

Multidisciplinary Approaches to Addressing the Needs of Patients with Gynecologic Cancers: A Call-to-Action Summit

Gynecologic cancer refers to any malignancy that begins in the reproductive organs.¹ There are 5 main types of gynecologic cancer including cervical, ovarian, uterine, vaginal, and vulvar. Gynecologic malignancies, while less common than other cancer types, affect 100,000 people annually in the United States.² In addition, an estimated 32,000 people died from gynecologic cancers in 2023.

Advanced stages of gynecologic cancers can lead to bowel obstructions, malnutrition, blood clots, impaired organ function, extreme fatigue, severe pain, fluid overload, and other distressing symptoms. Patients not only face disease complications, but they can also suffer from toxicities related to treatment. Invasive surgeries and procedures, radiation therapy, and systemic chemotherapy or immunotherapy can cause a variety of adverse effects. Furthermore, many patients have chronic comorbidities that may impair their overall health outcomes.

Racial disparities exist in gynecologic diseases. Rates of endometrial and cervical cancer deaths for Black patients are twice as high as their White counterparts.³ More research is needed in this area to address mortality rates.

In addition to disease- and treatment-specific complications, patients with gynecologic cancers may experience health disparities related

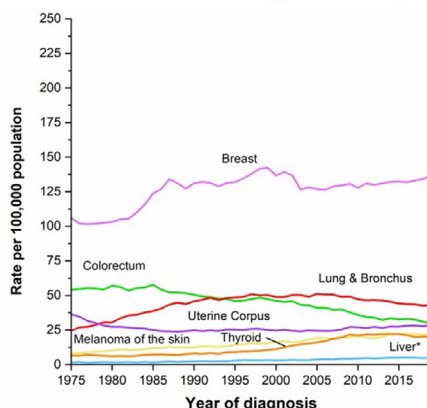
to socioeconomic status, educational level, ethnic background, and geographic location.³ Financial toxicity also remains a substantial concern because of the associated costs of subspecialty appointments, surgeries, hospital admissions, and systemic treatments. Until these complex barriers are addressed, disparities and compromised health outcomes will persist.

To better understand the problem and to brainstorm potential solutions, the Association of Cancer Care Centers (ACCC) held a Gynecologic Oncology Summit in Chicago, Illinois, on September 27, 2023. The half-day live summit brought together multidisciplinary experts from across the United States in the field of gynecologic cancers, along with representatives from patient advocacy organizations.

The session opened with a question posed to providers on what motivates them to improve equity and care in patients with gynecologic cancers. Sentiments ranged from bridging the gap, to care barriers in underserved cities, to bringing gynecologic cancer to the forefront because it is often overlooked. The general session also included a presentation by the ACCC's project advisory committee chair, Premal H. Thaker, MD, MS, professor of gynecologic oncology at the Washington University School of Medicine in St. Louis, Missouri. Dr. Thaker reviewed the current landscape in caring for patients with gynecologic cancers.

FIGURE 1. Trends in Cancer Incidence, SEER Data

Trends in Cancer Incidence Rates Among Females, US, 1975–2019



Rates are age-adjusted to the 2000 US standard population and adjusted for delays in reporting. *Includes the Intrahepatic bile duct. Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2022.

Statistics in Gynecologic Cancer Care:

- 66,000 people will have been diagnosed with endometrial cancer in 2023. Trends show this continues to rise year after year.
- 19,000 people are diagnosed each year with ovarian cancer; 13,270 will die from it.
- An estimated 13,000 people in the US died in 2023 from uterine cancer.
- An estimated 4,300 people in the US died from cervical cancer in 2023.

Dr. Thaker shared a trend report from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) program that reviewed data from 1975 to 2019. Trends show that uterine cancer has increased since the 1990s (Figure 1). Dr. Thaker also noted the drastic disparities by race in 5-year survival rates (Figure 2). She offered several reasons for these disparities, including biological, environmental, and access inequities for underserved populations.

Attendees then transitioned into breakout sessions and were tasked with defining challenges and opportunities in 3 key areas, including:

- Social Drivers of Health (SDOH)
- Multidisciplinary Care, Workforce, and Patient Navigation
- Community Support/Patient Advocacy

Social Drivers of Health

Challenges:

Social and environmental factors are proven to affect health outcomes.⁴ Social factors include resources needed for daily living such as food, housing, transportation, finances, and childcare, among others.

Challenges identified among the summit participants included:

- Financial toxicity related to treatments
- Distance traveled and transportation for patients
- Workforce burnout
- Establishing and maintaining care of patients
- Maintaining consistent and accurate patient education

“How do you establish and maintain care with patients who struggle with coverage and financial toxicity?” –Summit participant

Beyond the factors already highlighted, the question arose among the group of who is responsible for tackling social drivers of health and understanding that the challenge includes setting a threshold intervention designed to reduce the burden. Health care teams may not be equipped to address some of the drivers and must rely on public or social service agencies to support the barriers identified. ACCC supports these concerns by promoting links to community resources that can help to meet ongoing needs.

Opportunities:

To improve population health, health equity needs to be prioritized and measures must be integrated to reduce disparities⁵ Taking on social drivers of health is no small feat. The first step is to assist the patients in identifying any barriers present. This is done through screening tools, such as the Core 5 SDOH screening tool that evaluates factors such as food insecurity, housing, utilities, transportation, and safety.⁶ Only once challenges are identified can opportunities for improvement be initiated.

FIGURE 2. Survival Rates by Race, SEER Data

Five-year Relative Survival Rates (%) by Race, US, 2012–2018

	White	Black	Absolute Difference
All Sites	69	64	5
Breast (female)	92	83	9
Colon & Rectum	65	60	5
Esophagus	22	15	7
Melanoma of the Skin	94	70	24
Non-Hodgkin Lymphoma	75	70	5
Oral Cavity and Pharynx	70	52	18
Ovary	49	41	8
Prostate	97	97	<1
Urinary Bladder	78	65	13
Uterine Cervix	67	56	11
Uterine Corpus	84	64	20



5-year relative survival rates based on patients diagnosed in the SEER 18 registries from 2012 to 2018, all followed through 2019. Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2022.

Summit participants identified the following opportunities to address social drivers of health:

- Advocate for comprehensive cancer care delivery within insurance provider networks
- Increase funding for health equity initiatives
- Increase access to services by advocating for telehealth payment parity
- Implement a diverse workforce and leadership
- Streamline detection of multiple cancers (MCED) and related diagnostic testing

Social media was also mentioned as an opportunity for education and dissemination of important information to leverage existing clinical services for greater awareness of inclusivity. Participants touched on opportunities to expand access to care including the National Cancer Institute's Community Oncology Research Program, which offers opportunities for patients to be involved in clinical trials and study interventions to improve care delivery.

Multidisciplinary Care, Patient Navigation, and Workforce

Challenges:

Multidisciplinary care requires different professionals from various fields to come together for the joint purpose of providing patient-centered care.⁷ This can be difficult with limited staff due to retirement, burnout, or specialty training requirements. Patient navigation, while not always available due to funding or resources, may help to reduce health disparities.⁸

Summit participants identified many challenges in this area, including:

- Costs associated with childcare and caregiving
- Lack of care coordination for genetic testing
- Nonstandard implementation of SDOH screening tools
- Inequitable knowledge of and/or access to community resources

"We need to make sure to say 'people,' 'individuals,' or 'persons' when talking about gynecologic cancers because, yes, [one] patient could identify as a woman but...another may not."

–Summit participant

Attendees also conveyed lack of funding for clinical trials and sufficient clinical trial enrollment of diverse patients as struggles they face in their practices. Insufficient diversity among providers is also of concern, with some breakout group members addressing the need for multidisciplinary team training around the effects of explicit and implicit bias.

Opportunities for Improvement:

This group was tasked with finding opportunities for improvement in patient care, including navigation resources and health care workforce needs.

Opportunities for improvement exist around:

- Prioritization of diversity, equity, and inclusion
- Clinical pathways and advancement in treatment options
- Increased access to genetic counseling and testing through telehealth services
- Clinical trial flexibility
- Bolstering employee recruitment and retention programs

Workforce strategies focused on diversity, equity, and inclusion, as well as increasing incentives for workforce retention. An identified goal for multidisciplinary teams is to broaden diversity into sexual and reproductive care programs, and to encompass health care providers of all racial, ethnic, and cultural backgrounds.

Clinically, institutions have an opportunity to make clinical trials more flexible; to advocate for increased access to genetic counseling and testing; and to support patient navigation, SDOH triage, caregiver education, and automation through things like wearable technologies.

Community Support/Patient Advocacy

Challenges:

Individuals who are diagnosed with gynecologic cancers require high levels of supportive care. In addition to that need, there are continuing challenges in community support and patient advocacy that were identified by summit participants.

Some of those challenges are:

- Insufficient access to care
- Bringing gynecologic malignancies to the forefront
- Lack of community awareness and education

"We have to find community resources that can help provide financial aid to patients."

–Summit participant

In addition to the challenges listed above, participants expressed concerns regarding lack of patient educational resources (after treatment), program funding, and policy implications for genetic testing and insurance coverage. Resource needs were specifically identified around sexual dysfunction, financial assistance, and navigating the search for resources. Genetic testing concerns stemmed from customized treatments that are often needed in smaller communities.

Opportunities:

Sometimes a solution is as simple as promoting services that are already available. Communities and health care institutions can benefit through partnerships that help to spread awareness of available resources. Additionally, health care institutions need to advocate for national policy change around genetic and/or genomic testing and health insurance coverage for things like care-related transportation needs. Only once these topics become part of everyday conversations will they be normalized and will change be effected.

Actions to Overcome Challenges:

- Advocate for national policy change regarding access to genetic testing and counseling
- Coordinate and support patient advocacy for health equity in gynecologic health care
- Build or strengthen patient navigation programs
- Develop integrative and palliative care delivery roadmaps
- Promote early screenings to lower risk factors

Patient advocates at the summit shared the financial impact of grants with restricted funding and limitations, both of which have a detrimental impact on patients. There is also a great need for standardization of patient navigation across centers, which will improve access to care and community awareness for unmet patient needs.

Spotlights

“The ACCC gynecological summit brought together key stakeholders such as physicians, physician extenders, social workers, geneticists, pharmacists, patient advocates, and hospital administration to discuss challenges and opportunities for improved multidisciplinary care and patient advocacy for gynecologic malignancies. Having this opportunity to brainstorm together will help all the attendees to bring back novel ideas/concepts to their institutions.”

—Premal Thaker, MD, MS

University of Pittsburgh Medical Center Sexual Health Education Program

Sexual health and well-being are fundamental parts of an individual's overall health care. For oncology patients, sexual health is often impacted by surgeries, chemotherapy, radiation, and hormonal therapies, among other things. With greater advancements in therapies in recent years, patients have benefited from longer survival, but unfortunately, they experience more symptoms and adverse effects from cancer treatment.

Opening an oncology sexual health clinic at the University of Pittsburgh Medical Center (UPMC Magee Women's Gynecologic Cancer Program) has allowed for more focus on promoting overall wellness and targeting unmet needs for patients. To begin the process, a target population needs to be defined. UPMC chose to focus on patients with vulvas. They created a list of problems and diagnoses that would be treated in the clinic, and made a list of the possible tools, staff, etc. that the clinic would require. Internal resources were also identified, such as the office manager, medical director, operations, and so forth, and meetings were held to discuss needs and feasibility. It was imperative that a trusted referral network was built to ensure that the patient would receive comprehensive care.

Some possible referrals include pelvic floor physical therapists, menopause specialists, and sex therapists, among many others. The biggest recommendation for health care providers in oncology is to make sure they ask about the sexual well-being of your patients and then listen to their answers. Often oncology patients feel that if sexuality during their cancer journey was important, their providers would bring it up. Providers often refrain from discussing sexuality and intimacy to avoid embarrassing the patient. However, talking about sexual health and well-being with patients is a key step in offering comprehensive, compassionate, and quality care.

Conclusion

The summit wrapped up with a call to action, where participants generated action steps for the next 2 to 5 years to establish, build, and provide solutions for providers and key stakeholders. Thirteen distinct priorities were identified that ranged from expansion of coverage to developing a national advocacy campaign to increasing visibility of existing education and creating an education library.

There were 5 key areas identified:

- **Legislate to Eliminate Burdensome Prior Authorizations**
Advocate for policy change to eliminate onerous prior authorization requirements and highlight successful models where this has been implemented at the program and/or state levels and can be replicated.
- **Expand Access to Reimbursement for Telemedicine and Genetic Testing**
Create a national licensure system to develop joint messaging on awareness and prevention that is specific to gynecologic cancer.
- **Develop a National Advocacy Campaign for Gynecologic Cancer**
Develop a national awareness campaign for gynecologic cancers, similar to campaigns for breast, prostate, and other



common cancers. Additionally, an advocacy network is needed to garner more research funds and other resources for patients with gynecologic cancers.

- **Legislate to Standardize Electronic Medical Records (EMR)**

Participants mentioned several high-priority items that should be built into the EMR. Among them are standardized reporting of imaging, genetics, and genomics; self-reporting of gender identity, ethnicity, and race should be considered mandatory.

- **Empower Diversity in Leadership**

Partner with professional societies to encourage health systems to mirror the communities they serve.

Summit participants shared their thoughts regarding the need for care teams with diverse cultural backgrounds to treat gynecologic cancers. Reasons included increased innovation, decision-making, and reaching a broader patient population. They also shared ways for current providers to embrace diversity such as continually learning about unconscious bias, being an active listener, communicating with clarity, and serving as an example for peers. In addition, participants recognized a need to advocate for change regarding prior authorizations, to expand coverage of the 10 essential health benefits outlined in the Affordable Care Act, and to demonstrate the value for patient navigation through data.

The Gynecologic Oncology Summit brought together experts across many disciplines with the same goal—to face barriers and challenges head-on by calling them out, as well as to identify actionable solutions. Through the initiative, Multidisciplinary Approaches to Addressing the Needs of Patients with Gynecologic Cancers, ACCC will continue to work with partner organizations to identify, develop, and disseminate resources to support multidisciplinary care teams as they aim to provide the highest quality care for patients with gynecologic cancers.

To learn more about the ACCC's work on gynecologic cancers, please visit: acc-cancer.org/gynecologic-cancer-care.

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This project is made possible by support from:



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