Ovarian cancer prevention in high-risk population: the patient & previvor perspective

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Disclosures

- I have no conflicts of interests to disclose
Learning objectives

❖ To review the pathway to prevention for individuals at high risk for ovarian cancer, including current gaps and inequities

❖ To introduce Ovarian Cancer Canada’s national Prevention Task Force

❖ To highlight the important role that family doctors can play in preventing ovarian cancer

“I’m frustrated that I didn’t get genetic testing sooner. I would have moved forward with risk-reducing surgeries and maybe never would have gotten cancer.”
- Sheree, 44 years old -
You have a new 39-year-old patient with no health complaints who tells you that her paternal aunt and paternal grandmother were diagnosed with breast cancer in their early 40s. She is talking with you about birth control and wants a tubal ligation for permanent contraception as soon as possible. What would you do first?

a) Arrange booking for the tubal ligation
b) Discuss opportunistic salpingectomy instead of a tubal ligation
c) Refer this patient to genetic counselling
Who is at risk for ovarian cancer?

❖ Anyone born with ovaries is at some risk for ovarian cancer (~1.4% in the general population)
❖ However, certain individuals may have an up to 40% lifetime risk due to:

- **Family history** of specific cancers (ovarian, breast, endometrial, colorectal, pancreatic, prostate)
- **Ancestry** e.g., Ashkenazi Jewish
- **Inherited mutation** in a hereditary cancer gene (e.g., BRCA1/2)
- **Personal history** of breast cancer
- Endometriosis
- Increasing age
Prevention in high-risk population: a simplified view

1) Identify individuals who may be at increased risk for ovarian cancer

- Inherited mutation in ovarian cancer risk gene in close relative
- Relevant family or personal cancer history or ethnicity

2) Confirm ovarian cancer risk

- Timely referral to genetic counselling
- Genetic testing of hereditary cancer genes

3) Reduce ovarian cancer risk

- Timely referral to gynecologic surgeon
- Pre-surgical consult, surgery + after-care

Interviews/surveys with 60+ previvors, 29 genetics clinics and 15 gynecologic surgeons from across Canada have identified many gaps and inequities along this pathway.
Gaps & inequities in pathway to OC prevention

**Systemic Gaps**
- Lack of discussion on family history with family doctors
- Many not accessing counselling services?
- Limited counselling on psychosocial impact of testing
- Limited counselling on communicating genetic results with family members
- Lack of readily available information on surgeons performing risk-reducing surgery
- Limited counselling on recovery process, side effects of surgery and options for post-surgical care
- Few specialized clinics for risk-reducing surgery and menopausal management
- Need better adherence to age guidelines

**Regional Differences**
- Genetic testing criteria for women with OC and unaffected relatives
- Wait-times for genetic counselling and testing
- Unequal access to testing when no known familial mutation
- Path for Nunavut/NWT patients unclear

**Flowchart**
1. PRE-test genetic counselling
2. Genetic testing for OC risk genes
3. POST-test genetic counselling
4. Surgical referral if positive for a mutation in OC risk gene
5. Pre-surgical consult
6. Risk-reducing surgery
7. Post-surgical care/follow-up

- Who refers patient for risk-reducing surgery
- Wait-times for consult and surgery
- Care of women found to have an isolated pre-cancer lesion
Gaps & inequities: Lack of discussion on family history of ovarian or related cancers with family doctors

Preivor discussed family history with their family doctor prior to genetic testing

- Yes: 11%
- Yes but not in detail/patient brought up: 17%
- No: 11%
- N/A - no family doctor: 61%

Who recommended genetic testing

- Family member: 51%
- Family doctor: 18%
- Gynecologist: 11%
- Oncologist: 11%
- Other healthcare provider: 5%
- Self: 3%

Yes: 17%
Yes but not in detail/patient brought up: 11%
No: 61%
Gaps & inequities: Risk-reducing surgery in high-risk population

Who sent referral for risk-reducing surgery

- Genetic counsellor/ geneticist: 43%
- Family doctor: 28%
- Oncologist: 10%
- Doctor at high-risk clinic: 7%
- Gynecologist: 5%
- Other/not sure/no one: 7%

Management of women with pre-cancer lesion detected during risk-reducing surgery

- no follow-up or treatment: 40%
- will follow (CA125): 13%
- will follow (imaging): 13%
- advise secondary staging: 27%
- refer to gyn oncology: 13%
- have not encountered: 7%
Previvors: an underserved population

Lack of programmatic follow-up of high-risk patients in most Canadian jurisdictions, to ensure that previvors are referred to the appropriate specialists or pursue prevention strategies. Individuals are essentially “orphaned” after discovering they are at high risk for cancer (Dr. Lesa Dawson and colleagues, PLoS One, 2022 Dec 22)

Few specialized centres focused on care of women at high risk for ovarian cancer
“Every breast or ovarian cancer patient with a BRCA1 or BRCA2 mutation detected after diagnosis is a missed opportunity to prevent a cancer. No woman with a mutation in BRCA1 or BRCA2 should die of breast or ovarian cancer.”

- Dr. Mary-Claire King, 2018 -
Gaps & inequities: Missed opportunities for prevention revealed through the Every Woman Study
Gaps & inequities: Genetic testing among ovarian cancer patients with a family history

Genetic testing among respondents with a family history of ovarian cancer

- Tested before diagnosis: 78%
- Tested after diagnosis: 10%
- Not offered testing: 3%
- Not interested in testing: 1%
- Not sure/can't remember: 1%

Mutation in BRCA1/2 (39%)
Mutation in other gene (9%)
Variant of uncertain significance (13%)

Genetic testing among respondents with a first-degree relative with ovarian cancer

- Tested before diagnosis: 68%
- Tested after diagnosis: 13%
- Not offered testing: 3%
- Not interested in testing: 16%
- Not sure/can't remember: 3%

Mutation in BRCA1/2 (62%)
Mutation in other gene (14%)
Variant of uncertain significance (5%)
Ovarian Cancer Canada’s Prevention Task Force

Ovarian Cancer Canada staff, researchers, oncologists, gynecologists, genetic counsellors, family doctors, patients and previvors working together to decrease the incidence of ovarian cancer in Canada, by maximizing opportunities for prevention.
Collaborative research projects in the pipeline (2023-2025)

- **Dr. Intan Schrader**
  1. Evaluation of novel parent-of-origin detection sequencing tool: improving cascade testing through innovation

- **Dr. Yvonne Bombard**
  2. Mainstream Adviser digital health application study; expansion of app to support cascade testing
  3. Toward equity in cancer genetics: identifying racial disparities in cancer genetics services

- **Drs. Janice Kwon, Lesa Dawson, Michelle Jacobson**
  4. Assessing uptake of salpingectomy in young breast cancer patients undergoing oophorectomy for breast cancer treatment
  5. Understanding the experience of previvors undergoing pre-surgical consultation, risk-reducing surgery and after-care at a specialized centre using semi-structured interviews
  6. Risk-reducing salpingo-oophorectomy in women at risk for ovarian cancer: assessing national practices through surveys of GOC and SOGC membership

- **Eva Villalba (QC)**
  7. Value-based health care - experience group research with previvors and BRCA+ ovarian cancer patients
How family doctors can help prevent ovarian cancer: identifying patients at high risk

If your patient:
✓ Has a family history (on either the maternal or paternal side) of ovarian, breast, pancreatic, prostate, colorectal and/or endometrial cancer; AND/OR
✓ Has a personal history of breast cancer

Send referral to genetic counselling

Additional consideration - ancestry:
❖ Ashkenazi Jewish
❖ French-Canadian
❖ Icelandic/Dutch
❖ others

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How family doctors can help prevent ovarian cancer: management of previvors

If your patient:
✓ Has been found to have an inherited mutation in an ovarian cancer risk gene; AND
✓ Has not been diagnosed with ovarian cancer

1) Discuss risks and benefits of RRSO (risk-reducing salpingo-oophorectomy)
2) Refer patient to high-risk clinic or gynecologic surgeon who has experience performing RRSO
How family doctors can help prevent ovarian cancer: 
**cascade testing**

If your patient:

✓ Has been diagnosed with ovarian cancer; AND

✓ Has **not** had genetic testing

Reinforce potential benefits of genetic testing for both the patient themselves (treatment, prevention of other cancers) and their family members (prevention)

✓ Has had an inherited mutation revealed through genetic testing

Advise/encourage the patient to discuss their genetic result with their family members, and the importance of cascade testing to understand their own risks
How family doctors can help prevent ovarian cancer: resources for patients

**Online tools**
- Talking to your family doctor about ovarian cancer: risk factors, family history, symptoms
- The power of genetics
- Clinical trials
- Understanding ovarian cancer follow-up care

**By Your Side guide**
- Includes information on prevention

Go to: ovariancanada.org
We want to hear from you

FPON webinar survey: role of family doctors in ovarian cancer prevention and diagnosis

As a family physician, you can provide Ovarian Cancer Canada with valuable input about what stands in your way in preventing and diagnosing ovarian cancer.

1. What barriers /gaps in the system have you faced in identifying those at high risk of ovarian cancer? (ex: reviewing family history, referring to genetic counseling, etc.)

2. What barriers /gaps in the system have you faced in diagnosing patients with ovarian cancer? (ex: identifying symptoms, referrals for diagnostic tests, referrals to cancer centres, etc.)

3. Would you be willing to speak directly with Ovarian Cancer Canada about the role family doctors play, and the challenges they experience, in ovarian cancer prevention and diagnosis? If yes, please provide your email in the space provided.
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As the only registered Canadian charity solely dedicated to overcoming ovarian cancer, Ovarian Cancer Canada provides leadership in research, advocacy, and support, so that women live fuller, better, longer lives.

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