivering data is presented in case of missing data.
Table 3 Improved intestinal health aspects as explanatory variables for improved level of satisfaction with overall sexual life and wellbeing aspects

| Frequency of defecation | Satisfaction with overall sexuality and sexual health | Quality of life | How often feeling depressed | How often feeling worried or anxious |
|-------------------------|-----------------------------------------------------|----------------|-----------------|-----------------|
| No improvement          | N (%): 4/22 (18.2)                                | N (%): No improvement 6/14 (42.9) | N (%): No Improvement 9/15 (60) | N (%): No improvement 10/23 (43.5) |
| Improvement             | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| 10/39 (25.6)            | 1.41 (0.50–3.97)                                 | 1.77 (0.93–3.35) | 1 (0.60–1.66)   | 1.55 (0.66–2.00) |
| Frequency of loose stool| No improvement                                    | No improvement 22/27 (75.9) | No improvement 15/29 (51.7) | No improvement 20/41 (48.8) |
| 6/36 (16.7)             | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Improvement             | 1.4 (0.60–3.24)                                  | 0.962          | 0.255           | 0.693           |
| Unable to hold gas when needed | No improvement 5/22 (22.7) | No improvement 16/20 (80) | No improvement 11/19 (37.9) | No improvement 14/27 (51.9) |
| 6/50 (20)               | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Urgency to defecate     | No improvement                                    | No improvement 16/23 (69.6) | No improvement 18/26 (69.2) | No improvement 17/36 (47.2) |
| 5/46 (10.9)             | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Improvement             | 3.12 (1.27–7.68)                                 | 0.744          | 1.019           | 0.899           |
| For how long able to hold stool | No improvement 22/102 (21.6) | No improvement 34/37 (64.9) | No improvement 17/34 (53.1) | No improvement 23/51 (45.1) |
| 18/65 (27.7)            | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Urgency to defecate with fecal leakage | No improvement 11/53 (20.8) | No improvement 18/31 (58.1) | No improvement 18/34 (52.9) | No improvement 20/57 (35.1) |
| 21/77 (27.3)            | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Leakage volume          | No improvement                                    | No improvement 20/34 (58.8) | No improvement 27/42 (64.3) | No improvement 27/63 (42.9) |
| 13/59 (22)              | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Improvement             | 1.31 (0.69–2.49)                                 | 1.28 (0.92–1.78) | 1.35 (0.95–1.192)| 1.56 (1.04–2.33) |
| Leakage without forewarning | N/A*                                     | No improvement 46/62 (74.2) | No improvement 48/67 (71.6) | No improvement 47/86 (54.7) |
| 18/71 (25.4)            | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Leakage without forewarning | No improvement 2/50 (1.00) | No improvement 1/2 (50) | No improvement 3/6 (50) | No improvement 3/8 (37.5) |
| 21/6 (0.62–2.15)        | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Leakage without forewarning | No improvement 1/2 (50) | No improvement 1/2 (50) | No improvement 3/6 (50) | No improvement 3/8 (37.5) |
| 21/62 (80.8)            | Ref. 1.0                                        | Ref. 1.0       | Ref. 1.0         | Ref. 1.0         |
| Number (N) and proportion (%) of women is presented. Relative risk (RR), reference category (Ref.), confidence interval (CI). p values in bold font indicate statistical significance (≤0.05). *Not applicable (N/A). At least one step of change in a positive direction from baseline to follow-up, in each aspect assessed, was considered an improvement.
Table 4  Frequencies and proportions of self-reported aspects of sexual health, wellbeing, and intestinal symptoms pre- and post-intervention

| Categories                                      | Pre-intervention | Post-intervention |
|-------------------------------------------------|------------------|-------------------|
| Sexual health                                   |                  |                   |
| Feeling of sexual attractiveness                |                  |                   |
| Not at all                                      | 153 (61.9)       | 120 (53.6)        |
| A little                                        | 51 (20.6)        | 49 (21.9)         |
| Moderate                                        | 35 (14.2)        | 47 (21.0)         |
| A lot                                           | 8 (3.2)          | 8 (3.6)           |
|                                                        | N=247            | N=224             |
| Sexual thoughts, frequency                      |                  |                   |
| Never                                           | 84 (34.1)        | 95 (43.0)         |
| A few times                                     | 116 (47.2)       | 90 (40.7)         |
| Every month                                     | 23 (9.3)         | 4 (1.8)           |
| Every week                                      | 20 (8.1)         | 24 (10.9)         |
| Every day                                       | 3 (1.2)          | 8 (3.6)           |
|                                                        | N=223            | N=203             |
| If thoughts of sex persist, how satisfied       |                  |                   |
| Not at all                                      | 76 (34.1)        | 57 (28.1)         |
| A little                                        | 47 (21.1)        | 42 (20.7)         |
| Moderate                                        | 53 (23.8)        | 51 (25.1)         |
| A lot                                           | 47 (21.1)        | 53 (20.4)         |
|                                                        | N=242            | N=218             |
| Level of sexual thoughts and fantasies          |                  |                   |
| No level at all                                 | 78 (32.2)        | 78 (35.8)         |
| Low level                                       | 119 (49.2)       | 97 (44.5)         |
| Moderate level                                  | 41 (16.9)        | 37 (17.0)         |
| High level                                      | 4 (1.7)          | 6 (2.8)           |
|                                                        | N=241            | N=219             |
| Arousal in sexual situations                    |                  |                   |
| Not relevant                                    | 116 (48.1)       | 111 (50.7)        |
| Never                                           | 17 (7.1)         | 15 (6.8)          |
| Less than one of five times                     | 23 (9.5)         | 18 (8.2)          |
| Less than half of the times                     | 11 (4.6)         | 8 (3.7)           |
| About half of the times                         | 16 (6.6)         | 16 (7.3)          |
| More than half of the times                     | 18 (7.5)         | 13 (5.9)          |
| Every time                                      | 40 (16.6)        | 38 (17.4)         |
|                                                        | N=241            | N=220             |
| Lubrication in sexual situations                |                  |                   |
| Not relevant                                    | 118 (49.0)       | 114 (51.8)        |
| Never                                           | 24 (10)          | 20 (9.1)          |
| Less than one of five times                     | 17 (7.1)         | 17 (7.7)          |
| Less than half of the times                     | 9 (3.7)          | 8 (3.6)           |
| About half of the times                         | 19 (7.9)         | 14 (6.4)          |
| More than half of the times                     | 15 (6.2)         | 15 (6.8)          |
| Every time                                      | 39 (16.2)        | 32 (14.5)         |
|                                                        | N=242            | N=219             |
| Lubrication sufficient for vaginal sex          |                  |                   |
| Not relevant                                    | 127 (52.5)       | 120 (54.8)        |
| Never sufficient                                | 34 (14.0)        | 32 (14.6)         |
| Frequently reduced/insufficient                 | 31 (12.8)        | 18 (8.2)          |
| Sometimes reduced/insufficient                  | 31 (12.8)        | 33 (15.1)         |
| Always sufficient                               | 19 (7.9)         | 16 (7.3)          |
|                                                        | N=235            | N=215             |
| Table 4 (continued) | Categories                                      | Pre-intervention N (%) | Post-intervention N (%) |
|----------------------|-------------------------------------------------|------------------------|-------------------------|
| Noticed genital swelling during sexual arousal | Not relevant                                   | 141 (60.0)             | 129 (60.0)              |
|                      | Less than one of five times                      | 23 (9.8)               | 18 (8.4)                |
|                      | Less than half of the times                      | 12 (5.1)               | 8 (3.7)                 |
|                      | About half of the times                          | 14 (6.0)               | 18 (8.4)                |
|                      | More than half of the times                      | 17 (7.2)               | 20 (9.3)                |
|                      | Every time                                      | 28 (11.9)              | 22 (10.2)               |
|                      | N = 246                                         |                        | N = 219                 |
| Orgasm frequency     | Not relevant                                    | 106 (43.1)             | 107 (48.9)              |
|                      | Never                                           | 37 (15.0)              | 28 (12.8)               |
|                      | A few times                                     | 43 (17.5)              | 28 (12.8)               |
|                      | 1–2 times per month                             | 24 (9.8)               | 16 (7.3)                |
|                      | 3–4 times per month                             | 18 (7.3)               | 24 (11.0)               |
|                      | 1–2 times per week                              | 16 (6.5)               | 13 (5.9)                |
|                      | <2 times per week                               | 2 (0.8)                | 3 (1.9)                 |
|                      | N = 245                                         |                        | N = 219                 |
| How easy orgasm during sexual stimulation or vaginal sex | Not relevant                                    | 118 (48.2)             | 113 (51.6)              |
|                      | Very easy                                       | 15 (6.1)               | 7 (3.2)                 |
|                      | Easy                                            | 54 (22)                | 53 (24.2)               |
|                      | Difficult                                       | 42 (17.1)              | 35 (16.0)               |
|                      | Very difficult                                  | 16 (6.5)               | 11 (5.0)                |
|                      | N = 246                                         |                        | N = 216                 |
| Noticed vaginal shortness during vaginal sex       | Not relevant                                    | 134 (54.5)             | 112 (51.9)              |
|                      | Not at all                                      | 39 (15.9)              | 32 (14.8)               |
|                      | A little                                        | 20 (8.1)               | 28 (13.0)               |
|                      | Moderate                                        | 16 (6.5)               | 13 (6.0)                |
|                      | A lot                                           | 37 (15.0)              | 31 (14.4)               |
|                      | N = 244                                         |                        | N = 217                 |
| Noticed vaginal inelasticity during vaginal sex    | Not relevant                                    | 135 (55.3)             | 115 (53.0)              |
|                      | Not at all                                      | 34 (13.9)              | 27 (12.4)               |
|                      | A little                                        | 29 (11.9)              | 30 (13.8)               |
|                      | Moderate                                        | 14 (5.7)               | 14 (6.5)                |
|                      | A lot                                           | 32 (13.1)              | 31 (14.3)               |
|                      | N = 240                                         |                        | N = 196                 |
| Level of distress if vaginal shortness or inelasticity persists | Not relevant                                    | 136 (56.7)             | 135 (68.9)              |
|                      | Not at all                                      | 5 (2.1)                | 18 (9.2)                |
|                      | A little                                        | 9 (3.8)                | 19 (9.7)                |
|                      | Moderate                                        | 29 (12.1)              | 6 (3.1)                 |
|                      | A lot                                           | 61 (25.4)              | 18 (9.2)                |
|                      | N = 242                                         |                        | N = 196                 |
| Numbness in labia or inside of thighs              | Never                                           | 158 (68.1)             | 135 (68.9)              |
|                      | Seldom                                          | 14 (6.0)               | 18 (9.2)                |
|                      | Sometimes                                       | 25 (10.8)              | 19 (9.7)                |
|                      | Often                                           | 18 (7.8)               | 6 (3.1)                 |
|                      | Always                                          | 17 (7.3)               | 18 (9.2)                |
|                      | N = 244                                         |                        | N = 217                 |
|                                                                 | Categories              | Pre-intervention N (%) | Post-intervention N (%) |
|-----------------------------------------------------------------|-------------------------|------------------------|-------------------------|
| Superficial genital pain during vaginal sex                      | Not relevant            | 144 (59.0)             | 131 (60.4)              |
|                                                                 | Not at all              | 31 (12.7)              | 29 (13.4)               |
|                                                                 | A little                | 24 (9.8)               | 30 (13.8)               |
|                                                                 | Moderate                | 22 (9.0)               | 12 (5.5)                |
|                                                                 | A lot                   | 23 (9.4)               | 15 (6.9)                |
|                                                                 | N = 243                |                        | N = 217                 |
| Deep genital pain during vaginal sex                             | Not relevant            | 146 (60.1)             | 142 (65.4)              |
|                                                                 | Not at all              | 48 (19.8)              | 44 (20.3)               |
|                                                                 | A little                | 17 (7.0)               | 15 (6.9)                |
|                                                                 | Moderate                | 13 (5.3)               | 8 (3.7)                 |
|                                                                 | A lot                   | 19 (7.8)               | 8 (3.7)                 |
|                                                                 | N = 241                |                        | N = 210                 |
| Frequency of vaginal sex                                         | Never                   | 159 (66.0)             | 136 (64.8)              |
|                                                                 | A few times             | 31 (12.9)              | 19 (9.0)                |
|                                                                 | 1–2 times per month     | 21 (8.7)               | 24 (11.4)               |
|                                                                 | 3–4 times per month     | 17 (7.1)               | 18 (8.6)                |
|                                                                 | 1–2 times per week      | 11 (4.6)               | 8 (3.8)                 |
|                                                                 | < 2 times per week      | 2 (0.8)                | 5 (2.4)                 |
|                                                                 | N = 243                |                        | N = 221                 |
| Overall satisfaction with sexual life                            | Not relevant            | 93 (38.3)              | 84 (38.0)               |
|                                                                 | Not at all              | 80 (32.9)              | 53 (24.0)               |
|                                                                 | A little                | 24 (9.9)               | 24 (10.9)               |
|                                                                 | Moderate                | 29 (11.9)              | 36 (16.3)               |
|                                                                 | A lot                   | 17 (7.0)               | 24 (10.9)               |
| Wellbeing                                                        | N = 258                |                        | N = 247                 |
| Level of QoL<sup>a</sup>                                         | No QoL at all or very low | 22 (8.5)              | 9 (3.6)                 |
|                                                                 | Moderate QoL            | 175 (67.3)             | 159 (64.4)              |
|                                                                 | Very high               | 61 (23.5)              | 79 (32)                 |
|                                                                 | N = 258                |                        | N = 248                 |
| How often feeling depressed                                      | Always                  | 27 (8.5)               | 22 (8.9)                |
|                                                                 | Sometimes               | 143 (55.4)             | 119 (48.0)              |
|                                                                 | Never                   | 88 (34.1)              | 107 (43.1)              |
|                                                                 | N = 258                |                        | N = 248                 |
| How often feeling worried or anxious                             | Always                  | 34 (13.2)              | 26 (10.5)               |
|                                                                 | Sometimes               | 138 (53.5)             | 113 (45.6)              |
|                                                                 | Never                   | 86 (33.3)              | 109 (44.0)              |
| Intestinal function                                              | N = 250                |                        | N = 241                 |
| Frequency of defecation                                          | Every other day         | 26 (10.4)              | 21 (8.7)                |
|                                                                 | Less than every other day | 14 (5.6)              | 18 (7.7)                |
|                                                                 | Once per day            | 31 (12.4)              | 35 (14.5)               |
|                                                                 | 1–2 times per day       | 49 (19.6)              | 68 (28.2)               |
|                                                                 | 2–3 times per day       | 58 (23.2)              | 53 (22.0)               |
|                                                                 | 3–4 times per day       | 56 (22.4)              | 36 (14.9)               |
|                                                                 | 5 times per day or more often | 16 (6.4) | 10 (4.1) |
|                                                                 | N = 253                |                        | N = 248                 |
Table 4 (continued)

| Categories                                      | Pre-intervention N (%) | Post-intervention N (%) |
|------------------------------------------------|------------------------|-------------------------|
| **Frequency of loose stool**                    |                        |                         |
| No                                             | 34 (13.4)              | 62 (25.0)               |
| Occasionally                                   | 60 (23.7)              | 76 (30.6)               |
| At least once per month                        | 29 (11.5)              | 23 (9.3)                |
| At least once per week                         | 47 (18.6)              | 38 (15.3)               |
| At least 3 times per week                      | 39 (15.4)              | 21 (8.5)                |
| At least every day                             | 44 (17.4)              | 28 (11.3)               |
| N=248                                          | N=234                  |                         |
| **Flatulence**                                 |                        |                         |
| No self-perception of odor                     | 99 (39.9)              | 112 (47.9)              |
| Self-perception of odor                        | 149 (57.3)             | 122 (52.1)              |
| N=245                                          | N=231                  |                         |
| **Unable to hold gas when needed**             |                        |                         |
| No                                             | 53 (21.6)              | 66 (28.6)               |
| Occasionally                                   | 72 (29.4)              | 89 (38.5)               |
| At least once per month                        | 23 (9.4)               | 6 (2.6)                 |
| At least once per week                         | 27 (11.0)              | 24 (10.4)               |
| At least 3 times per week                      | 25 (10.2)              | 20 (8.7)                |
| At least every day                             | 45 (18.4)              | 26 (11.3)               |
| N=245                                          | N=238                  |                         |
| **Urgency to defecation**                      |                        |                         |
| No                                             | 42 (17.1)              | 52 (21.8)               |
| Occasionally                                   | 49 (19.9)              | 85 (35.7)               |
| At least once per month                        | 27 (11.0)              | 14 (5.9)                |
| At least once per week                         | 40 (16.3)              | 30 (12.6)               |
| At least 3 times per week                      | 35 (14.2)              | 25 (10.5)               |
| At least every day                             | 52 (21.1)              | 32 (13.4)               |
| N=253                                          | N=246                  |                         |
| **For how long able to hold stool**            |                        |                         |
| Not relevant, having a stoma                   | 38 (15)                | 42 (17.1)               |
| <1 min                                         | 47 (18.6)              | 28 (11.4)               |
| 1–5 min                                        | 94 (37.2)              | 82 (33.3)               |
| 5–10 min                                       | 38 (15.0)              | 42 (17.1)               |
| 10–30 min                                      | 21 (8.3)               | 33 (13.4)               |
| >30 min                                        | 15 (5.9)               | 19 (7.7)                |
| N=247                                          | N=238                  |                         |
| **Defecation urgency with fecal leakage**      |                        |                         |
| No                                             | 93 (37.7)              | 135 (56.7)              |
| Occasionally                                   | 95 (38.5)              | 70 (29.4)               |
| At least once per month                        | 18 (7.3)               | 14 (5.9)                |
| At least once per week                         | 24 (9.7)               | 10 (4.2)                |
| At least 3 times per week                      | 12 (4.9)               | 4 (1.7)                 |
| At least every day                             | 5 (2.0)                | 5 (2.1)                 |
| N=244                                          | N=239                  |                         |
| **Leakage volume**                             |                        |                         |
| Not relevant                                   | 91 (37.3)              | 138 (57.7)              |
| Soiling                                        | 76 (31.1)              | 50 (20.9)               |
| A small volume                                 | 53 (21.7)              | 42 (17.6)               |
| A large volume                                 | 21 (8.6)               | 8 (3.3)                 |
| The complete volume                            | 3 (1.2)                | 1 (0.4)                 |
| N=246                                          | N=237                  |                         |
differences in time since completed cancer treatment may be considered limitations. Furthermore, women referred to the clinic might report more severe late effects compared to the inventoried patients, possibly diluting the effects in our analysis. According to the dropout analysis, no differences in the magnitude of symptoms between the respondents and the non-respondents were recognized.

Except for the biometric data, all data used in the current study are “recalled”; thus, recall bias could be present. As with any single-arm prospective study, our results may be influenced by selection bias, more specifically that women with a high magnitude of radiotherapy-induced late effects may be more likely to take part in the interventions. In future studies, evaluating the impact of baseline patient characteristics, including age, previous sexual abuse, and side effects beyond sexual- and intestinal dysfunctions, will be of interest.

**Conclusions**

We conclude that poor quality of life and low levels of satisfaction with sexual health among female pelvic cancer survivors can be substantially improved through individualized interventions provided in a nurse-led clinic focusing on physical radiotherapy-induced late effects and diseases. Both
prehabilitation and rehabilitation of radiotherapy-induced physical late effects remain a great challenge in cancer care and more intervention studies are needed. In our opinion, oncology nurses with knowledge in medical, psychosocial, and sexual issues are well-placed and well-suited to lead cancer rehabilitation. Our data show the importance of healthcare professionals identifying the needs for support concerning sexual health issues at the start of treatment of pelvic cancer. Although treatment-induced late effects are to some extent inevitable, our data highlight the importance of initiating a careful discussion to establish preparedness for the side effects that may occur. Moreover, there is a need to advance the research in the area of sexual health rehabilitation to optimize treatment strategies to achieve improved sexual health.

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Data availability The datasets generated during and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Consent to participate Written informed consent was obtained from all participants prior to enrollment in the study.

Conflict of interest The authors declare no competing interests.

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