

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.

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.

[Assess participant's understanding and correct accordingly].

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

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

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

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

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

Section 2: Intimacy and communication [sexual relationships]

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

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

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

- 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?)

- 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? (If 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 you 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.

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

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.

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.

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

