Impaired body image and physical and sexual limitations after surgical therapy for vulvar cancer: a qualitative study

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Research Article

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Abstract

Purpose

Surgical treatment for vulvar cancer has impact on women's self-esteem, body image and sexuality. Health Care Professionals experience difficulties in discussing these issues with patients. The aim of this study was to explore the experiences of patients with vulvar cancer regarding sexual changes, and their needs and expectations regarding sexual counseling.

Methods

Individual semi-structured interviews were conducted with patients who were surgically treated for vulvar cancer. All interviews were transcribed verbatim and thematically analyzed.

Results

Seven patients (mean age 54, 86% stage 1B vulvar cancer) participated. Seven themes were identified and were linked to the biopsychosocial framework: 1) the impact of physical disabilities on body image, 2) sexual dysfunction, 3) grieving the loss of sexual health, 4) ambivalence in the acceptance of sexual changes, 5) the effect of the partner on sexual experience, 6) the attitude of the Health Care Professional (HCP), and 7) discussing sexuality: the right moment

Conclusion

Patients who are surgically treated for vulvar cancer experience problems related to impairment on daily activities, altered body image and sexuality. Especially difficulties in reaching an orgasm or anorgasmia are hard to accept. Both the partner and HCP play an important role in how patients experience discussing and exploring sexuality after treatment. Since informational needs regarding sexuality change over time and patients start to fantasize about sex after 4–6 months, it is recommended to schedule an appointment 4–6 months after surgery to discuss patients' needs regarding sexual information and counseling.

Introduction

Vulvar carcinoma (VC), mainly vulvar squamous cell carcinoma (VSCC), accounts for approximately 5% of gynecological malignancies and has a striking increase in annual incidence over the last decades from 200 to 450 patients in the Netherlands [1–3]. The majority of the patients is surgically treated, which severely impacts their Health-Related Quality of Life (HRQoL) [4, 5]. Studies have shown that surgery can have a negative impact on women's self-esteem, body image and sexuality [6, 7]. Short- and long-term
consequences can be explained by using the biopsychosocial framework, which differentiates between biological, psychological and social dimensions of illness [8, 9].

Physical changes that may occur after treatment are lymphoedema, vaginal stenosis, and loss of (sexual) sensation due to vulvar resections [6, 10, 11]. Psychosocial consequences are also frequent; 31% of women report symptoms of depression after surgery [12]. Moreover, patients experience emotions such as uncertainty, fear for recurrence, and embarrassment [13, 14]. After surgical treatment women suffer from sexual dysfunction, for example dyspareunia due to vaginal stenosis, and difficulties in lubrication or in reaching an orgasm [8, 10, 15]. Furthermore, patients experience an altered body image due to the changed appearance of their genital, which impacts their sexual well-being [8, 13, 16]. Currently, to the best of our knowledge, no studies about the altered sexual experience in women who are surgically treated for vulvar cancer are performed.

Health Care Professionals (HCPs) indicate that they experience barriers in discussing sensitive issues, for instance problems related to sexual wellbeing, because of a lack of knowledge, confidence and time [17–19]. A study by Del Pup et al. [20] highlights that providing information about the sexual consequences of the surgery can improve patients’ HRQoL. Therefore, it is important that HCPs address sexual wellbeing in their consultations [10]. However, it is unclear what professionals can offer to support these women. No information about sexual change during follow-up is mentioned in the Vulvar Cancer Guidelines developed by the European Society of Gynaecological Oncology (ESGO) nor in the British Gynaecological Cancer Society (BGCS) vulvar cancer guidelines [21, 22]. The aim of this study is to explore the experiences of patients with vulvar cancer regarding sexual changes, and their needs and expectations regarding sexual counseling.

Methods

Study design

A qualitative research design with a phenomenological approach was used. The goal of a phenomenological approach is to understand a phenomenon from the perspective of those who experienced it [23]. Individual semi-structured interviews were conducted with patients who were surgically treated for vulvar cancer. Semi-structured interviews allow respondents to expand on their answers, which is essential when a phenomenological approach is being used and the focus is on exploring subjective experiences [24]. The Medical Research Ethics Committees United has reviewed the study and declared that the Dutch Medical Research Involving Human Subjects Act (WMO) does not apply (W19.180). The study has been performed in agreement with the Declaration of Helsinki [25].

Study sample and recruitment

Participants were recruited by purposive sampling from patients treated in the Catharina Hospital between 2015–2018. Women were eligible for participation if they were diagnosed with vulvar neoplasm between stage 1B and 3A and if they were surgically treated by means of a wide local excision (WLE),
with sentinel node (SN), and/or with (partial) removal of the clitoris. Furthermore, they needed to be in a (sexual) relationship. Two recruitment rounds were conducted, in which thirty-one women met the inclusion criteria. Twelve participants were interested in participating and received an information letter and informed consent. Ten women agreed to participate, but at the time of data collection, three participants did not want to continue because of various reasons, e.g. unexpected private circumstances, a recurrent carcinoma, or experiencing difficulties in talking about sexuality (Fig. 1).

Data collection

Semi-structured interviews were conducted by the principal researcher (NV) between October and December 2019. Beforehand, an interview guide was developed and tested with experts in the working field [5]. The final interview guide contained questions about e.g., femininity, insecurities towards partner, sexual satisfaction, communication and professional guidance. Every interview started with the same question: ‘what do you understand by sexuality and intimacy?’, in order to use uniformity in terminology. The interviews were audio recorded and lasted approximately 45 minutes. Member checks were used after the interviews, and no adjustments were needed.

Data analysis

Data from the interview were transcribed verbatim by the principal researcher (NV). Thematic analysis were performed based on the six phases that have been described by Braun et al. [26]. All transcripts were open coded by a second independent researcher (SdM) to ensure reliability of the coding procedure. Several meetings between the researchers were held to reach consensus on the codes, and on the final themes. All analysis were performed using Atlas.ti.

Results

Participants’ characteristics

In total, seven patients participated in the study (Table 1). The mean age of the participants was 54 years old (range 42–70), and everyone was married. Six patients were diagnosed with stage 1B, and time since diagnosis ranged from approximately one year to twelve years, with a mean of approximately 3 years and a half years. The majority of the participants (57%) were diagnosed with Lichen Sclerosus prior to the occurrence of vulvar cancer.
### Table 1
Participants’ characteristics

<table>
<thead>
<tr>
<th>No.</th>
<th>Age</th>
<th>Marital status</th>
<th>Type of cancer</th>
<th>Time since diagnosis</th>
<th>Metastases</th>
<th>Type of treatment</th>
<th>LSEA</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>66</td>
<td>Married</td>
<td>Vulvar 3A</td>
<td>1 year, 8 months</td>
<td>Yes, lymph node</td>
<td>WLE + SN + lymph node resection</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>49</td>
<td>Married</td>
<td>Vulvar 1B</td>
<td>3 years, 4 months</td>
<td>No</td>
<td>WLE + SN</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>43</td>
<td>Married</td>
<td>Vulvar 1B</td>
<td>1 year, 5 months</td>
<td>No</td>
<td>WLE + SN bilateral</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>48</td>
<td>Married</td>
<td>Vulvar 1B</td>
<td>1 year, 2 months</td>
<td>No</td>
<td>WLE + SN bilateral</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>63</td>
<td>Married</td>
<td>Vulvar 1B</td>
<td>2 years, 6 months</td>
<td>No</td>
<td>WLE + SN bilateral</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>70</td>
<td>Married</td>
<td>Vulvar 1B</td>
<td>3 years, 4 months</td>
<td>No</td>
<td>WLE + SN bilateral</td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td>42</td>
<td>Married</td>
<td>Vulvar 1B</td>
<td>12 years, 1 months</td>
<td>No</td>
<td>WLE + SN bilateral</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Themes**

In total, seven themes were identified. Six themes could be categorized into biological, psychological and social aspects of sexual health, and are therefore organized around the biopsychosocial framework. The seventh theme is described separately from this framework and describes a timeline in discussing sexuality in clinical practice. A summary of the results is given in Fig. 2.

**The biological domain**

**The impact of physical disabilities on body image**

All participants stated that physical disabilities they encountered after the treatment had a huge impact on the performance of daily activities. Fatigue, the inability to lift something, and to wear certain clothes like jeans because of the pain, were the most mentioned complaints.

*P4: “For me, that was something to hold on to: when will I be able to wear that jeans again? All of a sudden, that is not so obvious anymore.”*
The changes that occurred in the anatomy of the vulva had a negative impact on patients’ body image and consequently on their sexual satisfaction.

**P4:** “You know, I do feel a little mutilated.”

Participants indicated that the sensations in their vulva changed after the treatment, which made them feel less confident in their body. Some participants were afraid of their partners’ touching them and that it would possibly lead to sexual intercourse.

**Sexual dysfunction**

All participants experienced orgasm difficulties after surgery, and some were not able to reach a climax anymore (anorgasmia). They described this as a predominant negative consequence of the treatment, as it resulted in less sexual pleasure and a decreased sex drive. The level of distress was especially high in patients in which the clitoris needed to be removed, and when penile-vaginal sex was not possible anymore. A few participants ultimately abandoned all sexual activities.

**P6:** “Our sex life really deteriorated, because I did not experience sexual pleasure anymore.”

**The psychological domain**

**Grieving the loss of sexual health**

The majority of the participants were grieving the loss of their sexual health. In addition, women worried about the acceptance of their partner, since their bodies changed after the surgery. The fear of being less attractive resulted in taking less initiative in sexual activities. Participants stated that cancer survivorship brings along various feelings. On the one hand, they perceived being cancer-free as important, but on the other hand, the loss of sexual health was difficult and painful. When comparing these feelings, it was shown that patients considered sexual health as important, but living cancer-free as much more important.

**P2:** “I often think about the fact that is was much nicer before, but I got through it well. Life is not all about sex, that is not the only thing that exists.”

Most of the participants indicated that they needed to accept the changes in sexual functioning, since it was not going to improve anymore. They found it especially hard to accept orgasm difficulties or anorgasmia.

**P1:** “A lot of things changes, but you need to accept it and think: that is just the way it is.”

**Ambivalence in the acceptance of sexual changes**

Participants showed ambivalence feelings when trying to accept orgasm difficulties or anorgasmia. While acceptance and resignation was a coping strategy for some participants, others kept searching for
possibilities to experience an orgasm.

P4: “An orgasm. If it does not happen, then it does not happen. But at least I know that I have tried everything to make it possible, or at least to create opportunities to make it possible.”

Some participants still feel a continuous desire for sexual activity so they can keep trying to reach a climax.

P5: “Sometimes, you try again and think: ‘let’s stop because it is not going to happen’. It is a disillusion every time.”

Further questioning revealed that participants who gave up trying, still hoped that it was possible to experience an orgasm. Sometimes, quitting was impossible because patients’ experienced it as an ongoing conflict. The level of distress over the loss of reaching a climax was high in some participants, even years after the treatment.

The social domain

The effect of the partner on sexual experience

The participants initially reconsidered their sexuality in order to be able to give something to their partner. Having a partner turned out to be an important motivation for making an effort to engage in sexual activity again.

P3: “Lord, I can’t even be a wife to my husband anymore.”

Participants stated that the attitude of the partner is utmost important in the experience of sexuality and when restarting sexual activities. For example, an understanding attitude of the partner leads to a positive experience of sexuality. A safe and secure relationship contributes to accepting the ‘new’ body, which participants described as mutilated.

P1 and P7: “Yes, the fact that he has been very patient is very positive, supportive and nice!”

Participants described that talking about sexual needs positively contributed to engage in sexual activity again. In all cases, this was a natural process, since sexuality was already a frequently discussed topic before diagnosis in most of the participants

P4: “Yes that never changed, that was a topic of conversation from the moment we met.”

Couples started to explore their sexuality again at an arbitrary moment, in which they seemed to feel each other.

P1: “It just went very naturally.”
Despite the supportive attitude of the partner, some participants described a feeling of inequality in this process. This was caused by the fact that the partner does not experience any sexual dysfunctions, such as anorgasmia. According to the participants, this felt unfair during sexual activities.

P4: “I miss, it sounds very harsh, I miss something while... he can still get an orgasm. Nothing changed for him, but it did for me.”

The attitude of the Health Care Professional (HCP)

Participants indicated that HCPs should be aware of their attitude. It is important that the HCP has an trustworthy and open appearance and provide enough space to discuss sexuality. This concerned the space that was felt by the patient; that discussing sexuality was part of the standard treatment and/or follow-up.

P7: “An open appearance, he makes me feel equally by asking how things are going... ‘do you need something?’ That means I can ask everything.”

Participants perceive it as important that the HCP ask for permission before discussing sexuality. In addition, personality traits of the HCP and the relationship between the patient and the HCP play an important role in discussing sexuality. The current occupation of the HCP was not relevant in discussing sexuality.

P4: “By the way, you do not even have to go to a doctor, because you can also discuss it with a nurse specialist. You are just a bit more accessible for most people.”

Discussing sexuality: the right moment

For HCPs, it might be unclear whether patients want to discuss sexuality and what their associated needs are. In the first 3–4 months after surgery, women are focused on (physical) recovery and surviving so changes that possibly occurred in sexuality are less important.

R6: “Not in the beginning, because you need to recover first.”

Most of the participants considered the moment when the HCP started discussing sexuality after surgery as too early in the process. Women indicated that sexual desire returned after approximately 3 to 4 months after surgery, and there was more room to think about sex. Around that time, women started to participate in ‘normal’ life again, of which sexuality was an important factor.

R6: “I think what I said before, after 4 months. You try to get back into the rhythm of normal life. And then you come across everything.”

Informational needs of participants change over time as well (Fig. 3). Participants stated that information about the disease and the treatment are most important before surgery. For example, they wanted to know if (parts of) the clitoris needed to be removed and what the consequences for their sexuality were.
Most participants needed information about practical issues, such as changed anatomy, wound care, and advices regarding vulva care. Participants desired to receive more explanation about the residual activity of the clitoris, since this often remains after the surgery.

After 6 to 12 months, participants explained that there was a growing need for substantive information about sexual health e.g., information about possibilities and alternative ways to experiment with sexual activities.

P6: “We briefly mentioned it to the doctor, and then he said: ‘you can try vibrators’. I sat there laughing. Because yeah, I am not going to start with that. We do not, uh hello, at that age! But, we did!”

After 10 to 12 months, participants start to think about support from an external professionals, such as a sexologist.

P4: “I actually started to think about it, and concluded that we cannot do it alone”.

Consultations with a sexologist in a later stage of recovery turned out to be unexpectedly positive. Some participants recommended it to other patients:

P7: “First, make sure you fully recover from the surgery, and then go on a journey of discovery together. And if that is not possible, go to a sexologist”.

Discussion

Main findings

This unique qualitative study using individual patient interviews in women treated for vulvar cancer highlights the impact of vulvar surgery on the performance of daily activities. Moreover, treatment had a negative effect on patients’ body image and sexual experience. All participants were confronted with orgasm difficulties or anorgasmia, which was experienced as a predominant negative consequence of the treatment and hard to accept for most of them. The level of distress was especially high among patients in which the clitoris needed to be removed and when penile-vaginal sex was not possible anymore. However, to put it in perspective, most patients explained that being cancer-free was much more important than their sexuality. A few participants maintain a continuous desire for sexual activity in order to try to reach a climax. It is important that the attitude of the partner and the HCP is understanding and open in discussing and exploring sexuality after treatment. Currently, information provision about sexuality does not meet patients’ needs. Participants recommend to start discussing sexuality preoperatively and after approximately 6–12 months, in which possibilities and alternatives ways to experiment with sexuality should be the focus.

Interpretation of findings
Our study showed that all participants experience physical disabilities that have a negative impact on performing daily activities. Physical changes, for example anatomical changes of the vulva, led to a poor body image in most of the participants. This is in line with a study by Senn et al. [13], who showed that women described the surgical treatment as disfiguring and mutilating, resulting in a changed female self-image. Our study underlines the extensive implications of vulvar cancer therapy on sexual functioning. The level of distress was especially high in patients in which the clitoris was resected and when penile-vaginal sex was impossible. Patients might not have been prepared for the possible consequences of the treatment on their sexuality, since they were mainly focused on surviving. In a study by Aerts et al. [11], it has been shown that there are no differences in sexual and psychosocial functioning in women with vulvar malignancy before and after the first year after vulvectomy. Nevertheless, in comparison with healthy controls, women with vulvar malignancy are at high risk for sexual dysfunction both before and after surgery [11]. Andersen et al. [27] described that women did not lose their desire for sexual activity after treatment of vulvar cancer despite the orgasm difficulties they reported, which was confirmed by some of the participants in our study. This might also be related to having a partner, which is associated with significantly better sexual desire [28]. Hazewinkel et al. [29] also found a positive association between living with a partner and sexual satisfaction after treatment for vulvar cancer. This could be explained by the fact that sexual satisfaction is not only defined by the quality of sexual functioning, but also by the possibilities of feeling intimate with the partner [30]. This was confirmed by participants who mentioned that an understanding and supportive attitude had a positive impact in the experience of sexuality [31].

The role of the HCP is pivotal in discussing sexuality. Participants indicated that HCPs start discussing sexuality too early in the process. Since the informational needs of patients regarding sexuality change over time, the content of the information should change over time as well. Before surgery, the focus should be on providing information about the consequences of the disease and treatment on sexuality. Different studies showed that there is a lack of information for patients and partners about the treatment and possible side effects [13, 32]. Improved information provision may lead to a better HRQoL [33, 34]. In the first 3–4 months after surgery, women are focused on (physical) recovery and surviving. Between 4–6 months, they start to think and fantasize about sexual activities. After 6 to 12 months, participants explained that there was a growing need for substantive information about sexual health. This entails information about possibilities and alternative ways to experiment with sexual activities. Some patients might feel uncomfortable in discussing sexuality, which is emphasized by the fact that it was difficult to recruit sufficient participants in this study. It is therefore crucial for HCPs to initiate the discussion about sexual issues themselves. It may help to ask questions about a patient’s relationship first, and then initiate the topic about sexuality [35]. Assessing sexual wellbeing at regular intervals helps to identify which patients suffer from sexual health issues and might contribute to improve the HRQoL of these patients [15, 36]. After 10 to 12 months, participants start to think about support from an external professionals, such as a sexologist. It is important that sexual counseling is addressed by HCPs, and that patients are referred for qualified sexual counseling when needed [10].

**Strengths and limitations**
This is the first study to investigate the experiences of patients with vulvar cancer regarding changed sexuality, and their needs and expectations regarding sexual counseling. Although this study has a small sample size, data saturation has been reached after six interviews. While most patients did not want to participate in the study, probably because of the experienced barrier to talk about sexuality, the patients in our study were relatively comfortable with talking about their altered sexuality. Therefore the participants in our study might not be a well representation for other patients with vulvar cancer.

Implications for research and practice

In future research, it is recommended to include more patients who experience difficulties in talking about their sexuality, in order to create a more representative group. A study among partners and patients without a partner may contribute to a broader understanding of the experiences of sexuality after surgical treatment for vulvar cancer. Furthermore, since sexual satisfaction is not assessed in this study, it is recommended to perform a study on PROMs in vulvar cancer patients. This research can assess the impact on HRQoL in patients with vulvar cancer and their partners. With regard to clinical practice, discussing sexuality should be initiated by the HCPs at different times in the trajectory. It is recommended to schedule a separate consultation around 4–6 months after surgery to discuss the needs for information and counseling related to sexuality.

Conclusion

Patients with vulvar cancer experience various problems related to impairment on daily activities, altered body image, and sexuality after surgical treatment, both on the biological, psychological and social domain. Patients consider is especially hard to accept the difficulties or the loss in reaching a climax. The support from both partner and HCP is important in discussing and exploring sexuality after treatment. Informational needs regarding sexuality vary over time, and after 6 to 12 months, patients feel a growing need for information about their sexual health. Therefore, we recommend to schedule a fixed appointment 4–6 months after surgery to discuss the needs regarding information and sexual counseling.

Declarations

Funding   No funding was received for conducting this study

Conflict of interest statement   The authors declare that they have no conflict of interest

Author contribution Jessy van Dongen: Conceptualization, Writing – Original draft and Review & Editing, Visualization Noor J.B. Vincent: Conceptualization, Methodology, Formal analysis, Investigation, Writing – Review & Editing, Project administration Suzanne de Munnik: Conceptualization, Formal analysis, Writing – Review & Editing Nicole P.M. Ezendam: Writing – Review & Editing Edith M.G. van Esch: Resources, Writing – Review & Editing Dorry Boll: Conceptualization, Methodology, Resources, Writing – Review & Editing, Supervision, Project administration
**Ethics approval**  The Medical Research Ethics Committees United has declared that the Dutch Medical Research Involving Human Subjects Act (WMO) does not apply (W19.180). This study was performed in line with the principles of the Declaration of Helsinki.

**Consent to participate**  Informed consent was obtained from all individual participants included in the study.

**Consent to publish**  Patients signed informed consent regarding publishing their data.

**Data availability**  The data that supports the findings of this study are available from the principal researcher (NV) upon reasonable request.

**References**


Figures
Figure 1

Flowchart of participants
Figure 2

Results summarized in biopsychosocial framework
Figure 3

Informational needs in patients treated for vulvar cancer