Sexual rehabilitation after treatment for gynaecological cancer

Bakker, R.M.

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Author: Bakker, R.M.
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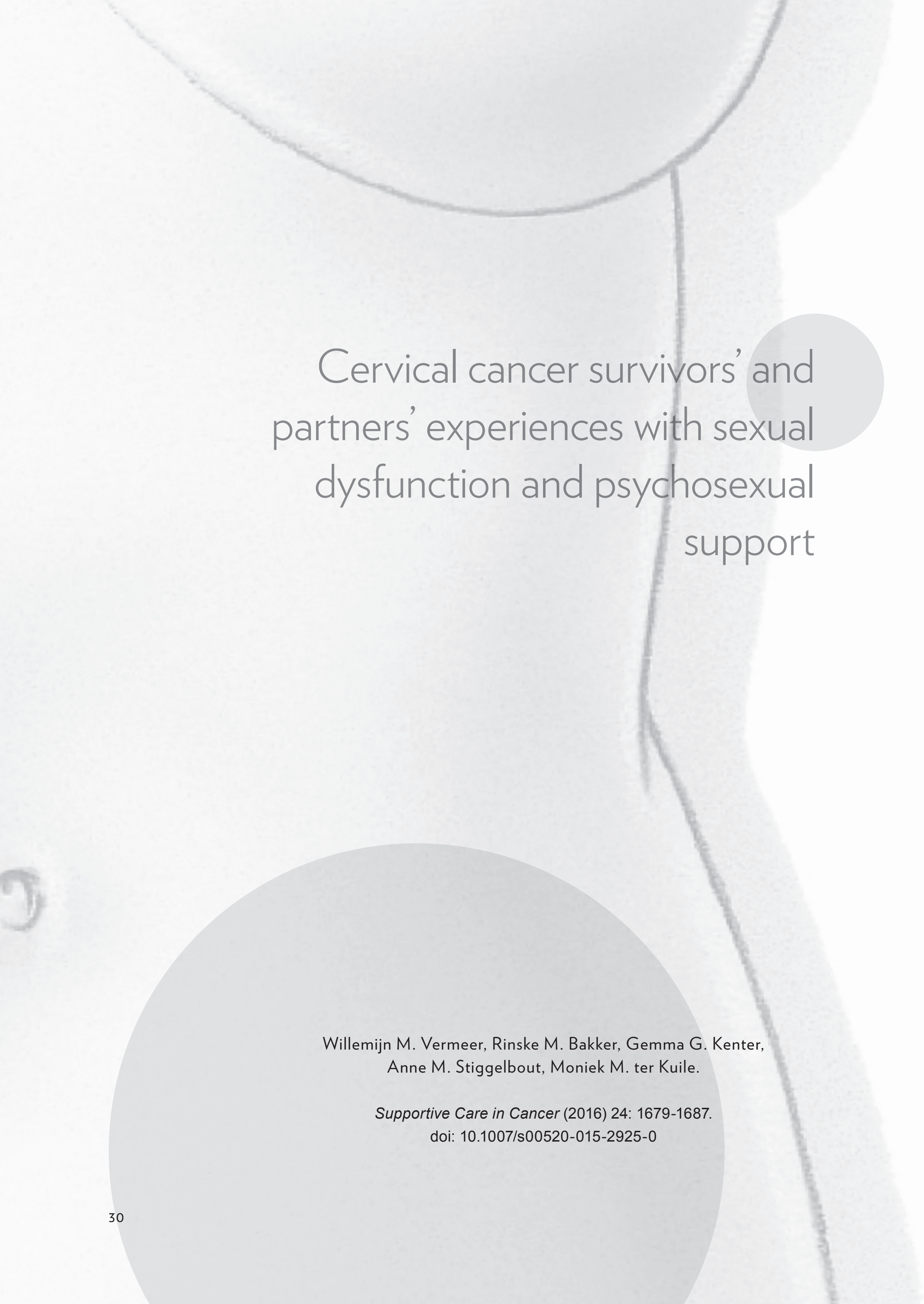

Cervical cancer survivors' and partners' experiences with sexual dysfunction and psychosexual support

Willemijn M. Vermeer, Rinske M. Bakker, Gemma G. Kenter,
Anne M. Stiggelbout, Moniek M. ter Kuile.

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CHAPTER 3

Abstract

Objectives

To assess experiences with sexual dysfunctions, psychosexual support, and psychosexual healthcare needs among cervical cancer survivors (CCSs) and their partners.

Methods

Semi-structured interviews were conducted with CCSs ($n = 30$) and their partners ($n = 12$).

Results

Many participants experienced one or more sexual dysfunctions often causing feelings of distress. Most participants reported having been asked about their sexual functioning, although attention for sexual functioning was often limited and medically oriented. Considering sexuality a taboo topic hampered some participants to seek help. Many participants desired information about treatment consequences for sexual functioning, practical advice on dealing with dysfunctions, and reassurance that it is common to experience sexual dysfunction. A website was generally considered a useful and accessible first resource for information about sexual functioning after cancer.

Conclusions

Sexual dysfunctions are often distressing. Many patients and partners experience psychosexual healthcare needs, but the provided information and care is generally limited. Psychosexual support should go beyond physical sexual functioning, and should take aspects such as sexual distress, relationship satisfaction, and the partner perspective into account. Additionally, offering more practical and reassuring information about sexuality after cervical cancer would be valuable for both CCSs and their partners.

Introduction

Attention to cancer and treatment side effects is increasingly becoming part of survivorship care.[104] Cervical cancer (CC) has a yearly incidence rate of around 700 in the Netherlands, and a ten-year survival of 60%.[1] Sexual dysfunctions (e.g. vaginal dryness, pain at intercourse, decreased interest in sex) are an important treatment side effect and studies show that 23% to 70% of the cervical cancer survivors (CCSs) report problems with their sexual functioning.[18,19,21,22,27,31,105] Distress, such embarrassment, guilt or sadness, is a common consequence of sexual dysfunctions.[29,32]

Relatively little is known about how sexual dysfunctions affect quality of life and relationship satisfaction. Additionally, few studies have focused on how patients perceive existing psychosexual support and which needs they have. From quantitative studies it is known that many more gynaecological cancer survivors (GCSs) report psychosexual healthcare needs compared to the number of women who actually seek help.[21,106] For instance, a recent study demonstrated that only one third of the CCSs with a need for psychosexual support had actually initiated a conversation with a professional.[57] Interviews with women treated for ovarian cancer, demonstrated that they hardly received psychosexual support from their healthcare providers .[107] Not yet well established are differences in psychosexual support needs between women experiencing sexual distress versus those who do not. Finally, more insight is needed into the partner perspective. Quantitative studies into the impact of cancer on partner's sexual satisfaction show conflicting results,[108-112] and few qualitative studies into sexuality after GC have incorporated the partner perspective.[113,114]

This qualitative study aimed to build upon the existing research by assessing CCSs' desired sexual-health-related services while distinguishing between women who are sexually distressed and women who are not, and by incorporating both the survivor and the partner perspective. The research questions were: 1) How do CCSs and partners experience sexual dysfunctions that have occurred as a result of the treatment?; 2) How do CCSs and partners experience the information and care provision with respect to sexual functioning after CC?; and 3) What are survivors' and partners' psychosexual healthcare needs, how do these relate to sexual distress, and what are their attitudes towards different modes of delivery of interventions targeting sexual dysfunctions?

Methods

Participants and recruitment procedures

A purposive sampling strategy was used aiming to recruit about 30 participants from a sample of CCSs who had expressed their willingness to participate in future studies during their participation in a multi-centre cross-sectional questionnaire study.[57] Sampling took place until no new relevant themes emerged (data saturation).

A random sample of 54 eligible women (treated at the Leiden University Medical Centre (LUMC) or the Academic Medical Centre Amsterdam (AMC) in the past 1 to 12 years who had indicated to have at least once experienced a need for information or help) was invited for the study. Women who did not respond to the invitation were telephoned two weeks later. Out of all CCSs who were invited for the study, 30 (56%) agreed to be interviewed (referred to as ‘participants’). The most frequently mentioned reasons for not participating were that the topic was too intimate or intimidating. All participants with a partner were requested to ask their partner to participate. Out of the 26 participants with a partner, 12 partners (33%) participated (referred to as ‘partners’). The LUMC Medical Ethical Committee approved the study.

Data collection and interview topics

The face-to-face interviews were conducted by WV and RB either in a private room at the hospital or at the participant’s home. The interviews took approximately 65 minutes for the participants and 56 minutes for the partners. We chose to conduct the interviews with the participants and their partners separately, to facilitate participants to speak freely about their individual experiences. All interviews were audio taped and transcribed verbatim. Topics that were discussed were the impact of the cancer treatment on sexual functioning, the information and care provision, psychosexual healthcare needs, and attitudes towards different modes of information and intervention delivery (see Table 1, page 34). For the topics related to the impact of the treatment on sexual functioning and received information and support, a Life History Calendar (LHC) method was used. A LHC is a matrix with time units horizontally (i.e. one year before diagnosis, diagnosis, treatment, 3, 6, 12 months after diagnosis, until 5 years after diagnosis) and domain cues (i.e. work, relational status, important life events, holidays, disease and treatment, sexual functioning, received information and care) listed vertically. The LHC is a reliable method for collecting retrospective information.[115]

Based on the interviews with the first 19 participants (and seven partners), the development of a psychoeducational website about sexuality after CC seemed an acceptable intervention to the participants. To further study the feasibility of this specific intervention it was decided for the remaining interviews to ask participants to comment more extensively on the website instead of on each intervention delivery mode. Lastly, demographic characteristics and treatment information were retrieved from previously collected data and medical records.

Data analyses

The data were coded and analysed with NVivo using the framework approach.[116] This approach allowed us both to make use of already existing knowledge about this topic and insights that emerged directly from the data.[117] After familiarization with the data, WV made a first version of a coding scheme that was based on the interview guide. RB and WV independently coded a random sample of three interviews and compared their coding. New codes that emerged from the data were discussed and, if deemed of added value, added to the codebook. Any discrepancies in coding were resolved through discussion. WV and RB repeated this procedure five times until 15 interviews were coded. WV continued to code the remaining interviews while RB

Table 1
Interview guide.

Theme	Topics
Introductory questions	Living situation, job status, partner status, having children, relevant life events, description of period of cancer diagnosis and treatment.
Experiences with respect to sexual dysfunctions	- Pelvic floor functioning (miction, defecation, incontinence), lymphedema, fertility in relation to sexual functioning. - Sexuality now and a year before diagnosis (using the Life History Calendar method) with respect to: (sexual) partner, sexual functioning (i.e. desire/libido, lubrication, sexual intercourse and/or masturbation, pain or other complaints, orgasm), body image, intimacy, sexual satisfaction, and sexual distress. - Impact of cervical cancer (treatment) on the relationship and the perception of the partner. - Coping with (possible) sexual complaints. - Communication about sexual issues between partners.
Experiences with information and care provision	- Received information and care. - Initiator of the information and care provision. - Experiences with the information and care provision. - Personal and practical barriers of seeking information and professional help.
Healthcare needs and attitudes towards modes of intervention delivery and attitudes towards interventions targeting sexual dysfunctions	- Needs with respect to information and care provision. - Attitudes towards partner involvement in information and care provision. - Attitudes towards different forms of information and care provision (written information, online support, face-to-face consult with gynecologist, sexologist, nurse, or general practitioner).[1]

[1]Until interview 19 (and in the case of the partners until interview 7) participants were asked to comment on each mode. After that, participants were only explicitly asked how they thought about a psycho-educational website about sexuality after cervical cancer without systematically addressing the other modes.

independently coded every third interview. To promote reliability, WV and RB discussed these doubled coded interviews to cross-check and - if needed - complement the coding.[118]

Results

Participant characteristics

Table 2 (page 35) gives an overview of the participant and partner characteristics. The average age of the 30 participants was 47 years (*SD* = 8; range: 34-68). Twenty-five participants had a male and one had a female partner. The average time since treatment was 6 years (*SD* = 3). The mean age of the 12 participating partners was 46 years (*SD* = 8; range: 31-54). Eleven of the partners were male and one was female (all partners will however be addressed as ‘he’). A synthesis of the findings will be given structured around the research questions with Table 3 (page 40) providing an overview of exemplary quotes.

Table 2
Participant characteristics (*n* = 30 CC survivors and *n* = 12 partners).

		N **(%)**	**Mean (±** ***SD*****)**
Age patient (years)			47 (8)
Age partner (years)			46 (8)
Time since treatment (years)			6 (3)
Having children		19 (63)	
Having a partner		26 (87)	
Male partner		25 (96)	
Relationship duration (years)			13 (9)
New relationship since treatment (patient)[1]		7 (27)	
New relationship since treatment (participating partner)		4 (33)	
Educational level (patient)	Primary	1 (3)	
	Secondary	16 (53)	
	Tertiary	13 (43)	
FIGO ≤ stage IIA		27 (90)	
Radiotherapy (RT)		16 (53)	
Chemotherapy (CT)		10 (33)	
Surgery		27 (90)	
Menopause as a result of cancer treatment[2]		7 (39)	

Note. Percentages may not add up to 100 due to rounding.
[1] Out of *n* = 26 women with a partner.
[2] Out of *n* = 18 with whom this topic was discussed.

Experiences with respect to sexual dysfunctions

Factors related to sexuality after CC

Almost half of the participants stated having become infertile by their treatment. For many this had led to feelings of grief and had affected their feelings of womanhood (quote 1). About two thirds of the participants stated having incontinence or bowel problems. For some women sex had become less spontaneous as a consequence of worrying about urine leakage during sexual activity (quote 2). Almost half of the women reported having lymphedema, which caused swelling of the legs and sometimes forced them to wear compression stockings. Two thirds of the participants said that surgery and/or RT had caused physical changes to the vagina (e.g. shortening or narrowing). For about half of the participants their bodily changes had led to a negative body image or feelings of insecurity (quote 3). Although it was not a part of the interview guide, four participants mentioned the Human Papilloma Virus (HPV) as a cause of their disease or as a reason to be fearful resuming sexual activity.

Sexual functioning and distress

More than half of the participants experienced a decreased interest in sex since their treatment (quote 4). Some of them also explained their loss of libido as a result of relationship duration, age or sexuality having become less important. Seven participants had a new partner since their treatment, which had often evoked a renewed interest in sexual contact. Some partners of women with a decreased interest in sex felt an unchanged desire whereas others had noticed that their libido had decreased as well (quote 5).
About two thirds of the participants mentioned that their vagina had become dry since their treatment. More than half of the participants stated having (had) pain during intercourse or mentioned experiencing an anxiety of pain or penetration irrespective of actual experiences of pain. The (anxiety for) pain made participants avoid sexual intercourse (quote 6). Many partners said that they were more inhibited because they feared hurting their spouse or noticed her (anxiety for) pain (quote 7).

About half of the participants expressed an ability to cope with sexual dysfunctions or considered their sexual functioning as matching with their age or relationship duration. This did not prevent half of the participants from (also) expressing feelings of sexual distress. Some participants had a sense of loss because their sexual functioning was impaired by the cancer treatment. Other participants indicated experiencing feelings of guilt towards their partners because of their decreased interest in sex. Based on the expressed feelings of distress, 13 participants could be qualified as sexually distressed (quote 8). For two of the three single participants their history of cancer was a barrier to start a new relationship (quote 9).

Six of the seven partners, who were already in a relationship before the onset of the disease, reported some degree of problems in their sexual relationship. For all, this (currently or previously) induced negative emotions, such as experiencing a distance from their spouse or a sense of loneliness in the sexual relationship (quote 10). One man mentioned that before treatment, sexuality could serve as a means to reduce tension that was not available anymore. None of the partners who started their relationship after the treatment experienced sexual problems with their spouse.

Relationship functioning and communication about sexuality

For about half of the participants, the cancer (treatment) or the sexual dysfunction had negatively affected their previous or current (sexual) relationship (quote 11). Some participants stated talking openly about sexuality with their partner and/or that he was sensitive to their sexual needs and limitations (quote 12). Other participants experienced communication difficulties. According to some of them, their partner avoided sexual contact and/or seemed to have lost his sexual interest. In contrast, some others felt pressured by their partner being sexually active, or were aware that their partner had difficulties accepting her sexual limitations. Partners generally felt that they communicated openly about sexual issues with their spouses. When discussing how they coped with their partner’s sexual dysfunction, some wanted to leave the initiative for sexual contact to her. One partner however said that he was afraid that if he would do that, he would end up having no sexual contact at all (quote 13).

Experiences with information and care provision

As a result of the time interval between the cancer diagnosis and the interview, almost half of the participants acknowledged having difficulties remembering the content of the information about sexuality that was provided. There were also some participants who did not recall having received any information at all. Half of the participants said that they were not focused on their sexual functioning during treatment and recovery (quote 14). Nevertheless, they appreciated having received information about it. With respect to the time window when psychosexual support was desired most, about half of the participants with whom the topic was discussed said that this was the case between six and twelve months after treatment.

About one third remembered having received information about the impact of the treatment on sexual functioning. Specific pieces of information that were mentioned were for instance possible physical changes of the vagina, the importance of keeping the vagina accessible, and wound care after treatment. Some participants were not satisfied with the received information, considering it contradictory or incomplete, communicated in a too technical or upfront manner, or not tailored to their needs.

More than half of the participants said that during follow-up their healthcare provider (mostly the gynaecologist) asked them about sexuality, although in the majority of the cases this was only a brief question with a focus on physical aspects (quote 15). About one third of the participants had either been referred to or had initiated a consultation with a psychologist or sexologist. Six participants felt that their healthcare provider was accessible if they had sexual concerns. Six participants (three of which could be qualified as sexually distressed) indicated having received none or very little professional help for sexual concerns.

Two participants complained that the healthcare provider had insufficiently involved their partner in the information and care provision. When discussing this topic with the partner, two thirds said having been involved. One partner however added that the professional had a too feminine focus on sexuality.

Healthcare needs and attitudes towards modes of intervention delivery

Needs

When asking participants and partners about their psychosexual support needs, they most frequently mentioned a need for information (about consequences of the treatment, vaginal changes etcetera), followed by a need for receiving practical advice about coping with (their spouse's) sexual dysfunctions (quote 16). Distressed participants more often expressed a need for practical advices, being reassured that it was common to experience sexual complaints (quote 17), talking more extensively with a professional about sexual concerns (quote 15), and healthcare providers taking more initiative addressing sexual matters. Participants who were not distressed more often reported a need for general information and a more optimistic approach, for instance by communicating that sexual dysfunctions can improve over time.

Barriers to seek professional help

About one third of the participants indicated not experiencing any barriers to seek help or to consider these barriers as less important than the benefits of seeking help. Other participants were reluctant to seek help because they felt that they ought to solve sexual concerns on their own, or considered it a taboo to talk about sexual dysfunctions (quote 18). Some participants stated that (a combination of) time, transportation and costs were practical barriers to seek professional help.

According to the large majority of the participants, partners should be involved so as to provide them with information, teach them how to support their spouse in case of sexual concerns, or address a possible need for support on their side. One participant was more sceptical about partner involvement, because she believed that it could be more difficult discussing sexual concerns in the presence of the partner (quote 19). Generally, partners were in favour of being involved in the information and care provision, and would like receiving (practical) advice about communicating about sexual dysfunction and supporting their spouse.

Attitudes towards delivery mode of information and care

About half of the participants had positive attitudes towards written information. Advantages according to the participants were that it was practical to have a written overview and that it prevented them from a confrontation with an overload of (negative) information (quote 20).

Two thirds of the participants and more than half of the partners mentioned positive attributes of a website (with or without tailored advice), for instance that it was an easily accessible and practical source of information. Websites were particularly considered useful as a first resource in the case of sexual concerns. For more complex problems, face-to-face contact was considered more desirable (quote 21). Three partners stressed that the website should originate from a reliable source (e.g. the government or a hospital) and that doctors should refer to the site. Participants who were not sexually distressed were more likely to consider a website a suitable source of practical information. Sexually distressed participants on the other hand more often stated that a website provided information that was too general and therefore not sufficiently helpful. Many participants had positive attitudes towards websites offering tailored advice.

Participants' attitudes towards (online) support groups varied. Half of the women were reluctant to be confronted with other women's (negative) narratives. On the other hand, about one third of the participants were (also) interested in hearing possibly informative and useful patient narratives from other women. About one third of the participants thought that information from a professional would be more useful than from peers, or stressed the importance of a content manager checking the accuracy of the information provided. Partners were not interested in narratives from other CCSs or their partners (quote 22).

Since gynaecologists were generally the primary care provider during treatment and follow-up, participants considered them specialized, familiar, and hence the obvious professionals to consult for sexual concerns (quote 23). A few participants thought that gynaecologists were not sufficiently skilled to provide support in the case of complex and psychological sexual dysfunctions. The most frequently mentioned advantage of seeking help from sexologists was that they were specialized in this matter and could provide support with relational matters (quote 24). Some distressed participants were reluctant to seek help from a sexologist and considered it too confronting; participants who were not distressed did not mention this. Lastly, a few participants mentioned practical barriers of going to a sexologist (having to make a separate appointment, time, transportation, costs). The most frequently mentioned advantages of contacting a nurse or general practitioner for psychosexual support was that they were considered accessible and empathetic. On the other hand, participants questioned if they were sufficiently knowledgeable about sexuality (quote 25).

Table 3
Interview themes and exemplary quotes.

Theme or topic		Example quote
Experiences with respect to sexual dysfunctions		
Fertility	1	Woman, partnered, 47 years – Maybe I can see it separately from all the medical things that have happened, but I cannot disentangle it from the impact on my femininity. Interviewer – What do you mean by that? Woman – Am I attractive? So, in that sense is has had an impact, but I think that this is especially a result of not having had children, and not so much a result of the surgery. I really had to explore: what for a woman am I? So, I don't have children, what do I have?
Urinary incontinence	2	Woman, partnered, 40 years – Sex is less spontaneous, because you always reckon with: well I have to make sure that my bladder is empty, I have to pee before. […] When I have intercourse, then I feel an urge to urinate or sometimes a false urge, because if I go to the toilet nothing comes. All these things, like take away the spontaneity.
Body image	3	Woman, partnered, 47 years – Well, up to my breasts everything is fine. Everything between my breasts until my knees, that's awful. I consider that sort of a block, and I just don't want to see it or feel it.
Loss of libido	4	Woman, partnered, 40 years – Yes, then I noticed that, also because of the lack of energy, I just don't feel like it. I have been so busy all day, and for me… Yes, in that sense men and women are truly different. For men it's pure relaxation, and for me it's an effort. And after a busy day, it may sound stupid, but then I prefer to lie down on the couch. Yes, that is, that is very dull, but yes.
	5	Partner (male), 53 years – It (referring to sexual activity) is absolutely not spontaneous any more. Opposite to former times that I saw her walking or sitting or that we took a bath together, and that I was suddenly very aroused. That is gone. Interviewer – That spontaneity is… Partner – That is gone. I still can get aroused, but I cannot act on it. So the arousal is gone, not completely of course, but not comparable with before.
Pain	6	Woman, partnered, 53 years – Since the treatment, it (referring to her sexual functioning) hasn't been good. In that sense that I basically don't want. That I am afraid of it, and in pain. [..] And then, I have sort of given up, like 'forget it', don't feel like it anymore. Or maybe I do feel like it, but the door has sort of been closed, and probably it won't open again.
	7	Partner (male), 53 years – Sexually spoken, I'm not a very wild man. I am not into very harsh sex, on the contrary. But the male act, to penetrate, not like an idiot, but in a normal masculine manner, that is

		enjoyable for a man, at least for me. That has not been possible any more. Until now, it always has to be cautious, very cautious. Certain positions that we used to do and that we both enjoyed are hardly possible any more. She is always in pain.
Sexual distress	8	Woman, partnered, 47 years – For me it is very difficult to have sex. Interviewer – Yes, and by that you mean having intercourse? Woman – Yes, but touching is very difficult for me too, it is completely different. Well, comparable with urinating, it feels completely different. I have difficulty, because I cannot relax …, even thinking about sex or touching is difficult for me. I hardly want it. It is very difficult for me, as well as for my partner.
Finding a new partner	9	Woman, single, 45 years – Really, to seek out for intercourse, that's an anxiety. But also the, the insecurity on the side of the men. So, then I start thinking, when do I have to tell. Do I have to tell? How… yes, you cannot act like nothing happened, because you notice. I mean, of course it (referring to her vagina) is shortened and it doesn't lubricate without help. So yes, something needs to happen or to be said. Dealing with that is too much hassle, so then I leave it.
Partner's sexual satisfaction	10	Partner, 53 years – After the disease I have not been sexually together with X as it used to be. Sexually, I have become lonelier, even when I am making love with her. I cannot get as close as I used to.
Relationship functioning	11	Woman, partnered, 42 years – Well, it is simply not good, it's not good for your relationship. I mean my partner and I have talked about it in broad, that it is simply unfortunate, very unfortunate. Because he did expect other things from his life compared to how it is now. And of course for me too. Physically, I am not bothered that we don't have sex, but he needs that […]. Our relation is under pressure. While we absolutely want to stay together, but we do experience a lot of pressure from this.
Partner's attitude towards sexual problems (patient and partner perspective)	12	Woman, partnered, 55 years – That I could talk about it (referring to sexuality), but also the sensitivity when it came to making love. That he was very careful, and asked: "Is this OK like this? If it's not, please say so." And I am quite expressive and able to say so.
	13	Partner (male), 41 years – What I didn't realize, is that apparently I was nagging and that itdrove X (referring to partner) crazy sometimes. But if I don't nag, then nothing happens, and that the status quo that we have now. I don't want to make her unhappy by pressuring her [...] So, what we do is very classic. Sometimes, I look very obtrusively to another woman, and then she thinks: "He is in need". That's the balance we have.
Experiences with information and careprovision		
Not focused on sexual functioning during treatment and recovery	14	Woman, partnered, 49 years – Well, you are sitting at a table with a doctor who is telling you about the surgery and its consequences. And of course it is being told, that it can have an impact on sexuality, that it can all become less sensitive or that sort of things. And you hear that, but at that moment you are absorbed with the operation and with the cancer. About sexuality, you think, we'll see about that later.

Routine questions about sexual functioning during follow-up	15	Woman, single, 45 years – Well in my case, they asked: “well how is it with your sexuality?” I said: “I am not sexually active, because I don’t have a partner”, and then that was it. So yes, there was an answer and that was written down, and that’s it. “I don’t have intercourse.” “OK” […]. But well, at that moment you don’t say: “But I would like to have sex, but I experience problems having it” or you know. So, there is perhaps a task, even it has been a while, to inquire more profoundly. Not only: “Do you have intercourse?”
Psychosexual healthcare needs		
Need for practical advice	16	Woman, partnered, 53 years – If somebody would tell me that it is normal if it (referring to sexual intercourse) doesn’t feel pleasant. And that you can do certain things, and outlines a number of scenarios, like: “You just do absolutely nothing and leave it for a while. You’re not ready yet” or “You should now start to actively explore what else you can do to regain your pleasure in sexuality”.
Need to be reassured that it is normal to have complaints	17	Woman, partnered, 49 years – Well that (referring to a website providing information about sexuality after CC) could take away the insecurity that I do experience as a result of the complaints. Like, well OK, I am not the only one and it’s normal, and there are things that I can do.
Personal barriers	18	Woman, partnered, 53 years – Yes, it is a hurdle. Of course, anyhow it is something… It is a difficult topic. I find it a difficult topic. […]. Of course, it is easy to do nothing […], but I do realize that in that case I deny myself something -and not only myself- and that life could be much more fun. I do know that. But it’s easier to do nothing.
Partner involvement	19	Woman, partnered, 42 years – If he had been present there (referring to a follow-up consultation with gynaecologist discussing sexuality), and sexuality was problematic, then it is very difficult to raise that. Interviewer – So, actually you say that is more complicated having your partner present? Woman – Yes, in that case it is.
Attitudes towards interventions targeting sexual dysfunctions		
Written information	20	Woman, partnered, 40 years – So yes a brochure, that seems to me like a very pleasant, demarcated form of information, without the … horrible stories.
Starting with website, face-to-face for more complex or severe sexual concerns	21	Woman, partnered, 34 years – I think that I would start with looking it op on the Internet, because there is much available there and if I would not find it, then I would […], well OK, it’s not on the Internet, I am done with it. Then I would go for face-to-face contact with a well-informed professional.
(Online) support groups	22	Partner (male), 33 years – Yes, those (referring to support groups) are low on my list. Because, yes, that might be very egoistic, but I’m not interested in hearing other people’s experiences. Because you experience it differently than I do. So, you may talk about it very negatively, while that might not at all be how I feel about it. I am not so into support groups.

Face to face with gynaecologist	23	Woman, partnered 42 years – Yes, because you already are at the gynaecologist during follow-up. So, then you don’t have to make an appointment. Then it immediately becomes an issue, like: “Well, that bothers me, I am going to make an appointment, and I am going to the General Practitioner”. Then it becomes an issue on its own. While, at the gynaecologist you can naturally raise it, while you’re there anyway.
Face to face with sexologist	24	Woman, partnered, 36 years – And I think that it also depends on the nature of the problem. So, if it’s purely physical, I would be inclined to first see a gynaecologist. And if I notice, well that relational aspects play a role, for instance we cannot talk about it or it remains being a problem, then I would go to a sexologist.
Face to face with nurse	25	Woman, partnered, 53 years – With respect to nurses, I think: “Well, they would say something to comfort me.” And with the gynaecologist, I would think: “Well, I might get some assistance”. Maybe, that’s the difference.

Discussion

A decreased interest in sex and (fear of) pain were experienced by more than half of the participants. For some participants and partners, pain during intercourse lead to avoidance of sexual activity or feeling inhibited during intercourse. Furthermore, about half of the women and partners reported feelings of sexual distress such as guilt, grief, or feeling lonely in the sexual relationship. Interestingly, much less sexual distress was observed in couples that had started their relation more recently. A study among healthy participants demonstrated that women's sexual desire was negatively associated with relationship duration.[119] This, and the results of the present study, suggests that the impact of sexual dysfunctions on sexual distress and sexual satisfaction is not only related to physical sexual dysfunction.

Most participants reported having been asked about their sexual functioning or felt that, if needed, healthcare professionals were accessible. This was generally appreciated. Participants considered professionals' attention for sexual functioning often concise and medically oriented, which has also been demonstrated in other studies.[120]

In line with other studies, receiving information and practical advices were the most widely supported psychosexual support needs of participants and partners.[107,120–122] Furthermore, both participants and partners generally thought that it was valuable to involve partners.

Many participants and partners considered a website a useful and accessible first resource for information about sexual functioning after cancer. In case of sexual distress, more complex or severe sexual concerns, participants preferred face-to-face contact with a professional. Attitudes towards online support groups varied from an interest in patient narratives to concerns about unreliable information or a confrontation with negative stories. With respect to face-to-face contact, gynaecologists were generally perceived as the primary professional to contact in case of sexual concerns. Sexologists were perceived to be suitable for more complex problems, whereas nurses and general practitioners were more specifically appreciated because of their empathy and accessibility

A limitation that is worth considering is that CCSs and partners being relatively at ease talking about sexuality or having more pronounced experiences with or opinions about the provision of psychosexual support, were more likely to have participated in this study. Furthermore, a general difficulty with needs assessments is that people do not always have very specific ideas about their needs. Former Apple CEO Steve Jobs described this as following: 'It's really hard to design products by focus groups. A lot of times, people don't know what they want until you show it to them'.[123] During the interviews we noticed that participants' narratives were more vivid and flowing when they talked about their experiences with sexual dysfunctions and received psychosexual support, than when discussing their attitudes towards hypothetical interventions. Nevertheless, we do believe that asking survivors and their partners about their ideas with respect to future psychosexual support services is valuable because it gives a clear impression of which interventions are acceptable and which are not, and what possible obstacles should be kept in mind.

All in all, the lives and relationships of many CCSs and their partners are negatively affected by sexual dysfunctions. Psychosexual support should go beyond physical sexual functioning, and should take aspects such as sexual distress, relationship satisfaction, and the partner perspective into account. Additionally, offering more practical and reassuring information about sexuality and relationship consequences after cervical cancer would be valuable for both CCSs and their partners.

Part II

Prevention of treatment-induced vaginal changes