ORIGINAL RESEARCH—ONCOLOGY

Qualitative Accounts of Patients' Determinants of Vaginal Dilator Use after Pelvic Radiotherapy

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ABSTRACT

Introduction. Treatment with pelvic external beam radiotherapy with brachytherapy (EBRT/BT) for gynecological cancers may cause sexual dysfunction because of vaginal shortening and tightening. Regular vaginal dilator use is thought to reduce vaginal shortening and/or tightening, but compliance is poor.

Aims. This study identified determinants of patients' adherence with dilator use after EBRT/BT.

Methods. Semi-structured interviews were conducted with 30 women, aged 32–67 years, treated with EBRT/BT for gynecological cancers at two university medical centers in the past 36 months. Transcriptions were coded and analyzed with N-Vivo software.

Main Outcome Measures. Determinants of dilator use were clustered based on the Health Action Process Approach, which describes (i) motivation processes that lead to a behavioral intention and (ii) volition processes that lead to the initiation or maintenance of actual behavior.

Results. Almost all women attempted to perform long-term regular vaginal dilator use. Intended dilator use was determined by the expectation that it would prevent the development of vaginal adhesions and stenosis. Planning dilator use and making it part of a routine, using it under the shower, using lubricants, a smaller dilator size, or vibrators helped women. Others reported a lack of time or privacy, forgetting, or feeling tired. Women self-regulated dilator use by rotating the dilator and timing dilator use. Influencing factors were negative emotions regarding dilator use or its hard plastic design, (being anxious for) pain or blood loss, and an association with EBRT/BT. Some women mentioned a lack of instrumental support, for example, lubricants. Others received reassurance through informational support or were supported socially.

Conclusion. Motivation and volition processes that determined dilator use were identified and used in the development of a sexual rehabilitation intervention. It is important to provide sufficient patient information and support, and enlarge patients' perceived self-efficacy. **Bakker RM, Vermeer WM, Creutzberg CL, Mens JWM, Nout RA, and ter Kuile MM. Qualitative accounts of patients' determinants of vaginal dilator use after pelvic radiotherapy. J Sex Med 2015;12:764–773.**

Key Words. Gynecological Cancer; Pelvic Radiotherapy; Sexual Rehabilitation; Vaginal Dilator Use; Qualitative Research

Introduction

Treatment for gynecological cancers may cause sexual dysfunction, especially when treatment includes pelvic external beam radiotherapy with brachytherapy (EBRT/BT) [1–7].

The negative effect of treatment with EBRT/BT is attributed to vaginal shortening and tightening induced by fibrosis and stenosis [8,9]. Regular vaginal dilator use is thought to reduce vaginal shortening and/or tightening [10–12]. Although more empirical evidence is needed [13], dilator use

has become established practice worldwide [14–16]. Gynecological cancer experts in the Netherlands have reached consensus in a Delphi panel consensus process on how vaginal dilation should be performed.¹

Despite the proposed benefits of regular dilator use, patients have difficulties following the instructions and compliance is poor [17–21]. In previous studies, 1% to 35% of the participating gynecological cancer patients used a dilator with the recommended frequency within the first 12 months following EBRT/BT [17,18,20–22]. In two studies, 10 to 15 gynecological cancers patients were interviewed after EBRT/BT about their experiences with dilator use and reasons for (non)compliance [23,24]. Reported barriers were painful insertion, embarrassment, fear, reliving the invasive treatment, lack of information or time, forgetting, or dilation not being a priority during recovery [23,24]. Facilitating factors mentioned by patients were concern about the development of vaginal adhesions, belief that dilators help, reminders of adhesion development, acceptance of dilator use as part of a routine or an extension of treatment, or focusing on positive aspects of dilator use [23].

Aims

It remains unclear how these barriers and facilitators explain the women's compliance with dilator use. Therefore, this qualitative study aimed to identify the determinants of intention, initiation, and maintenance of long-term regular dilator use and to describe dilator use as a health behavioral process. Moreover, the identified determinants were supported by the theoretical constructs of the Health Action Process Approach (HAPA), which has been used to explain and predict numerous health behaviors [25].

Methods

Participants and Recruitment

Eligible women (aged 20–70 years) were treated with EBRT/BT for gynecological cancers at two university medical centers 2 to 36 months prior to the interview. Exclusion criteria were signs of

recurrent or metastatic cancer, medical or psychological problems, living abroad, or insufficient knowledge of the Dutch language.

Three radiation oncologists informed women about the study during their follow-up consultations between November 2012 and July 2013. It was ascertained that the participants consented to be interviewed. Participants received a 20-euro gift voucher. The Leiden University Medical Center (LUMC) Medical Ethics Committee approved the study protocol.

Data Collection

Two female researchers (R.M. Bakker and W.M. Vermeer) conducted semi-structured face-to-face interviews, in private, either at home or at the medical center. Two interviews were conducted by telephone because of practical reasons. The average duration of the interviews was 42 minutes (range: 27 to 62 minutes). As psychologists (MSc and PhD, respectively), the researchers were trained and experienced in interviewing patients, and not involved in the treatment of the women. All interviews were digitally recorded and transcribed verbatim.

Data Analyses

The transcriptions were analyzed with QSR International's NVivo 10 software using the Framework Approach [26,27]. The Framework Approach is used in health research to systematically analyze qualitative data by applying a combination of deductive and inductive coding. Therefore, emerging themes were identified using an a priori coding scheme based on the interview topics. The coding of the two researchers was compared and discussed after every third interview. Agreement on the adequacy of new emerging codes was achieved through negotiated consensus. At first, R.M. Bakker and W.M. Vermeer coded a random sample of 10 interviews. Secondly, R.M. Bakker coded the remaining 20 interviews using the definitive coding scheme. Lastly, they coded and cross-checked five of these interviews to ensure consensus on the definitive coding scheme and—if needed—complement the coding (R.M. Bakker and W.M. Vermeer) [28]. Descriptive statistics (e.g., age) were calculated using IBM SPSS version 21 (IBM Corp., Armonk, NY, USA).

Main Outcome Measures

Socio-demographic data were obtained from both women's medical records and the interview.

¹Experts reached consensus that it is best to use plastic dilator sets, to start around 4 weeks after EBRT/BT, to perform dilator use two to three times a week, for 1 to 3 minutes, and to continue for 9 to 12 months. The frequency of dilator use could be lowered each time patients had sexual intercourse [29].

Table 1 Interview themes and topics*

Themes	Topics
Demographic characteristics	Relationship, job and housing status, important life events, dates of cancer diagnosis, and treatment
Sexual rehabilitation since treatment	Sexual activity
Received information and support	<ul style="list-style-type: none"> • Received information and support regarding sexual health and vaginal dilator use after pelvic external beam radiotherapy with brachytherapy • Satisfaction with and suggestions for information provision and support
Adopted vaginal dilator use	<ul style="list-style-type: none"> • Evaluation of the vaginal dilator use in detail • Alternative dilator use other than the plastic dilator set • Partner involvement (if applicable) • Use of other possible components (e.g., lubricants)
Reasons for (non)compliance	<ul style="list-style-type: none"> • Personal motivation and experiences with dilator use • Practical, psychological, or physical reasons for (non)compliance • Role of received instructions • Experienced effect of (non)compliance • Experienced effect of alternative dilator use • Effect of experiences with treatment on dilator use • Experiences with the design of the plastic dilator set • Role of the partner (if applicable) • Applicability of other possible components (e.g., lubricants)

*The order and relevance of the topics discussed could vary because of the semi-structured nature of the interview.

Participants were interviewed about (i) received information and support, regarding sexual rehabilitation and vaginal dilator use; (ii) experiences with dilator use; and (iii) reasons for (non)compliance with dilator use. Table 1 describes the interview topics in detail.

The determinants of dilator use reported by the participants were analyzed using the theoretical constructs of the HAPA [25]. The HAPA describes the intention, initiation, and maintenance of health behaviors as a process. According to the HAPA, the intention to perform long-term regular dilator use is influenced by *risk perception* (the perceived likelihood of vaginal shortening and tightening) and *outcome expectancies* (the pros and cons of regular dilator use). Transforming the intention into initiation and maintenance of dilator use requires *planning* (where and when to perform dilator use and how to cope with possible difficulties), *action control* (evaluating the ongoing dilator use), and *resources* (instrumental, informational, or social support). Also, for example, negative emotions may form a barrier to perform dilator use. The perceived self-efficacy (the belief to be able to perform, continue, and resume dilator use after relapse) also affects dilator use. See also Figure 1, which represents example determinants and their interrelations.

Results

Participant Characteristics

At the LUMC, 13 out of 17 (77%) and at the Erasmus Medical Center 17 out of 35 (49%) eli-

gible women participated (in total 58%). Five women declined participation because the subject was too upsetting or intimate, four because of personal reasons, and two others could not be reached by phone. The other 11 women declined participation for unknown reasons (as the women were not obliged to specify their reason for refusing participation).

No new themes emerged after interviewing 25 women and thus data saturation was reached [30]. Participants were treated with primary ($n = 25$) or postoperative EBRT/BT ($n = 5$) (together with chemotherapy in $n = 25$) for cervical cancer ($n = 29$) or vaginal cancer ($n = 1$). The majority of the women had squamous cell carcinoma ($n = 26$) and a minority adenocarcinoma ($n = 4$). Furthermore, participants were treated 16 months ago on average ($\pm$ standard deviation [SD] = 9, range: 2–36 months). The mean age was 49 years ($\pm$ SD = 11, range: 32–67 years). All participants under the age of 45 years were offered hormone replacement therapy until they were 50 because of their treatment-induced postmenopausal status. Of all participants, 23 participants were partnered and 20 women reported to be sexually active.

All participants reported sexual problems and half of the women reported sexual distress since treatment. Almost all women reported pain during sexual contact. The majority reported symptoms of a shortened and/or tightened vagina, vaginal adhesions, loss of sexual desire, lubrication problems, a burning sensation and sensitive vaginal skin, loss of blood after penetration, reduced sexual enjoyment, and/or fear for sexuality (e.g.,

Figure 1 Example determinants of vaginal dilator use and their interrelations according to the Health Action Process Approach.

because of possible pain or infections). Also, one-third reported loss of sexual satisfaction.

Reported Dilator Use

Two women treated more than 2 years ago never intended to perform dilator use. All other participants reported to have (had) the intention to use a dilator and also used a dilator at least once. Furthermore, almost half of the participants performed dilator use at least two times a week. Half of those women, a quarter of all participants, were treated at 9 to 12 months previously and completed the instructed period of use.

However, the other half of the participants were not able to translate their intention and attempts in dilator use as recommended. Some of these women reported dilating regularly only during the first few months after treatment. Others performed dilator use infrequently or attempted not more than a few times. The majority was treated between 1 and 2 years previously.

Determinants of the Intention to Perform Dilator Use

Table 2 provides example quotes of the findings structured according to the HAPA.

Risk Perception

For most women, the intention to start or continue dilator use was determined by a motivation to prevent the development of vaginal adhesions and subsequent possible occlusion of the vagina (Quote 1, Table 2). Furthermore, half of the women became motivated and convinced that they were at risk of adhesions because they were bothered or scared to notice that adhesions had formed. Some already noticed adhesions before they ever used a dilator and others noticed adhesions after infrequent or lack of dilator use. Some of the women stated that dilator use was not a priority because sexuality was irrelevant at that moment.

Participants' risk perception was influenced by the way they perceived the instructions from their health care providers. The two women who never intended to perform dilator use reported insufficient information provision. One of them received some information, but no dilator set or instructions. She thought her doctor estimated it was not necessary. Another woman refused a dilator set at the time because she thought it was advised to stimulate sexual contact, which she did not

Table 2 Interview topics and example quotes of vaginal dilator use determinants

Topic	Example quote
The intention	
<i>Risk perception</i>	1 Partnered, 32 – If you don't insert anything in your vagina when it is one big wound [after treatment], it will just completely occlude.
<i>Outcome expectancies</i>	2 Partnered, 50 – I feel that I have to do it [referring to dilator use], so it's not enjoyable, but it is important I think. Otherwise my vagina gets too small I think.
The initiation and maintenance	
<i>Planning</i>	3 Partnered, 53 – Well, I just take a shower and perform dilator use every Tuesday and Friday. Just regular days and then I take the dilator and just insert it.
<i>Action control</i>	4 Single, 62 – Well, I perform . . . Yes, it's weird, but I perform dilator use while listening to music from Wagner. Because it is a music piece that lasts exactly 10 minutes.
Negative emotions	
<i>Anxious for pain or blood loss</i>	5 Partnered, 41 – And because of the radiotherapy I had some burning feeling, some kind of burns, also vaginal. So yes, it [referring to dilator use] was all very sensitive and very painful. It was mostly the fear of pain.
<i>Association with cancer diagnosis or pelvic radiotherapy</i>	6 Partnered, 48 – The idea repulsed me a little. Well maybe because, just after that operation and brachytherapy and such, the medical world frequently inserted all kinds of objects [referring to vaginally], and that made you feel like: not now.
<i>Bothersome chore</i>	7 Partnered, 44 – I think it's odd to have something in and out of your vagina every day. I don't know. I can't explain really. It's like an extra chore. A bothersome job.
Resources	
<i>Instrumental support</i>	8 Partnered, 41 – Those things [referring to dilators] aren't enjoyable sex toys. [. . .] Then I think: then you also have to pay for them as well. [. . .] I also let them know that I found that very disturbing.
<i>Informational support</i>	9 Partnered, 36, actor – But it was also kind of scary [referring to blood loss during dilator use], then I heard from my doctor that . . . “Look, I understand that you have a negative association with blood loss, but it is understandable that you have it.” That did reassure me.
<i>Social support</i>	10 Partnered, 32 – It was just something I did [referring to dilator use] [. . .] And my partner helped me a lot and the doctor says: “Use it as often as you can and if it hurts a little . . .” He was really coaching me like: try to keep it up.
Perceived self-efficacy	
	11 Partnered, 49 – Because it is some kind of obligation, it's not . . . That you have to continue as a routine. I just couldn't do it . . . I couldn't get it done in the beginning; I just didn't know how to handle it.

consider necessary. Furthermore, some women mentioned to have stopped dilator use after a while, even though this was not recommended or approved for by their health care provider. They hoped that they performed dilator use long enough to prevent adhesions.

Outcome Expectancies

Participants generally expected that dilator use would prevent the development of vaginal adhesions and would keep the vagina accessible after EBRT/BT (Quote 2, Table 2). Also, half of the women expected to facilitate sexual contact or intercourse, now or in the future. A couple of women intended to facilitate physical examination during posttreatment follow-up appointments. For one woman, facilitating follow-up examinations was the only well-known purpose to her. Some women acknowledged continuing dilator use just because they received the instruction that it was important or because they saw it as part of their treatment.

Discovering adhesions after a short period of not using dilators not only heightened women's

risk perception but also convinced them of its beneficial effect against adhesions. Some women also indicated being supported by experiencing benefits like reduction in vaginal tightening and pain, and an increase in vaginal sensations. A few women also experienced these beneficial effects while having sexual intercourse. Retrospectively, however, participants that adhered to long-term regular dilator use did not mention to be more sexually active or satisfied, or have a sexual relationship more often.

Some women attempting regular dilator use stated that it did not prevent adhesions or even caused pain. Half of the women mentioned experiencing pain during dilator use and some reported blood loss or vaginal discharge. Experiencing pain or blood loss during dilator use motivated a few women to continue dilator use, because that would reduce anxiety and pain.

About half of the women indicated that their doctor evaluated their vaginal dilator use. A couple of women became convinced that dilator use was useful because the doctor told them that the condition of their vagina looked good and accessible

after examination. Others had become less convinced because their doctors did not talk about it or because physical examination was still painful.

Determinants of the Initiation and Maintenance of Dilator Use

Planning

A group of women explained that planning dilator use and making it part of a routine helped them to transform their intention into action (Quote 3, Table 2). A few women mentioned choosing a fixed time or day. Someone recommended starting dilator use shortly after treatment to make it less of an obstacle. However, some women found it difficult to make time for dilator use and cleaning afterward. A couple of women reported forgetting, being tired, or finding the privacy for dilator use as a problem.

To anticipate on difficulties during dilator use, some women lay down on their bed, made sure not to be disturbed, or playing relaxing music to relax. About half of the women used neutral (water- or silicone-based) lubricants during dilator use and some experienced less discomfort because of it. Other women used a dilator under the shower to save lubricant and time. And some women found it helpful to build up in dilator size in order to reduce anxiety. A few women placed the dilator against the vaginal opening or waited before pushing it inside to get used to the device.

A couple of women preferred using a vibrator, because they expected it to be more enjoyable, less alien, and possible to integrate during sexual contact. However, a few older women could not even imagine it to be more enjoyable. A couple of women stopped using a vibrator because they read that the material could cause cancer or it confronted them with a lack of sexual desire. A couple of partnered women reported being helped by making dilator use as part of sexual contact. About half of the women frequently had sexual intercourse as an alternative means of dilation and could therefore lessen (or even stop) dilator use. However, another few felt pressured by their partner to have intercourse instead.

Action Control

A few women indicated to rotate the dilator while inserted in order to better prevent the formation of adhesions. A few others indicated being helped by reading something or trying to stop thinking about daily concerns to be able to continue. Almost half of the participants inserted a dilator during 1 to 5 minutes and some women during 10

minutes. A few women mentioned timing the insertion of dilator use by looking at their watch or listening to a music piece of a certain length (Quote 4, Table 2).

Factors Influencing Vaginal Dilator Use

Negative Emotions

More than half of the women expressed negative emotions about dilator use. Experiencing pain, blood loss, or discharge during dilator use made half of the women anxious to use a dilator (Quote 5, Table 2), and a few were bothered by tension of the pelvic floor muscles. Some had stopped dilator use because of it. A couple of women indicated a negative association with blood loss during dilator use, or sexual contact, and cancer (fear of recurrence). Women acknowledged that dilator use confronted them with the fact that they were still dealing with the cancer. Also, some women negatively associated dilator insertion with the invasive brachytherapy treatment, or were not ready for dilator use yet (Quote 6, Table 2). Almost half of the women acknowledged that regular dilator use felt like homework or a bothersome chore (Quote 7, Table 2). Also, some women felt resistant or even repulsed toward dilator use. A few women felt so repulsed that they stopped dilator use. Lastly, a few women stated not being the type to perform dilator use as if it embarrassed them.

Resources

A couple of women were frustrated about their health insurance company not paying for the dilator set (as one of the two hospitals itself did not supply them) (Quote 8, Table 2) or having to buy neutral (water- or silicone-based) lubricants themselves. One older woman stated being embarrassed by having to explain at her local drugstore why she would need lubricants. Informational support from health care providers reassured some women that it was normal experiencing certain setbacks during dilator use, such as blood loss (Quote 9, Table 2). However, some women stated to lack professional advice or support and therefore did not use a dilator more often. Another woman regretted not getting more follow-up appointments with her helpful oncology nurse. Several women suggested that it would be helpful to have at least one consult with a psychologist or other health care provider to support them with dilator use at the end or just after treatment.

A few women mentioned being supported socially and received encouragement to continue from their partner, friends, or health care provider

(Quote 10, Table 2). Most partnered women did not involve their partner in dilator use. However, a few women felt supported and experienced less anxiety by doing so. Also, a few mentioned their partner remembering more of the received instructions regarding vaginal dilator use than they did.

Perceived Self-Efficacy of Vaginal Dilator Use

A few women acknowledged that it was not the action itself that was hard to achieve, but that other barriers (such as negative emotions) made it hard to perform regular dilator use. Another few mentioned doubting that dilator insertion was physically possible. A few women expressed not being able to build dilator use into their routine (Quote 11, Table 2). Whereas a few participants mentioned that dilator use made them feel in control of the prevention of adhesions.

Importantly, someone indicated that experiencing pain during dilator use made her not want to have sexual intercourse anymore. Nevertheless, a few women indicated that dilator use helped them to initiate sexual intercourse, because it made them aware that it was physically possible without a lot of pain and therefore reduced anxiety.

Dilator Design

More than half of the women had negative feelings about the (“hard and clinical”) design of the plastic dilator set. Besides, some women desired a more pleasurable dilator made out of softer material; a few women mentioned a dilator should have a bigger diameter, a (nontransparent) color, be pointier, or able to rotate itself. Others wanted a more pleasurable design that would be suitable to integrate in sexual contact. Half of the women rather saw dilators as a technical tool or medical device. Therefore, some added that its neutral design is appropriate. Also, a group of women suggested it was not necessary to provide a dilator set containing four sizes. Some women never used the smallest size, because according to them, it did not serve a purpose. Whereas others never used the biggest size, because it was too painful and the doctor told them that using this size was not necessary to prevent adhesions.

Discussion

This study distinguished determinants of the intention, initiation, and maintenance of dilator use. Almost all women intended and attempted to perform long-term regular vaginal dilator use. The intention to perform dilator use was deter-

mined by the motivation to prevent the development of vaginal adhesions and stenosis, with the expectation that it would keep the vagina accessible. The intention was influenced by the quality and quantity of instructions, the degree to which dilator use was evaluated during follow-up appointments, and experienced benefits. Women reported planning dilator use and made it part of a routine, used lubricants or vibrators, or performed dilator use under the shower. Others had difficulties planning dilator use and reported a lack of time or privacy, forgetting, and feeling tired when performing dilator use. Women regulated dilator use by rotating the dilator and timing dilator use. Influencing factors were negative emotions about dilator use, pain or blood loss during dilator use, and the association with brachytherapy. Some women mentioned a lack of instrumental resources. Others were helped by informational or social support.

The reported determinants of dilator use confirm the limiting and facilitating factors that were previously described [23,24]. The representativeness of the study population might be limited, because women with insufficient knowledge of the Dutch language were excluded from participation. Also, women that feared to talk about the subject or had great resistance toward dilator use might have declined participation more often. Therefore, it is possible that this study's population was more motivated to use dilators compared with an average patient. However, almost all participants were diagnosed with cervical cancer and two-thirds had a sexual relationship. Therefore, the selected participants did represent the target group that receives EBRT/BT and the recommendation to perform long-term regular dilator use.

A few partnered women indicated that dilator use had beneficial effects regarding sexual intercourse. It makes sense that having a satisfactory sexual intercourse might be an important incentive for long-term regular dilator use. In this study, compliant participants did not mention to be more sexually active or satisfied, nor did they seem to differ in relationship status. It is, however, interesting to investigate whether sexual behavior could influence dilator use in a prospective (quantitative) study.

Women mentioned the dilator design to be relevant for their dilator use behavior. In the Netherlands, white or transparent plastic dilator sets are advised. However, in other countries, different dilator sets might be used. It is not known

Table 3 Recommendations for health care providers regarding the intention formation, initiation, or maintenance of patients' vaginal dilator use

<p>The intention to start dilator use</p> <p>Provide explanation and/or learning experience regarding risk of vaginal adhesions and positive outcomes of dilator use</p> <ul style="list-style-type: none"> • Provide clear rationale that dilator use: <ul style="list-style-type: none"> — Prevents the formation of vaginal adhesions — Keeps the vagina accessible for penetration (in the future; for women without partner) — Also makes future vaginal examination during follow-up appointments more convenient — Can be useful to help reduce fear for bodily changes and sexual activity • Provide clear instructions (regarding the frequency, duration [minutes], period of dilator use [months], how to insert) and psycho-education regarding dilator use through oral information, a specific information brochure, and/or websites • Discuss and consider demonstrating various types of dilators (e.g., commercially available plastic dilator sets, softer dilators, vibrators) and let the patient ultimately decide • Provide a dilator set or specific recommendations after discussing options. • Encourage that inserting a dilator vaginally is physically possible after treatment <p>The initiation and maintenance of dilator use</p> <p>Help to plan and control dilator use</p> <ul style="list-style-type: none"> • Encourage gradually increasing the dilator size that is used, once a smaller size is used without difficulty • Encourage building dilator use into a routine (on convenient time and fixed days during the week) • Help to time dilator use, e.g., by setting a clock • Advise to guarantee privacy during dilator use • Advise to find comfortable position in bed or under the shower • Advise to place dilator against vaginal opening first in order to reduce anxiety <p>Provide support</p> <ul style="list-style-type: none"> • Monitor and evaluate dilator use during every follow-up appointment • Emphasize experienced benefits while evaluating dilator use • Involve women's partners during consultations depending on the patient's needs • Actively involving the partner during dilator use itself should depend on the patient's needs • Extra consultations with a specialized oncology nurse, psychologist, or sexologist should be made possible <p>Help to prepare for situations in which women tend to stop dilator use</p> <ul style="list-style-type: none"> • Recommend using lubricants to prevent painful experiences; discuss various types of lubricants and their specific properties • Give simple advice, such as how to relax the pelvic floor muscles • Provide reassurance that dilator use might feel uncomfortable or painful, or may cause minor blood loss or vaginal discharge <p>Help to deal with negative emotions, behavioral skills, and motivational issues</p> <ul style="list-style-type: none"> • Challenge women's resistance, repulsion, embarrassment, and other negative emotions regarding dilator use by using cognitive behavioral therapeutic techniques • Explore and resolve patients' ambivalence and lack of self-efficacy regarding dilator use (i.e., motivational interviewing counseling approach may be helpful) • Fear of dilator use may be reduced during a health care provider-guided dilator use practicing session at the hospital • Refer women to a sexologist in case simple sexological advice does not suffice

whether women would have adhered to long-term regular dilator use when their health care providers discussed or demonstrated different dilator sets. It is important to provide women with alternative types of dilators, such as vibrators, when possible and to let the patient decide on which type of dilator to use [29] (see Table 3 for more recommendations).

In order to effectively support women with dilator use, interventions should match whether women need help with the intention formation, initiation, or maintenance of dilator use. According to Schwarzer et al., women with no intention can be expected to benefit from the confrontation or learning experience that regular dilator use has positive outcomes [25]. This was confirmed by the reported influence of the quantity and quality of received instructions, dilator use evaluation, and experienced benefits on participants' intention to start or continue dilator use. Previous studies also

described that information provision can help women adhere (see Table 3) [18,20,22,29,31,32].

Some participants reported that they were not readily able to use dilators because of anxieties or other barriers. However, participants' perceived self-efficacy to maintain dilator use, or to resume after discontinuing dilator use, was hardly spontaneously discussed. The HAPA constructs were not part of the interview guideline and it remains unclear whether participants saw themselves as capable of long-term regular dilator use. Because almost all participants at least attempted dilator use but only part of them continued, the main challenge appears to be to increase long-term regular adherence among women. According to participants in the current study, women could benefit from planning, and preparing for situations in which they tend to stop using dilators is imminent. Therefore, also in concordance with the HAPA [25], interventions should help this group

of women change their routine and negative emotions about dilator use or enlarge their perceived self-efficacy. Such a supportive intervention could comprise a short cognitive behavioral therapy intervention and apply motivational interviewing [33] to help women deal with behavioral skills and motivational issues [18,20]. Specialized nurses could provide this after EBRT/BT [31]. Furthermore, participants mentioned that social support was helpful. This confirms previous results that including partners or a peer group in such an intervention is beneficial as well (see Table 3) [20,34].

Conclusion

In the current study, useful motivation and volition processes that determined initiation and maintenance of dilator use were identified. These and the principles discussed above were used in the development of a sexual rehabilitation intervention for gynecological cancer patients, which is currently pilot-tested.

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References

- 1 Incrocci L, Jensen PT. Pelvic radiotherapy and sexual function in men and women. *J Sex Med* 2013;10:53–64. doi: 10.1111/jsm.12010.
- 2 Krychman M, Millheiser ML. Sexual health issues in women with cancer. *J Sex Med* 2013;10:5–15. doi: 10.1111/jsm.12034.
- 3 Pieterse QD, Kenter GG, Maas CP, de Kroon CD, Creutzberg CL, Trimbos JB, ter Kuile MM. Self-reported sexual, bowel and bladder function in cervical cancer patients following different treatment modalities: Longitudinal prospective cohort study. *Int J Gynecol Cancer* 2013;23:1717–25. doi: 10.1097/IGC.0b013e3182a80a65.
- 4 Abbott-Anderson K, Kwekkeboom KL. A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecol Oncol* 2012;124:477–89. doi: 10.1016/j.ygyno.2011.11.030.
- 5 Greimel ER, Winter R, Kapp KS, Haas J. Quality of life and sexual functioning after cervical cancer treatment: A long-term follow-up study. *Psychooncology* 2009;18:476–82. doi: 10.1002/pon.1426.
- 6 Lindau ST, Gavrilova N, Anderson D. Sexual morbidity in very long term survivors of vaginal and cervical cancer: A comparison to national norms. *Gynecol Oncol* 2007;106:413–8. doi: 10.1016/j.ygyno.2007.05.017.
- 7 Frumovitz M, Sun CC, Schover LR, Munsell MF, Jhingran A, Wharton JT, Eifel P, Bevers TB, Levenback CF, Gershenson DM, Bodurka DC. Quality of life and sexual functioning in cervical cancer survivors. *J Clin Oncol* 2005;23:7428–36. doi: 10.1200/JCO.2004.00.3996.
- 8 Jensen PT, Groenvold M, Klee MC, Thranov I, Petersen MA, Machin D. Longitudinal study of sexual function and vaginal changes after radiotherapy for cervical cancer. *Int J Radiat Oncol Biol Phys* 2003;56:937–49. doi: 10.1016/S0360-3016(03)00362-6.
- 9 Brand AH, Bull CA, Cakir B. Vaginal stenosis in patients treated with radiotherapy for carcinoma of the cervix. *Int J Gynecol Cancer* 2006;16:288–93.
- 10 Gondi V, Bentzen SM, Sklenar KL, Dunn EF, Petereit DG, Tannehill SP, Straub M, Bradley CK. Severe late toxicities following concomitant chemoradiotherapy compared to radiotherapy alone in cervical cancer: An inter-era analysis. *Int J Radiat Oncol Biol Phys* 2012;84:973–82. doi: 10.1016/j.ijrobp.2012.01.064.
- 11 Velaskar SM, Martha R, Mahantashetty U, Badakare JS, Shrivastava SK. Use of indigenous vaginal dilator in radiation induced vaginal stenosis. *Indian J Occup Ther* 2007;39:3–6.
- 12 Decruze SB, Guthrie D, Magnani R. Prevention of vaginal stenosis in patients following vaginal brachytherapy. *Clin Oncol* 1999;11:46–8. doi: 10.1053/clon.1999.9008.
- 13 Miles T, Johnson N. Vaginal dilator therapy for women receiving pelvic radiotherapy. *Cochrane Database Syst Rev* 2010;9:CD007291, doi: 10.1002/14651858.CD007291.pub2.

- 14 Clinical Guideline Group. International guidelines on vaginal dilation after pelvic radiotherapy. Oxon, Owen Mumford. 2012. Available at: <http://www.ncsi.org.uk/wp-content/uploads/Inter-Best-Practice-Guide-Vaginal-Dilators-July-2012.pdf> (accessed February 12, 2014).
- 15 Grigsby PW, Russell A, Bruner D, Eifel P, Koh WJ, Spanos W, Stetz J, Stitt JA, Sullivan J. Late injury of cancer-therapy on the female reproductive-tract. *Int J Radiat Oncol Biol Phys* 1995;31:1281-99. doi: 10.1016/0360-3016(94)00426-L.
- 16 Crowther ME, Corney RH, Shepherd JH. Psychosexual Implications of Gynecological Cancer. *Br Med J* 1994;308:869-70. doi: 10.1136/bmj.308.6933.869.
- 17 Friedman LC, Abdallah R, Schluchter M, Panneerselvam A, Kunos CA. Adherence to vaginal dilation following high dose rate brachytherapy for endometrial cancer. *Int J Radiat Oncol Biol Phys* 2011;80:751-7. doi: 10.1016/j.ijrobp.2010.02.058.
- 18 Jeffries SA, Robinson JW, Craighead PS, Keats MR. An effective group psychoeducational intervention for improving compliance with vaginal dilation: A randomized controlled trial. *Int J Radiat Oncol Biol Phys* 2006;65:404-11. doi: 10.1016/j.ijrobp.2005.12.009.
- 19 Juraskova I, Butow P, Robertson R, Sharpe L, McLeod C, Hacker N. Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. *Psychooncology* 2003;12:267-79. doi: 10.1002/pon.639.
- 20 Robinson JW, Faris PD, Scott CB. Psychoeducational group increases vaginal dilation for younger women and reduces sexual fears for women of all ages with gynecological carcinoma treated with radiotherapy. *Int J Radiat Oncol Biol Phys* 1999;44:497-506. doi: 10.1016/S0360-3016(99)00048-6.
- 21 Schover LR, Fife M, Gershenson DM. Sexual dysfunction and treatment for early stage cervical-cancer. *Cancer* 1989;63: 204-12. doi: 10.1002/1097-0142(19890101)63:1<204::AID-CNCR2820630133>3.0.CO;2-U.
- 22 Brand AH, Do V, Stenlake A. Can an educational intervention improve compliance with vaginal dilator use in patients treated with radiation for a gynecological malignancy? *Int J Gynecol Cancer* 2012;22:897-904. doi: 10.1097/IGC.0b013e31824d7243.
- 23 Bonner C, Nattress K, Anderson C, Carter J, Milross C, Philp S, Juraskova I. Chore or priority? Barriers and facilitators affecting dilator use after pelvic radiotherapy for gynaecological cancer. *Support Care Cancer* 2012;20:2305-13. doi: 10.1007/s00520-011-1337-z.
- 24 Cullen K, Fergus K, Dasgupta T, Fitch M, Doyle C, Adams L. From "sex toy" to intrusive imposition: A qualitative examination of women's experiences with vaginal dilator use following treatment for gynecological cancer. *J Sex Med* 2012;9:1162-73. doi: 10.1111/j.1743-6109.2011.02639.x.
- 25 Schwarzer R, Lippke S, Luszczynska A. Mechanisms of health behavior change in persons with chronic illness or disability: The Health Action Process Approach (HAPA). *Rehabil Psychol* 2011;56:161-70. doi: 10.1037/a0024509.
- 26 QSR International Pty Ltd. NVivo [Qualitative data analysis software]. Version 10, 2012.
- 27 Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *Br Med J* 2000;320:114-6. doi: 10.1136/bmj.320.7227.114.
- 28 Mays N, Pope C. Rigour and qualitative research. *Br Med J* 1995;311:109-12. doi: 10.1136/bmj.311.6997.109.
- 29 Bakker RM, ter Kuile MM, Vermeer WM, Nout RA, Mens JWM, van Doorn LC, de Kroon CD, Hompus WCP, Braat C, Creutzberg CL. Sexual rehabilitation after pelvic radiotherapy and vaginal dilator use: Consensus using the delphi method. *Int J Gynecol Cancer* 2014;24:1499-506. doi: 10.1097/IGC.0000000000000253.
- 30 Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 2006;18:59-82. doi: 10.1177/1525822X05279903.
- 31 Punt L. Patient compliance with the use of vaginal dilators following pelvic radiotherapy for a gynaecological cancer. *J Radiother Prac* 2011;10:13-25. doi: 10.1017/S1460396910000476.
- 32 Carter J, Goldfrank D, Schover LR. Simple strategies for vaginal health promotion in cancer survivors. *J Sex Med* 2010;8:549-59. doi: 10.1111/j.1743-6109.2010.01988.x.
- 33 Hetttema J, Steele J, Miller WR. Motivational interviewing. *Annu Rev Clin Psychol* 2005;1:91-111. doi: 10.1146/annurev.clinpsy.1.102803.143833.
- 34 Scott JL, Kayser K. A review of couple-based interventions for enhancing women's sexual adjustment and body image after cancer. *Cancer J* 2009;15:48-56. doi: 10.1097/PPO.0b013e31819585df.