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# 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 |

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|---|---|---|---|---|---|
| **Tamzin** | 59 | Separated | Uterine | Surgery | 16 |
| **Ursula** | 61 | Widowed | Cervical | Concurrent chemo-radiation | 35 |
| **Wendy** | 29 | Married | Ovarian | Surgery | 36 |
| **Xoliswa** | 50 | Single | Cervical | Concurrent chemo-radiation | 24 |
| **Yvonne** | 41 | Single | Cervical | Concurrent chemo-radiation | 26 |
| **Zelda** | 52 | Cohabiting | Vulvar | Surgery | 36 |

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Table 1. *Participant demographics*

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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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Opening questions to help participant relax

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

1) Can you tell me about how you came to be diagnosed with cancer?
2) What treatment/s have you had?

Explanation of pile sorting activity

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

In this bag here are a lot of different words that are written on cards. Each word is a word that you could use to describe an experience, for example: ‘good’, ‘difficult’, ‘painful’, ‘exciting’. I am going to put all of these words on the table in front of you and then I am going to ask you a question about your experiences before and after your cancer treatment. You will then have some time to choose the words that you feel best describe your experience. Once you have chosen the words we will discuss them and I will ask you a few more questions about your experiences before and after cancer.

Do you have any questions about this activity?

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

Let us do a quick practise exercise. From these words, which ones would you choose to describe your day yesterday.

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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?

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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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c. Has there been in a change in how often you have sex? (If yes, explore further.)

d. Which words would you use to describe what the communication about sex has been like **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 communication **before** treatment? (If yes, ask which words would describe their communication before)

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

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

I would now like to talk to you about some things relating to your sexual health after treatment.

1) Which words would you use to describe your sex life **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 sexual functioning **before** treatment? (If yes, ask which words would describe their sexual functioning before)

2) How often do you feel a desire to have sex, now that your **treatment is over**?

   a. Is this level of desire any different to **before** your treatment? (If yes, how is it different?)

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3) Has there been a change in how you become physically excited about sex? (If yes, how is it different?)
4) Has there been a change in how often you are able to orgasm during sex? (Is yes, how is it different?)
5) How do you feel about your sexual performance **after** treatment?
    a. Is this any different to **before** your treatment? (If yes, how is it different?)
6) How do you think about yourself as a sexual person **after** your treatment?
    a. Is this any different to **before** your treatment? (If yes, how is it different?)

Section 4: Questions relating to treatment adherence

[No more pile sorting].

1. Did any of the sexual changes you have told me about make you think about stopping your treatment?
    a. If yes, explore further:
        i. Which changes in particular made you want to stop your treatment?
        ii. What would have made it easier for you to cope with these changes?

Section 5: Questions relating to support services

I would now like to talk to you about the information your received during your diagnosis and/or treatment.

1) During your diagnosis and/or treatment, did a doctor or nurse talk to you about sexual functioning?
    a. If yes:
        i. What did they discuss with you?
        ii. How did you feel about this talk?

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2) What types of support do women need after treatment to meet their sexual health needs?
    a. If they say anything about receiving more information: How would you like to receive this information?

<u>Closing comments</u>

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

By speaking with us today you are contributing to research that will hopefully help in supporting cancer patients better.

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

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

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

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

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

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

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

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

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

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

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

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## 8. After the interview

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

## 9. Who do I speak to if I have any questions about the study?

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

- **Professor Jennifer Moodley**, Deputy Director of the Gynaecological Cancer Research Center, School of Public Health & Family Medicine, University of Cape Town

  Tel: 021 406 6798

  Email: jennifer.moodley@uct.ac.za

- **Sorrel Pitcher**, Qualitative researcher with the Gynaecological Cancer Research Center, School of Public Health & Family Medicine, University of Cape Town

  Email: sorrel.p@gmail.com

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

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

This proposal has been reviewed and approved by the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee (reference number: 716/2017), whose task it is to make sure that research participants are protected from harm.

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By signing below you are saying that the study has been explained to you and that you understand all of the procedures and the risks and benefits of the study. Your signature also says that you would like to participate in the project.

**Participant full name:**

**Participant Signature OR thumbprint (in case of illiteracy)** **Date**

**Interviewer full name:**

**Interviewer Signature** **Date**

**Witness full name (in case of illiterate participant):**

**Witness signature:** **Date**

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## 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. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| 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? | |
| *Relationship with participants* | | | |
| 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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | |
| *Participant selection* | | | |
| 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? | |
| *Setting* | | | |
| 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 | |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | |
| Repeat interviews | 18 | Were repeat inter views 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 inter view or focus group? | |
| Duration | 21 | What was the duration of the inter views or focus group? | |
| Data saturation | 22 | Was data saturation discussed? | |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | |

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| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| | | correction? | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| 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? | |
| *Reporting* | | | |
| 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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# Sexuality post gynaecological cancer treatment: A qualitative study with South African women

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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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Opening questions to help participant relax

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

1) Can you tell me about how you came to be diagnosed with cancer?
2) What treatment/s have you had?

Explanation of pile sorting activity

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

In this bag here are a lot of different words that are written on cards. Each word is a word that you could use to describe an experience, for example: 'good', 'difficult', 'painful', 'exciting'. I am going to put all of these words on the table in front of you and then I am going to ask you a question about your experiences before and after your cancer treatment. You will then have some time to choose the words that you feel best describe your experience. Once you have chosen the words we will discuss them and I will ask you a few more questions about your experiences before and after cancer.

Do you have any questions about this activity?

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

Let us do a quick practise exercise. From these words, which ones would you choose to describe your day yesterday.

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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?

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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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c. Has there been in a change in how often you have sex? (If yes, explore further.)

d. Which words would you use to describe what the communication about sex has been like **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 communication **before** treatment? (If yes, ask which words would describe their communication before)

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

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

I would now like to talk to you about some things relating to your sexual health after treatment.

1) Which words would you use to describe your sex life **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 sexual functioning **before** treatment? (If yes, ask which words would describe their sexual functioning before)

2) How often do you feel a desire to have sex, now that your **treatment is over**?

   a. Is this level of desire any different to **before** your treatment? (If yes, how is it different?)

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3) Has there been a change in how you become physically excited about sex? (If yes, how is it different?)

4) Has there been a change in how often you are able to orgasm during sex? (Is yes, how is it different?)

5) How do you feel about your sexual performance **after** treatment?

   a. Is this any different to **before** your treatment? (If yes, how is it different?)

6) How do you think about yourself as a sexual person **after** your treatment?

   a. Is this any different to **before** your treatment? (If yes, how is it different?)

Section 4: Questions relating to treatment adherence

[No more pile sorting].

1. Did any of the sexual changes you have told me about make you think about stopping your treatment?

   a. If yes, explore further:

      i. Which changes in particular made you want to stop your treatment?

      ii. What would have made it easier for you to cope with these changes?

Section 5: Questions relating to support services

I would now like to talk to you about the information your received during your diagnosis and/or treatment.

1) During your diagnosis and/or treatment, did a doctor or nurse talk to you about sexual functioning?

   a. If yes:

      i. What did they discuss with you?

      ii. How did you feel about this talk?

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2) What types of support do women need after treatment to meet their sexual health needs?
    a. If they say anything about receiving more information: How would you like to receive this information?

Closing comments

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

By speaking with us today you are contributing to research that will hopefully help in supporting cancer patients better.

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

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

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

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

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

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

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

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

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

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

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

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## 8. After the interview

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

## 9. Who do I speak to if I have any questions about the study?

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

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

Tel: 021 406 6798

Email: jennifer.moodley@uct.ac.za

• **Sorrel Pitcher**, Qualitative researcher with the Gynaecological Cancer Research Center, School of Public Health & Family Medicine, University of Cape Town

Email: sorrel.p@gmail.com

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

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

This proposal has been reviewed and approved by the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee (reference number: 716/2017), whose task it is to make sure that research participants are protected from harm.

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By signing below you are saying that the study has been explained to you and that you understand all of the procedures and the risks and benefits of the study. Your signature also says that you would like to participate in the project.

**Participant full name:**

**Participant Signature OR thumbprint (in case of illiteracy)** **Date**

**Interviewer full name:**

**Interviewer Signature** **Date**

**Witness full name (in case of illiterate participant):**

**Witness signature:** **Date**

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## 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. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| 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? | |
| *Relationship with participants* | | | |
| 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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | |
| *Participant selection* | | | |
| 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? | |
| *Setting* | | | |
| 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 | |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | |
| Repeat interviews | 18 | Were repeat inter views 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 inter view or focus group? | |
| Duration | 21 | What was the duration of the inter views or focus group? | |
| Data saturation | 22 | Was data saturation discussed? | |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | |

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| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| | | correction? | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| 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? | |
| *Reporting* | | | |
| 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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# Sexuality post gynaecological cancer treatment: A qualitative study with South African women

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**Word count:** 5736

## 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

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## 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.

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## Background

Sexuality[1] 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

[1] 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.

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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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understanding of sexuality, this framework also guided the research questions and interview schedule and informed the deductive stage of data coding.

**Study design**

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

**Sampling and recruitment**

Participants were recruited using purposive sampling which is a non-random sampling technique whereby participants are chosen because they have experience with a phenomenon of interest and thus can provide rich information on the topic (29). Women who had received treatment for gynaecological cancers at a tertiary level, public sector hospital in Cape Town were recruited from the weekly follow-up clinic that takes place within the Radiation Oncology Unit.

Participants were eligible for the study if they were 18 years or older and had received treatment for cervical, uterine, vulvar, or ovarian cancer, or a combination of these, in the

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past 6-36 months. Participants had to fall into one of the following treatment categories: surgery only, radiation (with or without preceding surgery), or surgery followed by radiation or concurrent chemo-radiation. Participants needed to be conversant in either English, Afrikaans, isiXhosa or isiZulu and needed to score 0, 1 or 2 on the Eastern Cooperative Oncology Group (ECOG) performance status to be recruited.

Women who met the inclusion criteria were identified through their hospital files by the radiation oncologist (NF) and gynae-oncologist (TA) involved in the follow-up clinic. Upon completion of their follow-up appointment, eligible women were informed about the study and interested women were referred to the research nurse. The research nurse gave further information about the study and, if potential participants wished to proceed, completed the informed consent procedures. This process was conducted in the participant's home language. In accordance with established qualitative research protocols, recruitment ceased when information redundancy was reached (30).

**Data collection and analysis**

Data collection occurred in two phases: pilot interviews and actual data collection. The pilot interviews were used to test the interview guide and the data from these interviews were not included in the final analysis. Both sets of interviews were conducted in participants' home language by either the research nurse or the GCRC's qualitative researcher (SP) – both of whom are female. Interviews took place in a private space in the Radiation Oncology Unit and lasted between 30-90 minutes. Only the participant and interviewers were present for the interviews. Before beginning the interview, the participants signed a consent form and completed a brief demographic questionnaire asking about age, home language/s, current relationship status, diagnosis, treatment/s and time post treatment. At the beginning of the interview, the participants were asked to choose a pseudonym which was used to ensure their anonymity throughout the research process, including their

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transcripts, during analysis, and in any published material (see Table 1). Partner's and children's names as well as any other identifying information was removed.

The pilot interviews, conducted in May 2018, demonstrated that, despite extensive training of the interviewers with regards to interviewing about sensitive topics, participants struggled to articulate their experiences of sexuality post treatment. This is not unexpected as this study exists at the intersection of two topics which remain highly stigmatised in contemporary South African society: female sexuality and cancer. Given these challenges, the interview guide was rearranged to flow more logically, and pile sorting was incorporated to facilitate participants' expression (31-33).

Pile sorting is a well-established qualitative research methodology and can be used in multiple ways (34). It involves presenting a participant with words, objects or images and asking them to sort these into categories that make sense to them. The purpose of this is to identify the ways in which people think about certain concepts and experiences (34). A structured pile sort using words was employed, where participants were guided as to how to sort the words. For example, 'Please select all the words that describe how you felt about your body image before your cancer treatment.' Participants were also allowed to include any words of their own that they felt best described their experiences but were not on the cards presented by the interviewer. The pile sorting acted as a catalyst for discussion and formed concrete reference points that could be used throughout the interview. This methodology has been widely used in public health research (34-36) and has been shown to be effective in gender and sexuality research in LMIC countries (37, 38).

Following the pilot interviews, data was collected through semi-structured, face-to-face, in-depth interviews in conjunction with pile sorting. Interview questions were based on the central elements of the Neo-Theoretical Framework of Sexuality (22): 1) sexual self-

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concept, 2) sexual relationships, and 3) sexual function. Participants were asked how they experienced these aspects of their sexual lives before and after treatment. They were also asked about the sexual functioning information they received from healthcare providers during their treatment and what kind of support they think women need post treatment (see Appendix A: Interview guide) Each participant was interviewed once between September 2018 and February 2019. Interviews were audio recorded with participants' consent, transcribed for meaning and, where necessary, translated. Fieldnotes were written after each interview was completed. The interview excerpts that appear in this paper have been edited only to the extent that a few irrelevant sentences and words have been replaced with ellipses, and excessive use of colloquialisms, such as ''like'' and ''um'' have been removed.

In keeping with the iterative and cyclical nature of qualitative research, the data analysis and writing stages happened simultaneously and informed each other. NVivo 12 Pro was used to manage the data and facilitate analysis. Data was analysed using the thematic analysis steps outlined by Braun and Clarke (39) which comprises of six stages: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. The coding process made use of inductive and deductive approaches. Deductive coding was based on the Neo-Theoretical Framework of Sexuality (22). For the inductive coding, the concepts and categories that emerged from the data were used as codes, rather than being informed by existing theory or preconceptions about gynaecological cancer and sexuality. Transcripts were not given to participants for review.

**Patient and public involvement**

First language Afrikaans and isiXhosa speaking members of the public were asked to give feedback on the comprehensibility of the translated interview schedule and pile sorting

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words. This took place in the form of focus group discussions. Patients were not involved in this research.

## Results

### Participant demographics

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

### Overview of results

Four main themes emerged from the interview data: complexity and nuance in sexual functioning experiences; the influence of heteronormative gender role expectations on sexuality; re-embodiment of the sexual self, and psycho-sexual support during the cancer journey (see Table 2). The complexity and nuance in sexual functioning theme is comprised of the sub-themes: material changes in sexual functioning; impact of pre-diagnosis symptoms; intimate partnership dynamics, and the coexistence of pleasure and discomfort. The heteronormative gender role expectations theme includes the sub-themes: 'failing' at femininity and sexual violence. Psycho-sexual support during the cancer journey consists of the sub-themes: information received from healthcare providers and the need for comprehensive support. These findings contribute to expanding understandings of sexuality within the context of gynaecological cancer as well as trouble existing dominant narratives 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*

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| Main theme | Sub-theme/s | Quotes |
|---|---|---|
| Complexity and nuance in sexual functioning experiences | *Material changes in sexual functioning* | 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. – *Ivy*<br>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. – *Fiona* |
| | *Impact of pre-diagnosis symptoms* | 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. – *Sam*<br>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. – *Fiona*<br>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. - *Wendy* |
| | *Intimate partnership dynamics* | 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. – *Roxy*<br>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. - *Ivory*<br>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. - *Busiswa* |
| | *Coexistence of pleasure and discomfort* | 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. - *Jane* |

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| | | 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 [*laughs*] 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. – *Priscilla* |
| The influence of heteronormative gender role expectations on sexuality | *'Failing' at femininity* | 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. – *Grace* |
| | *Sexual violence* | 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 - *Cebisa*<br>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. – *Maggie* |
| Re-embodiment of the sexual self | *n/a* | 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." - *Edith*<br>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. - *Fiona* |
| Psycho-sexual support during the cancer journey | *Information received from healthcare professionals* | 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. – *Gia*<br>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. – *Bonnita*<br>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. - *Fatiema* |
| | *The need for comprehensive support* | 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 |

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| | | 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. - *Xoliswa*<br>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. – *Roxy*<br>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.– *Ivy* |

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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Discomfort such as numbness, itching or burning also bothered a few participants along with some forms of gastrointestinal distress such as constipation, nausea or vomiting.

**The impact of pre-diagnosis symptoms**

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

**Intimate partnership dynamic**

The results of this study also highlight is how partnership level factors, such as partners' health issues and sexual functioning difficulties, can influence women's sexual experiences post treatment. Roxy, Ivory, and Busiswa's quotes emphasise how a woman's partner is a vital factor to consider in sexual rehabilitation and renegotiation post treatment. For, as Roxy and Ivory explain, partners' sexual functioning difficulties – such as lack of desire and diabetic erectile dysfunction - can impede sexual intimacy. Busiswa acknowledges that she is still healing from her surgery but contemplates whether her husband might also be

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experiencing a change in sexual functioning - “he might also have a problem” – and thus it is not only her sexuality that is problematized.

**The co-existence of pleasure and discomfort**

Participants reported experiencing pleasure and fulfilment in one part of their sexual lives while also experiencing difficulties in others. These results further emphasise that women’s sexuality post treatment should not be considered homogenous nor wholly ruined. Both Jane and Priscilla articulate varied experiences of their sexuality post treatment. Jane describes how, even though her level of desire has decreased, she still finds sex pleasurable when she does have it and that she is free of discomfort and able to lubricate naturally. Priscilla explains how even though she usually has a desire for sex, that her fatigue makes it difficult for her to be intimate with her partner and that this leads to tension and coercion in their relationship. Other women in the study had similar stories of diverse experiences of their sexuality post treatment and not only in relation to physical intercourse. For example, some women described major changes in their physical sexual functioning yet the continuation of other forms of intimacy with their partners. Likewise, some women spoke of feeling differently about their bodies but not having major changes in their ability to have intercourse.

**The influence of heteronormative gender role expectations on sexuality**

Sexuality cannot be understood outside of gender, for, “sexuality and gender go hand in hand; both are creatures of culture and society, and both play a central and crucial role in maintaining power relations in our societies…Hence, gender provides the critical analytical lens through which any data on sexuality must logically be interpreted….”- (40) (p. 1). Thus, within this theme, the material effects of cancer treatments on sexuality are acknowledged, while also highlighting how discursive constructions of gender provide the context within which individuals experience their sexual relationships post treatment (41).

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The main trope that participants drew on to describe their relationships post treatment was that of heteronormativity, which is the assumption that heterosexuality is the 'normal' and default sexual orientation and that gender roles and gender differences are immutable and innate (42). A heteronormative view thus involves alignment of biological sex, sexuality, gender identity and gender roles. In this study, participants narrated a sense of femininity failure post treatment because they were no longer able to fulfil the gender roles expected of them as women. Participants also described how heteronormative expectations of masculinity made sexual violence from their male partners permissible before and after treatment.

**'Failing' at femininity**

Within the heteronormative gender system women are expected to fulfil certain roles, which are deemed inherent to womanhood, within society and within their relationships. These may include having children, looking attractive, taking care of your husband and child(ren), being responsible for domestic tasks, having a uterus, having an intact and functional vulva and vagina, having intercourse with your male partner, and always desiring this. Hence, if a woman is unable to fulfil these gender role expectations, her femininity is questioned by herself and others. Grace's quote encapsulates the variety of ways in which women in the study felt that they were 'failing' at being a woman post treatment.

Grace experiences the period post treatment as a disruption to her enactment of femininity because she feels she cannot fulfil the expected roles of mother, wife and sexual partner. Her inability to perform these socially prescribed tasks leads her to question her feminine identity. Although these roles are socially constructed, Grace has internalised them which leads her to be the first to question her feminine subjectivity, however, she explains that her husband is having similar doubts because "he doesn't see anything in [me]". Other participants also experienced both internal and external shaming of their changed womanhood. For example, Wendy stated how, before her treatment, when she was

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experiencing severe symptoms: “Sometimes I would see myself as not good enough as a woman because I used to doubt myself by not being able to satisfy my husband.” However, after treatment, she was once again able to fulfil the role of ‘good sexual partner’ – according to her and her husband – because “He sees me as a good woman, as sexy and as a person that he is willing to sleep with.” However, other women only experienced shaming from their male partners. This theme highlights how experiences surrounding gynaecological cancer are embedded within broader unequal gendered systems which have the potential to exacerbate an already trying period in women’s lives. Hence we see, how in this theme, broader societal ideas around femininity become internalised and used as a standard against which women post treatment (and their partners) evaluate their gender and sexuality.

**Sexual violence**

Heteronormative gender role expectations also create space for sexual violence to take place within the context of gynaecological cancer. Participants experienced various forms of sexual violence, such as coercion; forced sex through threats of violence, aggression and infidelity; and rape. As is evident in the quotes by Cebisa and Maggie, many of the women felt that their inability to have sex with their partners due to cancer symptoms or healing post treatment was the trigger for violence. This stems from the idea within the heterosexual script that women are expected to give sex to male partners which if ‘denied’ is punishable with violence. Also underlying this violence is the male sexual drive discourse (43) which is the idea that men need sex all the time whereas women generally are not interested in sex, “men are not like us, we can go months even years without it but men want to do it all the time”. The internalisation of this discourse resulted in some participants putting pressure on 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
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5 working in gynae-oncology to receive further training about discussing sexuality with
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7 patients.
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11 **The need for comprehensive support**
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13 At the end of each interview participants were asked what kind of support would have
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15 been most beneficial to them post treatment. The majority mentioned that they would have
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17 liked more detailed sexual wellbeing information from their healthcare providers. Participants
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19 also highlighted that this information could be delivered in a variety of ways, such as in
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21 person as well as with informational pamphlets. As is foregrounded in Roxy's quote,
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23 participants also want healthcare providers to be the first to broach the topic of sexual
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25 functioning. The second most common response was having a support group for
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27 gynaecological cancer survivors, and some participants mentioned more empathy from
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29 partners, and going for individual counselling.
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34 **Discussion**
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36
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
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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-
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45 psychic and discursive aspects of sexuality post gynaecological cancer (23). It also expands
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47 this understanding of sexuality post gynaecological cancer by detailing the ways that it is
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49 complex, nuanced, relational, and ever shifting.
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53 Most women in this study experienced a change in their sexual functioning post
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55 treatment, but half of the participants also reported a significant disruption to their sexual
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57 lives *prior* to treatment due to severe symptoms. Women with late stage gynaecological
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cancers often live with symptoms such as abdominal pain, heavy bleeding, unpleasant discharge, and fatigue (45, 46) for an extended period and therefore their sexuality has been negatively impacted beyond the treatment and post treatment phases (23). Limited literature is available on how gynaecological cancer symptoms disrupt sexual functioning before diagnosis and treatment. A few older studies have shown how these symptoms lead to negative changes in all aspects of women's sexual lives (9, 47-50). However, it has been argued that treatment for gynaecological cancer has a greater negative effect on women's sexual functioning than the symptoms of the disease (47). The results from the present study challenge this argument by highlighting that, for some women in South African, the symptoms prior to diagnosis are worse – or at least on par – with treatment side effects.

Other important findings were that not all women experienced a negative sexuality change post treatment, and many reported both pleasurable and difficult sexual experiences. Additionally, many women described a process of re-embodiment post treatment where they came to accept and celebrate their sexual identity. Williams' theory of embodiment and chronic illness (51) suggests that the presence of illness disrupts 'normal' embodiment and therefore persons make attempts at "re-embodiment" (p. 32) to make sense of the bodily changes brought about by chronic conditions. When investigating sexual subjectivities post cancer, Gilbert et al. found that some individuals took up a position of re-embodied sexual subjectivity comprised of acceptance, confidence and engaging in non-coital sexual activity (52). The dominant narrative around female sexuality post gynaecological cancer treatment in most research and clinical contexts is one of tragedy. The results of the present study trouble catastrophising narratives of sexual identity post treatment and create options for accessing sources of strength and resilience in the recovery process. Feelings of re-embodiment can also be used as a starting point for many women post gynaecological cancer treatment who

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want to reacquaint themselves with their post-cancer body as part of a journey towards resuming their sexual lives.

Some women in this study explained how their partner's sexual dys/function was a factor in their sexual rehabilitation. Partners are generally overlooked in research on sexuality after cancer (53) but existing literature has shown that partners experience a decline in their own libido; fear initiating sex; struggle with regaining a 'normal' sex life; and feel unattractive and unwanted because of sex cessation (54-56). Limited research is available on how partners' sexual difficulties are a factor in sexuality post gynaecological cancer, however, Greimel et al. (57) found that 12% of their participants were not able to have sexual intercourse post treatment because of their partners' health problems. An interview-based study with male partners of gynaecological cancer survivors (58) found that male partners also experienced sexual problems after treatment. As an explanation for this, Van De Wiel et al. (59) suggest that the cancer diagnosis and its treatment are also a crisis for the male partner, which may lead to methods of coping which are signified by withdrawal and can lead to sexual functioning difficulties. However, it is worth noting is that IVO felt her partner's sexual difficulties due to diabetes had made him more empathetic about her sexual difficulties post treatment. Thus, partner comorbidity can be positioned as a catalyst for compassion, bonding, and deeper intimacy.

Other participants mentioned how the state of the relationship before treatment either facilitated or hindered sexual intimacy post treatment. For example, pre-existing alcoholism, possessiveness, infidelity, and verbal aggression made intimacy post treatment strained. Women who reported that they were generally happy in their relationships and felt supported pre-treatment stated that them and their partners were still "going strong" post treatment. Maree et al. (60) found similar results in their qualitative study with South African women about partner support through their cervical cancer journey, in that the support experienced

post treatment depended on the nature of the relationship prior to treatment. These findings highlight how cancer diagnosis, treatment, and rehabilitation is a shared experience for women and their intimate partners (54) and thus discussions around sexuality post treatment should focus on the implications for partnerships and not only the individual receiving the treatment. There is debate within the literature about which treatment modality has the greatest negative impact on sexual functioning (22, 61-64) with some studies suggesting that radiotherapy leads to higher levels of sexual dysfunction than surgery or chemotherapy (19, 65-68). Yet, what this finding suggests is that sexuality post treatment is dependent on more than which treatment modality was utilised. Considering how intimate *relationships* have been affected by the cancer treatment allows for movement beyond problematizing women's sexuality alone.

This study showed how heteronormative gender role expectations negatively impacted women's recovery post treatment and created space for male partners to be sexually violent. Research from the global north has explored the ways in which heterosexual scripts interact with the psychosexual recovery process post treatment (41, 69-72). Findings from these studies highlight how the 'coital imperative' (73) impacts couples' ability to renegotiate sexual intimacy. The coital imperative constructs penetrative vaginal sex as the only 'real sex' and as a sign of 'normal', healthy relationships and therefore those who fall outside of this discursive category are positioned as abnormal and dysfunctional (74, 75). It follows then that women who cannot engage in intercourse post treatment begin to doubt their gender and sexual identity.

The same heterosexual scripts that emphasise the 'coital imperative' also make sexual violence post treatment possible. Research on sexual violence within the context of gynaecological cancer care is extremely limited. A few studies regarding the relationship between intimate partner violence (IPV) and cancer exist, however, their focus is largely

about whether IPV creates greater risk for cancer among women (76-78). The focus of this research is about abuse in general, not sexual abuse, and most of the focus is on cervical cancer. Little attention is paid to whether gynaecological cancer can trigger the perpetration of sexual violence or how it might worsen existing sexual abuse. This issue demands further investigation in South Africa given the country's high levels of sexual violence and cervical cancer (15, 79).

Participants in this study stated that they wanted to receive support in the form of more sexual functioning information from their healthcare providers, as well as from support groups. Previous research affirms that people with cancer want healthcare providers to discuss sexuality issues such as when to resume sexual activity (80), appropriate sexual positioning or the use of sexual aids (81) and adjusting to sexual changes (72). Healthcare providers can also give psychoeducation about the effects of gynaecological cancer and its treatments on sexuality throughout the cancer journey (82), as well as help couples renegotiate their sexual intimacy by challenging heteronormative discourses of sexuality which stress the coital imperative (41, 70, 83, 84). In this way, healthcare providers can play a vital role in patients' psychosexual recovery. For, if a healthcare provider legitimises sexuality discussions within a clinical setting, it gives permission to individuals and couples to discuss this on their own (85). This can create opportunities for conversations about sexual issues and potentially mitigate relationship tension and sexual violence (41, 86). Healthcare providers working with gynaecological cancer patients should endeavour to improve their knowledge about sexuality in the context of cancer by staying up to date with the relevant literature as well as attending workshops and conferences. Additionally, healthcare providers should be the first to broach the topic with their patients as patients want to receive more information about sexuality but often feel uncomfortable asking questions.

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Other types of interventions that have been aimed at sexual functioning post gynaecological cancer include psychoeducational interventions (87-89), peer support interventions (90, 91), vaginal dilators after pelvic radiotherapy (92, 93), specialist nurse-led interventions (89, 94-97), reflection based interventions (98), and internet based interventions (99). Systematic reviews show that solely information-based interventions do not provide long-term benefits to women with gynaecological cancer but that counselling based interventions are useful in improving quality of life factors (100, 101). Other reviews have shown that interventions are most effective when they include information provision, cognitive-behavioural therapy, social support and counselling (87) and are led by specialist nurses (87, 95). There is currently no research on such interventions within the South African public healthcare context. Thus, future research should focus on ascertaining what – if any – interventions exist in South Africa and, if not, what resources are available to create comprehensive support interventions post treatment and how these might fit into the existing healthcare system.

## Conclusion

Research and clinical work need to make room for the complexities highlighted in these findings so that sexuality post treatment can be engaged with beyond biomedical assessments of dys/function, performance, and satisfaction. This research has expanded understandings of sexuality within the context of gynaecological cancer and problematized some taken-for-granted assumptions about sexuality post treatment. Researchers should explore how comprehensive sexuality education and sensitivity training can be better incorporated into healthcare providers' training curriculums. Further research is required to understand how partners of women with gynaecological cancer experience and cope with the sexual changes post treatment, how the couple as a partnership negotiates changes post

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treatment, and the facilitators and barriers that healthcare providers experience regarding discussing sexuality issues with patients.

This study had several limitations. The study was cross-sectional in nature and therefore only captured women's experiences of their sexuality at one moment in time post treatment and comments therefore cannot be made on how they experienced their sexuality over time. This study made use of a holistic framework of sexuality, however, this framework is not exhaustive and did not include socio-cultural factors relating to sexuality. Given South Africa's diverse socio-cultural landscape such an avenue of exploration would have been beneficial. The authors would also recommend adding a socio-cultural component to the holistic framework. The sample of this study was predominantly comprised 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 women who have intimate relationships with women. Lastly, insufficient attention was paid to the ways in which the different components of sexuality post gynaecological cancer treatment interact with each other.

It is hoped that this research will further scholarly and clinical work within this field in South Africa because all gynaecological cancer survivors and their partners should have the resources to create a sexual life that is pleasurable, consensual and fulfilling.

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**Competing interests' statement**

No competing financial interests exist.

**Author contributions**

S.P. was the project leader and J.M. was the senior author. NF and TA were responsible for the recruitment of participants. S.P. was responsible for the data collection and analysis. J.M., L.D., and S.P. drafted the manuscript. All authors gave critical comment throughout the writing process. All authors were responsible for the conceptualisation and design of the project. All authors approved the final version to be published.

**Data sharing statement**

Raw data from this study is currently not publicly available but can be made available upon reasonable request.

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## References

1. Hordern A. Intimacy and sexuality after cancer: a critical review of the literature. Cancer nursing. 2008;31(2):E9-E17.

2. Hughes MK, editor Sexuality and cancer: The final frontier for nurses. Oncology Nursing Forum; 2009: Oncology Nursing Society.

3. Shildrick M. Unreformed bodies: Normative anxiety and the denial of pleasure. Women's Studies. 2005;34(3-4):327-44.

4. Reis N, Beji NK, Coskun A. Quality of life and sexual functioning in gynecological cancer patients: results from quantitative and qualitative data. European Journal of Oncology Nursing. 2010;14(2):137-46.

5. Organization WH. The World Health Organisation quality of life assessment (WHOQOL): position paper from the World Health Organisation. Social science & medicine (1982). 1995;41:1409-.

6. Audette C, Waterman J. The sexual health of women after gynecologic malignancy. Journal of Midwifery & Women's Health. 2010;55(4):357-62.

7. Wiggins DL, Wood R, Granai C, Dizon DS. Sex, intimacy, and the gynecologic oncologist: survey results of the New England Association of Gynecologic Oncologists (NEAGO). Journal of psychosocial oncology. 2007;25(4):61-70.

8. Guner O, Gumussoy S, Celik N, Saruhan A, Kavlak O. An examination of the sexual functions of patients who underwent a gynecologic cancer operation and received brachytherapy. Pakistan journal of medical sciences. 2018;34(1):15.

9. Bourgeois-Law G, Lotocki R. Sexuality and gynaecological cancer: a needs assessment. The Canadian Journal of Human Sexuality. 1999;8(4):231.

10. Tierney DK, editor Sexuality: a quality-of-life issue for cancer survivors. Seminars in oncology nursing; 2008: Elsevier.

11. Ratner ES, Foran KA, Schwartz PE, Minkin MJ. Sexuality and intimacy after gynecological cancer. Maturitas. 2010;66(1):23-6.

12. Reese JB, Bober SL, Daly MB. Talking about women's sexual health after cancer: Why is it so hard to move the needle? Cancer. 2017;123(24):4757-63.

For peer review only

13. Reese JB, Sorice K, Beach MC, Porter LS, Tulsky JA, Daly MB, et al. Patient-provider communication about sexual concerns in cancer: a systematic review. Journal of Cancer Survivorship. 2017;11(2):175-88.

14. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-Oncology. 2012;21(6):594-601.

15. Registry NC. Cancer in South Africa, 2014: Full Report In: Diseases NIfC, editor. South Africa: National Health Laboratory Service 2014.

16. Health SADo. Cervical cancer prevention and control policy. 2017.

17. Snyman L. Prevention of cervical cancer-how long before we get it right? South African Journal of Obstetrics and Gynaecology. 2013;19(1):2.

18. Snyman LC, Herbst U. Reasons why unscreened patients with cervical cancer present with advanced stage disease. Southern African Journal of Gynaecological Oncology. 2013;5(1):16-20.

19. Lind H, Waldenström AC, Dunberger G, al-Abany M, Alevronta E, Johansson KA, et al. Late symptoms in long-term gynaecological cancer survivors after radiation therapy: a population-based cohort study. British Journal of Cancer. 2011;105(6):737-45.

20. Andersen BL, Woods X, Cyranowski J. Sexual self-schema as a possible predictor of sexual problems following cancer treatment. Canadian Journal of Human Sexuality. 1994;3(2).

21. Woods NF. Toward a holistic perspective of human sexuality: Alterations in sexual health and nursing diagnoses. Holistic Nursing Practice. 1987;1(4):1-11.

22. Cleary V, Hegarty J. Understanding sexuality in women with gynaecological cancer. European Journal of Oncology Nursing. 2011;15(1):38-45.

23. Gilbert E, Ussher JM, Perz J. Sexuality after gynaecological cancer: a review of the material, intrapsychic, and discursive aspects of treatment on women's sexual-wellbeing. Maturitas. 2011;70(1):42-57.

24. Thorne S. Interpretive description: Qualitative research for applied practice: Routledge; 2016.

25. Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. International journal of qualitative methods. 2004;3(1):1-11.

26. Sandelowski M, Barroso J. Classifying the findings in qualitative studies. Qualitative health research. 2003;13(7):905-23.

For peer review only

27. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. Research in nursing & health. 1997;20(2):169-77.

28. Giacomini M. Theory matters in qualitative health research. The Sage handbook of qualitative methods in health research. 2010:125-56.

29. Etikan I, Musa SA, Alkassim RS. Comparison of convenience sampling and purposive sampling. American journal of theoretical and applied statistics. 2016;5(1):1-4.

30. Miles MB, Huberman AM, Huberman MA, Huberman M. Qualitative data analysis: An expanded sourcebook: sage; 1994.

31. Bayer AM, Cabrera LZ, Gilman RH, Hindin MJ, Tsui AO. Adolescents can know best: Using concept mapping to identify factors and pathways driving adolescent sexuality in Lima, Peru. Social science & medicine. 2010;70(12):2085-95.

32. Harrison A, Xaba N, Kunene P, Ntuli N. Understanding young women's risk for HIV/AIDS: adolescent sexuality and vulnerability in rural KwaZulu/Natal. Society in transition. 2001;32(1):69-78.

33. Trotter RT, Potter JM. Pile sorts, a cognitive anthropological model of drug and AIDS risks for Navajo teenagers: Assessment of a new evaluation tool. Drugs & Society. 1993;7(3-4):23-39.

34. Barton KC. Elicitation techniques: Getting people to talk about ideas they don't usually talk about. Theory & Research in Social Education. 2015;43(2):179-205.

35. Ensign J, Gittelsohn J. Health and access to care: Perspectives of homeless youth in Baltimore City, USA. Social science & medicine. 1998;47(12):2087-99.

36. Yeh H-W, Gajewski BJ, Perdue DG, Cully A, Cully L, Greiner KA, et al. Sorting it out: pile sorting as a mixed methodology for exploring barriers to cancer screening. Quality & quantity. 2014;48(5):2569-87.

37. Bourey C, Stephenson R, Bartel D, Rubardt M. Pile sorting innovations: Exploring gender norms, power and equity in sub-Saharan Africa. Global public health. 2012;7(9):995-1008.

38. Maitra S, Schensul SL. Reflecting diversity and complexity in marital sexual relationships in a low-income community in Mumbai. Culture, Health & Sexuality. 2002;4(2):133-51.

39. Clarke V, Braun V, Hayfield N. Thematic analysis. Qualitative psychology: A practical guide to research methods. 2015:222-48.

40. Tamale S. African sexualities: A reader: Fahamu/Pambazuka; 2011.

For peer review only

41. Gilbert E, Ussher JM, Perz J. Renegotiating sexuality and intimacy in the context of cancer: the experiences of carers. Arch Sex Behav. 2010;39(4):998-1009.

42. Shefer T, Boonzaier F, Kiguwa P. The gender of psychology: Juta Academic; 2006.

43. Hollway W, editor Women's power in heterosexual sex. Women's studies international forum; 1984: Elsevier.

44. Embodiment [Internet]. Oxford University Press. 2016 [cited 17 February 2020].

45. Stead ML, Fallowfield L, Selby P, Brown JM. Psychosexual function and impact of gynaecological cancer. Best Practice & Research Clinical Obstetrics & Gynaecology. 2007;21(2):309-20.

46. Laganà L, McGarvey EL, Classen C, Koopman C. Psychosexual dysfunction among gynecological cancer survivors. Journal of Clinical Psychology in Medical Settings. 2001;8(2):73-84.

47. Andersen BL, Hacker NF. Treatment for gynecologic cancer: A review of the effects on female sexuality. Health Psychology. 1983;2(2):203.

48. Gamel C, Hengeveld M, Davis B. Informational needs about the effects of gynaecological cancer on sexuality: a review of the literature. Journal of clinical nursing. 2000;9(5):678-88.

49. Juraskova I, Butow P, Robertson R, Sharpe L, McLeod C, Hacker N. Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. Psycho-Oncology. 2003;12(3):267-79.

50. Lamb MA, Sheldon T. The sexual adaptation of women treated for endometrial cancer. Cancer Practice. 1994;2(2):103-13.

51. Williams SJ. The vicissitudes of embodiment across the chronic illness trajectory. Body & Society. 1996;2(2):23-47.

52. Gilbert E, Ussher JM, Perz J. Embodying sexual subjectivity after cancer: a qualitative study of people with cancer and intimate partners. Psychol Health. 2013;28(6):603-19.

53. Riechers EA. Including partners into the diagnosis of prostate cancer: a review of the literature to provide a model of care. Urologic Nursing. 2004;24(1):22-9.

54. Maughan K, Heyman B, Matthews M. In the shadow of risk.: How men cope with a partner's gynaecological cancer. International Journal of Nursing Studies. 2002;39(1):27-34.

55. Harden J, Schafenacker A, Northouse L, Mood D, Smith D, Pienta K, et al., editors. Couples' experiences with prostate cancer: focus group research. Oncology nursing forum; 2002.

For peer review only

56. Sanders S, Pedro LW, Bantum EOC, Galbraith ME. Couples surviving prostate cancer: Long-term intimacy needs and concerns following treatment. Clinical Journal of Oncology Nursing. 2006;10(4).

57. Greimel ER, Winter R, Kapp KS, Haas J. Quality of life and sexual functioning after cervical cancer treatment: A long-term follow-up study. Psycho-Oncology. 2009;18(5):476-82.

58. Schultz WW, Van De Wiel H, Bouma J, Lappöhn R. Gynaecological conditions and sexual dysfunction. Sexual and marital therapy. 1991;6(2):177-94.

59. Van de Wiel H, Schultz WW, Wouda J, Bouma J. Sexual functioning of partners of gynaecological oncology patients: a pilot study on involvement, support, sexuality and relationship. Sexual and marital therapy. 1990;5(2):123-30.

60. Maree JE, Mosalo A, Wright SCD. 'It depends on how the relationship was before you became ill': Black South African women's experiences of life partner support through the trajectory of cervical cancer. European Journal of Cancer Care. 2013;22(4):459-67.

61. Becker M, Malafy T, Bossart M, Henne K, Gitsch G, Denschlag D. Quality of life and sexual functioning in endometrial cancer survivors. Gynecologic oncology. 2011;121(1):169-73.

62. Nout RA, van de Poll-Franse LV, Lybeert MLM, Wárlám-Rodenhuis CC, Jobsen JJ, Mens JWM, et al. Long-term outcome and quality of life of patients with endometrial carcinoma treated with or without pelvic radiotherapy in the post operative radiation therapy in endometrial carcinoma 1 (PORTEC-1) trial. Journal Of Clinical Oncology: Official Journal Of The American Society Of Clinical Oncology. 2011;29(13):1692-700.

63. Onujiogu N, Johnson T, Seo S, Mijal K, Rash J, Seaborne L, et al. Survivors of endometrial cancer: who is at risk for sexual dysfunction? Gynecologic oncology. 2011;123(2):356-9.

64. Sekse RJT, Hufthammer KO, Vika ME. Sexual activity and functioning in women treated for gynaecological cancers. Journal of clinical nursing. 2017;26(3-4):400-10.

65. Ditto A, Martinelli F, Borreani C, Kusamura S, Hanozet F, Brunelli C, et al. Quality of life and sexual, bladder, and intestinal dysfunctions after class III nerve-sparing and class II radical hysterectomies: a questionnaire-based study. International Journal of Gynecological Cancer. 2009;19(5):953-7.

66. Korfage IJ, Essink-Bot M-L, Mols F, van de Poll-Franse L, Kruitwagen R, van Ballegooijen M. Health-related quality of life in cervical cancer survivors: a population-based survey. International Journal of Radiation Oncology* Biology* Physics. 2009;73(5):1501-9.

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67. Donovan KA, Taliaferro LA, Alvarez EM, Jacobsen PB, Roetzheim RG, Wenham RM. Sexual health in women treated for cervical cancer: characteristics and correlates. Gynecologic oncology. 2007;104(2):428-34.

68. Rowlands IJ, Lee C, Beesley VL, Webb PM, Group ANECS. Predictors of sexual well-being after endometrial cancer: results of a national self-report survey. Supportive Care in Cancer. 2014;22(10):2715-23.

69. Hyde A. The politics of heterosexuality--a missing discourse in cancer nursing literature on sexuality: a discussion paper. Int J Nurs Stud. 2007;44(2):315-25.

70. Parton C, Ussher JM, Perz J. Experiencing menopause in the context of cancer: Women's constructions of gendered subjectivities. Psychol Health. 2017;32(9):1109-26.

71. Ussher JM, Perz J, Gilbert E, Wong WK, Hobbs K. Renegotiating sex and intimacy after cancer: resisting the coital imperative. Cancer Nurs. 2013;36(6):454-62.

72. Ussher JM, Perz J, Gilbert E. Women's Sexuality after Cancer: A Qualitative Analysis of Sexual Changes and Renegotiation. Women & Therapy. 2014;37(3-4):205-21.

73. Potts A. The science/fiction of sex: Feminist deconstruction and the vocabularies of heterosex: Psychology Press; 2002.

74. Tiefer L. The medicalization of sexuality: Conceptual, normative, and professional issues. Annual Review of Sex Research. 1996;7(1):252-82.

75. Tiefer L. The selling of'female sexual dysfunction'. Journal of sex & marital therapy. 2001;27(5):625-8.

76. Coker AL, Sanderson M, Fadden MK, Pirisi L. Intimate partner violence and cervical neoplasia. Journal of women's health & gender-based medicine. 2000;9(9):1015-23.

77. Coker AL, Hopenhayn C, DeSimone CP, Bush HM, Crofford L. Violence against women raises risk of cervical cancer. Journal of women's health. 2009;18(8):1179-85.

78. Bergmark K, Åvall-Lundqvist E, Dickman PW, Henningsohn L, Steineck G. Synergy between sexual abuse and cervical cancer in causing sexual dysfunction. Journal of sex & marital therapy. 2005;31(5):361-83.

79. Service SAP. CRIME SITUATION IN REPUBLIC OF SOUTH AFRICA TWELVE (12) MONTHS (APRIL TO MARCH 2018_19). In: Police Do, editor. South Africa: Department of Police; 2019.

80. Rasmusson E-M, Thomé B. Women's Wishes and Need for Knowledge Concerning Sexuality and Relationships in Connection with Gynecological Cancer Disease. Sexuality & Disability. 2008;26(4):207-18.

For peer review only

81. Herbenick D, Reece M, Hollub A, Satinsky S, Dodge B. Young female breast cancer survivors: Their sexual function and interest in sexual enhancement products and services. Cancer nursing. 2008;31(6):417-25.

82. Rees CE, Bath PA, Lloyd-Williams M. The information concerns of spouses of women with breast cancer: patients' and spouses' perspectives. Journal of Advanced Nursing. 1998;28(6):1249-58.

83. Archibald S, Lemieux S, Byers ES, Tamlyn K, Worth J. Chemically-induced menopause and the sexual functioning of breast cancer survivors. Women & Therapy. 2006;29(1-2):83-106.

84. Liao L-M. Learning to assist women born with atypical genitalia: journey through ignorance, taboo and dilemma. Journal of reproductive and infant psychology. 2003;21(3):229-38.

85. Schwartz S, Plawecki HM. Consequences of chemotherapy on the sexuality of patients with lung cancer. Clinical Journal of Oncology Nursing. 2002;6(4).

86. Almont T, Farsi F, Krakowski I, El Osta R, Bondil P, Huyghe É. Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. Supportive Care in Cancer. 2019;27(3):887-94.

87. Chow KM, Chan CW, Chan JC. Effects of psychoeducational interventions on sexual functioning, quality of life and psychological outcomes in patients with gynaecological cancer: A systematic review. JBI Database of Systematic Reviews and Implementation Reports. 2012;10(58):4077-164.

88. Cleary V, McCarthy G, Hegarty J. Development of an educational intervention focused on sexuality for women with gynecological cancer. Journal of psychosocial oncology. 2012;30(5):535-55.

89. Sekse RJT, Blaaka G, Buestad I, Tengesdal E, Paulsen A, Vika M. Education and counselling group intervention for women treated for gynaecological cancer: does it help? Scandinavian Journal of Caring Sciences. 2014;28(1):112-21.

90. Pistrang N, Jay Z, Gessler S, Barker C. Telephone peer support for women with gynaecological cancer: recipients' perspectives. Psycho-Oncology. 2012;21(10):1082-90.

91. Huntingdon B, Schofield P, Wolfowicz Z, Bergin R, Kabel D, Edmunds J, et al. Toward structured peer support interventions in oncology: a qualitative insight into the experiences of gynaecological cancer survivors providing peer support. Supportive Care in Cancer. 2016;24(2):849-56.

For peer review only

92. Bonner C, Nattress K, Anderson C, Carter J, Milross C, Philp S, et al. Chore or priority? Barriers and facilitators affecting dilator use after pelvic radiotherapy for gynaecological cancer. Supportive Care in Cancer. 2012;20(10):2305-13.

93. Punt L. Patient compliance with the use of vaginal dilators following pelvic radiotherapy for a gynaecological cancer. Journal of Radiotherapy in Practice. 2011;10(1):13-25.

94. Seibaek L, Petersen LK. Nurse-led rehabilitation after gynaecological cancer surgery. Supportive care in cancer. 2009;17(5):601.

95. Cook O, McIntyre M, Recoche K. Exploration of the role of specialist nurses in the care of women with gynaecological cancer: a systematic review. Journal of clinical nursing. 2015;24(5-6):683-95.

96. Parkinson N, Pratt H. Clinical nurse specialists and the psychosexual needs of patients with gynaecological cancer. British Menopause Society Journal. 2005;11(1):33-5.

97. Maughan K, Clarke C. The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality. Journal of clinical nursing. 2001;10(2):221-9.

98. Olesen ML, Hansson H, Ottesen B, Thranov IR, Thisted LB, Zoffmann V. The psychosocial needs of gynaecological cancer survivors: A framework for the development of a complex intervention. European Journal of Oncology Nursing. 2015;19(4):349-58.

99. Schover LR, Yuan Y, Fellman BM, Odensky E, Lewis PE, Martinetti P. Efficacy trial of an Internet-based intervention for cancer-related female sexual dysfunction. Journal of the National Comprehensive Cancer Network. 2013;11(11):1389-97.

100. Hersch J, Juraskova I, Price M, Mullan B. Psychosocial interventions and quality of life in gynaecological cancer patients: a systematic review. Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer. 2009;18(8):795-810.

101. Teo I, Krishnan A, Lee GL. Psychosocial interventions for advanced cancer patients: A systematic review. Psycho-oncology. 2019;28(7):1394-407.

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# Appendix A: Interview Guide

<u>Introduction</u>

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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Opening questions to help participant relax

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

1) Can you tell me about how you came to be diagnosed with cancer?
2) What treatment/s have you had?

Explanation of pile sorting activity

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

In this bag here are a lot of different words that are written on cards. Each word is a word that you could use to describe an experience, for example: 'good', 'difficult', 'painful', 'exciting'. I am going to put all of these words on the table in front of you and then I am going to ask you a question about your experiences before and after your cancer treatment. You will then have some time to choose the words that you feel best describe your experience. Once you have chosen the words we will discuss them and I will ask you a few more questions about your experiences before and after cancer.

Do you have any questions about this activity?

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

Let us do a quick practise exercise. From these words, which ones would you choose to describe your day yesterday.

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[Assess participant's understanding and correct accordingly].

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

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

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?

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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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c. Has there been in a change in how often you have sex? (If yes, explore further.)

d. Which words would you use to describe what the communication about sex has been like **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 communication **before** treatment? (If yes, ask which words would describe their communication before)

<u>Section 3: Desire, orgasm, arousal, performance, and identity [*sexual functioning and sexual self-concept]*</u>

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

I would now like to talk to you about some things relating to your sexual health after treatment.

1) Which words would you use to describe your sex life **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 sexual functioning **before** treatment? (If yes, ask which words would describe their sexual functioning before)

2) How often do you feel a desire to have sex, now that your **treatment is over**?

  a. Is this level of desire any different to **before** your treatment? (If yes, how is it different?)

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3) Has there been a change in how you become physically excited about sex? (If yes, how is it different?)

4) Has there been a change in how often you are able to orgasm during sex? (Is yes, how is it different?)

5) How do you feel about your sexual performance **after** treatment?

   a. Is this any different to **before** your treatment? (If yes, how is it different?)

6) How do you think about yourself as a sexual person **after** your treatment?

   a. Is this any different to **before** your treatment? (If yes, how is it different?)

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<u>Section 4: Questions relating to treatment adherence</u>

[No more pile sorting].

1. Did any of the sexual changes you have told me about make you think about stopping your treatment?

   a. If yes, explore further:

      i. Which changes in particular made you want to stop your treatment?

      ii. What would have made it easier for you to cope with these changes?

<u>Section 5: Questions relating to support services</u>

I would now like to talk to you about the information your received during your diagnosis and/or treatment.

1) During your diagnosis and/or treatment, did a doctor or nurse talk to you about sexual functioning?

   a. If yes:

      i. What did they discuss with you?

      ii. How did you feel about this talk?

2) What types of support do women need after treatment to meet their sexual health needs?

    a. If they say anything about receiving more information: How would you like to receive this information?

Closing comments

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

By speaking with us today you are contributing to research that will hopefully help in supporting cancer patients better.

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

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

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

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

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

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

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

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

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

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

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

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## 8. After the interview

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

## 9. Who do I speak to if I have any questions about the study?

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

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

Tel: 021 406 6798

Email: jennifer.moodley@uct.ac.za

• **Sorrel Pitcher**, Qualitative researcher with the Gynaecological Cancer Research Center, School of Public Health & Family Medicine, University of Cape Town

Email: sorrel.p@gmail.com

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

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

This proposal has been reviewed and approved by the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee (reference number: 716/2017), whose task it is to make sure that research participants are protected from harm.

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By signing below you are saying that the study has been explained to you and that you understand all of the procedures and the risks and benefits of the study. Your signature also says that you would like to participate in the project.

**Participant full name:**

**Participant Signature OR thumbprint (in case of illiteracy)** **Date**

**Interviewer full name:**

**Interviewer Signature** **Date**

**Witness full name (in case of illiterate participant):**

**Witness signature:** **Date**

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## 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. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| 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? | |
| *Relationship with participants* | | | |
| 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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | |
| *Participant selection* | | | |
| 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? | |
| *Setting* | | | |
| 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 | |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | |
| Repeat interviews | 18 | Were repeat inter views 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 inter view or focus group? | |
| Duration | 21 | What was the duration of the inter views or focus group? | |
| Data saturation | 22 | Was data saturation discussed? | |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | |

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| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| | | correction? | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| 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? | |
| *Reporting* | | | |
| 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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