



Contents lists available at ScienceDirect

## European Journal of Oncology Nursing

journal homepage: [www.elsevier.com/locate/ejon](http://www.elsevier.com/locate/ejon)

# Barriers to and strategies for dealing with vaginal dilator therapy – Female pelvic cancer survivors' experiences: A qualitative study

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## ARTICLE INFO

## Keywords:

Female cancer survivor  
Late effect  
Pelvic radiotherapy  
Vaginal dilator therapy  
Vaginal stenosis

## ABSTRACT

**Purpose:** Vaginal changes, a frequently reported late effect among women treated with pelvic radiotherapy, can result in sexual dysfunction and distress. Women are recommended vaginal dilator therapy after completed radiotherapy; however, low adoption has been recognized. This study aims to provide insight into women's difficulties with carrying out vaginal dilator therapy and their experiences of information.

**Methods:** Face-to-face, semi-structured interviews were undertaken with 12 pelvic cancer survivors in a selected sample of women with difficulties adopting the therapy. Interviews were audio-recorded, transcribed and analyzed using qualitative content analysis.

**Results:** One overarching theme, *Being unprepared*, emerged from three identified categories relating to *Experience of received information*, *Experience of performing the therapy*, and *Motivation to perform the therapy*. The women experienced the information as unrealistic and insufficient, and requested clearer and earlier information. Bleeding, pain, fear of cancer recurrence, and recalling memories from treatments were experienced. Women described intestinal symptoms, fatigue, and feeling that the therapy was self-harm as barriers to performing the therapy. They described creating routines, breathing exercises, relaxation, pre-warming the dilator and performing therapy together with their partner as helpful strategies.

**Conclusions:** Careful discussion, early and clear communication, psychoeducation and supportive follow-up of vaginal changes should be integrated into cancer treatment and follow up. Healthcare professionals should be aware of potential difficulties with vaginal dilator therapy and identify women in need of extended support. Research is required to investigate interventions that suit the needs of female pelvic cancer survivors.

## 1. Introduction

Vaginal changes, such as stenosis and fibrosis, are troublesome late effects frequently reported by women treated with pelvic radiotherapy (Bergmark et al., 1999; Mirabeau-Beale et al., 2015). Vaginal dilator therapy is currently considered the best available recommendation to prevent and restore radiotherapy-induced vaginal changes (Damast et al., 2019, American Cancer, 2020; Miles, 2012). The therapy mechanically separates the vaginal walls and stretches the vaginal tissue. A vaginal dilator is a cylindrically shaped device that should be inserted into the vagina for approximately 10 min, 2–3 times a week, for about 2–3 years post completed radiotherapy (Bakker et al., 2014). Some

women are motivated to use vaginal dilator therapy to enable gynecological examinations to detect cancer recurrence. For others, the motivation could be enabling vaginal sex and/or preserving the female anatomy (Bonner et al., 2012).

Although vaginal changes after pelvic radiotherapy cause physical sexual dysfunctions (Bergmark et al., 1999; Hofsjö et al., 2017; Bruheim et al., 2010; DuHamel et al., 2016) and distress (Schover et al., 2014; Schover, 2019), low adherence to vaginal dilator use remains a problem (Punt, 2011; Law et al., 2015). Previous studies report a wide variety of barriers affecting dilator use, such as pain, uncertainty about how to use dilators, lack of time, negative experiences, and need for discretion (Bonner et al., 2012). An American study (Cullen et al., 2012) reports

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<https://doi.org/10.1016/j.ejon.2022.102252>

Received 5 July 2022; Received in revised form 11 November 2022; Accepted 3 December 2022

Available online 10 December 2022

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that low adherence is linked to deep psychological barriers and emotional implications that makes it intrusive. In addition, embarrassment, where the women refer to the dilator as a “sex toy”, anxiety, fear, and bad memories from cancer treatments, have been reported. Several studies have focused on women’s poor adoption of the therapy and different strategies to increase adherence (Carter et al., 2017; Miles and Johnson, 2014; Cullen et al., 2013; Brand et al., 2012; Jeffries et al., 2006). In the general population, a history of sexual abuse (European Union Agency For Fundamental Rights, 2014) and negative experience of vaginal penetration (sexual or non-sexual) among women are common (Elmerstig and Thomtén, 2016). However, research is lacking on whether there may be a link between such negative experiences and low adherence to vaginal dilator therapy. Nevertheless, the therapy is suggested to help women gain confidence, increase knowledge about their bodies, and reduce fear of pain (Cyr et al., 2020).

Understanding the difficulties with and experience of vaginal dilator therapy in relation to poor adherence is important for both theoretical and clinical reasons. First, this knowledge can help researchers and clinicians bridge disconnected insights into some of the biopsychosocial mechanisms that women struggle with in relation to dilator therapy. Second, this knowledge can help clinicians develop much-needed interventions in oncology settings for the improvement of information and counselling regarding radiotherapy-induced vaginal changes. A qualitative interview study is, therefore, well suited to our aim of gaining a deeper understanding of women’s experiences of receiving information and difficulties with carrying out vaginal dilator therapy. An additional aim was to learn how women would prefer to receive information, counselling and follow-up of vaginal changes and dilator therapy in a selected sample of women with difficulties adopting and performing the therapy.

## 2. Methods

### 2.1. Design

The study used a descriptive qualitative design, where the method involved interviewing female cancer survivors with a history of pelvic radiotherapy using a semi-structured interview guide. Interviews were used for data collection to avoid missing non-verbal information (Polit and Beck, 2018). The interviews were transcribed verbatim and analyzed using inductive qualitative content analysis (Patton, 2005). The Consolidated criteria for reporting qualitative research, COREQ, were followed.

### 2.2. Participants, setting, and procedure

A convenience sampling method was used. Female pelvic cancer survivors who had ongoing or previous contact with an outpatient cancer rehabilitation clinic in the western part of Sweden were asked to participate in the study. The study participants were selected based on them having received treatment with external beam radiation with or without brachytherapy (none received only brachytherapy) following gynecological, rectal, or anal cancer, and had expressed difficulties performing vaginal dilator therapy. Generally, information about vaginal fibrosis prevention is provided by a nurse or a physician in the oncology clinic after the patient’s completion of curative cancer treatment. Vaginal dilator therapy is recommended with start 6–8 weeks after completing radiotherapy, according to international guidelines (Miles, 2012). Although local routines may exist, in Sweden a cylindrical plastic vaginal dilator, 20 mm and/or 25 mm in diameter, is usually supplied by the hospital for free. The women most commonly receive a follow-up phone call.

The first author (Åkeflo) and two clinical nurses identified 12 female pelvic cancer survivors who reported poor adherence and struggling to practice vaginal dilator therapy. The exclusion criterion was ongoing nurse counselling with the interviewing researcher. Women eligible for

the study received written information about the study and a consent form by mail. The first author (Åkeflo) then contacted the women by telephone. After returning the consent form in a pre-addressed envelope, the participant chose a time and place for the interview, either a secluded room at the oncology department (n = 10) or the participant’s home (n = 2). The sample consisted of 12 women with previous cervical-, rectal-, anal-, or vaginal cancer, aged 30–69 years. Nine of the women had partners and three were single.

### 2.3. Interviews

All interviews were conducted between October 2016 and October 2021 by the first author (Åkeflo), a female oncology nurse and PhD-student with several years’ experience in nursing and sexual counselling in the oncology clinic. Two of the women had a previous care relationship with the interviewer and all women were informed of the interviewer’s clinical and research background.

An interview guide with open-ended questions was formulated by the authors based on questions about experiences of receiving vaginal dilator information, how the women would prefer to receive this information, experiences of performing vaginal dilator therapy, and advice to others who will start using a vaginal dilator.

The interview guide was tested in a pilot interview and remained unchanged for the interviews that followed. The pilot interview was included in the analysis. The women were encouraged to freely develop and expand their answers during the interviews. The interviews were audio-recorded on agreement from the women, lasted 27–62 min, and were transcribed verbatim by a professional transcriber.

### 2.4. Data analysis

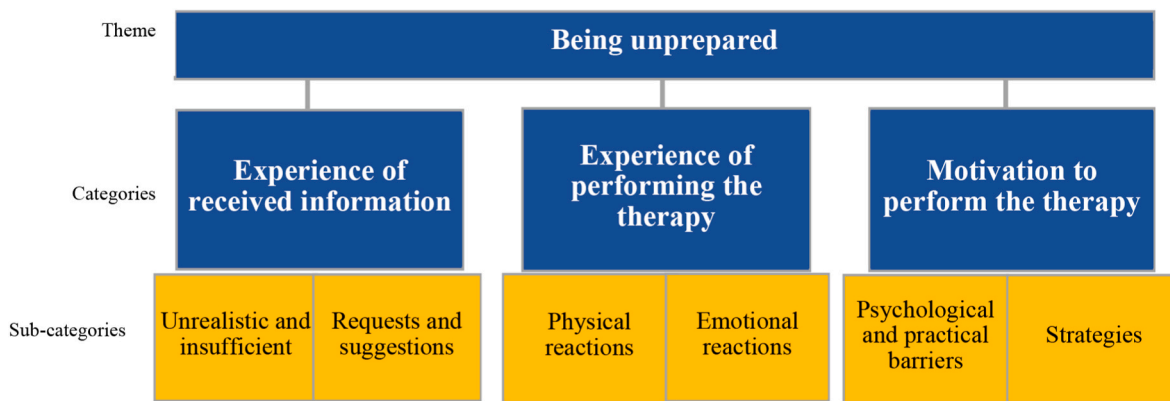
The interviews were analyzed using qualitative content analysis based on the methodology developed by Graneheim and colleagues (Graneheim and Lundman, 2004; Lindgren et al., 2020). NVivo (Version 12) SR International Pty Ltd. (2018) was used to facilitate organization of the interview text. First, two of the authors (Åkeflo, Dunberger) independently read the transcripts several times and performed an open coding where irrelevant information was excluded from the analysis. Subsequently, Åkeflo and Dunberger independently identified meaning units that captured the essence of the participants’ experiences of receiving information and carrying out the vaginal dilator therapy. The meaning units and notes that emerged from the data were compared and summarized. Meaning units were then condensed and assigned descriptive codes, which functioned as content labels. Similar sub-categories were grouped into main categories (Fig. 1) and this process analyzed differences and similarities in the categories. The last step was carried out by Åkeflo and Dunberger (PhD) and agreed by all authors. Validation of the analysis was conducted by rereading all the interview transcripts and searching for any inconsistencies in or between the categories. An example of the analysis process is shown in Table 1.

### 2.5. Ethical considerations

All women received verbal and written information about the study and gave written informed consent. They were informed that they could withdraw consent at any time without explanation, and that all data would be confidential and not shared with healthcare professionals. All participants received information about whom to contact if the interview raised thoughts or questions. The Ethical Review Board of Gothenburg approved the study (Dnr 605-18).

## 3. Results

The qualitative content analysis yielded one overarching theme with three categories and six sub-categories, presented in Fig. 1.



**Fig. 1.** The overall results based on the 12 interviews concerning female pelvic cancer survivors’ experiences of receiving information, how women would like the information to be given, experiences of performing the therapy, and women’s barriers and strategies concerning motivation to perform vaginal dilator therapy.

**Table 1**  
Example of the content analysis process.

Meaning unit	Condensed meaning unit Description close to the text	Code	Subcategory	Category	Theme
"The vagina is so fragile now after this, you know. So it bleeds and hurts and I have pain for several hours afterwards".	"Fragile, bleeding and pain".	Bleeding and pain	Physical reaction	Experience of performing vaginal dilator therapy	Being unprepared
"But it just reminds me that there has been something wrong, having been ill and such like".	"Reminder that something was wrong and diseased".	Reminds me of the disease	Emotional reactions	Experience of performing vaginal dilator therapy	
"And then I was kind of upset and thought what the hell - am I going to have to do this for the rest of my life. I hadn't received any information about that".	"Upset and perplexed".	Upset	Unrealistic and insufficient information	Experience of received information	

### 3.1. Experience of received information

There was variety in how the interviewed women reported receiving information about vaginal dilator therapy with regard to the setting where it was received and the procedure for giving information. Most women stated that they had received the information from a nurse or physician in the outpatient or radiotherapy clinic a few weeks after completed radiotherapy.

#### 3.1.1. Unrealistic and insufficient

The women experienced the information given as *unrealistic and insufficient*. Some women described being shocked to learn about the risk of developing vaginal stenosis. They experienced feeling that this information was not of relevance to their bodies.

*"No, I don't really know what I thought. It was really shocking that it can happen at all, that the vaginal walls can stick together, yeah. It felt unreal. And the person I talked to was good but it didn't really feel like it was that serious." (Participant 6)*

In order to prepare mentally, the women stated that information should be given in advance about the risk for treatment-induced vaginal effects, both before and during cancer treatment. They believed this could have prevented the shock they experienced from the radiation effects on the vaginal tissue. Furthermore, they stated that having knowledge about the risk of vaginal narrowing and inelasticity would have helped their adoption of vaginal dilator therapy.

*"I would have wanted to know that you could be damaged by the radiation. It would have helped me to understand afterwards. Because the shock I got afterwards, or got from the radiation damage and how long I have to work with the dilator and what enormous problems it has caused." (Participant 8)*

Women experienced that the information given about the risk for vaginal changes was strange, insufficient and poor, and caused sudden, unpredictable and complicated feelings. It also seemed as if the therapy imposed a considerable additional burden, described in terms of unexpected and overwhelming feelings interfering with existing struggles in the cancer survivorship experience.

*"Yeah, I thought it felt really weird, actually. So yes, I felt quite crushed. So much had happened so that just the idea of starting to use it and when to do it and that, and above all, why. The information about it was pretty poor." (Participant 2)*

#### 3.1.2. Requests and suggestions

The women expressed a desire for information and follow-up regarding vaginal dilator therapy. They suggested improvements such as providing clearer recommendations at an early stage. They understood the complexity of these matters in terms of being preoccupied, in a state of crisis with thoughts of survival, acute side effects, daily life issues, and self-care.

*Well though, to really get to grips with it from the beginning, because it's not anything that you can just ignore ... it is not a problem that will go away by itself. Therefore, stressing the importance of it and all the information is really, really good." (Participant 3)*

Healthcare professionals emphasizing the importance of the therapy when meeting their patients was described as important. Being left to deal with vaginal changes and dilator therapy on their own was experienced as stressful, and women requested extended support in these matters. Furthermore, women described feeling concerned about how vaginal stenosis would affect them in the future regarding sexuality and vaginal examinations, and again expressed a need for clear communication.

"Yes, give more weight to it, definitely! ... so why not tell us more about it. Just tell me when it should be done." (Participant 9)

Women reflected on the need for additional supportive care in specific situations, especially if there is a history of childhood- or sexual abuse. They suggested that healthcare professionals should ask patients about such experiences.

"Yes, and that there is support and help if she wants it. Because there can be a lot of things that a person has been through earlier in life. Which may not directly have anything to do with sex, or themselves having sex. Maybe more to do with others. Or something else that you've had drummed into you during childhood or something, whatever it might be." (Participant 11)

The shape of the dilator was of importance. The women described the dilator they received as a straight, stiff, unpleasant, clinical and cold device. They expressed a need for a softer design.

"I think it would have a positive effect if it was maybe made of softer materials ... maybe doesn't need to be straight ... maybe have a little more of a warm, human feeling." (Participant 5)

### 3.2. Experience of performing the therapy

#### 3.2.1. Physical reactions

Women described experiencing vaginal bleeding, pain and discomfort during the performance of vaginal dilator therapy. Since bleeding and pain normally signal injury, these negative physical reactions also generated mixed and contradictory feelings.

"It hurts, it's uncomfortable. But this hard ugly thing that goes in there and sort of grinds and ... almost stretches, like, and it does. So I get such awful menstrual cramps from it. And the day after as well." (Participant 2)

If women noticed vaginal adhesions during dilator use, emotional reactions and fear of recurrence of cancer followed. The opportunity for support was then of huge importance.

"At first I thought, oh god, now there's something else. A relapse or something. But NN (nurse) said that it's because it's narrowed." (Participant 12)

The women described how performing the therapy was unpleasant due to the comfortless shape of the dilator, perceived as a cold and deterrent device.

"Yes, it's oh so **not-nice!** Well, ...eh.. yes. I think that every time and ... I really think that it's like a candle that's rock hard and ... cold and so, of course you can warm it and hold it but it's like .. it is not ... no. no. it is not nice!" (Participant 4)

#### 3.2.2. Emotional reactions

Women described how the emotional reactions following vaginal adhesions caused unexpected distress. At the same time, on a more intellectual level, they described understanding that this distress was related to vaginal adhesions experienced during therapy, which reminded them of their previous cancer and cancer treatment.

"But it just reminds me that there has been something wrong, having been ill and such like ..." (Participant 10)

For some women, the dilator insertion was associated with anxious reactions. Furthermore, women described feelings of disassociation that seemed to cut off their mind from the lower part of their body.

"The whole of me just said No" (Participant 1).

### 3.3. Motivation to perform the therapy

#### 3.3.1. Psychological and practical barriers

The women experienced a range of psychological and practical barriers that contributed to low motivation to perform the therapy. The therapy seemed to be in conflict with being attentive to body signals. Previous unpleasant experience of dilator use likely contributed to their low motivation. The psychological barriers involved feelings of mental cut-off from their bodies.

"Cut me in two from the waist down, I don't need the rest" (Participant 11).

Some women expressed difficulty prioritizing vaginal dilator therapy in daily life due to family life, children, and struggling to take care of their basic needs. Previously experienced pain also created a barrier.

"... I don't get any anxiety immediately, it can feel strange if you've just put your child to bed, thinking oh now I have to go and use my vaginal dilator. So it's difficult to include it in everyday life. But then I thought to myself that it's difficult to include a shower in everyday life when you have children ... but the body doesn't want to. Of course, I think it's because you've had so much pain there". (Participant 1)

"Then it was very difficult with that dilator in many ways. Because it didn't feel important. I didn't care about any vaginal adhesions, I only cared that I wouldn't die. So then I didn't think it was a priority." (Participant 10)

Dealing with the dilator was in some cases experienced as a complicated psychological process. Some women referred to the therapy as self-harm and self-abuse, terms that are normally related to severe trauma. Although the purpose of the therapy is to support the women's rehabilitation, it evoked complicated emotions, including feelings of self-harm due to forcing their bodies to perform the therapy.

".. No, I thought it felt like abuse, actually. Yes ... pure and simple abuse with lubricants and painkillers and when will I have time to do this. You have a shower, yes you should lie in bed and relax, well and then you bleed and then you need a towel and you have children, well you know, it was the whole complicated process. So really quite difficult I have to say, unfortunately". (Participant 4)

Co-existing and bothersome treatment-induced late effects, such as intestinal symptoms and fatigue, affected women as they were time-consuming, limited them more-or-less daily and required energy-intensive self-care. These issues affected their quality of life and motivation to perform the therapy.

"During the day, the difficulties are with my stomach which lives its own life ... So all of a sudden, I have to rush to the toilet ..." (Participant 3)

"Yes, yes, oh my God. It's my pelvis. And my tummy. I have a lot of pain from my pelvis and lumbar region and stomach ... So life becomes limited, compared to what it was before. Then this thing with brain fatigue and so on. That you can't, you can't keep going for long periods, you don't have the ability to do things simultaneously. You can't hang out with friends in the same way. You have to choose." (Participant 12)

#### 3.3.2. Strategies

Some women described having found strategies for how to approach the therapy. Their tolerance improved, for example, through pre-warming the dilator and doing breathing exercises, which reduced tension in both body and mind.

"But I found ways. I did some exercises with my breathing that I still use. Then I noticed that oh, it went a bit further in." (Participant 9).

Some women found managing the therapy with their partner helpful, while routines, prioritizing the therapy, and searching for something positive to achieve from the therapy were useful to others. Women also



found distraction a useful strategy.

*“I just do it as soon as I wake up in the morning, early. I drink some tea first and turn on the TV, anything goes. And then I get the dilator ready, clean it and lubricate it and then I lie down on the sofa comfortably and then I have a blanket over me in case someone shows up. And then I lie there and watch TV and so ... yes. And then I take it out and feel, phew, now the day can start.” (Participant 8).*

An established contact with a nurse and sexual counselor was described as supportive and reduced uncertainty surrounding the vaginal dilator therapy, which improved the women’s motivation.

*“The best thing is to do it every day. Because then you keep going. But I think that since I had contact with NN, it’s become a lot better. Because I do it the right way ... I don’t go too fast.” (Participant 12).*

#### 4. Discussion

In this qualitative study involving a selected sample of female pelvic cancer survivors with difficulties adopting and performing vaginal dilator therapy following pelvic radiotherapy, the overarching theme that emerged from the analysis was *being unprepared* in relation to received information and performing the therapy. We found similarities and differences with previous studies (Bonner et al., 2012; Cullen et al., 2012, 2013) investigating women’s experiences of vaginal dilator use. Unlike our study, previous research has not explicitly selected women who expressed difficulties related to the therapy.

The category *experience of received information* emerged from the strong emotional reactions of astonishment, shock and dismay among the women. The information was perceived as insufficient and unrealistic, which could reflect inadequate communication. However, whether there was a lack of communication about the expected radiation-induced vaginal changes during and after previous cancer treatment or it was not prioritized is beyond the scope of this study. However, our findings support previous studies showing that relational communication is vital for effective information exchange (Mazor et al., 2013). We found that women would prefer early and clear information and follow-up concerning vaginal changes and vaginal dilator therapy, requesting that this be part of the cancer treatment. This could be developed by improving communication between patients and healthcare professionals, both before and during radiation therapy, about long-term treatment-induced late effects, including vaginal changes and the prevention of vaginal fibrosis. Guidance and specific suggestions, such as breathing and relaxation exercises, could also be provided. In a previous report, booklets were shown to be beneficial in increasing knowledge about vaginal side effects (Lubotzky et al., 2019). In our study, women’s suggestions to healthcare professionals, such as emphasizing the importance of the intervention, extending support with signs of vaginal narrowing or pain, providing a device with a softer design, and making the device more accessible, are all consistent with those previously reported by Cullen et al. (2013). Although there is no consensus regarding specific instructions to or education of patients in this framework, improvements in certain aspects of biopsychosocial and emotional support, through improved communication between patients and providers, are required to meet the patients’ needs. These are suggestions in line with a previous study (Matos et al., 2019). In addition, follow-up is necessary. In Sweden, and in other high-income countries, there are promising efforts being made to develop and provide vaginal dilators with softer designs, which are available in some of the oncology clinics for free. One could also argue that, since male cancer survivors have for decades been offered medical treatment and erectile devices to help with sexual dysfunctions following cancer treatment, it is time that gender equality was achieved through the availability of treatment and devices to female cancer survivors being prioritized.

Physical reactions, such as bleeding and pain during vaginal dilator use, evoked feelings of fear and distressing emotional reactions.

Struggling with physical and emotional reactions was sometimes overwhelming for the women, reminding them of their previous cancer disease and treatment, similar to findings of Cullen et al. (2012) who described this as “Reliving the Invasion of Treatment”. One study reported psychological late effects in terms of post-traumatic stress disorder following brachytherapy (Kirchheiner et al., 2014). Long-lasting psychological stress related to fear of cancer recurrence is common, despite most pelvic cancer patients now reaching full remission due to early diagnosis (Tsai et al., 2017).

The finding that women experienced feeling overwhelmed by practical barriers and lack of time for vaginal dilator therapy has been previously described (Bakker et al., 2015; Bonner et al., 2012). Our study showed that motivation for the therapy was impacted by co-existing intestinal treatment-induced late effects. As previously described in a study of the experiences of living with fecal leakage following cancer treatment, lack of control over the body significantly affects quality of life and hinders sexual activity (Krook et al., 2021). Fatigue, previously reported to affect cancer survivors’ daily life (Ahlberg et al., 2005) and sexual life (Basson, 2010), was also found to be a barrier to dilator therapy.

One important finding was the mind-body disconnection that occurred during the therapy. This area relates to body image and the process of reclaiming the body, which has been described in a study of psychological outcomes in gynecological cancer survivors (Wärja, 2018). We regard disconnection as an unconscious reaction, or strategy, to tolerate the therapy, while Cullen et al. (2012) described women expressing “rejecting that part of my body” as an attempt to put the invasion of treatment (using the dilator was like reliving the trauma) behind them. The mind-body disconnection might originate from the inevitable body exposure in examination and treatment situations during the cancer process, as described by breast cancer survivors who experienced diagnosis and treatment as objectifying and traumatic (Osypiuk et al., 2020). Mind-body disconnection is also reported in studies of women with a history of childhood- or sexual abuse (Sigurdardottir and Halldorsdottir, 2021). Although dilator therapy following cancer treatment should not directly be compared with previous sexual abuse, some similarities relating to the stressful experiences and long term consequences to women’s health could be discussed. Experiencing pain and a mind-body disconnection is likely highly relevant for the cancer rehabilitation process, which should be viewed from biopsychosocial- and sexual perspectives. In a previous study of female pelvic cancer survivors, we reported that significantly more women with a history of sexual abuse experienced genital pain during vaginal sex (Åkeflo et al., 2021). In the current study, sexual abuse was not found to be a primary cause of difficulties related to the therapy. Nevertheless, the women suggested that healthcare professionals should ask about previous childhood- and sexual abuse. If women express vaginal dilator therapy in terms of self-harm or abuse, this does not necessarily reveal a previous experience of sexual abuse but can reflect the complexity of experiences related to strong emotional reactions, pain and discomfort in connection with dilator therapy.

Despite barriers to *motivating the therapy*, the women in our study tried using different strategies. These were viewing the dilator as part of the cancer treatment, using distraction, breathing exercises, the “just do it” strategy, prioritizing, and making the interventions a daily routine, similar to the results reported by Cullen et al. (2013). For some women, performing the therapy with a partner was found to be helpful, which to our knowledge has not previously been studied. As mentioned, vaginal dilator therapy is considered to prevent vaginal stenosis, which not only facilitates gynecological examination and preserves the anatomy, but also may enable vaginal sex. Based on our findings, vaginal dilator consultations should include an individualized, careful, and nuanced discussion of the risk of vaginal stenosis that can lead to sexual dysfunction due to the inability to have vaginal sex, or pain and bleeding during vaginal sex. In order to gain broader perspectives, a wider spectrum of female sexuality should be discussed and exemplified by

variations of sexual practice. There is a strong penetration norm that can be problematic, especially in heterosexual relationships. Psychosocial aspects, such as feelings of guilt, grief, or feeling lonely in the sexual relationship (women and partners), are experiences reported in a study of cervical cancer survivors (Vermeer et al., 2016) that also need to be communicated. Some data describe the impact of sociocultural factors as important when assessing distressing sexual symptoms (Atallah et al., 2016), which are probably also important in counselling concerning vaginal dilator use. Nevertheless, as reported in a Danish study (Traumer et al., 2019), sexual health issues constitute a taboo subject among both patients and healthcare professionals, leading to a risk that such issues are left unspoken.

Although nurses are often aware that they should talk about sexuality with cancer patients, previous research shows that they seldom do (Olsson et al., 2012). We believe awareness of women's struggles concerning vaginal changes and sexuality is of relevance when supporting women in finding a new orientation as cancer survivors. Both preparedness during the early stages of cancer treatment and guidance towards an acceptance of the new situation post cancer treatment can foster a feeling of normality and should preferably be part of the counselling. Similar to our results, previous studies report physical, psychosocial and sexual needs, fear of recurrence (Sekse et al., 2019), and fatigue (Seland et al., 2022). According to our recent findings (Åkeflo et al., 2022), nurse-led interventions, previously found to provide safe and high quality care during cancer treatment, can also offer a solution in the support of women in the aftermath of cancer (Charalambous et al., 2018). Women in our study requested consistent information from physicians and nurses. They also advised communicating with other patients about "getting to grips with it from the beginning, because it's not anything that you can just ignore ... it is not a problem that will go away by itself". In order to support and prepare women for these issues, nurses, along with other healthcare professionals, can develop prehabilitation interventions (Lukez and Baima, 2020).

Experiences related to vaginal dilator therapy are complex. On the one hand women experienced inner resistance, and on the other a willingness to go quite far in preventing vaginal stenosis or restoring the vagina. This particular viewpoint must be carefully balanced in clinical practice. Previous research shows that one-third of all cancer patients suffer from serious and often under-recognized post-traumatic stress disorder and distress, with an especially high prevalence among female cancer patients (Unselde et al., 2019). In the current study, the findings concerning emotional and psychological barriers emphasize the importance of preparedness and psychosocial support. Regarding concerns about the development of counselling and follow-up of vaginal dilator use, there are promising results from a randomized controlled study. This shows statistically significant effects on long term vaginal dilator therapy through the use of a booklet intervention to increase knowledge about physical and psychosexual side effect compared to standard information material (Lubotzky et al., 2019). Such interventions could be a useful complement in communication and counselling about sexual issues for many women, although women with serious psychological burdens need more support.

In our study the women expressed feeling relief after completing cancer treatment. On subsequently receiving information about vaginal changes and dilator therapy, it seemed that these feelings were replaced with disorientation in their survivorship experience. Our findings showed that, rather than seeking a "new normal" in the situation, this new information reminded women of cancer and cancer treatment. Previous research on men with prostate cancer shows that unpreparedness for decreased sexual health leads to low self-esteem due to erectile dysfunction following cancer treatment, while those prepared for erectile dysfunction and other sexual problems reported feeling less bothered. Our results support the suggestion that preparedness for late effects can reduce uncertainty and positively influence outcomes of physical, psychosocial and sexual health (Derogar et al., 2016). The

observed lack of preparedness does not necessarily mean that the women had not received any information in advance but rather that they might not have been receptive to it when given. Follow-up interventions should preferably be accompanied by preventive actions to prepare patients for the risk of treatment-induced late effects.

The overarching theme was *being unprepared* and preparedness for survivorship also refers to patients' transition from oncology care to survivorship care. Previous research has found that patients of older age and with low depressive symptoms were more prepared for the transition (Leach et al., 2017). Furthermore, healthcare professionals thoroughly discussing long-term side effects with the patients throughout the treatment process and providing a survivorship care plan comprising information about potential long-term effects were related to high preparedness. Similar to Leach et al. (2017), who identified that younger age, advanced stage of disease, and lower perceived social support were associated with low preparedness, we consider that our finding of women *being unprepared* contributes to them being "lost in transition". The high information needs suggest that cancer patients frequently lack a survivorship care plan, as reported in an American study (Fong et al., 2022), indicating room for improvement in communication about late effects.

#### 4.1. Strengths and limitations

Qualitative content analysis is a commonly used method in nursing studies since it is considered suitable for various contexts and data (Graneheim and Lundman, 2004). It is argued that qualitative content analysis lacks depth, scientific rigor, and evidence compared to other qualitative methods, such as phenomenology and hermeneutics. However, qualitative content analysis was recognized as suitable for our research question since our study involves both descriptions and interpretations of abstraction at some level. We aimed to stay close to the text in our analysis to reveal the participants' voices and initially formed categories and sub-categories. During the analytic process, a higher level of abstraction emerged from the latent content and a higher degree of interpretation emerged, resulting in an overarching theme, which is in accordance with Lindgren et al. (2020). Data collected through individual interviews were considered appropriate to catch intimate problems of vaginal changes and gain a deeper understanding of women's experiences of vaginal dilator therapy.

To enhance trustworthiness, we have tried to outline all the phases of the analysis process. We also intended to outline the distinction and complex relationship between abstraction and interpretation during the process. The fact that the sample was selected from women who all had difficulties with maintaining dilation therapy most likely contributed to saturation being reached relatively early. Notably, the selected women struggled with a range of difficulties associated with dilator therapy, which might have enriched the data. From our clinical experience, not all women encounter such lack of information or resistance and lack of preparedness that was presented in this study. For this reason, the sample is considered not representative of all female cancer survivors treated with pelvic radiotherapy. We argue that our pre-understanding in the field could be both a strength and a limitation. On the one hand this may bias our results and affect the interpretation, on the other hand, and more likely, the pre-understanding contributed depth in the understanding.

A limitation is the lack of information about the study participants' cultural background, educational level, and comorbidities, since these aspects might affect how women experience information and the performance of vaginal dilator therapy, as well as the motivation to deal with therapy. These characteristics have been previously investigated and shown not to influence preparedness for survivorship (Fong et al., 2022); however, to our knowledge, they have not been studied in relation to preparedness for vaginal dilator therapy.

## 5. Conclusions

The results of this study have important implications for both researchers and healthcare professionals. The lack of preparedness for the use of vaginal dilation found in our study conveys a message to healthcare professionals to provide consistent, early and clear information combined with individualized support and follow-up of physical, psychosocial, and sexual issues. The degree of motivation concerning vaginal dilator therapy varies and needs to be carefully discussed. Notably, Cullen et al. (2012) stated ten years ago that they had opened up an area that at the time was poorly understood, yet female pelvic cancer survivors still feel unprepared for this issue. Although efforts have been made to elucidate female sexuality in cancer survivorship, our results stress the importance of clinical improvement and further research in this area. Healthcare professionals should be aware of potential difficulties with vaginal dilator therapy. Interventions for preparedness and support of late effects should be prioritized. Research is required to investigate interventions that suit the needs of female pelvic cancer survivors.

## CRedit authorship contribution statement

**Linda Åkeflo:** Conceptualization, Methodology, Data collection, Data curation, Visualization, Writing of the manuscript. **Eva Elmerstig:** Conceptualization, Methodology, Writing – review & editing. **Karin Bergmark:** Conceptualization, Writing – review & editing, Supervision. **Gail Dunberger:** Conceptualization, Methodology, Data curation, Visualization, Writing of the manuscript.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Acknowledgements

We thank all participants who generously shared their experiences when interviewed. We also thank Professor Gunnar Steineck for valuable support.

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