Developing Education Materials for Ovarian Cancer Patients: Approach and Lessons Learned in Iowa

The most recent data show that Iowa was among the top 20 states with a high ovarian cancer age-adjusted mortality rate (6.4 per 100,000 women), despite having an average age-adjusted incidence rate (8.4 per 100,000 women).[1] There are only six practicing board-certified gynecologic oncologists in Iowa—five in Iowa City and one in Des Moines.[2] Based on an analysis of data collected for CDC's Patterns of Ovarian Cancer Care and Survival in the Midwest Region of the US investigation, almost one in five Iowans diagnosed with ovarian cancer in 2011 and 2012 was not referred to a gynecologic oncologist.[3]

Ovarian Cancer Demonstration Project

To increase survival from ovarian cancer, CDC funded a demonstration project to build evidence for strategies to increase knowledge and awareness of gynecologic oncologists' role in ovarian cancer treatment and to increase receipt of ovarian cancer care by a gynecologic oncologist. The Iowa Department of Public Health was one of three National Comprehensive Cancer Control Program awardees selected for this project.

Formative Studies to Inform the Project

The Iowa Cancer Registry, Iowa Department of Public Health, and the Iowa Cancer Consortium worked together to identify the barriers patients in Iowa face in receiving guideline-recommended treatment for ovarian cancer. To inform selection of strategies to increase referral to a gynecologic oncologist among women diagnosed with ovarian cancer, they conducted qualitative interviews with patients and providers to assess perceived barriers and attitudes in receiving surgical care from a gynecologic oncologist. They first interviewed 10 administrators and clinicians from hospitals across Iowa who reported that their patients faced many barriers obtaining

surgical care by a gynecologic oncologist, including fear, expense, travel burden, and time.

Following those interviews, 16 ovarian cancer survivors who appeared to have surgery at a hospital that did not have a gynecologic oncologist surgeon were interviewed. These survivors reported that they could have traveled and been treated anywhere and expressed a willingness to go wherever their doctor recommended they go. Many said the shock of their cancer diagnosis reduced their ability to make decisions and increased their need to rely on others for help with decision-making. None expressed any awareness of the importance of receiving care from a gynecologic oncologist.

Ovarian cancer survivors in the focus groups trusted their diagnosing physician and did not question the diagnosis or recommended treatment plan.

"I was so blown away by the diagnosis. I guess you would say I was in shock ... but I guess, in my mind I thought, if my family doctor recommended him, that should be good."

"For better or worse, I did pretty much what I was told to do."

"They're good doctors. We don't question what they say is okay. There are good doctors over there."

"I think I totally had a choice. They didn't say, 'We have to do this.' But they also didn't say, 'Maybe you should get a second opinion.' I just trusted them from the start. Maybe if they had said, 'If you want to get another opinion, we won't be bothered by it,' but they didn't say that and I trusted them, so I stayed with him."

Based on these findings, a project was designed with the goal of increasing awareness and knowledge among public health professionals, health care providers, and ovarian cancer patients about the important role of gynecologic oncologists in providing care for patients with ovarian cancer. Results of the formative studies affirmed the critical need for patient education. It was clear that the ovarian cancer patients interviewed trusted their providers to give them the best care possible and generally did not seek out gynecologic oncologists or second opinions, because they were not aware of benefits of receipt of ovarian cancer care from a gynecologic oncologist.

Material Development, Testing, and Refinement

A patient handout was developed to educate women with ovarian cancer on the basics of treatment, how to communicate with providers, and the importance of asking for a referral to a gynecologic oncologist. The handout would be an additional resource to providers, who would be able access it online to print and send home with patients following a diagnosis of ovarian cancer.

The following was used to make sure that women with a wide range of reading skills could understand the handout:

- Plain language and included medical terms only when necessary.
- Subheadings to guide the reader.
- Boldface text and text boxes to draw attention to key messages.
- Columns and lists to maximize white space and improve readability.

To ensure knowledge uptake, cognitive interviews were conducted with ovarian cancer survivors. The goals of the interviews

were to assess the handout's overall appeal, clarity, and success in communicating steps to obtain guideline-recommended treatment.

Interview participants were complimentary of the overall clarity of the handout, calling it "very clear and straightforward" and "not technical." Participants talked of the fear and anxiety that can accompany an ovarian cancer diagnosis and appreciated that this handout would not significantly contribute to this distress, saying "it's simple, not alarming" and "it's not scary." During the formative studies, the women interviewed indicated that they trust their physicians and do what they say. As a result, information on how to talk to one's doctor to empower readers to be their own health advocate was provided. Based on feedback from ovarian cancer survivors, the handout succeeded in accomplishing this.

While medical jargon was avoided whenever possible, one woman interviewed was concerned that the term "debulking" was used often by health care providers during appointments following her diagnosis and she did not know what it meant. For that reason, the term was included in the section that explains surgery for ovarian cancer. During interviews, we assessed how successful the handout was at communicating the importance of seeing a gynecologic oncologist for surgical care. Based on feedback received, a colored box around the section that addresses asking for a referral to a gynecologic oncologist was added and some of this information was made to stand out in boldface text.

The goal of widespread dissemination to women of all ages and reading levels guided the development of the handout content and layout so that the finished product looked appealing while being easy to read and understand. Cognitive interviews showed that we were successful in accomplishing this. The ovarian cancer survivors interviewed found the handout easy to read and not overwhelming. In addition, they all indicated they would readily share it with women they know who are diagnosed with ovarian cancer.

Dissemination and Marketing

Two webinars developed as part of this demonstration project were used to promote our handouts among providers. During the **Ovarian Cancer in Iowa (https://cme-learning.brown.edu/Iowa)** webinar, the process of developing the educational materials was described, and hyperlinks to both were included. Rhode Island's roundtable, **Making a Difference: Expediting Diagnosis of Ovarian Cancer (https://cme-learning.brown.edu/DifferenceOnDemand)**, included a summary of Iowa's activities during the demonstration project and a discussion of the handouts. Health care providers can view both webinars for continuing education credit.

Copies of the handouts were also mailed to providers. First, a list of obstetricians and gynecologists working in the state was purchased, including their place of employment and address. Using this information, both handouts were mailed to 67 health centers across Iowa; 130 provider handouts (one per doctor), and 1,675 patient handouts (25 per practice) were also mailed. Each mailing included a cover letter describing the demonstration project and hyperlinks to each handout and the Ovarian Cancer in Iowa webinar.

Leveraging the list servs and mailing lists of partners as well as the registration lists from the webinar was a cost-effective approach to reaching healthcare providers in Iowa directly so that they can share the handout with their patients.

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More From Iowa's Ovarian Cancer Demonstration Project

Understanding Your Ovarian Cancer Treatment
[PDF-313KB] (https://canceriowa.org/wp-content/uploads/2021/01/Handouts-for-patients-newly-diagnosed-with-ovarian-cancer.pdf)

Patients with Ovarian Cancer: Improving Health Outcomes
[PDF-310KB] (https://canceriowa.org/wp-content/uploads/2021/02/Ovarian-Cancer-Handout-for-Providers.pdf)

Ovarian Cancer in Iowa
(https://cme-learning.brown.edu/IowaOC)

Patient and Provider Perspectives on Barriers to Accessing Gynecologic Oncologists for Ovarian Cancer Surgical Care
(www.liebertpub.com/doi/full/10.1089/whr.2020.0090)

[1] U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2020 submission data (1999-2018): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; www.cdc.gov/cancer/dataviz, released in June 2021.

[2] Iowa Health Professions Inventory, Iowa Health Professions Tracking Center, Office of Statewide Clinical Education, University of Iowa Carver College of Medicine. https://medicine.uiowa.edu/oscep/iowa-health-professions-tracking-center.

[3] Weeks K, Lynch CF, West M, et al. Rural disparities in surgical care from gynecologic oncologists among Midwestern ovarian cancer patients. *Gynecologic Oncology*. 2021 Feb;160(2):477–484.