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# BMJ Open

## Sex(uality) post gynaecological cancer treatment: A qualitative study with South African women

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N = 34

Pseudonym	Age	Relationship status	Cancer site	Treatment modality	Months post treatment
Abigail	51	Dating	Vulvar	Surgery & radiation	36
Annabelle	68	Married	Uterine	Surgery & radiation	11
Bonnita	65	Cohabiting	Cervical	Surgery & concurrent chemo-radiation	15
Busiswa	44	Married	Ovarian	Surgery	3
Cebisa	40	Single	Cervical	Concurrent chemo-radiation	5
Cheryl	49	Divorced	Vulvar	Surgery & concurrent chemo-radiation	27
Doris	70	Widowed	Cervical	Concurrent chemo-radiation	19
Dumisa	53	Dating	Cervical	Concurrent chemo-radiation	13
Edith	62	Married	Cervical	Surgery	7
Faith	57	Married	Cervical	Surgery & concurrent chemo-radiation	18
Fatiema	38	Cohabiting	Ovarian	Surgery	22
Fiona	48	Married	Cervical	Surgery & concurrent chemo-radiation	20
Gia	59	Single	Cervical	Concurrent chemo-radiation	17
Grace	46	Married	Vulvar	Surgery	33
Ivory	56	Married	Uterine	Surgery	6
Ivy	50	Sexual partner	Ovarian	Surgery & chemotherapy	18
Jadeen	47	Married	Vulvar	Surgery	26
Jane	49	Married	Ovarian	Surgery	24
Kamilieta	36	Married	Cervical	Surgery & concurrent chemo-radiation	10
Kathy	58	Separated	Uterine	Surgery	36
Kayla	53	Single	Uterine	Surgery & radiation	15
Lucy	41	Single	Cervical	Concurrent chemo-radiation	20
Maggie	58	Single	Uterine	Surgery	22
Nadine	54	Single	Uterine	Surgery	12
Octavia	45	Divorced	Uterine	Surgery & chemotherapy	8
Priscilla	56	Cohabiting	Cervical	Concurrent chemo-radiation	33
Roxy	53	Cohabiting	Cervical	Concurrent chemo-radiation	28
Sam	63	Dating	Vulvar	Surgery	16

1					
2					
3	<b>Tamzin</b>	59	Separated	Uterine	Surgery
4	<b>Ursula</b>	61	Widowed	Cervical	Concurrent chemo-radiation
5	<b>Wendy</b>	29	Married	Ovarian	Surgery
6	<b>Xoliswa</b>	50	Single	Cervical	Concurrent chemo-radiation
7	<b>Yvonne</b>	41	Single	Cervical	Concurrent chemo-radiation
8	<b>Zelda</b>	52	Cohabiting	Vulvar	Surgery
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Table 1. *Participant demographics*

## Appendix A: Interview Guide

### Introduction

Welcome and thank you for agreeing to talk to me today. My name is .....  
and I work at a cancer research centre at Groote Schuur Hospital.

We want to better understand women's experiences of gynaecological cancer. To do this we are talking to women who have received treatment for gynaecological cancer at Groote Schuur Hospital and patients from Somerset Hospital that have received treatment at Groote Schuur. By treatment, we mean any surgery, radiotherapy, and/or chemotherapy that you have had for your cancer. We want to get more information about women's experiences so that we can create better support services for them. In particular, we are interested in hearing about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment.

We would like to know about your experiences and what issues are important to you. I know that for some people, being asked about personal issues by a stranger or by someone younger can be uncomfortable. Please know that your well-being is the most important thing to me and that I do not want to make you feel awkward. You do not have to answer any questions that you do not want to and you can stop the interview at any point.

The information and audio recordings received from this interview will be kept private. Your real name will not be associated with the audio recording and only the small team of researchers for this project will have access to the audio recordings.

The interview should not take longer than an hour. Please let me know if you need to leave urgently due to transport reasons.

1  
2  
3  
4  
5  
6 Opening questions to help participant relax  
7

8  
9 We are going to have a relaxed conversation about your experiences before and after your  
10 cancer treatment. But first....

- 11  
12  
13  
14 1) Can you tell me about how you came to be diagnosed with cancer?  
15  
16 2) What treatment/s have you had?  
17  
18

19  
20 Explanation of pile sorting activity  
21

22  
23 In this interview, we are going to be talking about some of your experiences before and after  
24 your cancer treatment. I know that some of these things can be difficult to express. So, we are  
25 going to do a short activity before each section of the interview to help you feel more  
26 comfortable.  
27  
28  
29

30  
31  
32 In this bag here are a lot of different words that are written on cards. Each word is a word that  
33 you could use to describe an experience, for example: 'good', 'difficult', 'painful', 'exciting'.  
34  
35

36  
37 I am going to put all of these words on the table in front of you and then I am going to ask  
38 you a question about your experiences before and after your cancer treatment. You will then  
39 have some time to choose the words that you feel best describe your experience. Once you  
40 have chosen the words we will discuss them and I will ask you a few more questions about  
41 your experiences before and after cancer.  
42  
43  
44

45  
46  
47 Do you have any questions about this activity?  
48

49  
50 [Put all practise cards on table. Make sure they are all clearly visible to participant.]  
51

52  
53  
54 Let us do a quick practise exercise. From these words, which ones would you choose to  
55 describe your day yesterday.  
56  
57  
58  
59  
60

[Assess participant's understanding and correct accordingly].

We will be doing this type of activity before most of the questions.

Section 1: Body image, femininity, and emotions [*sexual self-concept*]

We are going to start by talking about emotions and body image.

- 1) [Lay out words relating to Section 1A] **[Remember to clearly state the words the participant has chosen for each question]**
  - a. Which words would you use to describe your emotions **after** your treatment?
    - i. Why did you choose these words? Probe...
    - ii. Are there any words that are not here that could describe your experience?
    - iii. Was this a change from your emotions **before** treatment? (If yes, ask which words would describe their emotions before)
- 2) [Lay out words relating to Section 1B] **[Remember to clearly state the words the participant has chosen for each question]**
  - a. Body image is how you think or feel about your body. Which words would you use to describe your body image **after** your cancer treatment?
    - i. Why did you choose these words? Probe...
    - ii. Are there any words that are not here that could describe your experience?
    - iii. Was this a change from how you felt about your body **before** treatment? (If yes, ask which words would describe their body image before)
  - b. Which words would you use to describe how you feel about yourself as a woman **after** your cancer treatment?



- i. Why did you choose these words? Probe...
- ii. Are there any words that are not here that could describe your experience?
- iii. Was this a change from how you felt about yourself **before** treatment?  
(If yes, ask which words would describe their femininity before)

Section 2: Intimacy and communication [sexual relationships]

[Lay out words relating to Section 2] [**Remember to clearly state the words the participant has chosen for each question**]

I would now like to talk to you about your relationship.

- a. Which words would you use to describe your relationship in general **after** your treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your relationship **before** treatment? (If yes, ask which words would describe their relationship before)
- b. Before, we spoke about your relationship in general. Now, I would like to talk about your sexual relationship. Which words would you choose to describe the sexual relationship with your partner been **after** treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your sexual relationship **before** treatment? (If yes, ask which words would describe their sexual relationship before)

- 1  
2  
3 c. Has there been in a change in how often you have sex? (If yes, explore  
4 further.)  
5  
6  
7  
8 d. Which words would you use to describe what the communication about sex  
9  
10 has been like **after** your treatment?  
11  
12 i. Why did you choose these words? Probe...  
13  
14 ii. Are there any words that are not here that could describe your  
15  
16 experience?  
17  
18 iii. Was this a change from your communication **before** treatment? (If yes,  
19  
20 ask which words would describe their communication before)  
21  
22  
23  
24

25 Section 3: Desire, orgasm, arousal, performance, and identity [*sexual functioning and sexual*  
26 *self-concept*]  
27  
28

29  
30 [Lay out words relating to Section 3] [**Remember to clearly state the words the participant**  
31 **has chosen for each question**]  
32  
33

34  
35 I would now like to talk to you about some things relating to your sexual health after  
36  
37 treatment.  
38  
39

- 40 1) Which words would you use to describe your sex life **after** your treatment?  
41  
42 i. Why did you choose these words? Probe...  
43  
44 ii. Are there any words that are not here that could describe your  
45  
46 experience?  
47  
48 iii. Was this a change from your sexual functioning **before** treatment? (If  
49  
50 yes, ask which words would describe their sexual functioning before)  
51  
52  
53  
54 2) How often do you feel a desire to have sex, now that your **treatment is over**?  
55  
56 a. Is this level of desire any different to **before** your treatment? (If yes, how is it  
57  
58 different?)  
59  
60

- 1
- 2
- 3 3) Has there been a change in how you become physically excited about sex? (If yes,
- 4 how is it different?)
- 5
- 6
- 7
- 8 4) Has there been a change in how often you are able to orgasm during sex? (Is yes, how
- 9 is it different?)
- 10
- 11
- 12 5) How do you feel about your sexual performance **after** treatment?
- 13
- 14 a. Is this any different to **before** your treatment? (If yes, how is it different?)
- 15
- 16
- 17 6) How do you think about yourself as a sexual person **after** your treatment?
- 18
- 19 a. Is this any different to **before** your treatment? (If yes, how is it different?)
- 20
- 21

#### 22 Section 4: Questions relating to treatment adherence

23 [No more pile sorting].

- 24
- 25
- 26
- 27
- 28 1. Did any of the sexual changes you have told me about make you think about stopping
- 29 your treatment?
- 30
- 31
- 32 a. If yes, explore further:
- 33
- 34 i. Which changes in particular made you want to stop your treatment?
- 35
- 36 ii. What would have made it easier for you to cope with these changes?
- 37
- 38
- 39

#### 40 Section 5: Questions relating to support services

41 I would now like to talk to you about the information you received during your diagnosis

42 and/or treatment.

- 43
- 44
- 45
- 46
- 47
- 48
- 49 1) During your diagnosis and/or treatment, did a doctor or nurse talk to you about
- 50 sexual functioning?
- 51
- 52 a. If yes:
- 53
- 54 i. What did they discuss with you?
- 55
- 56 ii. How did you feel about this talk?
- 57
- 58
- 59
- 60

1  
2  
3 2) What types of support do women need after treatment to meet their sexual health  
4  
5 needs?  
6

7  
8 a. If they say anything about receiving more information: How would you  
9  
10 like to receive this information?  
11  
12

### 13 Closing comments

14  
15  
16 We have come to the end of the interview. Thank you so much for taking the time to talk to  
17  
18 me today. I really appreciate it. Do you have any questions you would like to ask? Thank  
19  
20 them for their time and for talking to me.  
21  
22

23  
24 By speaking with us today you are contributing to research that will hopefully help in  
25  
26 supporting cancer patients better.  
27  
28

29 Please accept this drink and snack as a small thank you for your time.  
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## Informed consent form

### Women's experiences after gynaecological cancer treatment

#### 1. Why is this study being done?

My name is..... and I work at the Gynaecological Cancer Research Centre at the University of Cape Town. You are invited to take part in a project that aims to better understand women's experiences after gynaecological cancer treatment. To do this we are talking to various women who have received treatment at Groote Schuur Hospital and patients from Somerset Hospital that have received treatment at Groote Schuur. By treatment, we mean any surgery, radiotherapy, and/or chemotherapy that you have had for your cancer. It is important for us to understand your experiences and what issues are important to you. In particular, we are interested in hearing about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment. We want to understand these things so that we can create better support services after cancer treatment.

#### 2. What will happen in the study?

If you decide to participate, we will talk to you for about 1 hour about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment and what these things were like before your treatment. This interview will take place in a private room and will be in your home language. The interview will be private and your partner and/or family member will not be in the room with you and the interviewer.

#### 3. Your rights

Taking part in this study or not taking part in this study is your choice. You do not have to answer any questions that make you feel uncomfortable. You can also decide to stop the interview at any time without anything bad happening. Stopping the interview or not taking part in the interview will not affect the care you receive from Groote Schuur Hospital in any way.

To help us remember what you talked about today the interview will be recorded on a recording device. Only the small research team will be able to listen to your recording. Your name will not be used as part of any of the results from this study. In order to keep your

1  
2  
3 identity private, you will be given another name (pseudonym) for this study. Nobody outside  
4 of the research team will have access to your information or audio recording.  
5  
6

7 **4. What are the risks and discomforts of this study?**  
8

9  
10 This is a very low risk study. You may feel uncomfortable talking about some of the topics.  
11 However, we do not want you to feel uncomfortable or that you have shared too much. You  
12 may refuse to answer any question or not take part in a section of the interview if you feel the  
13 question(s) are too personal or if talking about them makes you uncomfortable.  
14  
15

16  
17 If at any point in the interview you become very distressed we will stop the interview and  
18 give you some time to calm down. You will then be able to choose whether you wish to  
19 continue the interview or not. We will also refer you for counselling if necessary.  
20  
21

22  
23 **5. Will this study benefit you in any way?**  
24

25 You are given an opportunity to share your experiences, views and tell us what is important  
26 to you. This will help us find out more about women's experiences after gynaecological  
27 cancer treatment and how we can support them better. You will also receive a refreshment  
28 and a light snack.  
29  
30  
31

32  
33 **6. Who will see the information which is collected about you during the study?**  
34

35 We will follow strict guidelines to keep your personal information safe throughout the study.  
36 All information that we collect from this research project will be kept private. Information  
37 about you that is collected during the study will be stored in a file on a password protected  
38 computer. The file will not have your name on it, but rather a fake name (pseudonym) that  
39 has been assigned to you. Your name or any other identifying factors will not be used as part  
40 of any of the results from this study.  
41  
42  
43  
44

45  
46 **7. What happens if you decide you do not want to participate anymore?**  
47

48 You do not have to take part in this research if you do not want to, and deciding not to  
49 participate will not affect your current or future treatment at Groote Schuur Hospital in any  
50 way. You will still have all the benefits that you would otherwise have at this hospital. You  
51 may stop participating in the interview at any time that you wish without losing any of your  
52 rights as a patient.  
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3 **8. After the interview**  
4

5 If this interview raises issues for you about your sexual health that you would like to discuss  
6 further with a professional. Please ask your interviewer to refer you to our sexual health  
7 specialist Dr Ros Boa or to the psychologist that works in this department.  
8  
9

10  
11  
12  
13  
14 **9. Who do I speak to if I have any questions about the study?**  
15

16 If you have any questions about the study you may ask these now. If you think of a question  
17 later on in the interview please feel free to ask it then. If there is anything that is unclear or  
18 you need further information about; we will be happy to provide it. If you wish to ask  
19 questions once the interview has finished and you are at home, you may contact:  
20  
21  
22

23  
24 • **Professor Jennifer Moodley**, Deputy Director of the Gynaecological Cancer Research  
25 Center, School of Public Health & Family Medicine, University of Cape Town  
26

27 Tel: 021 406 6798

28 Email: jennifer.moodley@uct.ac.za  
29

30  
31  
32 • **Sorrel Pitcher**, Qualitative researcher with the Gynaecological Cancer Research Center,  
33 School of Public Health & Family Medicine, University of Cape Town  
34  
35

36 Email: sorrel.p@gmail.com  
37  
38  
39  
40  
41

42 **For questions about your rights as a participant please contact:**  
43

44 The UCT's Faculty of Health Sciences Human Research Ethics Committee can be contacted  
45 on 021 406 6338 in case you have any ethical concerns or questions about your rights or  
46 welfare as a participant on this research study  
47  
48

49 This proposal has been reviewed and approved by the University of Cape Town's Faculty of  
50 Health Sciences Human Research Ethics Committee (reference number: 716/2017), whose  
51 task it is to make sure that research participants are protected from harm.  
52  
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2  
3 By signing below you are saying that the study has been explained to you and that you  
4 understand all of the procedures and the risks and benefits of the study. Your signature also  
5 says that you would like to participate in the project.  
6  
7  
8  
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10

11 **Participant full name:**  
12  
13  
14

15  
16 **Participant Signature OR thumbprint (in case of illiteracy)**  
17  
18

**Date**  
19  
20  
21  
22

23 **Interviewer full name:**  
24  
25  
26

27  
28 **Interviewer Signature**  
29  
30  
31

**Date**  
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33  
34

35 **Witness full name (in case of illiterate participant):**  
36  
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40 **Witness signature:**  
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**Date**



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For peer review only

## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

# BMJ Open

## Sexuality post gynaecological cancer treatment: A qualitative study with South African women

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-038421.R1
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<b>Primary Subject Heading</b>:	Oncology
Secondary Subject Heading:	Qualitative research, Public health, Sexual health, Patient-centred medicine
Keywords:	Gynaecological oncology < GYNAECOLOGY, QUALITATIVE RESEARCH, SEXUAL MEDICINE

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## Appendix A: Interview Guide

### Introduction

Welcome and thank you for agreeing to talk to me today. My name is .....  
and I work at a cancer research centre at Groote Schuur Hospital.

We want to better understand women's experiences of gynaecological cancer. To do this we are talking to women who have received treatment for gynaecological cancer at Groote Schuur Hospital and patients from Somerset Hospital that have received treatment at Groote Schuur. By treatment, we mean any surgery, radiotherapy, and/or chemotherapy that you have had for your cancer. We want to get more information about women's experiences so that we can create better support services for them. In particular, we are interested in hearing about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment.

We would like to know about your experiences and what issues are important to you. I know that for some people, being asked about personal issues by a stranger or by someone younger can be uncomfortable. Please know that your well-being is the most important thing to me and that I do not want to make you feel awkward. You do not have to answer any questions that you do not want to and you can stop the interview at any point.

The information and audio recordings received from this interview will be kept private. Your real name will not be associated with the audio recording and only the small team of researchers for this project will have access to the audio recordings.

The interview should not take longer than an hour. Please let me know if you need to leave urgently due to transport reasons.

1  
2  
3  
4  
5  
6 Opening questions to help participant relax  
7

8  
9 We are going to have a relaxed conversation about your experiences before and after your  
10 cancer treatment. But first....

- 11  
12  
13  
14 1) Can you tell me about how you came to be diagnosed with cancer?  
15  
16 2) What treatment/s have you had?  
17  
18

19  
20 Explanation of pile sorting activity  
21

22  
23 In this interview, we are going to be talking about some of your experiences before and after  
24 your cancer treatment. I know that some of these things can be difficult to express. So, we are  
25 going to do a short activity before each section of the interview to help you feel more  
26 comfortable.  
27  
28  
29

30  
31  
32 In this bag here are a lot of different words that are written on cards. Each word is a word that  
33 you could use to describe an experience, for example: 'good', 'difficult', 'painful', 'exciting'.  
34  
35

36  
37 I am going to put all of these words on the table in front of you and then I am going to ask  
38 you a question about your experiences before and after your cancer treatment. You will then  
39 have some time to choose the words that you feel best describe your experience. Once you  
40 have chosen the words we will discuss them and I will ask you a few more questions about  
41 your experiences before and after cancer.  
42  
43  
44

45  
46  
47 Do you have any questions about this activity?  
48  
49

50  
51  
52 [Put all practise cards on table. Make sure they are all clearly visible to participant.]  
53  
54

55  
56 Let us do a quick practise exercise. From these words, which ones would you choose to  
57 describe your day yesterday.  
58  
59  
60

[Assess participant's understanding and correct accordingly].

We will be doing this type of activity before most of the questions.

Section 1: Body image, femininity, and emotions [*sexual self-concept*]

We are going to start by talking about emotions and body image.

- 1) [Lay out words relating to Section 1A] **[Remember to clearly state the words the participant has chosen for each question]**
  - a. Which words would you use to describe your emotions **after** your treatment?
    - i. Why did you choose these words? Probe...
    - ii. Are there any words that are not here that could describe your experience?
    - iii. Was this a change from your emotions **before** treatment? (If yes, ask which words would describe their emotions before)
- 2) [Lay out words relating to Section 1B] **[Remember to clearly state the words the participant has chosen for each question]**
  - a. Body image is how you think or feel about your body. Which words would you use to describe your body image **after** your cancer treatment?
    - i. Why did you choose these words? Probe...
    - ii. Are there any words that are not here that could describe your experience?
    - iii. Was this a change from how you felt about your body **before** treatment? (If yes, ask which words would describe their body image before)
  - b. Which words would you use to describe how you feel about yourself as a woman **after** your cancer treatment?



- i. Why did you choose these words? Probe...
- ii. Are there any words that are not here that could describe your experience?
- iii. Was this a change from how you felt about yourself **before** treatment?  
(If yes, ask which words would describe their femininity before)

## Section 2: Intimacy and communication [sexual relationships]

[Lay out words relating to Section 2] [**Remember to clearly state the words the participant has chosen for each question**]

I would now like to talk to you about your relationship.

- a. Which words would you use to describe your relationship in general **after** your treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your relationship **before** treatment? (If yes, ask which words would describe their relationship before)
- b. Before, we spoke about your relationship in general. Now, I would like to talk about your sexual relationship. Which words would you choose to describe the sexual relationship with your partner been **after** treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your sexual relationship **before** treatment? (If yes, ask which words would describe their sexual relationship before)

- 1  
2  
3 c. Has there been in a change in how often you have sex? (If yes, explore  
4 further.)  
5  
6  
7  
8 d. Which words would you use to describe what the communication about sex  
9  
10 has been like **after** your treatment?  
11  
12 i. Why did you choose these words? Probe...  
13  
14 ii. Are there any words that are not here that could describe your  
15  
16 experience?  
17  
18 iii. Was this a change from your communication **before** treatment? (If yes,  
19  
20 ask which words would describe their communication before)  
21  
22  
23  
24

25 Section 3: Desire, orgasm, arousal, performance, and identity [*sexual functioning and sexual*  
26 *self-concept*]  
27  
28  
29

30 [Lay out words relating to Section 3] [**Remember to clearly state the words the participant**  
31 **has chosen for each question**]  
32  
33  
34

35 I would now like to talk to you about some things relating to your sexual health after  
36  
37 treatment.  
38  
39

- 40 1) Which words would you use to describe your sex life **after** your treatment?  
41  
42 i. Why did you choose these words? Probe...  
43  
44 ii. Are there any words that are not here that could describe your  
45  
46 experience?  
47  
48 iii. Was this a change from your sexual functioning **before** treatment? (If  
49  
50 yes, ask which words would describe their sexual functioning before)  
51  
52  
53  
54 2) How often do you feel a desire to have sex, now that your **treatment is over**?  
55  
56 a. Is this level of desire any different to **before** your treatment? (If yes, how is it  
57  
58 different?)  
59  
60

- 1
- 2
- 3 3) Has there been a change in how you become physically excited about sex? (If yes,
- 4 how is it different?)
- 5
- 6
- 7
- 8 4) Has there been a change in how often you are able to orgasm during sex? (Is yes, how
- 9 is it different?)
- 10
- 11
- 12 5) How do you feel about your sexual performance **after** treatment?
- 13
- 14 a. Is this any different to **before** your treatment? (If yes, how is it different?)
- 15
- 16
- 17 6) How do you think about yourself as a sexual person **after** your treatment?
- 18
- 19 a. Is this any different to **before** your treatment? (If yes, how is it different?)
- 20
- 21

#### 22 Section 4: Questions relating to treatment adherence

23 [No more pile sorting].

- 24
- 25
- 26
- 27
- 28 1. Did any of the sexual changes you have told me about make you think about stopping
- 29 your treatment?
- 30
- 31
- 32 a. If yes, explore further:
- 33
- 34
- 35 i. Which changes in particular made you want to stop your treatment?
- 36
- 37
- 38 ii. What would have made it easier for you to cope with these changes?
- 39

#### 40 Section 5: Questions relating to support services

41 I would now like to talk to you about the information you received during your diagnosis

42 and/or treatment.

- 43
- 44
- 45
- 46
- 47
- 48
- 49 1) During your diagnosis and/or treatment, did a doctor or nurse talk to you about
- 50 sexual functioning?
- 51
- 52 a. If yes:
- 53
- 54
- 55 i. What did they discuss with you?
- 56
- 57
- 58 ii. How did you feel about this talk?
- 59
- 60

1  
2  
3 2) What types of support do women need after treatment to meet their sexual health  
4  
5 needs?  
6

7  
8 a. If they say anything about receiving more information: How would you  
9  
10 like to receive this information?  
11  
12

### 13 Closing comments

14  
15  
16 We have come to the end of the interview. Thank you so much for taking the time to talk to  
17  
18 me today. I really appreciate it. Do you have any questions you would like to ask? Thank  
19  
20 them for their time and for talking to me.  
21  
22

23  
24 By speaking with us today you are contributing to research that will hopefully help in  
25  
26 supporting cancer patients better.  
27  
28

29 Please accept this drink and snack as a small thank you for your time.  
30  
31  
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## Informed consent form

### Women's experiences after gynaecological cancer treatment

#### 1. Why is this study being done?

My name is..... and I work at the Gynaecological Cancer Research Centre at the University of Cape Town. You are invited to take part in a project that aims to better understand women's experiences after gynaecological cancer treatment. To do this we are talking to various women who have received treatment at Groote Schuur Hospital and patients from Somerset Hospital that have received treatment at Groote Schuur. By treatment, we mean any surgery, radiotherapy, and/or chemotherapy that you have had for your cancer. It is important for us to understand your experiences and what issues are important to you. In particular, we are interested in hearing about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment. We want to understand these things so that we can create better support services after cancer treatment.

#### 2. What will happen in the study?

If you decide to participate, we will talk to you for about 1 hour about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment and what these things were like before your treatment. This interview will take place in a private room and will be in your home language. The interview will be private and your partner and/or family member will not be in the room with you and the interviewer.

#### 3. Your rights

Taking part in this study or not taking part in this study is your choice. You do not have to answer any questions that make you feel uncomfortable. You can also decide to stop the interview at any time without anything bad happening. Stopping the interview or not taking part in the interview will not affect the care you receive from Groote Schuur Hospital in any way.

To help us remember what you talked about today the interview will be recorded on a recording device. Only the small research team will be able to listen to your recording. Your name will not be used as part of any of the results from this study. In order to keep your

1  
2  
3 identity private, you will be given another name (pseudonym) for this study. Nobody outside  
4 of the research team will have access to your information or audio recording.  
5  
6

7 **4. What are the risks and discomforts of this study?**  
8

9  
10 This is a very low risk study. You may feel uncomfortable talking about some of the topics.  
11 However, we do not want you to feel uncomfortable or that you have shared too much. You  
12 may refuse to answer any question or not take part in a section of the interview if you feel the  
13 question(s) are too personal or if talking about them makes you uncomfortable.  
14  
15

16  
17 If at any point in the interview you become very distressed we will stop the interview and  
18 give you some time to calm down. You will then be able to choose whether you wish to  
19 continue the interview or not. We will also refer you for counselling if necessary.  
20  
21

22  
23 **5. Will this study benefit you in any way?**  
24

25 You are given an opportunity to share your experiences, views and tell us what is important  
26 to you. This will help us find out more about women's experiences after gynaecological  
27 cancer treatment and how we can support them better. You will also receive a refreshment  
28 and a light snack.  
29  
30  
31

32  
33 **6. Who will see the information which is collected about you during the study?**  
34

35 We will follow strict guidelines to keep your personal information safe throughout the study.  
36 All information that we collect from this research project will be kept private. Information  
37 about you that is collected during the study will be stored in a file on a password protected  
38 computer. The file will not have your name on it, but rather a fake name (pseudonym) that  
39 has been assigned to you. Your name or any other identifying factors will not be used as part  
40 of any of the results from this study.  
41  
42  
43  
44

45  
46 **7. What happens if you decide you do not want to participate anymore?**  
47

48 You do not have to take part in this research if you do not want to, and deciding not to  
49 participate will not affect your current or future treatment at Groote Schuur Hospital in any  
50 way. You will still have all the benefits that you would otherwise have at this hospital. You  
51 may stop participating in the interview at any time that you wish without losing any of your  
52 rights as a patient.  
53  
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2  
3 **8. After the interview**  
4

5 If this interview raises issues for you about your sexual health that you would like to discuss  
6 further with a professional. Please ask your interviewer to refer you to our sexual health  
7 specialist Dr Ros Boa or to the psychologist that works in this department.  
8  
9

10  
11  
12  
13  
14 **9. Who do I speak to if I have any questions about the study?**  
15

16 If you have any questions about the study you may ask these now. If you think of a question  
17 later on in the interview please feel free to ask it then. If there is anything that is unclear or  
18 you need further information about; we will be happy to provide it. If you wish to ask  
19 questions once the interview has finished and you are at home, you may contact:  
20  
21  
22

23  
24 • **Professor Jennifer Moodley**, Deputy Director of the Gynaecological Cancer Research  
25 Center, School of Public Health & Family Medicine, University of Cape Town  
26

27 Tel: 021 406 6798

28 Email: jennifer.moodley@uct.ac.za  
29

30  
31  
32 • **Sorrel Pitcher**, Qualitative researcher with the Gynaecological Cancer Research Center,  
33 School of Public Health & Family Medicine, University of Cape Town  
34  
35

36 Email: sorrel.p@gmail.com  
37  
38  
39  
40  
41

42 **For questions about your rights as a participant please contact:**  
43

44 The UCT's Faculty of Health Sciences Human Research Ethics Committee can be contacted  
45 on 021 406 6338 in case you have any ethical concerns or questions about your rights or  
46 welfare as a participant on this research study  
47  
48

49 This proposal has been reviewed and approved by the University of Cape Town's Faculty of  
50 Health Sciences Human Research Ethics Committee (reference number: 716/2017), whose  
51 task it is to make sure that research participants are protected from harm.  
52  
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3 By signing below you are saying that the study has been explained to you and that you  
4 understand all of the procedures and the risks and benefits of the study. Your signature also  
5 says that you would like to participate in the project.  
6  
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11 **Participant full name:**  
12  
13  
14

15  
16 **Participant Signature OR thumbprint (in case of illiteracy)**  
17  
18

**Date**  
19  
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21  
22

23 **Interviewer full name:**  
24  
25  
26

27  
28 **Interviewer Signature**  
29  
30  
31

**Date**  
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34

35 **Witness full name (in case of illiterate participant):**  
36  
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40 **Witness signature:**  
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**Date**



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For peer review only

## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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<b>Primary Subject Heading</b>:	Oncology
Secondary Subject Heading:	Qualitative research, Public health, Sexual health, Patient-centred medicine
Keywords:	Gynaecological oncology < GYNAECOLOGY, QUALITATIVE RESEARCH, SEXUAL MEDICINE

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4 **Sexuality post gynaecological cancer treatment: A qualitative study with South African**  
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6 **women**  
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12 **Pitcher, S.**<sup>i</sup> – sorrel.pitcher@uct.ac.za [Corresponding author]  
13

14  
15 **Fakie, N.**<sup>iii, i</sup> – n.fakie@uct.ac.za  
16

17  
18 **Adams, T.**<sup>ii, i</sup> – tracey.adams@uct.ac.za  
19

20  
21 **Denny, L.**<sup>ii, i</sup> – lynette.denny@uct.ac.za  
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24 **Moodley, J.**<sup>iv, v, i</sup> – jennifer.moodley@uct.ac.za  
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29

- 30 i. UCT/SAMRC Gynaecological Cancer Research Centre  
31  
32 ii. UCT Department of Obstetrics and Gynaecology  
33  
34 iii. UCT Department of Radiation Oncology  
35  
36 iv. Cancer Research Initiative, UCT School of Public Health and Family Medicine  
37  
38 v. Women's Health Research Unit, UCT School of Public Health and Family Medicine  
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## Abstract

**Objectives:** This study investigated women's experiences of their sexuality post gynaecological cancer treatment. Using a holistic sexuality framework, the study explored how women felt their sexual functioning, sexual relationships, and sexual identity had been affected by treatment. **Design:** The study was qualitative in nature and made use of an interpretive descriptive design. The data was analysed using thematic analysis. **Setting:** Data collection took place at a follow-up clinic within the Gynae-Oncology Unit at a public-sector tertiary hospital in Cape Town, South Africa. **Participants:** Purposive sampling was used to recruit participants and the final sample consisted of 34 women aged 29-70 ( $\bar{x} = 52$ ). All women had received a gynaecological cancer diagnosis and had been treated with either surgery, chemotherapy, radiation, or a combination of these. On average, the participants were between 12-30 months post treatment. **Results:** Women expressed how their sexual functioning post treatment was both nuanced and complex; how heteronormative gender expectations influenced their intimate relationships, and how they experienced a re-embodiment of their sexual subjectivity post treatment. Participants felt that more sexual functioning information from healthcare providers, as well as peer support groups, would assist them in navigating the sexuality changes they experienced. **Conclusions:** The findings of this study broaden conceptualisations of sexuality post treatment by detailing the ways that it is complex, nuanced, relational and ever shifting. More research is needed about how to incorporate holistic psycho-sexual support post treatment into the public healthcare system in South Africa.

**Keywords:** Sexuality, gynaecological cancer, onco-sexology, psycho-sexuality, qualitative, South Africa

### Strengths and limitations

- The use of a holistic sexuality framework allowed for sexual functioning to be considered beyond physical acts of intercourse.
- The cross-sectional nature of the study means that comments cannot be made about how participants experienced their sexuality post treatment longitudinally.
- The theoretical framework used is not exhaustive and did not include socio-cultural factors relating to sexuality.
- The sample of this study was comprised predominantly of older women in long term relationships with men and therefore this study could not explore the experiences of younger women, women who are not partnered, and queer women.



## Background

Sexuality<sup>1</sup> in the context of gynaecological cancer treatment is frequently side-lined in clinical contexts because it does not relate to the eradication of the cancer itself (1, 2).

Persons living with cancer are often asexualized because they fall outside of conceptualisations of ‘normative’ sexuality (3). Yet, for many individuals, sexual well-being is an important quality of life factor (4, 5). Research suggests that 40-100% of women with gynaecological cancer will experience sexual difficulties post treatment (6-8). Common problems include decreased desire; low frequency of sexual activity, sexual pleasure and satisfaction; high levels of discomfort; loss of vaginal elasticity; deep dyspareunia; vaginal dryness and shortening; and difficulty with orgasm (9). Side effects that manifest in other areas of the body – such as urinary or bowel dysfunction, and fatigue – also hinder sexual activity. These alterations can last for years into survivorship and may become chronic (10). Healthcare providers find it difficult and often feel ill-equipped to communicate about sexuality with their patients (11-13) which leads to inconsistencies in psycho-sexual support post treatment (14).

Gaining a comprehensive understanding of women’s lived experiences of sexuality post treatment is imperative to patient-centred care and comprehensive support programs in South Africa.

Cervical cancer is the most common gynaecological cancer in South Africa, and the second most common cancer in women after breast cancer with an age standardised incidence rate per 100 000 of 23 (15). The age standardised incidence rates per 100 000 for cancer of the uterus, ovary, vulva and vagina are 5, 2, 1, and 0.7 respectively (15). Accordingly, most

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<sup>1</sup> In this article, the World Health Organisation’s (2006) definition of sexuality is used as the underlying understanding of sexuality. This states that sexuality encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction and is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

of the research has focused on cervical cancer compared to other gynaecological cancers. Cervical cancer prevention has concentrated on population-based screening in the form of free Papanicolaou smears (16). Unfortunately, most women typically self-present to health facilities when symptomatic and in advanced stages - commonly stage IIIB - (17, 18) where definitive radiotherapy is the treatment of choice. The higher doses received, compared with adjuvant radiotherapy, may likely result in higher levels of sexual dysfunction (19).

### Methods

The research was approved by the University of Cape Town's Health Research Ethics Committee (HREC REF: 716/2017) and given hospital institutional approval. The main research question that was: How do women experience their sexuality post gynaecological cancer treatment? The sub-questions were as follows: 1) What are women's experiences of their sexual functioning post treatment?, 2) In what ways has this impacted their sexual self-concept? 3), How has this affected their sexual relationships?, and 4) What are their thoughts on how best their sexual health needs can be addressed as part of cancer care.

### Theoretical framework

This study utilised the Neo-theoretical Framework of Sexuality, a framework conceptualised by Woods (20, 21) and then expanded upon by Cleary and Hegarty through the analysis of empirical literature about sexuality in the context of gynaecological cancer (22). This framework posits that sexuality in the context of gynaecological cancer is comprised of three interconnected factors: 1) sexual self-concept, 2) sexual relationships, and 3) sexual function (22). The framework was chosen for this study in order to move away from solely biomedical understandings of sexuality post gynaecological cancer treatment to more comprehensive conceptualisations which acknowledge the material, intrapsychic and relational aspects of sexuality (23). Apart from outlining this study's theoretical

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3 understanding of sexuality, this framework also guided the research questions and interview  
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5 schedule and informed the deductive stage of data coding.  
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### 8 **Study design**

10 This was a qualitative study that utilised an interpretive descriptive design.  
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12 Interpretive description aligns philosophically with naturalistic observation and borrows  
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14 strongly from grounded theory, ethnography and phenomenology (24, 25). Interpretive  
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16 description aims to provide a comprehensive summary of a phenomenon as well as offer  
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18 explanations of what the themes within the data signify (26). It also pays attention to  
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20 subjective perceptions and acknowledges the contextual and constructed nature of human  
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22 experiences (27) which creates space for exploring multiple perspectives within the data.  
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24 Interpretive descriptive studies are largely problem-driven and aim to generate knowledge  
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26 that is clinically applicable (28). Such a research design is effective for health sciences  
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28 research because it creates “tentative truth claims” (25) about what is common about people’s  
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30 experiences of a clinical phenomenon. In this way, the research output can provide the  
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32 background for health-related planning, assessment, and interventions (25).  
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### 39 **Sampling and recruitment**

41 Participants were recruited using purposive sampling which is a non-random sampling  
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43 technique whereby participants are chosen because they have experience with a phenomenon  
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45 of interest and thus can provide rich information on the topic (29). Women who had received  
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47 treatment for gynaecological cancers at a tertiary level, public sector hospital in Cape Town  
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49 were recruited from the weekly follow-up clinic that takes place within the Radiation  
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51 Oncology Unit.  
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55 Participants were eligible for the study if they were 18 years or older and had received  
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57 treatment for cervical, uterine, vulvar, or ovarian cancer, or a combination of these, in the  
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3 past 6-36 months. Participants had to fall into one of the following treatment categories:  
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5 surgery only, radiation (with or without preceding surgery), or surgery followed by radiation  
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7 or concurrent chemo-radiation. Participants needed to be conversant in either English,  
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9 Afrikaans, isiXhosa or isiZulu and needed to score 0, 1 or 2 on the Eastern Cooperative  
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11 Oncology Group (ECOG) performance status to be recruited.  
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16 Women who met the inclusion criteria were identified through their hospital files by  
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18 the radiation oncologist (NF) and gynae-oncologist (TA) involved in the follow-up clinic.  
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20 Upon completion of their follow-up appointment, eligible women were informed about the  
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22 study and interested women were referred to the research nurse. The research nurse gave  
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24 further information about the study and, if potential participants wished to proceed,  
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26 completed the informed consent procedures. This process was conducted in the participant's  
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28 home language. In accordance with established qualitative research protocols, recruitment  
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30 ceased when information redundancy was reached (30).  
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### 34 **Data collection and analysis**

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36 Data collection occurred in two phases: pilot interviews and actual data collection.  
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38 The pilot interviews were used to test the interview guide and the data from these interviews  
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40 were not included in the final analysis. Both sets of interviews were conducted in  
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42 participants' home language by either the research nurse or the GCRC's qualitative  
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44 researcher (SP) – both of whom are female. Interviews took place in a private space in the  
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46 Radiation Oncology Unit and lasted between 30-90 minutes. Only the participant and  
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48 interviewers were present for the interviews. Before beginning the interview, the participants  
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50 signed a consent form and completed a brief demographic questionnaire asking about age,  
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52 home language/s, current relationship status, diagnosis, treatment/s and time post treatment.  
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54 At the beginning of the interview, the participants were asked to choose a pseudonym which  
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56 was used to ensure their anonymity throughout the research process, including their  
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3 transcripts, during analysis, and in any published material (see Table 1). Partner's and  
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5 children's names as well as any other identifying information was removed.  
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9 The pilot interviews, conducted in May 2018, demonstrated that, despite extensive  
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11 training of the interviewers with regards to interviewing about sensitive topics, participants  
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13 struggled to articulate their experiences of sexuality post treatment. This is not unexpected as  
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15 this study exists at the intersection of two topics which remain highly stigmatised in  
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17 contemporary South African society: female sexuality and cancer. Given these challenges,  
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19 the interview guide was rearranged to flow more logically, and pile sorting was incorporated  
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21 to facilitate participants' expression (31-33).  
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26 Pile sorting is a well-established qualitative research methodology and can be used in  
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28 multiple ways (34). It involves presenting a participant with words, objects or images and  
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30 asking them to sort these into categories that make sense to them. The purpose of this is to  
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32 identify the ways in which people think about certain concepts and experiences (34). A  
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34 structured pile sort using words was employed, where participants were guided as to how to  
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36 sort the words. For example, 'Please select all the words that describe how you felt about  
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38 your body image before your cancer treatment.' Participants were also allowed to include any  
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40 words of their own that they felt best described their experiences but were not on the cards  
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42 presented by the interviewer. The pile sorting acted as a catalyst for discussion and formed  
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44 concrete reference points that could be used throughout the interview. This methodology has  
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46 been widely used in public health research (34-36) and has been shown to be effective in  
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48 gender and sexuality research in LMIC countries (37, 38).  
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54 Following the pilot interviews, data was collected through semi-structured, face-to-  
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56 face, in-depth interviews in conjunction with pile sorting. Interview questions were based on  
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58 the central elements of the Neo-Theoretical Framework of Sexuality (22): 1) sexual self-  
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3 concept, 2) sexual relationships, and 3) sexual function. Participants were asked how they  
4 experienced these aspects of their sexual lives before and after treatment. They were also  
5 asked about the sexual functioning information they received from healthcare providers  
6 during their treatment and what kind of support they think women need post treatment (see  
7 Appendix A: Interview guide) Each participant was interviewed once between September  
8 2018 and February 2019. Interviews were audio recorded with participants' consent,  
9 transcribed for meaning and, where necessary, translated. Fieldnotes were written after each  
10 interview was completed. The interview excerpts that appear in this paper have been edited  
11 only to the extent that a few irrelevant sentences and words have been replaced with ellipses,  
12 and excessive use of colloquialisms, such as "like" and "um" have been removed.  
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27 In keeping with the iterative and cyclical nature of qualitative research, the data  
28 analysis and writing stages happened simultaneously and informed each other. NVivo 12 Pro  
29 was used to manage the data and facilitate analysis. Data was analysed using the thematic  
30 analysis steps outlined by Braun and Clarke (39) which comprises of six stages:  
31 familiarisation with the data, generating initial codes, searching for themes, reviewing  
32 themes, defining and naming themes, and producing the report. The coding process made use  
33 of inductive and deductive approaches. Deductive coding was based on the Neo-Theoretical  
34 Framework of Sexuality (22). For the inductive coding, the concepts and categories that  
35 emerged from the data were used as codes, rather than being informed by existing theory or  
36 preconceptions about gynaecological cancer and sexuality. Transcripts were not given to  
37 participants for review.  
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### 52 **Patient and public involvement**

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54 First language Afrikaans and isiXhosa speaking members of the public were asked to  
55 give feedback on the comprehensibility of the translated interview schedule and pile sorting  
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3 words. This took place in the form of focus group discussions. Patients were not involved in  
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5 this research.  
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## 8 9 **Results**

### 10 11 **Participant demographics**

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13 In total, 34 participants were recruited (see Table 1). The average age was 52 with a  
14 range of 29-70. Most of the women were either married or single, however, although some  
15 women classified themselves as 'single' they did still have a consistent sexual partner.  
16 Afrikaans and English were the most common languages spoken by participants. Cervical  
17 cancer was the most common cancer which is in accordance with national prevalence rates  
18 and most of the women had been treated with surgery. The average time post treatment was  
19 20,3 months with most women being within 12-30 months post treatment.  
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### 30 31 **Overview of results**

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33 Four main themes emerged from the interview data: complexity and nuance in sexual  
34 functioning experiences; the influence of heteronormative gender role expectations on  
35 sexuality; re-embodiment of the sexual self, and psycho-sexual support during the cancer  
36 journey (see Table 2). The complexity and nuance in sexual functioning theme is comprised  
37 of the sub-themes: material changes in sexual functioning; impact of pre-diagnosis  
38 symptoms; intimate partnership dynamics, and the coexistence of pleasure and discomfort.  
39 The heteronormative gender role expectations theme includes the sub-themes: 'failing' at  
40 femininity and sexual violence. Psycho-sexual support during the cancer journey consists of  
41 the sub-themes: information received from healthcare providers and the need for  
42 comprehensive support. These findings contribute to expanding understandings of sexuality  
43 within the context of gynaecological cancer as well as trouble existing dominant narratives  
44 regarding sexuality post treatment.  
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Pseudonym	Age group	Cancer site	Treatment modality	Months post treatment
Abigail	51-55	Vulvar	Surgery & radiation	31-36
Annabelle	66-70	Uterine	Surgery & radiation	10-16
Bonnita	61-65	Cervical	Surgery & concurrent chemo-radiation	10-16
Busiswa	41-45	Ovarian	Surgery	3-9
Cebisa	36-40	Cervical	Concurrent chemo-radiation	3-9
Cheryl	46-50	Vulvar	Surgery & concurrent chemo-radiation	24-30
Doris	66-70	Cervical	Concurrent chemo-radiation	17-23
Dumisa	51-55	Cervical	Concurrent chemo-radiation	10-16
Edith	61-65	Cervical	Surgery	3-9
Faith	56-60	Cervical	Surgery & concurrent chemo-radiation	17-23
Fatiema	36-40	Ovarian	Surgery	17-23
Fiona	46-50	Cervical	Surgery & concurrent chemo-radiation	17-23
Gia	56-60	Cervical	Concurrent chemo-radiation	17-23
Grace	46-50	Vulvar	Surgery	31-36
Ivory	56-60	Uterine	Surgery	3-9
Ivy	46-50	Ovarian	Surgery & chemotherapy	17-23
Jadeen	46-50	Vulvar	Surgery	24-30
Jane	46-50	Ovarian	Surgery	24-30
Kamilieta	36-40	Cervical	Surgery & concurrent chemo-radiation	10-16
Kathy	56-60	Uterine	Surgery	31-36
Kayla	51-55	Uterine	Surgery & radiation	10-16
Lucy	41-45	Cervical	Concurrent chemo-radiation	17-23
Maggie	56-60	Uterine	Surgery	17-23
Nadine	51-55	Uterine	Surgery	10-16
Octavia	41-45	Uterine	Surgery & chemotherapy	3-9
Priscilla	56-60	Cervical	Concurrent chemo-radiation	31-36
Roxy	51-55	Cervical	Concurrent chemo-radiation	24-30
Sam	61-65	Vulvar	Surgery	10-16
Tamzin	56-60	Uterine	Surgery	16
Ursula	61-65	Cervical	Concurrent chemo-radiation	35
Wendy	26-30	Ovarian	Surgery	36
Xoliswa	46-50	Cervical	Concurrent chemo-radiation	24
Yvonne	41-45	Cervical	Concurrent chemo-radiation	26
Zelda	51-55	Vulvar	Surgery	36

Table 1. *Participant demographics*



Main theme	Sub-theme/s	Quotes
Complexity and nuance in sexual functioning experiences	<i>Material changes in sexual functioning</i>	<p>The sexual relationship, I couldn't, there was no sex involved the next year or so, even now it's still a bit, not sore, but two months ago I was very uncomfortable, because I had a yeast infection. It's your whole bottom body is on fire all the time, constipated, I have been constipated since the chemo started, feeling constipated all the time. So, your sexual being, it doesn't exist. – <i>Ivy</i></p> <p>They said the radiation caused scar tissue that is why I think I'm too tight. The dryness is also from the treatment they said, and sometimes he has to do stuff to make me wet, and that is uncomfortable, that is an uncomfortable feeling, when I'm too tight and too dry I'm very uncomfortable. And after sex I'm always tired, I feel so weak, like I have no energy left in my body. – <i>Fiona</i></p>
	<i>Impact of pre-diagnosis symptoms</i>	<p>I actually had this uncomfortable feeling and itchiness all the time for years. Yes, it was about three to four years that I had it, I went to the doctor and then I had a Pap smear, and then she said that it's just fine, I must just use the ointment. And then, because I think I went twice to different doctors, and because it's a gynae problem and you don't want just any doctor to just look into you, you don't feel comfortable. – <i>Sam</i></p> <p>Before, I don't even want to talk about before, before I also didn't want to have sex, because you know I told you that when we were having intercourse I would start to bleed, that was really messy and that is why we never bothered having sex that much. – <i>Fiona</i></p> <p>Before I received the treatment, I didn't have a desire to have sex with my husband, because that desire to have sex was not there. So, after the operation that feeling of being a woman came back, that feeling of being woman... So, after the treatment I felt different. I am the one that wants it most of the time, I feel that I am always ready for my husband, there isn't a time where I feel tired or worried about the pain. – <i>Wendy</i></p>
	<i>Intimate partnership dynamics</i>	<p>I don't know why but sometimes we won't have sex for two weeks and we sleep in the same bed. For instance, I touch him and then he will, but if I don't touch... It's like that, so I can't say from his side what's the problem there, maybe he doesn't feel like it, maybe he is too tired or whatever. – <i>Roxy</i></p> <p>I will be honest with you, it's been down [their sex life]. Most of the time, it's not all the time... After the treatment and before because he is a diabetic. So, I had to compromise with his sickness as well, and be patient and tolerant. So, I think that is where the understanding comes from on both sides. – <i>Ivory</i></p> <p>Yes, it's after the treatment, so I think the operation hasn't healed on the inside, yes. And unsatisfied on his side, I would say he might also have a problem because I don't feel him the way I used to. I think that the problem is with him. He thinks about going to the doctor. – <i>Busiswa</i></p>
	<i>Coexistence of pleasure and discomfort</i>	<p>I don't like it as often as I used to, so not often, so that is how I would like to describe it. I'm very well lubricated, not dry at all but I don't like it that often. I'm quite comfortable, there is no discomfort. I mean it's still as pleasurable, it's as still pleasurable but I still don't like it as often, and I'm very well lubricated and very comfortable. – <i>Jane</i></p>

		There's always a desire, I make myself available after I finish my work, and I wash myself and I make myself sexy but I'm tired [ <i>laughs</i> ] that is the problem. I'm tired and he would force me and then we would argue and then I become angry; because sometimes when I'm tired I don't feel like it. – <i>Priscilla</i>
The influence of heteronormative gender role expectations on sexuality	<i>'Failing' at femininity</i>	You doubt your femininity, because now your life has changed – you are sick now. There's always anger in the household because you are sick, everything is going backwards. It seems like there is no mother in the home because mom is sick. So, everything is unpleasant, and so you start to doubt whether you are a real woman. So, all of that makes me feel empty when I am not take care of at home. And also, you aren't desirable because you are sick, and you are always lying in bed, so you lose your desirability and your husband loses interest in you, he doesn't see anything in you because you are also not fixing yourself up because of your health. – <i>Grace</i>
	<i>Sexual violence</i>	What caused it is if we were intimate I would bleed, it wasn't nice and blood clots would come out. And when all is done I would get an itchy discharge which is constant and that is not treatable, so I ended up going to check myself out to see what is going on. That is how I felt but he was also persistent. I would bleed when I'm intimate with a man, it wasn't nice, and I would be in pain, the pain caused me to act. So, what he would do is he would force me, but I would tell him that the discharge would come out while I'm standing. So, he was forcing things, so I ended up calling the police to chase him out of the house - <i>Cebisa</i> Let me put it like this he is a man and he wants sex, right but you can't give it to him. You can't give it to him, so he is going to become angry, or he will hit me, and he will fight with me because I don't want to give it to him. Look I must avoid him because why do I have to do that, look he wants to sleep with me, and now my wound has not healed. It's still raw on the inside, now that is why I'm avoiding him. – <i>Maggie</i>
Re-embodiment of the sexual self	<i>n/a</i>	I'm still a woman no matter what has been done to my body, I'm still a woman, it happened and it's done. The operation has been done and I have to live with that.” - <i>Edith</i> I would say that I still find myself attractive, confident, feminine. I'm still whole and I'm comfortable because that is who I was before. And I'm still that person, it doesn't matter what operation I had, what was removed from me, that is from the inside. But I'm a person, my heart is whole, so I still feel attractive and I still feel confident. - <i>Fiona</i>
Psycho-sexual support during the cancer journey	<i>Information received from healthcare professionals</i>	They just call you into the boardroom to tell you what the procedure is going to be, what they will be doing here in the treatment; but not on a sexual, not telling you about how or you know. – <i>Gia</i> No, the doctor said I am quite old age, he doesn't think that I am somebody that is a young girl that likes to have a lot of sex and things like that. – <i>Bonnita</i> They did tell me yes, they explained to me I'm not going to get the feelings because every, they told me that not every woman is the same, every woman has a different body. - <i>Fatiema</i>
	<i>The need for comprehensive support</i>	I would say that they should explain it to a person in more detail, just like myself I don't have much information on what sex would do to me...Even if

		<p>you give us pamphlets, yes to read, a person to read on their own and see whether sex has an effect or not, and for us not to be worried, or to be too anxious. - <i>Xoliswa</i></p> <p>I think that when you come for your visit, doctors don't need to wait for you to say, "Doctor, I'm getting sore when I have intercourse," or "Doctor if I bend too low having sex, I'm getting sore." I think they need to, when you come, they must sit with you and must have a chat with you about that part; because that part is the most, that is the part where you find it most difficult. - <i>Roxy</i></p> <p>And to have a support group would be nice, I mean I know about cancer, cancer is expensive to go through and even some of the other support groups it's very difficult, but to have something as part of the hospital that's here.- <i>Ivy</i></p>
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Table 2. *Summary of results*

### **Complexity and nuance in sexual functioning experiences**

This theme confirms existing literature relating to material changes in sexual functioning post treatment as well as foregrounding how sexuality in the context of gynaecological cancer involves a diverse array of experiences and feelings that are nuanced, complex, fluctuating, and contingent on the relational context. In particular, these results show that symptoms *prior* to diagnosis also have a detrimental impact on women's sexuality; that women's partners' health and sexual functioning also need to be considered as a factor in sexuality post treatment; and lastly, that most participants reported experiencing difficulties in one area of their sexual lives while simultaneously experiencing pleasure and fulfillment in other areas.

### **Material changes in sexual functioning**

Just over half of the participants mentioned sexual difficulties as a result of fatigue post treatment and just under half of the participants struggled with a lack of desire post treatment that was not present beforehand. In addition to this, ongoing pain and dryness were common complaints for approximately a third of participants. Some participants reported significant tightness of the vagina and that it took them longer to lubricate post treatment.

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3 Discomfort such as numbness, itching or burning also bothered a few participants along with  
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5 some forms of gastrointestinal distress such as constipation, nausea or vomiting.  
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### 8 **The impact of pre-diagnosis symptoms**

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10 Women in this study reported that their symptoms pre-diagnosis negatively affected  
11 their sexual functioning. As shown in Sam and Fiona's quotes (see Table 2), living with  
12 symptoms such as itchiness and heavy bleeding for an extended period creates disturbances  
13 in sexual functioning even before treatment has been received. Sam highlights how her  
14 discomfort with having to talk with various doctors about gynaecological problems impeded  
15 her from seeking further help even though her symptoms persisted. These excerpts align with  
16 what is known in the literature regarding late presentation for diagnosis of gynaecological  
17 cancers in South Africa (18). For these participants, it took time before a cancer diagnosis  
18 was made and further research on factors that delay timely diagnosis is required. However,  
19 some women in this study (e.g. Wendy) reported experiencing an improvement in their  
20 sexual functioning post treatment because they were no longer burdened with unpleasant  
21 symptoms. This highlights the possibility for a diverse range of sexual functioning outcomes  
22 post treatment.  
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### 40 **Intimate partnership dynamic**

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42 The results of this study also highlight is how partnership level factors, such as  
43 partners' health issues and sexual functioning difficulties, can influence women's sexual  
44 experiences post treatment. Roxy, Ivory, and Busiswa's quotes emphasise how a woman's  
45 partner is a vital factor to consider in sexual rehabilitation and renegotiation post treatment.  
46 For, as Roxy and Ivory explain, partners' sexual functioning difficulties – such as lack of  
47 desire and diabetic erectile dysfunction - can impede sexual intimacy. Busiswa acknowledges  
48 that she is still healing from her surgery but contemplates whether her husband might also be  
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3 experiencing a change in sexual functioning - “he might also have a problem” – and thus it is  
4  
5 not only her sexuality that is problematized.  
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### 8 **The co-existence of pleasure and discomfort**

9  
10 Participants reported experiencing pleasure and fulfilment in one part of their sexual  
11  
12 lives while also experiencing difficulties in others. These results further emphasise that  
13  
14 women’s sexuality post treatment should not be considered homogenous nor wholly ruined.  
15  
16 Both Jane and Priscilla articulate varied experiences of their sexuality post treatment. Jane  
17  
18 describes how, even though her level of desire has decreased, she still finds sex pleasurable  
19  
20 when she does have it and that she is free of discomfort and able to lubricate naturally.  
21  
22 Priscilla explains how even though she usually has a desire for sex, that her fatigue makes it  
23  
24 difficult for her to be intimate with her partner and that this leads to tension and coercion in  
25  
26 their relationship. Other women in the study had similar stories of diverse experiences of  
27  
28 their sexuality post treatment and not only in relation to physical intercourse. For example,  
29  
30 some women described major changes in their physical sexual functioning yet the  
31  
32 continuation of other forms of intimacy with their partners. Likewise, some women spoke of  
33  
34 feeling differently about their bodies but not having major changes in their ability to have  
35  
36 intercourse.  
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### 43 **The influence of heteronormative gender role expectations on sexuality**

44  
45 Sexuality cannot be understood outside of gender, for, “sexuality and gender go hand  
46  
47 in hand; both are creatures of culture and society, and both play a central and crucial role in  
48  
49 maintaining power relations in our societies...Hence, gender provides the critical analytical  
50  
51 lens through which any data on sexuality must logically be interpreted...”- (40) (p. 1). Thus,  
52  
53 within this theme, the material effects of cancer treatments on sexuality are acknowledged,  
54  
55 while also highlighting how discursive constructions of gender provide the context within  
56  
57 which individuals experience their sexual relationships post treatment (41).  
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3 The main trope that participants drew on to describe their relationships post treatment  
4 was that of heteronormativity, which is the assumption that heterosexuality is the ‘normal’  
5 and default sexual orientation and that gender roles and gender differences are immutable and  
6 innate (42). A heteronormative view thus involves alignment of biological sex, sexuality,  
7 gender identity and gender roles. In this study, participants narrated a sense of femininity  
8 failure post treatment because they were no longer able to fulfil the gender roles expected of  
9 them as women. Participants also described how heteronormative expectations of masculinity  
10 made sexual violence from their male partners permissible before and after treatment.  
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### 22 **‘Failing’ at femininity**

23  
24 Within the heteronormative gender system women are expected to fulfil certain roles,  
25 which are deemed inherent to womanhood, within society and within their relationships.  
26 These may include having children, looking attractive, taking care of your husband and  
27 child(ren), being responsible for domestic tasks, having a uterus, having an intact and  
28 functional vulva and vagina, having intercourse with your male partner, and always desiring  
29 this. Hence, if a woman is unable to fulfil these gender role expectations, her femininity is  
30 questioned by herself and others. Grace’s quote encapsulates the variety of ways in which  
31 women in the study felt that they were ‘failing’ at being a woman post treatment.  
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43 Grace experiences the period post treatment as a disruption to her enactment of  
44 femininity because she feels she cannot fulfil the expected roles of mother, wife and sexual  
45 partner. Her inability to perform these socially prescribed tasks leads her to question her  
46 feminine identity. Although these roles are socially constructed, Grace has internalised them  
47 which leads her to be the first to question her feminine subjectivity, however, she explains  
48 that her husband is having similar doubts because “he doesn’t see anything in [me]”. Other  
49 participants also experienced both internal and external shaming of their changed  
50 womanhood. For example, Wendy stated how, before her treatment, when she was  
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3 experiencing severe symptoms: “Sometimes I would see myself as not good enough as a  
4 woman because I used to doubt myself by not being able to satisfy my husband.” However,  
5  
6 after treatment, she was once again able to fulfil the role of ‘good sexual partner’ – according  
7  
8 to her and her husband – because “He sees me as a good woman, as sexy and as a person that  
9  
10 he is willing to sleep with.” However, other women only experienced shaming from their  
11  
12 male partners. This theme highlights how experiences surrounding gynaecological cancer are  
13  
14 embedded within broader unequal gendered systems which have the potential to exacerbate  
15  
16 an already trying period in women’s lives. Hence we see, how in this theme, broader societal  
17  
18 ideas around femininity become internalised and used as a standard against which women  
19  
20 post treatment (and their partners) evaluate their gender and sexuality.  
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### 26 **Sexual violence**

27  
28 Heteronormative gender role expectations also create space for sexual violence to take  
29  
30 place within the context of gynaecological cancer. Participants experienced various forms of  
31  
32 sexual violence, such as coercion; forced sex through threats of violence, aggression and  
33  
34 infidelity; and rape. As is evident in the quotes by Cebisa and Maggie, many of the women  
35  
36 felt that their inability to have sex with their partners due to cancer symptoms or healing post  
37  
38 treatment was the trigger for violence. This stems from the idea within the heterosexual script  
39  
40 that women are expected to give sex to male partners which if ‘denied’ is punishable with  
41  
42 violence. Also underlying this violence is the male sexual drive discourse (43) which is the  
43  
44 idea that men need sex all the time whereas women generally are not interested in sex, “men  
45  
46 are not like us, we can go months even years without it but men want to do it all the time”.  
47  
48  
49 The internalisation of this discourse resulted in some participants putting pressure on  
50  
51 themselves to have sex even when they did not feel ready.  
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### **Sexual self-concept: Re-embodiment post treatment**

The concept of embodiment maintains that the human body and its “visceral, felt, enlivened bodily experiences” (44) are a worthwhile object of study. Results from the present study show that most of the participants also partook in a process of re-embodiment post treatment. Participants took up a re-embodied sexual subjectivity by emphasising feelings of feminine identity, confidence, strength and attractiveness that exist despite changes to the physical body as a result of treatment. For example, Edith states that she is still a woman regardless of her operation and FI says that she is still “attractive, confident, feminine”.

### **Psycho-sexual support during the cancer journey**

The last part of the interview asked participants about the information they had received from healthcare providers about sexual functioning, as well as what kinds of support would have been most beneficial to them throughout their cancer journey. The results show that participants had mixed experiences with regards to the information they received and that most participants would like to receive more information from their healthcare providers as well as be able to participate in a support group.

#### **Information received from healthcare providers**

Participants reported a variety of experiences regarding the sexual functioning information they received. Some participants, such as Gia, stated that they did not receive any information, however, most participants did receive information from a healthcare provider about their sexual functioning post treatment, but the results show that this information varied greatly in quality. For example, it appears that some doctors made assumptions about participants’ sexual activity based on their age and relationship, as can be seen in the quote from Bonnita. Other participants were told that their sex lives would never be the same again and that this is something they would just have to accept. Other participants, like Fatiema, were given information that was overly generalised and not based on the individual



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2  
3 participant's needs and side effects. This emphasises the dire need for healthcare providers  
4  
5 working in gynae-oncology to receive further training about discussing sexuality with  
6  
7 patients.  
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### 10 **The need for comprehensive support**

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12 At the end of each interview participants were asked what kind of support would have  
13  
14 been most beneficial to them post treatment. The majority mentioned that they would have  
15  
16 liked more detailed sexual wellbeing information from their healthcare providers. Participants  
17  
18 also highlighted that this information could be delivered in a variety of ways, such as in  
19  
20 person as well as with informational pamphlets. As is foregrounded in Roxy's quote,  
21  
22 participants also want healthcare providers to be the first to broach the topic of sexual  
23  
24 functioning. The second most common response was having a support group for  
25  
26 gynaecological cancer survivors, and some participants mentioned more empathy from  
27  
28 partners, and going for individual counselling.  
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### 34 **Discussion**

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37 Sexuality within the context of gynaecological cancer has predominantly been thought  
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39 of in limiting ways, however, the findings of this study broaden conceptualisations of  
40  
41 sexuality post treatment and trouble dominant tropes of onco-sexological research. The  
42  
43 results of this study support previous literature which calls for a focus on the material, intra-  
44  
45 psychic and discursive aspects of sexuality post gynaecological cancer (23). It also expands  
46  
47 this understanding of sexuality post gynaecological cancer by detailing the ways that it is  
48  
49 complex, nuanced, relational, and ever shifting.  
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55 Most women in this study experienced a change in their sexual functioning post  
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57 treatment, but half of the participants also reported a significant disruption to their sexual  
58  
59 lives *prior* to treatment due to severe symptoms. Women with late stage gynaecological  
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3 cancers often live with symptoms such as abdominal pain, heavy bleeding, unpleasant  
4 discharge, and fatigue (45, 46) for an extended period and therefore their sexuality has been  
5 negatively impacted beyond the treatment and post treatment phases (23). Limited literature  
6 is available on how gynaecological cancer symptoms disrupt sexual functioning before  
7 diagnosis and treatment. A few older studies have shown how these symptoms lead to  
8 negative changes in all aspects of women's sexual lives (9, 47-50). However, it has been  
9 argued that treatment for gynaecological cancer has a greater negative effect on women's  
10 sexual functioning than the symptoms of the disease (47). The results from the present study  
11 challenge this argument by highlighting that, for some women in South African, the  
12 symptoms prior to diagnosis are worse – or at least on par – with treatment side effects.  
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27 Other important findings were that not all women experienced a negative sexuality  
28 change post treatment, and many reported both pleasurable and difficult sexual experiences.  
29 Additionally, many women described a process of re-embodiment post treatment where they  
30 came to accept and celebrate their sexual identity. Williams' theory of embodiment and  
31 chronic illness (51) suggests that the presence of illness disrupts 'normal' embodiment and  
32 therefore persons make attempts at "re-embodiment" (p. 32) to make sense of the bodily  
33 changes brought about by chronic conditions. When investigating sexual subjectivities post  
34 cancer, Gilbert et al. found that some individuals took up a position of re-embodied sexual  
35 subjectivity comprised of acceptance, confidence and engaging in non-coital sexual activity  
36 (52). The dominant narrative around female sexuality post gynaecological cancer treatment in  
37 most research and clinical contexts is one of tragedy. The results of the present study trouble  
38 catastrophising narratives of sexual identity post treatment and create options for accessing  
39 sources of strength and resilience in the recovery process. Feelings of re-embodiment can  
40 also be used as a starting point for many women post gynaecological cancer treatment who  
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3 want to reacquaint themselves with their post-cancer body as part of a journey towards  
4  
5 resuming their sexual lives.  
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9 Some women in this study explained how their partner's sexual dys/function was a  
10 factor in their sexual rehabilitation. Partners are generally overlooked in research on sexuality  
11 after cancer (53) but existing literature has shown that partners experience a decline in their  
12 own libido; fear initiating sex; struggle with regaining a 'normal' sex life; and feel  
13 unattractive and unwanted because of sex cessation (54-56). Limited research is available on  
14 how partners' sexual difficulties are a factor in sexuality post gynaecological cancer,  
15 however, Greimel et al. (57) found that 12% of their participants were not able to have sexual  
16 intercourse post treatment because of their partners' health problems. An interview-based  
17 study with male partners of gynaecological cancer survivors (58) found that male partners  
18 also experienced sexual problems after treatment. As an explanation for this, Van De Wiel et  
19 al. (59) suggest that the cancer diagnosis and its treatment are also a crisis for the male  
20 partner, which may lead to methods of coping which are signified by withdrawal and can lead  
21 to sexual functioning difficulties. However, it is worth noting is that IVO felt her partner's  
22 sexual difficulties due to diabetes had made him more empathetic about her sexual  
23 difficulties post treatment. Thus, partner comorbidity can be positioned as a catalyst for  
24 compassion, bonding, and deeper intimacy.  
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46 Other participants mentioned how the state of the relationship before treatment either  
47 facilitated or hindered sexual intimacy post treatment. For example, pre-existing alcoholism,  
48 possessiveness, infidelity, and verbal aggression made intimacy post treatment strained.  
49 Women who reported that they were generally happy in their relationships and felt supported  
50 pre-treatment stated that them and their partners were still "going strong" post treatment.  
51 Maree et al. (60) found similar results in their qualitative study with South African women  
52 about partner support through their cervical cancer journey, in that the support experienced  
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3 post treatment depended on the nature of the relationship prior to treatment. These findings  
4  
5 highlight how cancer diagnosis, treatment, and rehabilitation is a shared experience for  
6  
7 women and their intimate partners (54) and thus discussions around sexuality post treatment  
8  
9 should focus on the implications for partnerships and not only the individual receiving the  
10  
11 treatment. There is debate within the literature about which treatment modality has the  
12  
13 greatest negative impact on sexual functioning (22, 61-64) with some studies suggesting that  
14  
15 radiotherapy leads to higher levels of sexual dysfunction than surgery or chemotherapy (19,  
16  
17 65-68). Yet, what this finding suggests is that sexuality post treatment is dependent on more  
18  
19 than which treatment modality was utilised. Considering how intimate *relationships* have  
20  
21 been affected by the cancer treatment allows for movement beyond problematizing women's  
22  
23 sexuality alone.  
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29 This study showed how heteronormative gender role expectations negatively  
30  
31 impacted women's recovery post treatment and created space for male partners to be sexually  
32  
33 violent. Research from the global north has explored the ways in which heterosexual scripts  
34  
35 interact with the psychosexual recovery process post treatment (41, 69-72). Findings from  
36  
37 these studies highlight how the 'coital imperative' (73) impacts couples' ability to renegotiate  
38  
39 sexual intimacy. The coital imperative constructs penetrative vaginal sex as the only 'real  
40  
41 sex' and as a sign of 'normal', healthy relationships and therefore those who fall outside of  
42  
43 this discursive category are positioned as abnormal and dysfunctional (74, 75). It follows then  
44  
45 that women who cannot engage in intercourse post treatment begin to doubt their gender and  
46  
47 sexual identity.  
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52 The same heterosexual scripts that emphasise the 'coital imperative' also make sexual  
53  
54 violence post treatment possible. Research on sexual violence within the context of  
55  
56 gynaecological cancer care is extremely limited. A few studies regarding the relationship  
57  
58 between intimate partner violence (IPV) and cancer exist, however, their focus is largely  
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2  
3 about whether IPV creates greater risk for cancer among women (76-78). The focus of this  
4  
5 research is about abuse in general, not sexual abuse, and most of the focus is on cervical  
6  
7 cancer. Little attention is paid to whether gynaecological cancer can trigger the perpetration  
8  
9 of sexual violence or how it might worsen existing sexual abuse. This issue demands further  
10  
11 investigation in South Africa given the country's high levels of sexual violence and cervical  
12  
13 cancer (15, 79).  
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18 Participants in this study stated that they wanted to receive support in the form of  
19  
20 more sexual functioning information from their healthcare providers, as well as from support  
21  
22 groups. Previous research affirms that people with cancer want healthcare providers to  
23  
24 discuss sexuality issues such as when to resume sexual activity (80), appropriate sexual  
25  
26 positioning or the use of sexual aids (81) and adjusting to sexual changes (72). Healthcare  
27  
28 providers can also give psychoeducation about the effects of gynaecological cancer and its  
29  
30 treatments on sexuality throughout the cancer journey (82), as well as help couples  
31  
32 renegotiate their sexual intimacy by challenging heteronormative discourses of sexuality  
33  
34 which stress the coital imperative (41, 70, 83, 84). In this way, healthcare providers can play  
35  
36 a vital role in patients' psychosexual recovery. For, if a healthcare provider legitimises  
37  
38 sexuality discussions within a clinical setting, it gives permission to individuals and couples  
39  
40 to discuss this on their own (85). This can create opportunities for conversations about sexual  
41  
42 issues and potentially mitigate relationship tension and sexual violence (41, 86). Healthcare  
43  
44 providers working with gynaecological cancer patients should endeavour to improve their  
45  
46 knowledge about sexuality in the context of cancer by staying up to date with the relevant  
47  
48 literature as well as attending workshops and conferences. Additionally, healthcare providers  
49  
50 should be the first to broach the topic with their patients as patients want to receive more  
51  
52 information about sexuality but often feel uncomfortable asking questions.  
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3 Other types of interventions that have been aimed at sexual functioning post  
4 gynaecological cancer include psychoeducational interventions (87-89), peer support  
5 interventions (90, 91), vaginal dilators after pelvic radiotherapy (92, 93), specialist nurse-led  
6 interventions (89, 94-97), reflection based interventions (98), and internet based interventions  
7 (99). Systematic reviews show that solely information-based interventions do not provide  
8 long-term benefits to women with gynaecological cancer but that counselling based  
9 interventions are useful in improving quality of life factors (100, 101). Other reviews have  
10 shown that interventions are most effective when they include information provision,  
11 cognitive-behavioural therapy, social support and counselling (87) and are led by specialist  
12 nurses (87, 95). There is currently no research on such interventions within the South African  
13 public healthcare context. Thus, future research should focus on ascertaining what – if any –  
14 interventions exist in South Africa and, if not, what resources are available to create  
15 comprehensive support interventions post treatment and how these might fit into the existing  
16 healthcare system.

### 36 Conclusion

37  
38 Research and clinical work need to make room for the complexities highlighted in  
39 these findings so that sexuality post treatment can be engaged with beyond biomedical  
40 assessments of dys/function, performance, and satisfaction. This research has expanded  
41 understandings of sexuality within the context of gynaecological cancer and problematized  
42 some taken-for-granted assumptions about sexuality post treatment. Researchers should  
43 explore how comprehensive sexuality education and sensitivity training can be better  
44 incorporated into healthcare providers' training curriculums. Further research is required to  
45 understand how partners of women with gynaecological cancer experience and cope with the  
46 sexual changes post treatment, how the couple as a partnership negotiates changes post  
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3 treatment, and the facilitators and barriers that healthcare providers experience regarding  
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5 discussing sexuality issues with patients.  
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8  
9 This study had several limitations. The study was cross-sectional in nature and  
10 therefore only captured women's experiences of their sexuality at one moment in time post  
11 treatment and comments therefore cannot be made on how they experienced their sexuality  
12 over time. This study made use of a holistic framework of sexuality, however, this framework  
13 is not exhaustive and did not include socio-cultural factors relating to sexuality. Given South  
14 Africa's diverse socio-cultural landscape such an avenue of exploration would have been  
15 beneficial. The authors would also recommend adding a socio-cultural component to the  
16 holistic framework. The sample of this study was predominantly comprised of older women  
17 in long term relationships with men and therefore this study could not explore the experiences  
18 of younger women, women who are not partnered, and women who have intimate  
19 relationships with women. Lastly, insufficient attention was paid to the ways in which the  
20 different components of sexuality post gynaecological cancer treatment interact with each  
21 other.  
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39 It is hoped that this research will further scholarly and clinical work within this field  
40 in South Africa because all gynaecological cancer survivors and their partners should have  
41 the resources to create a sexual life that is pleasurable, consensual and fulfilling.  
42  
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17  
18

### 19 **Competing interests' statement**

20  
21 No competing financial interests exist.  
22  
23  
24  
25

### 26 **Author contributions**

27  
28 S.P. was the project leader and J.M. was the senior author. NF and TA were responsible for  
29 the recruitment of participants. S.P. was responsible for the data collection and analysis. J.M.,  
30  
31 L.D., and S.P. drafted the manuscript. All authors gave critical comment throughout the  
32  
33 writing process. All authors were responsible for the conceptualisation and design of the  
34  
35 project. All authors approved the final version to be published.  
36  
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### 40 **Data sharing statement**

41  
42 Raw data from this study is currently not publicly available but can be made available upon  
43  
44 reasonable request.  
45  
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### 48 **Exclusive licence statement**

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## Appendix A: Interview Guide

### Introduction

Welcome and thank you for agreeing to talk to me today. My name is .....  
and I work at a cancer research centre at Groote Schuur Hospital.

We want to better understand women's experiences of gynaecological cancer. To do this we are talking to women who have received treatment for gynaecological cancer at Groote Schuur Hospital and patients from Somerset Hospital that have received treatment at Groote Schuur. By treatment, we mean any surgery, radiotherapy, and/or chemotherapy that you have had for your cancer. We want to get more information about women's experiences so that we can create better support services for them. In particular, we are interested in hearing about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment.

We would like to know about your experiences and what issues are important to you. I know that for some people, being asked about personal issues by a stranger or by someone younger can be uncomfortable. Please know that your well-being is the most important thing to me and that I do not want to make you feel awkward. You do not have to answer any questions that you do not want to and you can stop the interview at any point.

The information and audio recordings received from this interview will be kept private. Your real name will not be associated with the audio recording and only the small team of researchers for this project will have access to the audio recordings.

The interview should not take longer than an hour. Please let me know if you need to leave urgently due to transport reasons.

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5  
6 Opening questions to help participant relax  
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8  
9 We are going to have a relaxed conversation about your experiences before and after your  
10 cancer treatment. But first....

- 11  
12  
13  
14 1) Can you tell me about how you came to be diagnosed with cancer?  
15  
16 2) What treatment/s have you had?  
17

18  
19  
20 Explanation of pile sorting activity  
21

22  
23 In this interview, we are going to be talking about some of your experiences before and after  
24 your cancer treatment. I know that some of these things can be difficult to express. So, we are  
25 going to do a short activity before each section of the interview to help you feel more  
26 comfortable.  
27

28  
29  
30  
31  
32 In this bag here are a lot of different words that are written on cards. Each word is a word that  
33 you could use to describe an experience, for example: 'good', 'difficult', 'painful', 'exciting'.  
34

35  
36  
37 I am going to put all of these words on the table in front of you and then I am going to ask  
38 you a question about your experiences before and after your cancer treatment. You will then  
39 have some time to choose the words that you feel best describe your experience. Once you  
40 have chosen the words we will discuss them and I will ask you a few more questions about  
41 your experiences before and after cancer.  
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48  
49 Do you have any questions about this activity?  
50

51  
52 [Put all practise cards on table. Make sure they are all clearly visible to participant.]  
53

54  
55 Let us do a quick practise exercise. From these words, which ones would you choose to  
56 describe your day yesterday.  
57  
58  
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[Assess participant's understanding and correct accordingly].

We will be doing this type of activity before most of the questions.

Section 1: Body image, femininity, and emotions [*sexual self-concept*]

We are going to start by talking about emotions and body image.

1) [Lay out words relating to Section 1A] **[Remember to clearly state the words the participant has chosen for each question]**

- a. Which words would you use to describe your emotions **after** your treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your emotions **before** treatment? (If yes, ask which words would describe their emotions before)

2) [Lay out words relating to Section 1B] **[Remember to clearly state the words the participant has chosen for each question]**

- a. Body image is how you think or feel about your body. Which words would you use to describe your body image **after** your cancer treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from how you felt about your body **before** treatment? (If yes, ask which words would describe their body image before)
- b. Which words would you use to describe how you feel about yourself as a woman **after** your cancer treatment?

- i. Why did you choose these words? Probe...
- ii. Are there any words that are not here that could describe your experience?
- iii. Was this a change from how you felt about yourself **before** treatment?  
(If yes, ask which words would describe their femininity before)

## Section 2: Intimacy and communication [sexual relationships]

[Lay out words relating to Section 2] [**Remember to clearly state the words the participant has chosen for each question**]

I would now like to talk to you about your relationship.

- a. Which words would you use to describe your relationship in general **after** your treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your relationship **before** treatment? (If yes, ask which words would describe their relationship before)
- b. Before, we spoke about your relationship in general. Now, I would like to talk about your sexual relationship. Which words would you choose to describe the sexual relationship with your partner been **after** treatment?
  - i. Why did you choose these words? Probe...
  - ii. Are there any words that are not here that could describe your experience?
  - iii. Was this a change from your sexual relationship **before** treatment? (If yes, ask which words would describe their sexual relationship before)

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2  
3 c. Has there been in a change in how often you have sex? (If yes, explore  
4 further.)  
5  
6  
7  
8 d. Which words would you use to describe what the communication about sex  
9  
10 has been like **after** your treatment?  
11  
12 i. Why did you choose these words? Probe...  
13  
14 ii. Are there any words that are not here that could describe your  
15  
16 experience?  
17  
18 iii. Was this a change from your communication **before** treatment? (If yes,  
19  
20 ask which words would describe their communication before)  
21  
22  
23  
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25 Section 3: Desire, orgasm, arousal, performance, and identity [*sexual functioning and sexual*  
26 *self-concept*]  
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30 [Lay out words relating to Section 3] [**Remember to clearly state the words the participant**  
31 **has chosen for each question**]  
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33

34  
35 I would now like to talk to you about some things relating to your sexual health after  
36  
37 treatment.  
38  
39

- 40 1) Which words would you use to describe your sex life **after** your treatment?  
41  
42 i. Why did you choose these words? Probe...  
43  
44 ii. Are there any words that are not here that could describe your  
45  
46 experience?  
47  
48 iii. Was this a change from your sexual functioning **before** treatment? (If  
49  
50 yes, ask which words would describe their sexual functioning before)  
51  
52  
53  
54 2) How often do you feel a desire to have sex, now that your **treatment is over**?  
55  
56 a. Is this level of desire any different to **before** your treatment? (If yes, how is it  
57  
58 different?)  
59  
60

- 1
- 2
- 3 3) Has there been a change in how you become physically excited about sex? (If yes,
- 4 how is it different?)
- 5
- 6
- 7
- 8 4) Has there been a change in how often you are able to orgasm during sex? (Is yes, how
- 9 is it different?)
- 10
- 11
- 12 5) How do you feel about your sexual performance **after** treatment?
- 13
- 14 a. Is this any different to **before** your treatment? (If yes, how is it different?)
- 15
- 16
- 17 6) How do you think about yourself as a sexual person **after** your treatment?
- 18
- 19 a. Is this any different to **before** your treatment? (If yes, how is it different?)
- 20
- 21

#### 22 Section 4: Questions relating to treatment adherence

23 [No more pile sorting].

- 24
- 25
- 26
- 27
- 28 1. Did any of the sexual changes you have told me about make you think about stopping
- 29 your treatment?
- 30
- 31
- 32 a. If yes, explore further:
- 33
- 34 i. Which changes in particular made you want to stop your treatment?
- 35
- 36 ii. What would have made it easier for you to cope with these changes?
- 37
- 38
- 39

#### 40 Section 5: Questions relating to support services

41 I would now like to talk to you about the information you received during your diagnosis

42 and/or treatment.

- 43
- 44
- 45
- 46
- 47
- 48
- 49 1) During your diagnosis and/or treatment, did a doctor or nurse talk to you about
- 50 sexual functioning?
- 51
- 52 a. If yes:
- 53
- 54 i. What did they discuss with you?
- 55
- 56 ii. How did you feel about this talk?
- 57
- 58
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2  
3 2) What types of support do women need after treatment to meet their sexual health  
4  
5 needs?  
6

7  
8 a. If they say anything about receiving more information: How would you  
9  
10 like to receive this information?  
11  
12

### 13 Closing comments 14

15  
16 We have come to the end of the interview. Thank you so much for taking the time to talk to  
17  
18 me today. I really appreciate it. Do you have any questions you would like to ask? Thank  
19  
20 them for their time and for talking to me.  
21  
22

23  
24 By speaking with us today you are contributing to research that will hopefully help in  
25  
26 supporting cancer patients better.  
27  
28

29 Please accept this drink and snack as a small thank you for your time.  
30  
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## Informed consent form

### Women's experiences after gynaecological cancer treatment

#### 1. Why is this study being done?

My name is..... and I work at the Gynaecological Cancer Research Centre at the University of Cape Town. You are invited to take part in a project that aims to better understand women's experiences after gynaecological cancer treatment. To do this we are talking to various women who have received treatment at Groote Schuur Hospital and patients from Somerset Hospital that have received treatment at Groote Schuur. By treatment, we mean any surgery, radiotherapy, and/or chemotherapy that you have had for your cancer. It is important for us to understand your experiences and what issues are important to you. In particular, we are interested in hearing about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment. We want to understand these things so that we can create better support services after cancer treatment.

#### 2. What will happen in the study?

If you decide to participate, we will talk to you for about 1 hour about how you feel your relationship, your body, your emotions, and your sexual health have changed after your cancer treatment and what these things were like before your treatment. This interview will take place in a private room and will be in your home language. The interview will be private and your partner and/or family member will not be in the room with you and the interviewer.

#### 3. Your rights

Taking part in this study or not taking part in this study is your choice. You do not have to answer any questions that make you feel uncomfortable. You can also decide to stop the interview at any time without anything bad happening. Stopping the interview or not taking part in the interview will not affect the care you receive from Groote Schuur Hospital in any way.

To help us remember what you talked about today the interview will be recorded on a recording device. Only the small research team will be able to listen to your recording. Your name will not be used as part of any of the results from this study. In order to keep your

1  
2  
3 identity private, you will be given another name (pseudonym) for this study. Nobody outside  
4 of the research team will have access to your information or audio recording.  
5  
6

7 **4. What are the risks and discomforts of this study?**  
8

9  
10 This is a very low risk study. You may feel uncomfortable talking about some of the topics.  
11 However, we do not want you to feel uncomfortable or that you have shared too much. You  
12 may refuse to answer any question or not take part in a section of the interview if you feel the  
13 question(s) are too personal or if talking about them makes you uncomfortable.  
14  
15

16  
17 If at any point in the interview you become very distressed we will stop the interview and  
18 give you some time to calm down. You will then be able to choose whether you wish to  
19 continue the interview or not. We will also refer you for counselling if necessary.  
20  
21

22  
23 **5. Will this study benefit you in any way?**  
24

25 You are given an opportunity to share your experiences, views and tell us what is important  
26 to you. This will help us find out more about women's experiences after gynaecological  
27 cancer treatment and how we can support them better. You will also receive a refreshment  
28 and a light snack.  
29  
30  
31

32  
33 **6. Who will see the information which is collected about you during the study?**  
34

35 We will follow strict guidelines to keep your personal information safe throughout the study.  
36 All information that we collect from this research project will be kept private. Information  
37 about you that is collected during the study will be stored in a file on a password protected  
38 computer. The file will not have your name on it, but rather a fake name (pseudonym) that  
39 has been assigned to you. Your name or any other identifying factors will not be used as part  
40 of any of the results from this study.  
41  
42  
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45  
46 **7. What happens if you decide you do not want to participate anymore?**  
47

48 You do not have to take part in this research if you do not want to, and deciding not to  
49 participate will not affect your current or future treatment at Groote Schuur Hospital in any  
50 way. You will still have all the benefits that you would otherwise have at this hospital. You  
51 may stop participating in the interview at any time that you wish without losing any of your  
52 rights as a patient.  
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3 **8. After the interview**  
4

5 If this interview raises issues for you about your sexual health that you would like to discuss  
6 further with a professional. Please ask your interviewer to refer you to our sexual health  
7 specialist Dr Ros Boa or to the psychologist that works in this department.  
8  
9

10  
11  
12  
13  
14 **9. Who do I speak to if I have any questions about the study?**  
15

16 If you have any questions about the study you may ask these now. If you think of a question  
17 later on in the interview please feel free to ask it then. If there is anything that is unclear or  
18 you need further information about; we will be happy to provide it. If you wish to ask  
19 questions once the interview has finished and you are at home, you may contact:  
20  
21  
22

23  
24 • **Professor Jennifer Moodley**, Deputy Director of the Gynaecological Cancer Research  
25 Center, School of Public Health & Family Medicine, University of Cape Town  
26

27 Tel: 021 406 6798

28 Email: jennifer.moodley@uct.ac.za  
29

30  
31  
32 • **Sorrel Pitcher**, Qualitative researcher with the Gynaecological Cancer Research Center,  
33 School of Public Health & Family Medicine, University of Cape Town  
34  
35

36 Email: sorrel.p@gmail.com  
37  
38  
39  
40

41 **For questions about your rights as a participant please contact:**  
42

43  
44 The UCT's Faculty of Health Sciences Human Research Ethics Committee can be contacted  
45 on 021 406 6338 in case you have any ethical concerns or questions about your rights or  
46 welfare as a participant on this research study  
47  
48

49 This proposal has been reviewed and approved by the University of Cape Town's Faculty of  
50 Health Sciences Human Research Ethics Committee (reference number: 716/2017), whose  
51 task it is to make sure that research participants are protected from harm.  
52  
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3 By signing below you are saying that the study has been explained to you and that you  
4 understand all of the procedures and the risks and benefits of the study. Your signature also  
5 says that you would like to participate in the project.  
6  
7  
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10

11 **Participant full name:**  
12  
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14

15  
16 **Participant Signature OR thumbprint (in case of illiteracy)**  
17  
18

**Date**  
19  
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21  
22

23 **Interviewer full name:**  
24  
25  
26

27  
28 **Interviewer Signature**  
29  
30  
31

**Date**  
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35 **Witness full name (in case of illiterate participant):**  
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40 **Witness signature:**  
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**Date**

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For peer review only

## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**