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ARTICLE

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Women's experience of sexuality after radical cystectomy – a qualitative study

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ABSTRACT

Purpose: The aim of this study was to explore how women experienced sexuality after radical cystectomy due to bladder cancer.

Methods: We performed an interview study with qualitative design with content analysis. Inclusion criteria were age below 75 years. In total 10 women, with a median age of 64 years at surgery, were interviewed at median 24 months post radical cystectomy.

Results: The 10 women described sexual life as affected after surgery but they all tried to find ways to overcome the new situation together with their partner. The overall theme was 'A balance between emotional and physical closeness' emerged from 30 codes that were condensed into five subcategories and two categories: 'A sensual relationship' and 'A sexual relationship'. The first category constituted the subcategories 'Feeling of intimacy' and 'The importance of the relationship'. The category 'A sexual relationship' was revealed from the subcategories 'Reluctance to engage in sexual activity' and 'Partner inability to engage in sexual activity', and 'Acting for sexual rehabilitation'.

Conclusions: The uncertainty that the women felt about their anatomical changes after radical cystectomy created a sexual anxiety and reluctance to resume intercourse. Even though the surgery had a major impact on their sexual life, the women tried to be sexually active. However, the meaning of sexual life was not just having sexual activity but also included closeness, affirmation, affection, and feeling attractive. Sexual counseling at an appropriate timepoint is essential to assure a balance between emotional and physical closeness, i.e. to regain sexual health.

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Women; bladder cancer; radical cystectomy; sexuality; qualitative study

Introduction

Radical cystectomy (RC) with neoadjuvant chemotherapy is the gold standard for treatment of muscle-invasive bladder cancer. Given the gender distribution of bladder cancer, only a minority of patients subjected to radical cystectomy are females. In Sweden, the median age at cystectomy in 2021 was 74 years [1]. During the RC surgery, the neurovascular bundles are usually injured when excising the bladder, the urethra (partially or completely), and the anterior vaginal wall. Furthermore, devascularization of the clitoris, affecting sexual arousal and desire, is likely to develop as a consequence of dissecting and removing the distal urethra [2]. Additionally, the frequent practice to remove the ovaries in conjunction with radical cystectomy alters the hormonal balance post-surgery. Thus, the majority of women operated with cystectomy for bladder cancer are postmenopausal.

Sexual function in women undergoing RC is commonly assessed preoperatively using the Female Sexual Function Index (FSFI), which measures self-reported levels of desire, arousal, lubrication, orgasm, satisfaction, and pain during the past three months [3]. Four studies reporting outcome data from a total of 98 women and measuring FSFI after RC, showed sexual dysfunction defined as a low FSFI score post-surgery [4–7]. However, an interview study by Gupta et al. [8], with 16 women who had undergone RC, described physical obstacles to sexual life affecting desire, pain and urinary control during intercourse. As there is a lack of knowledge how RC-surgery affect women, the aim of this study was to explore women's experience of sexuality after RC.

Materials and methods

Design

This interview study used a qualitative design, and the outcomes were analyzed with content analysis according to Burnard [9]. Informants were identified among females subjected to RC at a university hospital in Sweden. Inclusion criteria were: below 75 years of age when undergoing RC, at least one year since RC, being cognitively intact, and fluent in the Swedish language. Each identified informant received an information letter together with an informed consent form. About two weeks later the investigator contacted each woman by phone to ask if she accepted to participate in the study. In total, 29 women were recruited, but 19 declined to participate. The women were given the opportunity to choose the location for the interview, which resulted in three individuals being interviewed in their homes and seven in

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a hospital setting. All 10 women were interviewed by the first author (AL) after signing the informed consent. The interview started with an open question: 'What is sexuality for you?' followed by 'How do you experience your sexuality after the surgery?'. Probing questions, like 'Can you clarify?', 'Do you want to tell me more about …?', or 'Can you give an example?', deepened the interview. The interviews were digitally recorded and lasted between 52 and 110 min (median 74 min), and were conducted between March 2018 and October 2020.

Analysis

All interviews were transcribed verbatim and read through several times by the first and second author, while making notes in the margin, i.e. 'open coding' was conducted in the original language [9]. A list of words and phrases from the interviews was assembled and placed in a new document. Overlapping and similar categories were merged. In the following analysis, three authors (AL, KS, AMW) were involved by discussing the codes, interpreting them, and sorting them into a final list of categories. The reduced number of categories was subsequently translated into English. After several rounds of discussions, the final theme emerged and validated the quality of the analysis [9]. An authorized translator checked the final translation of citations, codes, categories, and the theme. None of the analyzing authors were involved in the care of the informants.

The study was approved by a Regional Ethical Committee in Sweden (Reg.no. 2018/400).

Results

The age of the participants at the time of interview was between 59 and 73 years, that is, a median of 24 months post-surgery. All women had long-lasting heterosexual relationships. Background characteristics and their medical history are presented in Table 1.

The interviews revealed 30 codes, which were then condensed into five subcategories and two categories. The overall theme that emerged was *A balance between emotional and physical closeness*. The categories and subcategories are presented in Table 2. All the women gave similar answers to the opening question 'What is sexuality for you?' and one informant expressed herself like this:

> It's a lot about closeness. Yeah, my God, what to say …/…/Yes, to be close, there's tenderness and there's …/…/… Sexuality to me is not just sex. It's a lot about what comes before, that there's closeness and tenderness, and knowing each other and trusting one another. And maybe it has above all changed over time, in that you have another perspective than when you were young, when having sex had a different meaning. These days I think it [i.e., the sexuality] is more important when there's intimacy and you really care for each other and it's not just [having sexual activity] but there's something before and after. (#3)

A sensual relationship

This category emerged from the two subcategories 'Feeling of intimacy' and 'The importance of the relationship'. Within this category, women described how feeling sensual was connected to the daily interaction with the partner.

Table 1. Background and medical characteristics for the included women

Cohabitating women	10
Relationship in years (range)	3–52
Median age at surgery, (IQR) years	64 (62–68)
Median months since surgery (IQR)	24 (15–45)
Tumor stage, n	
Cis/Ta/T1 and N0	5
T2–T4a and N0	2
Any T-stage and N+	3
Chemotherapy preoperatively, n	
None	5
Induction therapy (MVAC[a])	3
Neoadjuvant therapy (MVAC[a])	2
Type of surgery, n	
Open	8
Robotic	2
Oophorectomy, n	
Bilateral oophorectomy	8
Unilateral ovarian sparing	1
Bilateral ovarian sparing	1
Nerve-sparing surgery, n	
Bilateral nerve-sparing surgery	1
Non-nerve-sparing surgery	9
Type of diversion, n	
Ileal conduit	9
Continent cutaneous diversion (Lundiana pouch)	1

[a]MVAC: Metotrexate/Vinblastine/Doxorubicin/Cisplatin.

Feeling of intimacy

Intimacy was something that the women described as being positive in the relationship and something that they desired. They recounted how receiving care, affirmation, and affection from their partner made them feel attractive. Feeling intimacy with one's partner was described as an important part of the relationship and when sexual activities had been reduced or become non-existent, intimacy was something that they appreciated more than before RC.

> On the other hand, we hug and cuddle, as we say, a lot. We take care to affirm each other/…/one has at least had this closeness and all that kind of thing. (#4)

The importance of the relationship

This subcategory arose from the women's description of the importance of having a trusting relationship with their partner and knowing each other well. Most of the women described their relationship as loving and long-lasting, but even among those with a shorter relationship, the women still described the importance of stability in order to feel comfortable and relaxed. Showing affection and tenderness and sharing interests and household work, as well as doing things for one's partner , were also described as important parts of the relationship. These aspects contributed to a sense of companionship and closeness to one's partner and a feeling of mutual appreciation and commitment.

> But we like to cook together, and that means a lot to me – it's a closeness that both he and I appreciate. Cooking together, helping each other with the dishes and all that afterwards. We are happy to have a glass of wine and such, talking about what the day has been like. It means a great deal to me. And to him, too, I think. (#1)

Table 2. Schematic description of the analyzing process and the resulting categories and theme.

Code	Subcategory	Category	Theme
Sitting/lying together	Feeling of intimacy	A sensual relationship	A balance between emotional and physical closeness
Holding hands			
Hugging			
Receiving affection			
Feeling attractive			
A feeling of affirmation			
Feeling safe	The importance of the relationship		
Knowing each other well			
Common interests			
Helping each other			
Showing each other affection			
Receiving comfort			
Receiving appreciation			
Soreness and pain	Her reluctance to engage in sexual activity	A sexual relationship	
Bleeding or fear of bleeding			
Accepting lack of ability			
No desire for sex			
Tolerating sex			
Lack of information about surgery			
Partner's poor health	Partner's inability to engage in sexual activity		
Partner's erectile dysfunction			
Partner's inability			
Accepting partner's inability			
Time for healing	Acting for sexual rehabilitation		
Re-learning			
Trying/finding new ways			
Reaching orgasm			
Caring for the stoma			
Desire for intercourse			
Mutual fondling and pleasure			

A sexual relationship

The second category highlights the existing sexual relationship. Although the women referred to certain obstacles, they also described how they, on their own or together with their partner, tried to cope with and maintain a sexual life.

Reluctance to engage in sexual activity

Some of the women described how their own desire for sexual activity and sexual intimacy had decreased and become more infrequent even before surgery, due to advancing age or symptoms from the bladder cancer prior to RC. The desire decreased further after the RC. Others described how their own sexual initiatives and thoughts and fantasies about sexual acts became less important. Instead, the women highlighted how other things, such as closeness and companionship with the partner, had gained increased importance. Some of the women stated that despite the fact that they themselves did not care for sexual intercourse, they were able to go along with it because the partner desired it.

Penetrative intercourse after RC tended to be painful and sometimes even caused bleeding. The women expressed a fear of pain and avoided penetrative intercourse or circumstances/situations that could lead to this. There was an uncertainty about how the vaginal anatomy had changed after surgery, and about whether, and if so how, sexual function was affected. Some of the women stated that preoperatively they were not at all or very briefly informed about the surgery and the consequences for their sexual life. This led to uncertainty about the healing process and about when to resume sexual activity as well as about whether vaginal intercourse was feasible at all. The variations in the reluctance to engage in sexual activity are captured by the following citations:

> I would like to be more sexually active than we are. I feel that it depends on me, really./ … /But it's like, I would like to feel more. And then there's no urge to take the initiative yourself so often. (#7)

> Now it has after all been a year and actually it's kind of more me that (sighing). Yes … Does it hurt? Will it hurt? … / … / … I guess I'm more afraid that it … well, will hurt or? … / … / … So, I can't put my finger exactly on what it is. But I think I'm probably more afraid that it's going to hurt. (#8)

Partner inability to engage in sexual activity

Some women felt that their partners had several obstacles that impaired sexual ability in the form of erectile dysfunction and limited desire due to their comorbidity and/or increased age. The partners' desire for sexual activities had subsided or disappeared completely. Still, the women accepted the men's inability. Furthermore, some women expressed relief at not feeling required to carry out, for example, sexual intercourse.

> I have no desire. Or I have no need. And it's very possible that it started long before, because I live with a man who has no needs. (#10)

Acting for sexual rehabilitation

The women described the post-RC period as involving both physical and mental recovery. The length of this period varied between the different individuals but ranged somewhere

from a couple of months up to a year. Sexual rehabilitation included the return of desire and of sexual thoughts and fantasies. The women together with their partner made adjustments that facilitated sexual activities, such as adopting new positions of intercourse. This included how to deal with the urostomy and the uribag during the act, or other ways of enjoying sexual pleasure, on their own or together with their partner. The women described the importance of being given the opportunity to control at what point they felt ready to resume sexual life. In some cases, the women themselves had decided to resume sexual activities. The fact that their partner had let them do so in their own time was perceived as considerate on the part of the partner, and in some cases, there had been a discussion together with the partner. There was, for example, a greater need for planning and preparing for sexual intercourse or sexual activity than before and the women felt that the spontaneity had disappeared. After about three months, thoughts and questions about sexual aspects returned and at this point the women expressed a wish to have a post-operative visit, where this type of concerns could be discussed, and requested an approval to start sexual activity.

> I'm not terribly afraid of things. I dare to try things. So, I was able to take the initiative and figure out all kinds of things with sex. I think I taught him a great deal about sex and then it was exciting and fun, even though you knew he couldn't [i.e., get an erection], there was other stuff. (#3)

Discussion

According to our interviews, sexual activity and intercourse post-surgery were connected to fear of pain and anxiety, although desirable for the women and their partner. The uncertainty about the anatomical changes created sexual anxiety and reluctance to resume intercourse, which has previously been reported as a barrier to sexual recovery [10]. The women in our study described how sexuality was still important up to 45 months post-surgery but different than before the RC and dependent on their partners' health and sexual ability. Due to these circumstances, women explained that they put their own desire for sexual activities aside. Thus, when the women were asked to describe the meaning of sexual life, they stated that it was not just about having intercourse but also involved a sense of closeness, affirmation, affection, and feeling attractive, which is similar to the study by Frost et al. [11]. A condition for establishing intimacy was having a stable and confident relationship with their partner, regardless of whether the relation was short or long-lasting. Intimacy became increasingly important after RC and the women strived for a balance between emotional and physical closeness. This latter finding has, to our knowledge, not previously been reported in women subjected to RC.

The women expressed that they would have preferred a healthcare professional to clarify their healing status and to give them some form of 'green light' to resume sexual activities. After about three months, thoughts and questions about sexual aspects returned and at this point in time it would have been appropriate to have a follow-up visit where this type of questions and concerns could be raised and discussed. Educational needs about the healing process have previously been reported by Westerman et al. [12] in a survey of 22 women operated with RC. Similarly, a recent qualitative study reported inadequacies in sexual health counseling and education [8], further underpinning the importance of information about sexual health in conjunction with RC. However, timing was, according to our interviews, an important factor in order to comprehend the information, as the women described that there was a time after surgery where the focus was to recover from a cancer diagnosis rather than resuming sexual activities. The women expressed that they were not susceptible to this type of information preoperatively. Despite this, they thought it was important that information about the impact of the surgery on sexuality was provided and not omitted preoperatively.

For healthcare professionals it is important to be aware that sexuality for women after RC is more than engaging in physical sexual activities. They should therefore encourage the couple to also develop their sensual expressions in the relationship, and a prerequisite for this is that the couple is offered post-surgery counseling explaining the importance of intimacy to preserve a sensual relationship. However, a recent study with women having undergone RC stated that more than half of the participants received no or inadequate counseling, highlighting that there is a need of specific group discussions for women [8]. In addition, according to Horden and Street and a review by Sinkovic and Towler [13,14], the healthcare staff have stereotypical assumptions about patients' sexuality, based on age, gender, culture, partnership, and diagnosis. Thus, aspects that concern a wider experience of sexuality, i.e. the balance between physical and emotional features, are not used in clinical practice either pre- or post-surgery but are essential [15]. According to WHO, 'Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious, and spiritual factors' [16]. Bearing in mind the symptoms leading to the bladder cancer diagnosis and the momentous period preceding surgery, measuring sexual function at least six months prior to surgery seems advisable. Currently, sexual function is usually measured with FSFI only during the past three months [3]. Thus, there seems to be a need to re-evaluate how to measure various experiences of sexuality and provide sexual counseling to women undergoing RC, pre- and post-surgery Although RC is lifesaving for women with bladder cancer, the cost of impaired sexuality needs to be considered already in the preoperative setting. Our study suggests that women still strive to be sexually active after RC, with intimacy being increasingly important in balance between emotional and physical closeness.

Methodological considerations

All the women were treated in the same hospital setting, but, due to the COVID-19 pandemic, data collection, analysis,

and manuscript writing were delayed. Thus, there were initially some difficulties finding informants, which infers a selection when establishing the study cohort. Consequently, only about one third of the invited women participated voluntarily in the interviews but they represent a variation [9] of the women undergoing RC. Another study limitation is related to the fact that all participants were Swedish, heterosexual women living in stable relationships. Future studies should therefore include a more varied study population in order to increase the transferability. In comparison with the Swedish National Bladder Cancer Register [1], where a median age of 74 years for cystectomy was reported in 2021, the women in this study were somewhat younger, which could affect the interpretation of the results. At the time of the interviews, the first author had five years of experience within the Department of Urology but did not have any caring responsibilities for the interviewed women. A strength of the current study is that all authors were involved in the analysis process to ensure rigor in the analysis. In addition, a large amount of transcribed material assured a rich depth in the interviews.

The women's sexuality in our study was affected in several ways, but their hormonal status was unknown based on type of surgery. However, an ongoing randomized prospective trial on ovarian-sparing cystectomy (ISRCTN18217210) might further elucidate the functional effect of ovarian-sparing RC. Additionally, not keeping the ovaries includes other health risks, such as stroke, coronary artery disease, parkinsonism, cognitive impairment, and osteoporosis [17].

Conclusions

New knowledge from this qualitative study with 10 women illuminated that they experienced an uncertainty about their anatomical changes after RC. This created anxiety, fear and reluctance with regard to engaging in sexual activities, and therefore the women desired a sort of 'green light' from healthcare professionals to resume intercourse. Even though the surgery had a major impact on their sexual life, the women tried to be sexually active. However, the meaning of sexual life was not just having sexual activity but also included closeness, affirmation, affection, and feeling attractive. Sexual counseling at an appropriate point in time is essential to assure a balance between emotional and physical closeness, i.e. to regain sexual health.

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