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ORIGINAL RESEARCH

Identifying the informational needs, challenges, and opportunities to improve quality of life for women with ovarian cancer at Tygerberg Hospital in Cape Town, South Africa

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Background: Ovarian cancer has the highest case-fatality ratio, and most women in the world with ovarian cancer live in low- to middle-income countries (LMICs).[1,4] The Every Woman Study™ (EWS) was introduced in LMICs, as there is limited data on ovarian cancer in these areas. The EWS's primary aim was to identify the challenges patients with ovarian cancer experience and to find opportunities to improve diagnosis time and quality of life outcomes.

Methods: An observational, cross-sectional study was conducted at the Tygerberg Hospital (TBH) Gynaecological Oncology Unit between 1 June and 31 December 2023. Women with ovarian cancer over the age of 18 who were diagnosed within five years of the date of their participation, were included.

Results: Surveys were completed by 36 women. The median age of patients was 54 years. The most common symptom experienced was increased abdominal size (72.2%). Most patients (66.7%) sought advice about their symptoms from their family doctor as their first healthcare provider. Only 25% of patients had heard about ovarian cancer before they were diagnosed. The most important sources of information were identified as attending healthcare workers. More than half of the women (65.5%) had never used the Internet to search for information. A large percentage of patients (82.4%) indicated that their hospital should provide information.

Conclusion: Few women were aware of ovarian cancer in this study. Patients diagnosed with ovarian cancer need more information. With an expected rise in the number of cases, awareness amongst patients and healthcare workers should be prioritised to improve earlier ovarian cancer diagnosis and better quality of life.

Keywords: ovarian cancer, information, quality of life, awareness, survivorship

Introduction

Ovarian cancer is the third most prevalent gynaecological cancer in South Africa, preceded by cervical and uterine cancer.[1] It has the highest case-fatality ratio of all cancers in women, as most present with advanced disease and a poor five-year prognosis.[2] The World Health Organization (WHO) Global Cancer Observatory estimates the incidence to rise worldwide, with the highest increase in developing countries. This translates to an estimated increase of 72.9% in cases in South Africa by 2050.[3]

Screening for ovarian cancer has shown limited evidence to improve oncological outcomes, and symptoms are frequently mistaken for less serious conditions. This often results in a late diagnosis, making treatment more challenging.[2,4] There is clearly an imperative to improve the knowledge of ovarian cancer in women and clinicians to prevent delays in seeking help or arranging referrals.

Once diagnosed, the significance of attending to the physical, psychological, and emotional needs of cancer patients at the different phases of their illness is becoming increasingly apparent. Meeting cancer patients' informational needs regarding matters unique to their diagnosis and treatment, as well as long-term effects and quality of life, are essential to providing quality survivorship, along with palliative and supportive care.[5] Knowledge about the diagnosis, therapy course, and potential side effects of cancer can lower anxiety and improve health outcomes in cancer patients.[6]

In 2018, the Every Woman Study™ (EWS) was conducted in high-income countries (HIC) through patient-led surveys completed within five years of their diagnosis. It included questions on knowledge of ovarian cancer, family history, symptom experience, diagnosis, treatment, and quality of life issues. With significant national differences, more than two-thirds of women had never heard of ovarian cancer or knew very little about it before receiving their diagnosis in this study. It was clear that women needed more information on the condition.[4]

However, most women in the world with ovarian cancer live in low- to middle-income countries (LMICs).[1,4] Therefore, the EWS was introduced in multiple LMICs, as there is limited data on ovarian cancer in these areas.[4] Tygerberg Hospital (TBH) is one of the centres that participated in the 2023 International EWS, which involved up to 31 (LMICs) countries worldwide.[5]

The EWS's primary aim was to identify the challenges patients with ovarian cancer experience and to find opportunities to improve diagnosis time and quality of life outcomes. As part of this study, the informational needs of patients from TBH's drainage area were identified to design an informational brochure (Appendix A and B) to distribute to patients and to assist healthcare workers in conveying information appropriate to patients' needs.

Materials and methods

We conducted an observational, cross-sectional study using paper-based surveys (Appendix C) at the TBH Gynaecological Oncology Unit in Cape Town, South Africa, between 1 June and 31 December 2023. The principal investigator reviewed all women who had recently attended an appointment during the specified period. Women over the age of 18 who had a diagnosis of ovarian, fallopian tube, or primary peritoneal cancer within five years of the date of their participation in the study were included.

The principal investigator identified which patients were eligible, explained the study to them in their language of choice, and, if they consented to participate, were given surveys to complete in English, Afrikaans, or isiXhosa. Translations and databases were provided by the World Ovarian Cancer Coalition. Patients were excluded if they were unable to consent, were younger than 18 years, or were identified on the day of being informed of their ovarian cancer diagnosis.

The principal investigator captured the data into the secure REDCap® database managed by the World Ovarian Cancer Coalition. The local administrators ensured that the participants' anonymity was maintained. Data about the informational needs of patients were extracted from the database for this study.

Results

A total of 38 women were identified as eligible, and 36 consented and completed paper surveys during the specified period. Two women declined to answer survey questions due to their symptom severity at the recruitment stage but consented to provide their demographic and clinical data.

Patient characteristics

The median age of the women (*n* = 38) was 54 (22–79 years). Most patients were diagnosed with epithelial ovarian cancer (29, 76.3%). All patients (38, 100%) were normally residents and had been diagnosed in South Africa. Patients were staged according to the International Federation of Gynaecology and Obstetrics (FIGO) staging system with the following breakdown (Table I):

- stage I, 34.2% (13)
- stage II, 10.5% (4)
- stage III, 28.9% (11)
- stage IV, 26.3% (10)

The majority (29, 76.3%) had surgery, and complete tumour cytoreduction was achieved in 65.7% of all cases (25/38). Nine patients (23.6%) did not have surgery due to advanced disease or being unfit for surgery. Most women (26, 68.4%) received chemotherapy at some point during their treatment.

With the option of choosing multiple answers, the most common symptoms women (*n* = 36) experienced were increased abdominal size (26, 72.2%), persistent bloating (22, 61.1%), abdominal pain (19, 52.8%), pelvic pain (18, 50.0%), feeling full (17, 47.2%), changes in bowel habits (17, 47.2%), and urinary frequency (15, 41.7%). Most women (34, 94.4%) sought advice about their symptoms, usually from their family doctor as the first healthcare provider (24, 66.7%).

The patients' opinions on whether the time to diagnosis could have been shortened were ambivalent: "yes" (15, 41.7%), "no" (14, 38.9%), and "not sure" (7, 19.4%). An overwhelming majority of

Table I: Patient characteristics (*n* = number)

Year of diagnosis (*n* = 38)	
2019	5.3% (2)
2020	15.8% (6)
2021	21.1% (8)
2022	26.3% (10)
2023	31.6% (12)

Age of participants (*n* = 38)	
< 20	0
21–30	7.9% (3)
31–40	10.5% (4)
41–50	10.5% (4)
51–60	36.8% (14)
61–70	18.4% (7)
71–80	15.8% (6)
> 80	0

FIGO stage at diagnosis (*n* = 38)	
Stage I	34.3% (13)
Stage II	10.5% (4)
Stage III	28.9% (11)
Stage IV	26.3% (10)

Types of ovarian cancer (*n* = 38)	
Borderline tumour	18.4% (7)
Epithelial (unspecified)	18.4% (7)
Epithelial (high-grade serous)	44.7% (17)
Epithelial (low-grade serous)	5.3% (2)
Epithelial (mucinous)	2.6% (1)
Epithelial (endometrioid)	2.6% (1)
Fallopian tube cancer	2.6% (1)
Sex cord-stromal ovarian cancer	5.3% (2)
Other	0

Treatment status (*n* = 38)	
In remission	52.6% (20)
Receiving palliative care	26.3% (10)
Undergoing treatment for newly diagnosed ovarian cancer	13.2% (5)
Undergoing treatment for recurrent ovarian cancer	7.9% (3)

FIGO – International Federation of Gynaecology and Obstetrics women (28, 77.8%) reported that in deciding which treatments (if any) they would take to control their ovarian cancer, the opinion of the doctor would mostly affect their decision. Only a few patients (4, 11.4%) stated that they wanted to get a second opinion about their ovarian cancer and treatment, and one chose not to answer. A large percentage (29, 82.9%) felt no need to, and two (5.7%) had not considered getting a second opinion.

Informational needs

When asked about their knowledge of ovarian cancer before diagnosis, only nine (25.0%) had heard of or knew something about ovarian cancer before they were diagnosed. A large percentage (26, 72.2%) had no knowledge of ovarian cancer (Figure 1). Only half of patients (18, 50.0%) were aware that having blood relatives with ovarian, breast, pancreas, prostate, bowel, or uterine cancer might increase their risk of developing ovarian cancer.

When asked if they felt in need of information since being diagnosed, most women who responded (*n* = 35) wanted to know more about ovarian cancer in general (20, 57.1%) and treatments for their cancer (16, 45.7%). Just over a quarter of women (9, 25.7%) felt they did not need more information, and only seven (20.0%) wanted more detail about survival and prognosis.

With the option of choosing up to two answers, the most important sources of information were identified as the

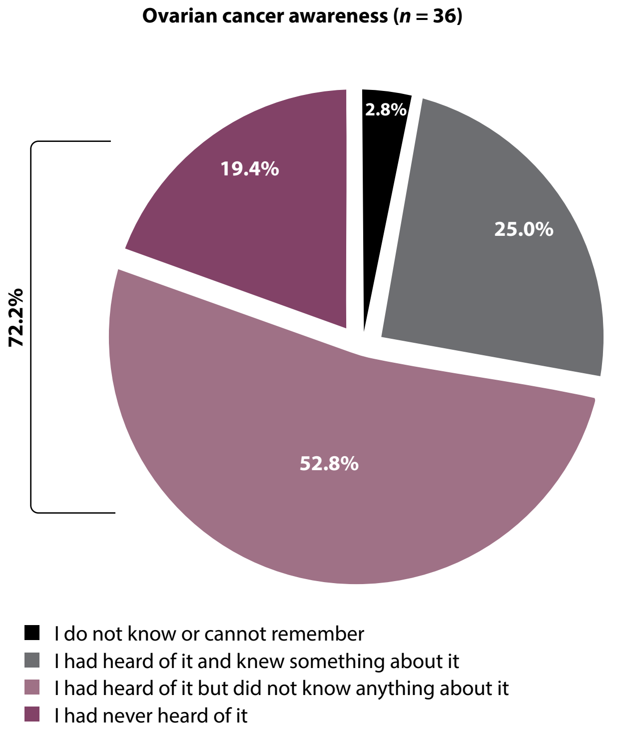

Figure 1: Women's answers when asked, "Before you were diagnosed with ovarian cancer, how much, if anything, did you know about ovarian cancer?"
n – number

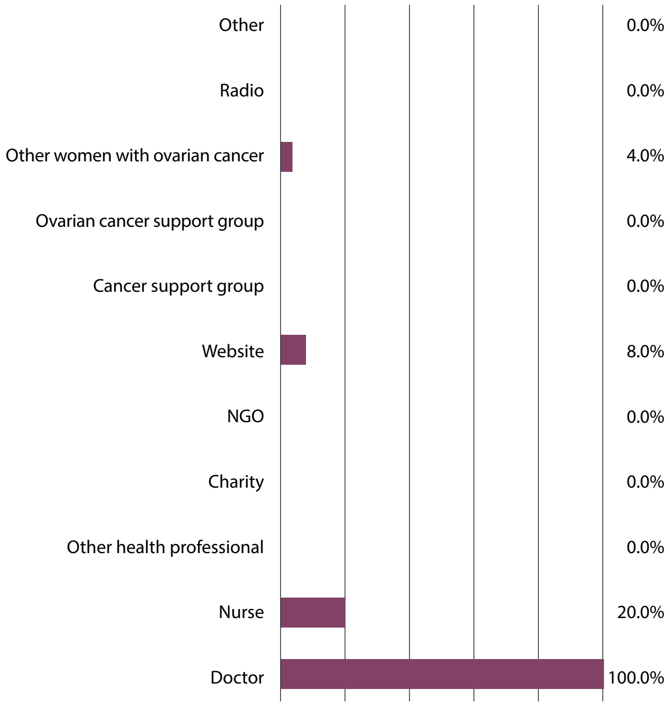

Figure 2: Chosen answers of most important information sources for women with ovarian cancer
n – number, NGO – non-governmental organisation

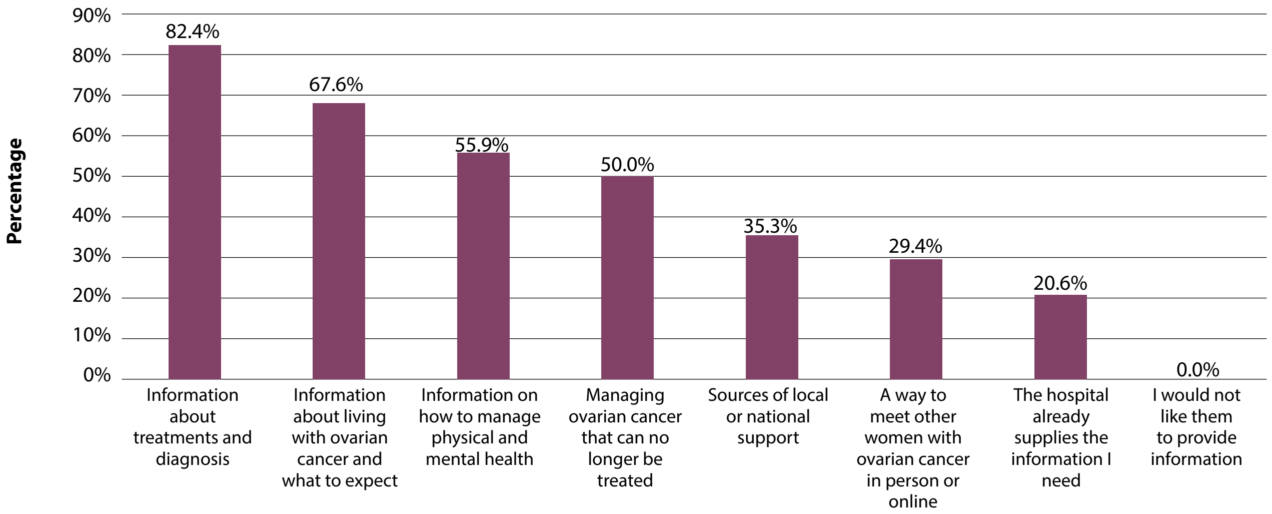

Figure 3: Women's answers about what information their hospital should share about living with ovarian cancer
n – number

attending doctor (25, 100%), nurse (5, 20.0%), and other women with ovarian cancer (1, 4.0%) (Figure 2). Of the 26 women who responded, nine women (34.6%) used the Internet to search for information, and only four (15.4%) felt that they found good information in their language of choice on the Internet. Three patients (11.5%) responded that they did not have Internet access. When they needed it, 11 women (42.3%) found the information they needed from available sources. The same number (11, 42.3%) felt they only "sometimes" found information, three (11.5%) only "minimal" information, and one patient (3.8%) answered that she did not find information at all.

A large percentage of women (28, 82.4%) indicated that their hospital should provide information about diagnosis and treatments. A further 23 women (67.6%) wanted details about what to expect while living with ovarian cancer. Only seven (20.6%) felt their hospital had already supplied the necessary information (Figure 3).

Women were asked if they had ever met or talked with another woman or group of women with ovarian cancer since their diagnosis. Many (27, 75.0%) had never talked to other survivors. Some (7, 19.4%) had talked to others in person, one (2.8%) had talked on the telephone, one (2.8%) communicated online in a social media setting, and two (5.6%) as part of a cancer group with other ovarian cancer survivors. When directly asked, 14 (38.9%) wanted to meet with other women with ovarian cancer, while the same number (14, 38.9%) did not want to, and eight (22.2%) were not sure.

Discussion

We wanted to identify the informational needs of women with ovarian cancer in a LMIC setting to improve patient awareness, counselling, and conveyance of information by healthcare workers.

Awareness

Alarmingly, many respondents in this study had never heard of or knew anything about ovarian cancer before their diagnosis, corresponding to published data. Internationally, awareness of ovarian cancer and its symptoms is low.[8] In the 2018 EWS (in HICs), only 18 out of 100 women had heard of ovarian cancer before their diagnosis.[4] Due to this lack of awareness in our study population, large-scale efforts to improve education regarding ovarian cancer and its symptoms are necessary to decrease delays in diagnoses, especially in LMICs. If patients were more aware of this disease, they would have presented for help earlier and been less tolerant of delays from healthcare centres. With increased awareness, clinicians would also better determine who needs prompt investigation and referral.

Despite being diagnosed and already aware of ovarian cancer, half of the women in this study were not aware that having blood relatives with cancer put them at higher risk. Had they known the genetic risk, some women may have presented for help earlier. Patients who are well informed can encourage relatives to present their symptoms promptly, further decreasing the numbers of not only ovarian cancer but also other familial or genetic cancers. Clinicians are reminded of the importance of taking a complete family history when speaking to cancer patients. Oncology providers at TBH should be trained to identify patients and family members with an increased genetic risk for certain cancers to refer them for appropriate genetic counselling promptly.

Sources of information

In this group of women, less than half searched the Internet for information, and it is apparent that Internet access in a LMIC could still be challenging. Only a small percentage (15.4%) felt they could get the information in their language of choice on the Internet. Of those who answered, about one out of ten reported not having Internet access. Although an upward trend is seen, there was an estimated 21.1% of households in South Africa without Internet access in 2022, and efforts to bridge this digital divide are ongoing.[9] Access to the web improves social support because connectivity to cancer support structures can be reached via online health communities.[10]

Although the Internet may be beneficial, it can also be detrimental in certain scenarios. Despite the large amount of health data online, there is also an unsettling expansion of misleading and irrelevant health information. The information conveyed electronically tends to be generalised and not individualised for a specific patient's condition.[11] The wrong information could negatively impact the patient's understanding of their disease, acceptance of treatment, and overall well-being. Searching the Internet cannot be the primary source of information for cancer patients. Doctors should adequately counsel all patients, especially Internet-misinformed patients, as they have specialised and individualised information for each of their patients.[12] Fortunately, all women that answered in this group considered their doctor and nurse as the most important sources of information.

In this study, all responders answered that their hospital should provide information about their condition; therefore, treatment centres must provide this. The treating doctor's opinion was also found to be the major influencer in patients' decisions of treatment acceptance. By building a relationship with the patient based on trust, compassion, and empathy, nurses and doctors appear to lessen the unmet informational needs of cancer patients.[13]

Healthcare workers should be trained appropriately to counsel and inform patients adequately using empathic communication techniques. Patients specifically request that clinicians keep in mind the specifics of their personal history and values, inquire about psychosocial problems, and provide information in a way that conforms to their preferences.[7] Physicians must be able to communicate diagnosis, prognosis, and treatment options to patients clearly and concisely. This is especially relevant to ovarian cancer, where determining the best course of therapy can have a significant impact on morbidity, mortality, and patient quality of life.[14]

Informational needs

A large percentage of women in our study (42.3%) found the information they needed when needed, a higher percentage than in the 2018 EWS in HICs. The numbers in this study varied from country to country, ranging from 4.2% in Japan to 34.7% in Italy. One in five women in the EWS (in HICs) said they found all the information they needed at any time (19.7%).[4] The slightly higher number in our study could reflect better communication from attending clinicians and an increased awareness by the clinician that patients might have less access to other sources of information. It could also be due to limited numbers and because patients are from a smaller geographic area.

There remains a significant unmet need for information, and our aim should be that *all* women can find information when they need it. Women who feel they have access to cancer information can cope better mentally and physically during their cancer journey. This has a significant impact on how they rate their quality of life.[4]

Survival

Unfortunately, there are often differences in how cancer patients and their doctors view their cancer and the potential survival rates. Discussing the prognosis is reported to be important to all ovarian cancer care providers.[14] We found only a small number of patients in this study who wanted to know more about this topic. Published data shows larger percentages of patients desiring this information than those reflected in our surveys.[14]

Once diagnosed with advanced disease, discussing the patient's road ahead, especially end-of-life care, has multiple benefits.[7] Gynaecological oncology providers need to be sympathetic to the individual ovarian cancer patient's expectations about survival and quality of life. They should be proactive in timely and appropriate palliative care discussions throughout the cancer journey.

Patient support

Although we found a clear need for women to have opportunities to meet with other women with ovarian cancer, a large part of this group of women (75%) had never talked to other ovarian cancer patients. Very few communicated electronically. Regrettably, only two had spoken with other women with ovarian cancer in an ovarian cancer survivor group. In the EWS in HICs, most women stated that they prefer to be in support groups for women with ovarian cancer than for women with other malignancies.[4] Women could be enormous sources of support to each other in emotional, informational, and practical ways. Clinicians can assist in connecting interested patients with local or online ovarian cancer support groups. Charities and survival groups could play an important role in providing information. It also expands the opportunity for the patient and family members to raise their voices for good advocacy and collaboration. An important opportunity for TBH to establish an ovarian cancer support group was identified.

Limitations

One of this study's limitations is that this is a selected group of patients attending treatment or follow-up visits, not the entire group of patients who were diagnosed with ovarian cancer in the last five years attending the above clinics. There might remain a group of patients not attending in the above time frame or, unfortunately, demised, whose answers remain unknown. Another limitation of this study is that participants could have had recall bias while answering the surveys. The overall number of respondents in this study is low, reflecting the lower incidence of this disease in the population compared to other gynaecological cancers. This, and the fact that patients who have demised are not included should be considered when looking at patient characteristics and clinical data.

Conclusion

Ovarian cancer is the gynaecological cancer with the lowest survival numbers; it is difficult to diagnose, and no proven screening programme has shown benefit.[2] Early detection through increased awareness of the disease can improve outcomes.[7] Patients can encourage family members to undergo screening or seek help for symptoms if they know that their diagnosis puts them at higher risk, which in turn can improve other cancer outcomes. Cancer care workers should be reminded of the importance of counselling and talking to patients about their disease. Greater patient-centred communication is associated with better quality of life in patients with ovarian cancer.[7]

If we are expecting a rise in ovarian cancer numbers, we should be increasing awareness of this disease. Patients should carry knowledge of worrying symptoms. Healthcare workers should be reminded of signs so patients can get help promptly. Without being aware of the disease, we are unable to decrease patient morbidity and mortality. Without being aware of the possible quality of life issues ovarian cancer patients face, healthcare workers cannot assist them. With knowledge comes the power to fight ovarian cancer and improve our patients' quality of life.

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Conflict of interest

The authors declare no conflict of interest.

Funding source

Participants did not receive any payments or benefits and were treated according to the standard of care. TBH will receive an honorarium of recognition for engagement in this study from the World Ovarian Cancer Coalition.

Ethical approval

The study protocol was approved by the Health Research Ethics Committee of Stellenbosch University (HREC S23/03/049), and permission to conduct the research was obtained from TBH management. No previous submissions or publications of this manuscript have been made.

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ORIGINAL RESEARCH

Identifying the informational needs, challenges, and opportunities to improve quality of life for women with ovarian cancer at Tygerberg Hospital in Cape Town, South Africa

Appendix A

Trifold brochure for patients: general information

Types of Ovarian cancer

The types of ovarian tumours are named after the type of cell in the ovary they come from:

- Epithelial cancer (called carcinomas)
- Germ cell tumours
- Sex cord stromal tumours

Other types include:

- Borderline tumours (ovarian pre-cancers)
- Metastases (spread from other sites)

Symptoms

Symptoms of ovarian cancer are very subtle and non-specific. They can also be experienced by women who do not have ovarian cancer. Other causes of symptoms usually need to be ruled out first. Most women experience multiple symptoms for longer periods of time. Some of these include:

- Bloating
- Difficuty eating/feeling full quickly
- Pain in pelvic area
- Urgent/frequent urination
- Loss of appetite or weight
- Change in bowel habits

Risk factors

- Increasing age, mostly over 50 years
- Family history of breast, ovary or womb cancer
- Genetic mutations, like BRCA

How can the risk be reduced?

If you don't have ovarian cancer, the following can reduce the risk, but there is no way to prevent ovarian cancer completely.

- Removal of ovaries and tubes
- The contraceptive pill
- Pregnancy and breastfeeding

Genetics

Anyone with ovaries can be affected.

Patients with a family history of ovarian, breast or related cancers are encouraged to inform their doctor to enquire if they are eligible for genetic counselling and testing

Testing and detection

There is no routine screening test to accurately detect ovarian cancer before symptoms occur.

Cervical screening (Pap smear) cannot detect it.

If you experience the above symptoms, your doctor may do a pelvic exam and use tests like a transvaginal ultrasound and a blood test to investigate. In some cases, a CT scan can be used. The only way of confirm a cancer diagnosis is through sending fluid, tissue or removing the ovaries.

Treatment

Your treatment will depend on

- the type of ovarian cancer
- the location and spread (stage)
- your general health

The main treatments include surgery and chemotherapy.

Surgery

If you have early stage disease, you may have surgery to remove both ovaries, the fallopian tubes, the womb and cervix. If the cancer has spread outside the ovaries, you might need more extensive surgery.

Chemotherapy

Medicine that is given through a drip into your veins. It may be given before and/or after surgery. It may also be given alone or when the cancer has come back.

Possible side effects

Surgery

Some pain can be experiencd at your wound site, some vaginal spotting. Infections at your wound or bladder, bloodclots in legs or lungs. Your doctor will give you medication to treat pain and injections in the hospital to prevent bloodclots.

Chemotherapy

Some, but not all, may experience nausea, fatigue , diarrhoea, some hair loss or tingling in hands or feet. Inform your doctor as they can assist in treating this.

What can you expect?

Surgery

You will be admitted the day before your surgery. You will be counselled on the type of surgery and risks and sign consent. You are welcome to ask questions about your surgery. After surgery you might stay in the hospital for a few days. You will go home when your doctors feel you are ready. We will see you at our clinic about 3-4 weeks later

Date _______________

We will check your wounds, give you the results of the surgery and discuss if further treatment, such as chemotherapy. is required.

Chemotherapy

Medication that is given in a drip in your arm. It is used to kill cancer cells throughout your body. You will be given an appointment in the Oncology building. The doctors will explain the process, you will sign consent. You will get the medicine in a drip and will go home on the same day.

TIPS

Eat a healthy diet with protein
Drink 2L water per day
Stay mobile and try to walk around
Contact your nearest hospital/clinic if you have fever, leg swelling, severe bleeding, pain, or shortness of breath

About you

Ovarian cancer type:

Treatment plan:

Surgery-

Chemotherapy-

Admission- Date
Time
Place

Clinic appointment-

You can do this!

Contact us

Gynaecologic Oncology Clinic
Tygerberg Hospital
Room 30, 3rd Floor
021 938 4428

Ovarian Cancer

Overview

"Ovarian cancer" is an umbrella term for different types of cancer that affect the ovaries, fallopian tubes and peritoneal lining. There are multiple subtypes of ovarian cancer and a wide variation of incidence and treatments between these types.

Appendix B

Trifold brochure for patients: living with ovarian cancer

Living with ovarian cancer

Your feelings

It is completely normal to feel multiple emotions when you are diagnosed with cancer. You might feel strong feelings like shock and not believing what is happening. Some women also feel scared, confused, sad, angry and uncertain. You might go through these all or some of these emotions and it may change daily.

TIPS

- Try to stay positive. It is not always easy but it can help you to cope if you try to keep your thoughts positive.
- If you are uncertain of something or uncomfortable, talk to your doctor or nurse about it.
- Identify a support network or someone you trust to talk to.
- If you are experiencing feelings of overwhelming sadness, tell someone about it so that they can help you.

CANSA support
0800 22 6622
Whatsapp 0721979305
info@cansa.org.za

Care for cancer
031 836 8302
admin@careforcancer.org.za

Your body

Some of the issues women with ovarian cancer face may affect their self esteem and body image.

- Hair loss

Chemotherapy can cause you to lose your hair. Some people feel very upset or depressed about this and that is totally normal. Tell the people who you love how you feel and remember it does not change who you are.

- Surgery

Having your womb, cervix and ovaries removed can be a very emotional experience for women. It will also leave a scar that will fade over time.

- Hormonal changes

You will go through menopause if you have not yet and may experience symptoms like hot flushes and moodiness. Discuss this with your doctor.

- Tiredness

It is normal to feel tired at times. Resting and some light exercise like walking can help.

Practical things

There are some things to think about and discuss with your family:

- work and sick leave
- finances or application for a grant
- travel to and from the hospital/clinic
- child care
- changes to your house

Talk to your doctor to find out who can help.

You are not alone!

Things to think about and discuss with your doctor and family

What are your important goals at the moment?

What are your fears and worries?

What gives you strength as you think about the future?

What abilities are crucial to your that you won't want to live without?

How much are you willing to go through for the possibility of gaining more time?

Is there anything you still want to do, realistically?

Coping if your cancer can't be cured

Finding out your cancer can't be cured can very distressing. A lot of people feel uncertain and scared of what is to come.

You should talk to your treating doctor as they are the best person to tell you what your outlook is. They can tell you what the stage of the cancer is or how much it has spread. Even though a cancer cannot be cured, there is usually some treatment that can make you feel better.

Some treatments can often control the cancer and relieve symptoms. It is important to tell your doctors or nurses what is bothering you so that they can assist.

"How long do I have to live?"

Not everyone wants to talk about this and that is OK. If you want to discuss this to plan ahead, ask your treating doctor about it.
Remember that your doctor won't be able to give you an exact answer. Everyone is different and the time given is just an estimate.

In ovarian cancer it depends on many factors like the stage, your condition, previous treatments and how well they worked.

Living with cancer
livingwithcancer.co.za
connect@livingwithcancersa.co.za

Look good feel better
lgfb.co.za
011 795 3927
0866815510
info@lgfb.co.za

Talk about it

Your friends and family could help and support you during this journey. It helps them to know how they can assist you, even if it is with something small.

Understand if they feel uncomfortable or emotional and tell them that you would like to discuss what is happening to you.

It might also be easier for you to talk to someone else. Let your doctor know if you would like counselling or referral to a social worker.

We are in this together!

Living with
Ovarian
Cancer

Appendix C

Eligibility criteria form for administrators

Questions filled in by the administrator	
Unique identifying number	…………………..
EQ1	**Is the patient normally a resident of this country?** Yes, and was diagnosed here Yes, but was diagnosed in another country (enter the country of diagnosis) No, but was diagnosed here No, was diagnosed elsewhere and has travelled for treatment (enter the country of diagnosis) ……………………………………………………
EQ2	**When was the patient diagnosed with ovarian cancer?** Diagnosis month: …………………..Diagnosis year: …………………..
EQ3	**What age was the patient when she was diagnosed with ovarian cancer?** ………………….. (number)
EQ4	**What type of ovarian cancer was the patient diagnosed with?** Epithelial ovarian cancer (unspecified) Epithelial (clear-cell) ovarian cancer Epithelial (high-grade serous) ovarian cancer Epithelial (low-grade serous) ovarian cancerEpithelial (endometrioid) ovarian cancer Epithelial (mucinous) ovarian cancer Germ cell ovarian cancer Sex cord-stromal ovarian cancer Primary peritoneal ovarian cancer Fallopian tube cancer Granulosa tumour of the ovary Borderline tumour Teratoma of the ovary If the patient has another type of ovarian cancer or an additional type of ovarian cancer, please enter it here:……………………………………………………
EQ5	**What form of staging of the patient's cancer has taken place?** Surgical or pathological stagingClinical staging (based on physical exam, biopsy, and imaging) Clinical opinion only I do not know
EQ6	**What stage was the ovarian cancer diagnosed at? Select the answer which best describes the stage.** ***FIGO stage I (T1, N0, M0), tumour limited to the ovaries (one or both)*** FIGO stage IA (T1a, N0, M0) FIGO stage IB (T1b, N0, M0) FIGO stage IC (T1c, N0, M0) ***FIGO stage II (T2, N0, M0), tumour involves one or both ovaries with pelvic extension below the pelvic brim*** FIGO stage IIA (T2a, N0, M0) FIGO stage IIB (T2b, N0, M0) ***FIGO stage III, tumour involves one or both ovaries with microscopically confirmed peritoneal metastasis outside the pelvis/retroperitoneal lymph node involvement*** FIGO stage IIIA (T1 or T2, N1, M0) or (T3a, N0 or N1, M0) FIGO stage IIIB (T3b, N0 or N1, M0) FIGO stage IIIC (T3c, N0 or N1, M0) ***FIGO stage IV, distant metastasis including cytology-positive pleural effusion, liver or splenic parenchymal involvement, extra-abdominal organ involvement, including inguinal lymph nodes, transmural intestinal involvement*** FIGO Stage IVA (Any T, Any N, M1a) FIGO Stage IVB (Any T, Any N, M1b) I do not know
EQ7	**Is the patient currently:** Undergoing or recovering from surgery? Undergoing treatment for newly diagnosed ovarian cancer? Undergoing treatment for recurrent ovarian cancer? In remission? Receiving palliative care? Choosing not to receive treatment? Other?

EQ8	**Has the patient's ovarian cancer ever returned?** Yes No It never went away If the cancer returned, please enter the date it FIRST returned Recurrence month: …………………..Recurrence year: …………………..
Inclusion criteria **EQ9**	**Does the patient meet the inclusion criteria? (Tick all that apply)**The patient can give informed consent for participation in the study. The patient is biologically female, aged between 18 and 99 years. The patient has been diagnosed with ovarian, fallopian tube, or primary peritoneal cancer within the previous five years (of the date of completing the survey). The patient has already been informed of their diagnosis of ovarian cancer at a previous appointment and understands the diagnosis. All answers need to be selected to proceed.
Exclusion criteria **EQ10**	**Does the patient meet any of the following exclusion criteria? (Tick all that apply)**The patient is attending the hospital or clinic to receive their diagnosis of ovarian cancer.The patient is deemed too unwell to be able to cope with the demands of filling in the survey or responding to questions. The patient is identified as having mental health concerns, learning difficulties, or medical conditions such as dementia, delirium, or psychosis to the extent that they would be unable to cope with the demands of filling in the survey or responding to questions. The patient has already completed the survey on a previous visit to the hospital. The patient does not meet any of the exclusion criteria. If any of the exclusion criteria are met, the patient will be excluded from the study at this point. Please record the results on REDCap and the paper log. If the patient is eligible to participate, please complete the information below.

AQ2	**Which tests were undertaken at any point to decide if the patient had ovarian cancer? (Tick all that apply)** Clinical examinationCA-125 blood test Abdominal ultrasound Transvaginal ultrasound MRI scan CT scan X-ray Other I do not know
AQ3	**Has the patient ever had surgery to treat or control their ovarian cancer?** No (go to AQ5) Yes, with complete tumour cytoreduction to no gross residual disease and all macroscopic residual disease removed (This definition is in line with the ASCO Stratified Guidelines for Ovarian Cancer, Vanderpuye et al. 2021) Yes, but not with complete tumour cytoreduction to no gross residual disease and all macroscopic residual disease removed
AQ4	**Has the patient ever had any of the following? (Tick all that apply)** Chemotherapy before first surgery (neoadjuvant chemotherapy)A second operation because the first operation did not remove enough of the cancerA second operation for a recurrence of ovarian cancer
AQ5	**Has the patient ever had chemotherapy to treat or control their ovarian cancer?** Yes No(If no, go to AQ7)
AQ6	**Which chemotherapy drugs has the patient been treated with at any point since their diagnosis of ovarian cancer? (Tick all that apply)** Carboplatin Cisplatin Paclitaxel (Taxol)Pegylated liposomal doxorubicin hydrochloride (Caelyx, Myocet, Doxil) Gemcitabine Trabectedin Topotecan Etoposide Cyclophosphamide Bleomycin Other

AQ7	**Has the patient ever been tested to find any genetic mutations?** Yes, pre-diagnosis Yes, post-diagnosis No, they have not, but it is available in this country No, it is not available in this country (If no, go to AQ9)
AQ8 (if answered yes to AQ7)	**Which genetic mutation was found?** BRCA1 BRCA2 Lynch syndrome Other No genetic mutation was found
AQ9	**Has the patient ever received one or more of the following hormone treatments? (Tick all that apply)** Tamoxifen Anastrozole Letrozole These drugs are not available
AQ10	**Are any of the following treatments available in your country, either routinely or occasionally? (Tick all that apply)** Intraperitoneal chemotherapy Hyperthermic chemotherapy Bevacizumab Olaparib Rucaparib Niraparib None of these treatments are available
AQ11	**If any of the above treatments were selected, has this patient ever received any of them as part of her treatment in your country? (Tick all that apply)** Intraperitoneal chemotherapy Hyperthermic chemotherapy Bevacizumab Olaparib Rucaparib Niraparib I don’t know

Appendix D

Informed consent and survey in English

This hospital (Tygerberg) is participating in a research study called the Every Woman Study™ in low- and middle-income countries, and we would like to invite you to participate. The study aims to identify the challenges and opportunities to improve survival for women with ovarian cancer. It does not involve you trying new medicines or procedures; it is a survey that will take at least 20 minutes to complete. It will ask about any symptoms you experienced, how you were diagnosed, your needs since diagnosis, and where you would like to see improvements in the diagnosis and care of women with ovarian cancer.

You do not have to participate in the study. It is entirely voluntary, so you can choose not to participate. The care you receive here will not be affected in any way. If you decide to participate and then change your mind, that is also fine.Your answers will be joining those of over two thousand women from 31 countries around the world, and together, they will help prioritise improvements in the diagnosis and care of women with ovarian cancer at this hospital, in this country, and more widely in other low- and middle-income countries.

The study is supported and funded by the World Ovarian Cancer Coalition (WOCC) and the International Gynaecologic Cancer Society (IGCS). These two international organisations do not aim to make any profit; they are partners with hundreds of members, survivors, and other partner organisations around the world. Through their own work and with this joint study, both organisations are committed to ensuring that women who have ovarian cancer get the best possible care, no matter where they live.

Risks and benefits of participation

Study participation will not directly benefit you. However, many women find it beneficial to share their experiences with others. The study's findings may help this hospital improve its care in the future and may impact policy changes, benefitting women with ovarian cancer in your country.

Occasionally, some women may find it upsetting to think about their experiences, but please be assured that the doctors will help where they can and will provide referrals for additional support. Please share with the doctor who gave you this survey if you are experiencing any distress. She can refer you to a social worker for a same-day consultation and counselling or assist in making a psychologist appointment if needed. If you leave and you feel distressed later, you can contact the Gynaecology Oncology Clinic at (021) 938 4428 from 08:00 to 16:00 during weekdays.

You do not have to provide an answer to every question, but we hope you will want to provide as many answers as possible.

You will be asked to fill in the survey on paper in the hospital or clinic setting, or if you'd prefer, someone could ask you the questions, and that person will make a record of your answers.

Whilst we will have to retain a separate paper record of your name and unique identifier number, your name will not be uploaded to the study electronic database with any of your answers. This means you will not be identifiable from your answers. In September 2023, we will destroy any physical information that links your name to your study number. If you change your mind about participating in the study, you can withdraw your consent by telling a member of your hospital team. They will use your unique identifier number to extract your answers from the study. You can do this at any point up to 30 September 2023.

Please enter your unique identifier number (UIN)

……………………………………………………

(paper copy only)

Please select only ONE of the following statements:

- I have understood the purpose of this study and my role in it. I give my consent that the researchers may use my answers (not linked to my name) as part of the study.
- I have understood the purpose of this study and my role in it. I consent to the presence of the survey administrator for the purpose of facilitating my participation in the study.
- I still have some questions about the study I would like answered before I decide.
- I have understood the purpose of this study and what you are asking me to do. However, I do not consent to participate.

If you would like to share the reason for this, please do so here:

Patient signature and date: (*for paper copy only)*

Unique identifier number (UIN)……………………………………………………

Administrator signature and date: *(for paper copy only)*

Who to contact?

If you have any questions about the study, you may ask them now. If you agree to participate in the study, you can contact the persons listed below at any time should you have further questions or feel any distress from completing this survey.

Dr Celeste van Drunick

Principal investigator

Department of Obstetrics and Gynaecology

Tygerberg HospitalPhone: 021 938 4428

Email: celestevd1@gmail.com

OR

Dr Jennifer Butt

Consultant in Gynaecological Oncology

Department of Obstetrics and Gynaecology

Tygerberg Hospital

Phone: 021 938 4428

Email: jbutt@sun.ac.za

Survey

About you	
Q1	**Are you filling in this questionnaire about your own experience of ovarian cancer?** Yes (go to Q2) No (go to Q1A)
Q1A (if answered no to Q1)	**If you are filling in this questionnaire with someone who has ovarian cancer, what is your role?** Doctor/trainee doctor/nurse/trainee nurse/researcher/social worker/other (please specify) The questions that follow are those that you should ask the woman with ovarian cancer about her experience. Other than a simple explanation, please ensure you do not suggest which answers they should give.
Q2	**Please indicate your ethnicity:** By ethnicity, we mean your feeling of belonging and attachment to a distinct group of a larger population that shares ancestry, colour, language, or religion. You may select more than one option. White Black Mixed descent Asian Other Prefer not to disclose/rather not say
Q3	**On average, how long does it take you to travel to the hospital where you are seen regarding your ovarian cancer?** Under 15 minutes15–30 minutes 30–60 minutes 1–2 hours 2–5 hours Over 5 hours Over 24 hours
Q4	**What is the highest level of education you have achieved?** No formal education Primary education (childhood, elementary, early years, ISCED level 1) Secondary education (middle school, high school, ISCED levels 2 and 3) Post-secondary, non-tertiary education (technical college, community college, ISCED levels 4 and 5) Tertiary education (university or similar professional skills, ISCED level 6) Postgraduate education (university master's, doctorate, or senior professional qualification, ISCED levels 7 or 8)
Q5	**Just before you were diagnosed with ovarian cancer, were you:** Married or living with a partner? Widowed? Divorced or separated? In a relationship but not living together? Single (never married)? Prefer not to say?
Q6	**Just before you were diagnosed, in your view, what was your household income?** Below average for your country Average for your country Above average for your country Prefer not to say
Q7	**Around the time of your diagnosis, did you have any caring responsibilities for others in your family? (Tick all that apply)** Yes, a child or children under the age of 18 Yes, an elderly relative Yes, a sick partner Other No, I have not had caring responsibilities

Q8	**Just before you were diagnosed with ovarian cancer, were you:** In paid full-time employment? In part-time employment? Self-employed? Not paid or self-employed? Retired? Other?
Q9	**How have you paid for your medical care/ovarian cancer care up to this point? (Tick all that apply)** Private medical insurance State medical insurance I have paid Family members have paid I have raised money to cover costs by crowdfunding I have sought financial help from a non-profit/non-governmental organisation (NGO)/charity Treatments for ovarian cancer are free Diagnostic tests for ovarian cancer are free
Q10	**In relation to your gynaecological history before you were diagnosed with ovarian cancer: (Tick all that apply)** I had entered menopause, where I no longer have monthly periods I have never given birth to a child I have given birth once I have given birth twice I have given birth three or more times I breastfed my children I used the oral contraceptive pill for up to five years I used the oral contraceptive pill for between five and ten years I received treatment for infertility

Family history	
Q11	**Have any of the following family relatives (i.e. blood relatives on your mother's or your father's side of the family) had ovarian cancer? (Tick all that apply)** Mother Daughter Sister Aunt Cousin Grandmother (mother's side) Grandmother (father's side) Other more distant relatives (mother's side) Other more distant relatives (father's side) No, none of my close family have been affected I do not know or cannot remember
Q12	**Have any of the following family relatives (i.e. blood relatives on your mother's or your father's side of the family) had breast cancer? (Tick all that apply)** Mother Father Daughter Son Sister Brother Aunt (either side) Uncle (either side) Cousin (either side) Grandmother (either side) Grandfather (either side) No, none of my close family have been affected I do not know or cannot remember
Q13	**Are you aware that having blood relatives with ovarian, breast, pancreatic, prostate, bowel, or womb cancer might increase the risk of a woman developing ovarian cancer?** Yes No Not sure

Leading up to the diagnosis	
Q14	**Before you were diagnosed with ovarian cancer, how much, if anything, did you know about ovarian cancer?** I had heard of it and knew something about it I had heard of it but did not know anything about it I had never heard of it I do not know or cannot remember

Q15	**Before your diagnosis of ovarian cancer, which, if any, of the following symptoms did you experience? (Tick all that apply)** Pain in the abdomen (stomach) Urinary frequency Difficulty eating Changes in bowel habit (e.g. diarrhoea or constipation) Extreme fatigue Increased abdominal size Feeling full Unexplained weight loss Urinary urgency Pain in the pelvis Persistent bloating Other symptoms(If you selected any of the above options, go to Q17) None of the above (go to Q16)
Q16 (only if answered none of the above in Q15)	**As you did not experience the symptoms outlined in the previous question before you were diagnosed, what led to your diagnosis? (Tick all that apply)** A routine examination A routine scan A routine blood test The cancer was discovered whilst I was being treated for something else Other (Now go to Q27)
Q17 (for women with symptoms listed in Q15)	**When did you first notice any of the symptoms selected above?** Please enter the month and the year. If you do not remember, please leave this blank. ………………….. (month symptoms began) ………………….. (year symptoms began)
Q18	**How concerned about your symptoms were you before your diagnosis?** Concerned Somewhat concerned Not very concerned Not at all concerned I do not know or cannot remember
Q19	**Did you seek advice from someone about your symptoms, for example, a doctor, nurse, pharmacist, or healer?** Yes (go to Q21) No (go to Q20)
Q20 (i f answered no to Q19)	**As you did not seek advice from someone about your symptoms, what led to your diagnosis? (Tick all that apply)** A routine examination A routine scan A routine blood test The cancer was discovered whilst I was being treated for something else Other (Go to Q26)
Q21	**Which type of person, other than a family member, did you first seek advice from about your symptoms? (Select only ONE answer)** A local healer An alternative health practitioner A family doctor A gynaecologist A gynaecologic oncologist (a doctor specialising in the treatment of ovarian cancer) A gastroenterologist An emergency room or accident and emergency doctor A nurse A pharmacist Someone else
Q22	**In addition to the first person you sought advice from about symptoms, who else did you visit or talk to about your symptoms in the time before you were diagnosed? (Tick all that apply)** A local healer An alternative health practitioner A family doctor A gynaecologist A gynaecologic oncologist (a doctor specialising in the treatment of ovarian cancer) A gastroenterologist An emergency room or accident and emergency doctor A nurse A pharmacist A family member Someone else No one else

Q23	**When did you first visit a medical doctor about your symptoms?** Please enter the month and the year. If you do not remember, please leave this blank. ………………….. (month visited a medical doctor for symptoms) ………………….. (year visited a medical doctor for symptoms)
Q24	**In your view, how seriously did the medical doctor you first saw take your concerns about your symptoms?** Very seriously Fairly seriously Not very seriously Not at all seriously I do not know or cannot remember
Q25	**Approximately how many times did you talk to or visit medical doctors (any type of doctor, not just the one you saw first) before you were told you had ovarian cancer?** If you cannot remember, please leave this blank ………………….. (enter a number)
Q26	**Do you feel that the time from you first experiencing symptoms to being diagnosed with ovarian cancer could have been shortened?** Yes No Not sure Please use the COMMENTS box to let us know how you think the time could have been shortened (e.g. doctor delay, health system delays such as having to wait for tests or appointments) or factors that may have delayed your seeking help.
Q27	**When were you told by a medical doctor that you had ovarian cancer?** Please enter the month and the year. If you do not remember, please leave this blank. ………………….. (month told by a medical doctor you had ovarian cancer) ………………….. (year told by a medical doctor you had ovarian cancer)

Treatments for ovarian cancer	
Q28	**When did you first begin any treatment for ovarian cancer, such as surgery or chemotherapy?** If you cannot remember or have not had any treatment, please leave this blank. ………………….. (month treatment began) ………………….. (year treatment began)
Q29	**In deciding what, if any, treatments you will have to control your ovarian cancer or deal with side effects from treatment, which of the following will affect your decision? (Tick all that apply)** The opinion of the doctor The opinion of my familyI will make up my own mind The cost of treatment drugs Other costs associated with treatment, such as transport or accommodation The chance for cure or to extend my life The treatment side effects(If you have selected any of the options above, please continue to Q30) None of the above (go to Q31)
Q30	**Which of the statements you selected in the previous question is most important in your decision-making? (Select only ONE answer)** The opinion of the doctor The opinion of my familyI will make up my own mind The cost of treatment drugs Other costs associated with treatment, such as transport or accommodation The chance for cure or to extend my life The treatment side effects
Q31	**Overall, do you feel as involved as you would like to be in decisions about your treatment throughout your cancer care, such as deciding which treatments or whether to have any treatment?** Yes, always Yes, most of the time Only sometimes Not at all I do not know or cannot remember

Q32	**Which, if any, of the following side effects of treatment for ovarian cancer have been most difficult to deal with at any point since you started treatment? (Select up to TWO answers)** I have not had any treatment (go to Q35) Tiredness or fatigue Anxiety Feeling or being sick (nausea or vomiting) Diarrhoea Loss of appetite Inability to fight infection Hair thinning or hair loss Dry skin Sore mouth Tingling or numbness in hands or feet Sleep loss Metal taste in mouth Constipation Allergic reaction Joint aches or pains Swelling Muscle aches or pains Menopausal symptoms Complications following surgery Another side effect(If you have selected any of the above, go to Q33) No side effects in particular (go to Q35)
Q33 (if they had side effects)	**Would you describe these most difficult side effects as "long-term"? (i.e. persisting for some weeks or months after treatment has ended)** Yes No I am still in treatment, so I cannot say if they are long-term I am not sure
Q34	**Have health professionals been able to help reduce the impact of side effects with other medicines or advice and information?** Yes, very much so Yes, to some extent Not at all I did not seek help, or I did not need to seek help about side effects I do not know or cannot remember
Q35	**Have you, at any time since your diagnosis, used herbal, complementary, or alternative treatments not prescribed by your doctor at the hospital to try to control your ovarian cancer or any pain caused by your ovarian cancer?** Yes, all the time Yes, at some point No, but I have thought about it No, not at all I do not know
Q36	**Have you ever wanted to get another opinion from a second doctor about your ovarian cancer and treatment?** No Yes, and I have been able to Yes, but I don't know who to ask I have not thought about it

Emotional support needs	
Q37	**Up to now, have there been times when you have felt in need of emotional support? (Tick all that apply)** At the time of diagnosis During treatment After treatment ended When the cancer returned When told the cancer was not curable Other(If you have selected any of the above, go to Q38) I have not needed any emotional support (go to Q42)
Q38 (if they have needed emotional support)	**Are there particular issues you have faced? (Tick all that apply)** Fear of the cancer returning Fear that treatment will not work Fear of dying Difficulty with getting back to "normal life" after treatment Partner or spouse leaving Other issues relating to family and friends Feelings of isolation Feeling unable to talk to others Loss of fertility Regaining sexual intimacy with a partner Coping with the menopause Dealing with stigma because of the cancer diagnosis Other(If you have selected any of the above, go to Q39) None in particular (go to Q41)

Q39	**Which issue have you found most challenging? (Select only ONE answer)** Fear of the cancer returning Fear that treatment will not work Fear of dying Difficulty with getting back to "normal life" after treatment Partner or spouse leaving Other issues relating to family and friends Feelings of isolation Feeling unable to talk to others Loss of fertility Regaining sexual intimacy with a partner Coping with the menopause Dealing with stigma because of the cancer diagnosis Other None in particular
Q40	**Regarding your emotional support needs, have you: (Tick all that apply)** Asked for help from a doctor or nurse? Been offered help from a doctor or nurse? Been offered psychotherapy by a psychologist? Asked for help from family or friends? Been offered help from family or friends? Asked for help from a charity or NGO? Been offered help from a charity or NGO?Asked for help from a religious organisation/person? Been offered help from a religious organisation/person? None of the above
Q41	**Have you been able to get the emotional support you needed?** Yes Yes, to some extent Not enough None
Q42	**Have you ever met and talked to another woman or group of women with ovarian cancer since your diagnosis? (Tick all that apply)** Yes, in person Yes, in person as part of a cancer group Yes, online (social media, chat room, forum) Yes, on the telephone No
Q43	**Would you like to be able to meet with other women who have ovarian cancer?** Yes No Not sure

Practical support needs	
Q44	**Which, if any, of the following forms of practical support do you feel you need, or have needed, because of your ovarian cancer diagnosis? (Tick all that apply)** Help with daily chores at home (e.g. shopping, cleaning, preparing food, gardening) Help with personal care (e.g. getting dressed, washing, wound care) Home adaptations (e.g. using a wheelchair, handrails) Help to care for dependants (parents, siblings, children) Help with transport, including travel to and from hospital Financial support Other(If you have selected any of the above, go to Q45) I have not needed any practical support (go to Q47)
Q45 (if they had support needs)	**Which, if any, of the following forms of practical support have you received following your diagnosis and treatment for ovarian cancer? (Tick all that apply)** Help with daily chores at home (e.g. shopping, cleaning, preparing food, gardening) Help with personal care (e.g. getting dressed, washing, wound care) Home adaptations (e.g. using a wheelchair, handrails) Help to care for dependants (parents, siblings, children) Help with transport, including travel to and from hospital Financial support Other
Q46	**Which group or person has given you the most practical support? (Tick all that apply)** Family member(s) Friends A charity A NGOA government agency A religious organisation or person A carer Someone else No one in particular

Q47	**Has having a diagnosis of ovarian cancer had an impact on your financial situation?** Yes, to a great extent Yes, to some extent Not much(If you selected any of the above, go to Q48) Not at all (go to Q49) I would prefer not to say (go to Q49)
Q48 (if there has been some financial impact)	**In what way has your financial situation been impacted by your diagnosis? (Tick all that apply)** I have been unable to work My household income has dropped below what we need to live on My family or I have had to pay for treatment or tests My family or I have had to spend extra money on travelling to or accommodation near the hospitalI have had to ask for financial help from family members I have had to ask for financial help from a charity or NGO I now find it hard to find the money for food, rent, and bills My partner has been unable to work because they care for me Other

Information needs	
Q49	**Since being diagnosed, have you felt in need of information about ovarian cancer? (Tick all that apply)** Ovarian cancer in general Treatments for ovarian cancer Coping with long-term side effects of treatment Clinical trials Genetic testing Living with ovarian cancer Reducing anxiety Symptoms that might indicate a recurrenceSurvival rates Managing ovarian cancer that can no longer be treated How to talk to family and friends Other(If you have selected any of the above, go to Q50) I have not needed any information (go to Q53)
Q50 (if they needed information)	**Have you found the information you needed when you needed it?** Yes, always Yes, sometimes Just a little information(If you have selected any of the above, go to Q51) Not at all (go to Q52)
Q51 (if they found some of the information)	**What have been the most important sources of information for you? (Select up to TWO answers)** Your doctor Your nurse Another health professionalA charity A NGO A government agencyA website An ovarian cancer support group (online or face-to-face) A cancer support group (online or face-to-face) Other women who have had ovarian cancerOther None in particular
Q52	**Have you ever searched for information on the Internet about your diagnosis? (Tick all that apply)** Yes, and found good information in my language Yes, but did not find any good information in my language Yes, but did not find useful information Yes, but found information that made me scared Yes, but I could not find information in my language I do not have easy access to the Internet Other No, I have not used the Internet to search for information
Q53	**If this hospital were able to provide women with information about living with ovarian cancer, what do you think it should include? (Tick all that apply)** Information about treatments and diagnosisInformation about living with ovarian cancer and what to expect Information on how to manage physical and mental health Managing ovarian cancer that can no longer be treated Sources of local or national support A way to meet other women with ovarian cancer in person or online The hospital already supplies the information I need Other I would not like them to provide information

Final questions	
Q54	**At this point in time, what factors indicate you have a good quality of life, given you are living with ovarian cancer? (Tick all that apply)** Feeling physically well Feeling mentally wellBeing able to work Being able to care for and support your family Not being a burden on your family Being able to maintain or have a physical relationship with your partner Being able to engage in hobbies and activities Being able to socialiseHaving a positive self-image Feeling in control of your life Being able to return to "normal" To be free from the fear of cancer Other
Q55	**Do you feel the COVID-19 pandemic has had an impact on your treatment and feelings regarding your cancer? (Tick all that apply)** I am or have been scared to visit a hospital I worry about catching COVID-19 I am worried the pandemic might affect my chances of getting treatmentI have worried about whether I should get a vaccine The COVID-19 pandemic has affected my treatment The COVID-19 pandemic contributed to a delay in my diagnosisIt has made me feel more isolated Other No, the pandemic has not impacted me in this way
Q56	**Would you be willing to consider taking part in a clinical trial, comparing new treatments to the normal standard of care if they were available at this or another hospital? (Tick all that apply)** I would not be interestedI would like to find out more information first I would be interested in taking part in a trial at this hospitalI would consider taking part in a clinical trial, even if it meant travelling to another hospital
Q57	**If money could be invested in improving the diagnosis and care of women with ovarian cancer in your country, which areas are most in need of improvement? (Select up to THREE answers)** Development of a screening programme to detect the disease before symptoms develop Ensuring women have free access to diagnostic tests Reducing delays in diagnosis Raising awareness of ovarian cancer and its symptoms Ensuring women have free access to treatmentsIncreasing the number of experienced surgeons Getting access to new drugs that are approved in high-income countries Ensuring women at risk of ovarian cancer are identified due to their family history Ensuring women can access clinical trials Funding for research Other
Q58	**Do you feel your government could do more to help women with ovarian cancer live a long and good life?** Definitely Yes, to some extent Not really They could not do any more
Q59	**Is there something that is particularly important to you about your experience of ovarian cancer that you would like toshare with the study team?**

Thank you so much for sharing your experiences.