Ovarian Cancer Survivorship Survey: Understanding Patient and Caregiver Priorities

Setting the stage - who, what, why and how:

Purpose

To define national priorities for ovarian cancer survivorship research and care in 2025 by gathering first-hand input on people's lived experience as a patient or caregiver. This lived experience is known as "survivorship," and it encompasses the physical, emotional, familial, and financial effects of cancer from diagnosis through treatment and beyond.

Methods

A bilingual, anonymous, 15-question survey was developed in partnership with a national committee of patients and caregivers and OCC's Patient Partners in Research team.

Questions addressed survivorship challenges, quality of life, the impact and need for specific support services, and research priorities to improve long-term health outcomes and survivorship care.

Surveys were distributed to Ovarian Cancer Canada's national community of patients and caregivers, through email, social media, OVdialogue and grassroots distribution by patients themselves. The survey was open on SurveyMonkey from March 6-28, 2025.

Responses were summarized by counts and percentages (quantitative data) or through thematic analysis of open-text responses.

Participants

We received **134** survey responses, including from 118 (88%) people with a personal diagnosis of ovarian cancer and 16 (12%) caregivers. A detailed breakdown of survey respondents is shown on **page 2**.

Results & Impact

Key survey findings are shown on **pages 3-6**. Results are informing Ovarian Cancer Canada's research and advocacy priorities in the area of survivorship, and have been communicated to researchers as part of the RISE (**R**esearch **I**mpact in **S**urvivorship and **E**ngagement) open funding competition.

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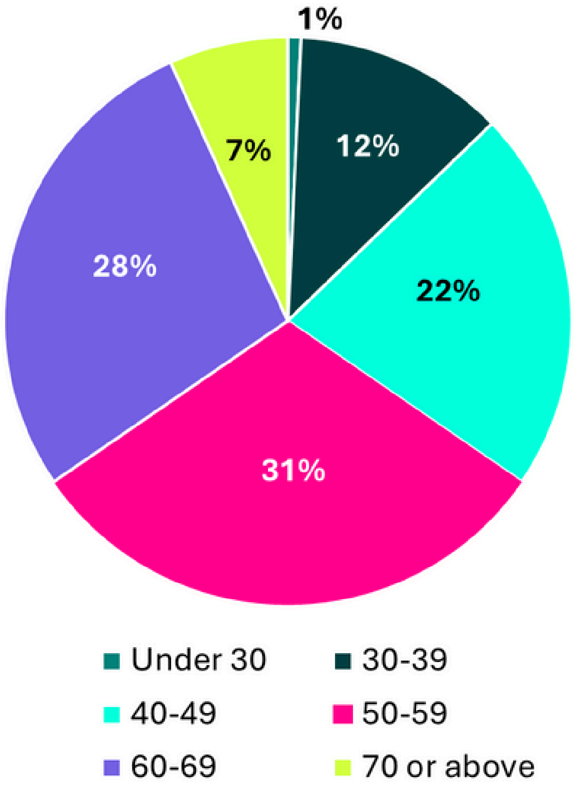
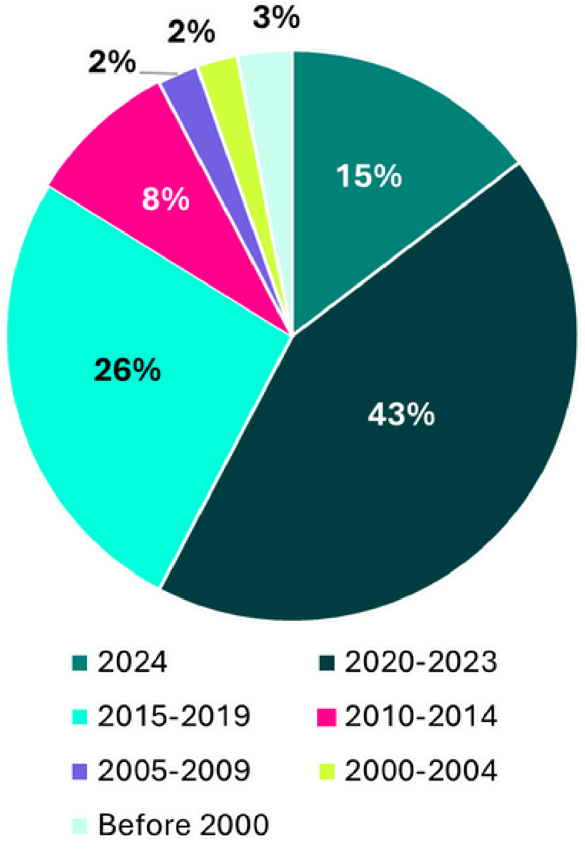
High-level overview of survey respondents:

- **110 (82%)** EN | **24 (18%)** FR
- **118 (88%)** personal diagnosis | **16 (12%)** caregivers
- **75 (58%)** diagnosed between 2020-2024
- **46 (35%)** diagnosed before age 50
- **5 (4%)** First Nations, Métis or Inuk (Inuit)
- **120 (87%)** self-described white ethnicity
- **101 (76%)** married | **16 (12%)** single
- **42 (31%)** household income <$75,000 | **39 (29%)** household income $100,000+
- **92 (70%)** urban | **37 (28%)** rural
- **4 (3%)** identify as member of 2SLGBTQI+ community



Age at diagnosis



Year of diagnosis

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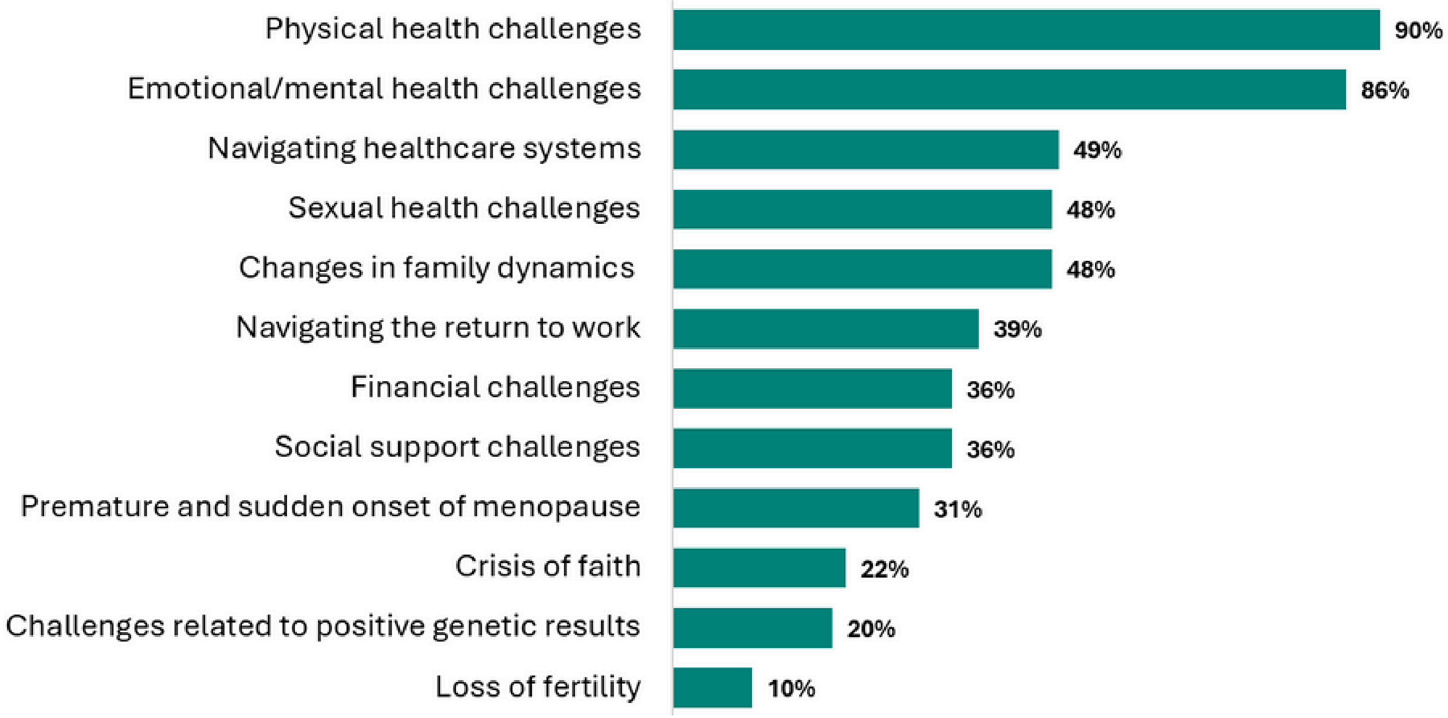
Significant or disruptive challenges (patient respondents):

The proportion of respondents with a personal history of ovarian cancer who indicated that each challenge was significant or disruptive, in either the short or long-term.



Examples of challenges (top 5 categories overall)

Physical health challenges (e.g., fatigue, pain, neuropathy, other side effects of treatment)

Emotional/mental health challenges (e.g., anxiety, depression, fear of recurrence, coping with a terminal diagnosis)

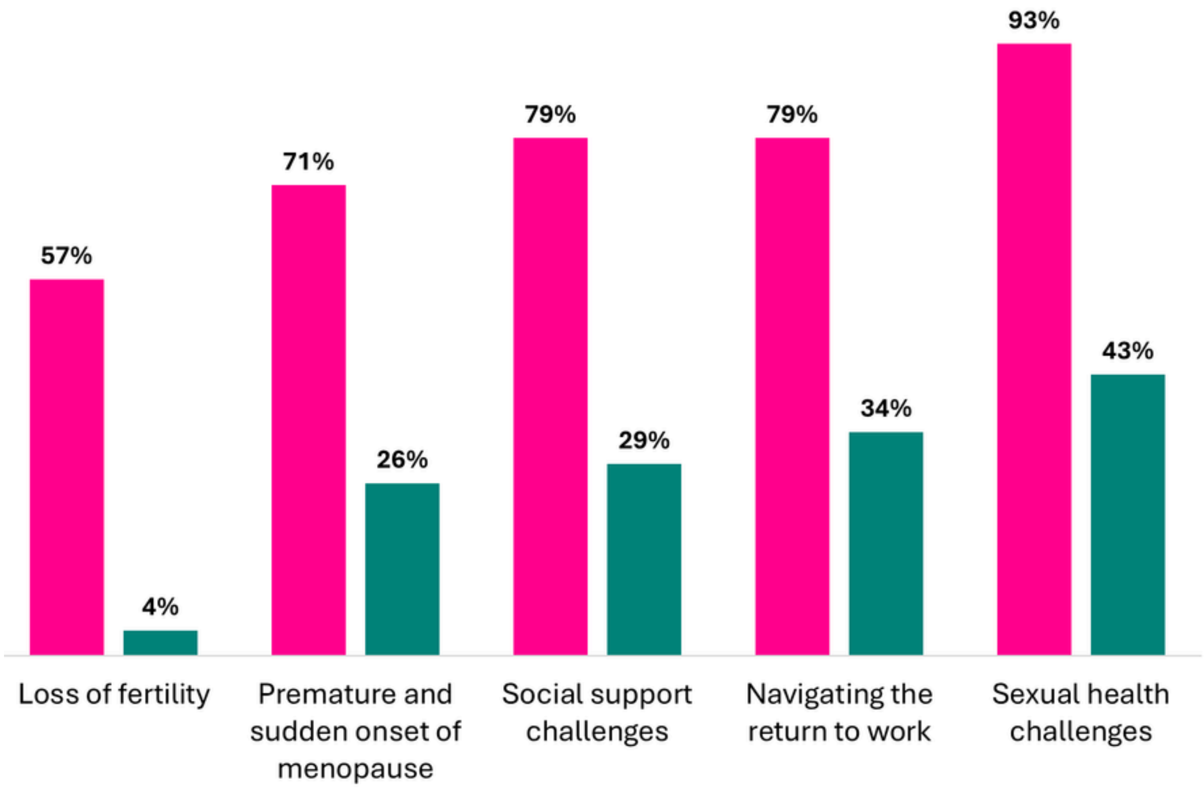
Navigating healthcare systems (e.g., understanding treatment options, access to care, self-advocacy, coordinating care between oncologists, family doctors and other specialists)

Sexual health challenges (e.g., physical or psychological difficulties related to sexual activity, body image changes, hormonal shifts, loss of interest in sex)

Changes in family dynamics (e.g., changes in caregiving roles, adjustment in responsibilities, short- and long-term effects on spouse/children)

Challenges more common in younger patients:

The proportion of respondents diagnosed at less than 40 years old *(pink bars)* vs. at age 40 or older *(teal bars)* who indicated that each challenge was significant or disruptive.



Examples of challenges (specific to younger patients)

Navigating the return to work (e.g., need for flexible hours, challenges with employer support, cognitive changes or "chemo brain", difficulty with physical tasks, workplace stigma, feelings of social isolation)

Social support challenges (e.g., isolation, difficulty asking for help, unsolicited advice, reduced social interaction)

Premature and sudden onset of menopause (e.g., onset before age 40, hot flashes, night sweats, mood swings, other health-related effects)

Loss of fertility (e.g., impact on family planning, emotional and physical effects)

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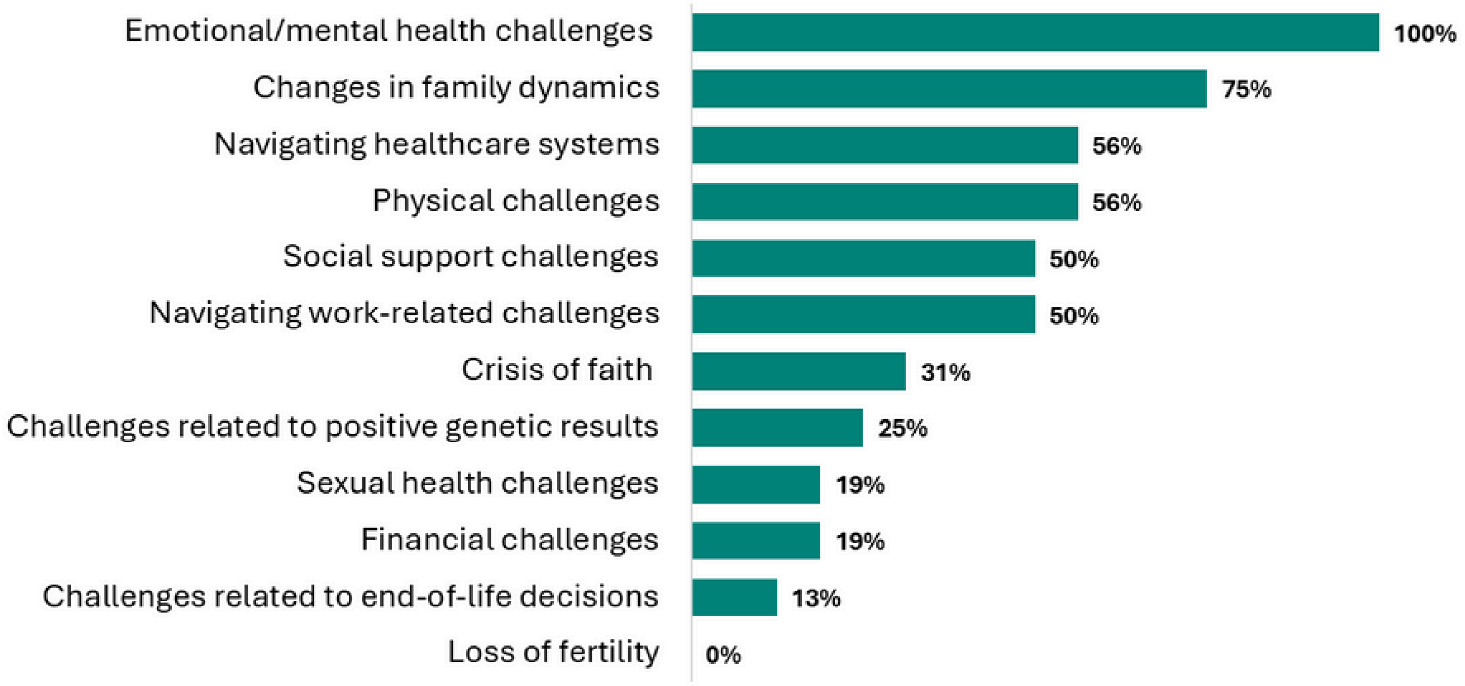
Significant or disruptive challenges (caregiver respondents):

The proportion of caregiver respondents who indicated that each challenge was significant or disruptive, in either the short or long-term.



Examples of challenges (top 6 categories overall)

Emotional/mental health challenges (e.g., anxiety, depression, feelings of helplessness, emotional exhaustion, anticipatory grief, hypervigilance)

Changes in family dynamics (e.g., adjusting to new caregiving roles, shifts in family responsibilities, tension in relationships with spouse/children)

Navigating healthcare systems (e.g., understanding treatment options, advocating for your loved one’s needs, difficulties with coordinating care)

Physical challenges (e.g., fatigue, exhaustion from helping with daily activities)

Social support challenges (e.g., isolation, difficulty asking for help, feeling unsupported)

Navigating work-related challenges (e.g., needing flexible hours, feeling isolated at work, difficulties balancing caregiving with job responsibilities)

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Top patient + caregiver priorities for survivorship research:

Physical well-being

✓ Improving physical recovery post-treatment

✓ Reducing or alleviating treatment-related long-term side effects, such as neuropathy, fatigue and cognitive issues

✓ Physical rehabilitation or therapies focused on strength, stamina and pain management

Psychosocial/emotional well-being

✓ Accessible and long-term psychological support to help patients navigate the emotional aftermath of cancer treatment and survivorship (anxiety, depression, PTSD, fear of recurrence, survivor guilt)

✓ Resilience-building programs and interventions that can help survivors regain a sense of identity, cope with stress, and manage the emotional toll of living with cancer

Treatment advances

✓ More targeted therapies to extend survival, reduce side effects and improve quality of life (options for non-BRCA or rare types of ovarian cancer, immunotherapy, personalized medicine)

Health & lifestyle

✓ Research into healthy lifestyle interventions to improve long-term health outcomes and decrease the risk of recurrence, including nutrition, exercise, and stress reduction programs

Health disparities & inequities

✓ Understanding and addressing health disparities related to ovarian cancer, including geographic, socio-economic, and racial/ethnic inequities

Relationships & family

✓ Research to improve family support, better understanding of caregiver needs, and the emotional and financial impacts that cancer has on loved ones

"There's this wild perception that once treatment is over and you've been told there's no evidence of disease, that you're okay and you are just supposed to slip back into the life you had before. And even when you are surrounded by loving family and friends, it is the loneliest experience and absolutely terrifying." ~survey respondent