



Talking Ovarian Cancer Project (TOCP) - Best Practice -

19 December 2022

PROGRAM SYNOPSIS

Designed to increase ovarian cancer awareness among all women, the Talking Ovarian Cancer Project (TOCP) is a community-based pilot intervention program in the Southern Seven Health Department counties. The TOCP consists of an educational program with presentations, videos, brochures, posters, newspaper articles, radio and television interviews and public service announcements (PSA's) and social media ads. The intervention's primary focus is on increasing knowledge, skills and abilities to promote ovarian cancer awareness among area women, clinics, hospitals, colleges/universities, healthcare workers and providers with a common interest in ovarian cancer early detection. The next phase of the program is to expand state-wide with a focus on women in rural and medically underserved communities.

PROGRAM HIGHLIGHTS

Purpose: Designed to promote ovarian cancer signs and symptoms awareness among women

Age: All ages (Women)

Sex: Female

Race/Ethnicity: All ethnicities

Program Focus: Ovarian cancer awareness building

Population Focus: Rural, Medically Underserved

Program Area: Ovarian cancer awareness, provider education, genetic testing and counseling, patient/survivor support

Delivery Location: Clinics, faith-based facilities, workplaces, health fairs, pharmacies, hospitals, local health department offices, local sororities

Community Type: Rural

THE NEED

In Illinois, ovarian cancer is the fifth leading cause of cancer-related deaths among women and takes more than 570 lives annually. In the United States, ovarian cancer takes more than 13,800 lives annually which accounts for more deaths than any other cancer of the female reproductive system. A woman's risk of getting ovarian cancer during her lifetime is about 1 in 78.

There are no reliable screening tests for ovarian cancer which makes it critically important to communicate ovarian cancer awareness among all women to be able to recognize signs and symptoms and decrease risks of late-stage detection. A study has shown that "rural ovarian cancer patients have greater odds of being diagnosed at stage IV in Midwestern states independent of the distance they lived from their primary care physician and their socioeconomic status and could affect treatment options and mortality. The researchers suggest that if rural women had better access to gynecological specialists in urban areas, it could make a difference, since those doctors are highly trained and may be able to recognize



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the symptoms of ovarian cancer sooner than other health-care providers." *Journal of Rural Health* (20 February 2020)

In most rural counties, residents do not have access to large hospitals with gynecological specialists, e.g., gynecologic oncologists, and have to rely on general practitioners to recognize ovarian cancer signs and symptoms that may be unknown by them and their patients. In some cases these symptoms may be passed off as other less serious disorders which women may have learned to live with and treat with OTC drugs. Based on this information, ovarian cancer may never be detected nor diagnosed in some rural women due to lack of awareness and may result in deaths resulting from secondary/distant organ diseases as the cancer spreads to the liver, the fluid around the lungs, the spleen, the intestines, the brain, skin or lymph nodes outside of the abdomen. Interventions designed to promote early ovarian cancer detection are needed to reduce the mortality among women in medically underserved, rural communities.

THE PROGRAM

The TOCP is a community-based intervention program designed to increase knowledge of ovarian cancer signs and symptoms among all women in medically underserved, rural communities. The mission of the TOCP is to “communicate ovarian cancer signs and symptoms to educate women and their healthcare providers on how to detect the disease in early stages when it is easier to treat and survive”. The TOCP is implemented in community settings such as churches, pharmacies, libraries, health fairs, food pantries, low-income housing complexes, grocery stores, community centers, local health department facilities, hospitals, colleges/ universities, and clinics. The intervention works to increase awareness of ovarian cancer signs and symptoms by locating informational brochures and posters in public places/other areas with frequent traffic and promoting in newspaper ads and television and radio interviews and PSA’s. The intervention consists of four components: a women’s awareness program, a healthcare provider educational program, a local ovarian cancer support program and a genetic testing and counseling program. It is delivered by local health departments, hospitals, Federally Qualified Health Centers (FQHC’s) and community volunteers who are trained to educate their peers about ovarian cancer.

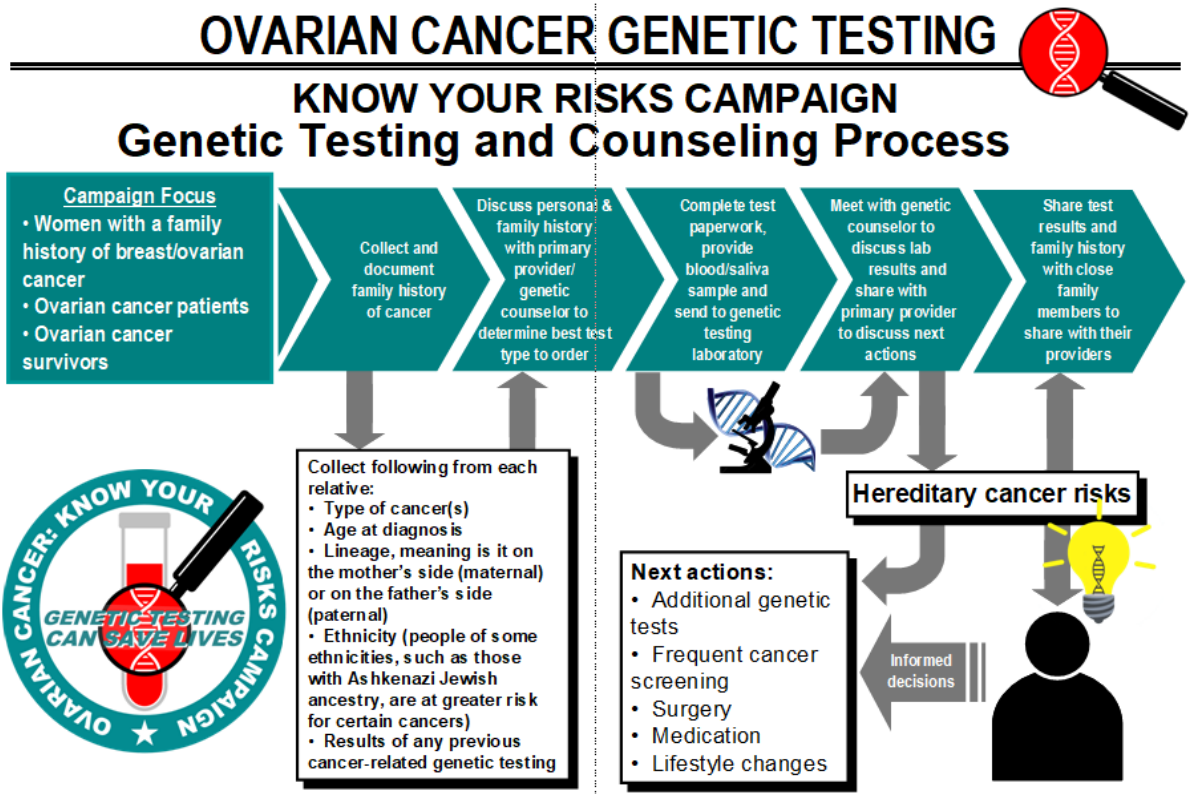
- **Women’s Awareness** involves an intense program of circulating ovarian cancer awareness brochures, pamphlets and posters throughout the community; hosting lunch and learn events; speaking at women’s sororities; publishing articles and ads in local newspapers; developing and airing PSA’s; being in radio and television interviews.
- **Healthcare Provider Education** involves hosting ovarian cancer educational events that provides CME’s for local healthcare workers and educators that are either in-person and/or online during lunch breaks and after-hours.
- **Ovarian Cancer Support** involves organizing local ovarian cancer support groups for both patients and survivors to meet in-person and/or online to share their personal experiences, ways of coping and obtain helpful resources.
- **Genetic Testing and Counseling** involves working with genetic counseling specialists to look for inherited gene mutations, e.g., BRCA1 or BRCA2, that might



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put a woman at a higher risk of getting ovarian cancer and for ovarian cancer patients to work with their doctors to review treatment options and make informed decisions about treatment and understand risks for other cancers.

The TOCP developed the following process as a model to show how to work with a genetic counselor to evaluate risks of getting certain types of cancer based on the family's medical history and to learn which genetic tests can give the most information about an individual's risk level. The major focus of the genetic testing and counseling program is on women with a family history of breast and/or ovarian cancer, ovarian cancer patients and ovarian cancer survivors.



COMMUNITY PREVENTIVE SERVICES TASK FORCE FINDING

The TOCP used unique evidence-based ovarian cancer awareness communication interventions due no recommended approaches being addressed in the Community Preventive Services Task Force. The TOCP pilot did not produce sufficient evidence to determine the effectiveness of the intervention is in saving lives. As a result, it is imperative that additional research be accomplished after three years to determine the intervention's effectiveness using state-wide ovarian cancer incidence and mortality data in a comparative analysis approach in the counties where implemented.



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INTENDED AUDIENCE

This intervention is recommended for all women in rural and medically underserved communities with full consideration given to health equity.

SUITABLE SETTINGS

This intervention is designed to be implemented in community and clinic settings.

REQUIRED RESOURCES

The following resources were developed/acquired for the TOCP based on results of the Community Needs Assessment Provider Questionnaire.

- Ovarian cancer action plan (communication, education, support)
- Ovarian cancer program funding and materials acquisition plan
- Ovarian cancer awareness briefing
- Ovarian cancer print and digital Public Service Announcements
- Ovarian cancer awareness brochure and posters (bilingual-English & Spanish)
- Ovarian cancer print/social media postings
- Ovarian cancer website
- Ovarian cancer Facebook page
- Ovarian cancer genetic testing and counseling program
- Ovarian cancer provider education program materials for webinars and workshops
- NOCC ovarian cancer materials and videos
- CDC gynecologic/ovarian cancer *Inside Knowledge* materials and videos (bilingual – English & Spanish)

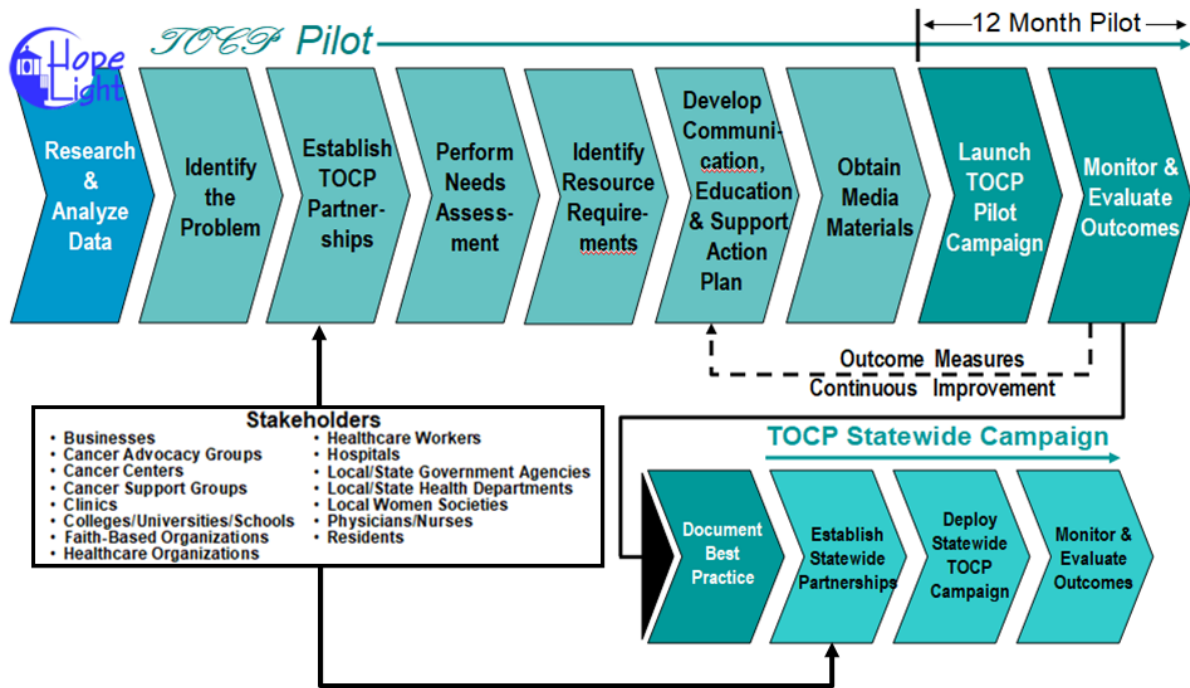
ABOUT THE PROCESS

The TOCP pilot process involved representatives from the Southern Seven Health Department, three hospitals (Massac Memorial, Union County, Hardin County) and two FQHC's (Community Health and Emergency Services, Inc and Rural Health Inc.) within the southern seven counties, and representatives from Shawnee Community College, American Cancer Society, National Ovarian Cancer Coalition (NOCC), Siteman Cancer Center/Washington University, Northwestern Medical Group, University of Illinois at Chicago College of Medicine, Cass County Health Department and The Hope Light Foundation.

The TOCP used the following process model to achieve the desired outcomes and ensure continuous improvement.



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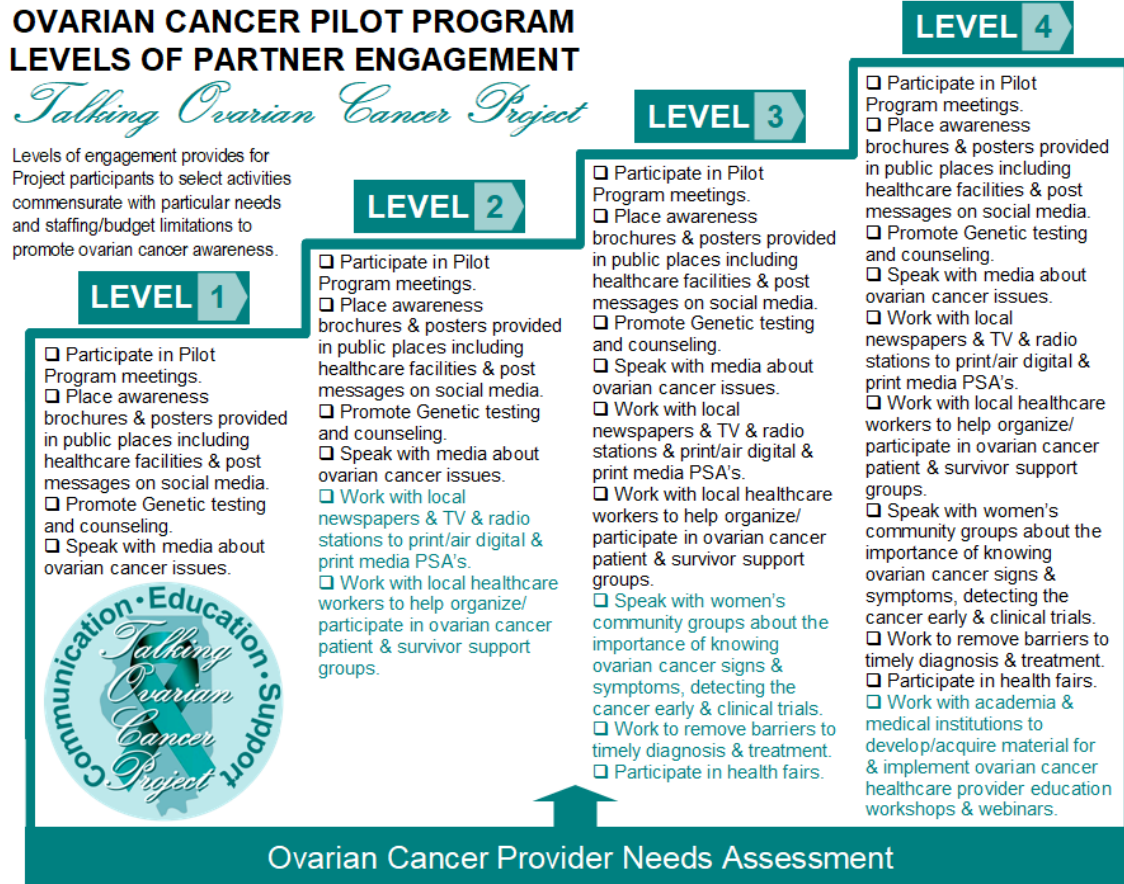
The TOCP process began with researching and analyzing ovarian cancer-related incidence and mortality data, identifying the problem and barriers, establishing partnerships and conducting a provider needs assessment and preparing a Communication, Education and Support Action Plan. The needs assessment was sent to hospitals, FQHC’s and health department personnel to collect ovarian cancer-related needs and disparities information within the southern seven counties as well as identify available/new resource requirements to address barriers and maximize awareness of ovarian cancer signs and symptoms. The needs assessment was also used to ensure awareness materials and communication methods are both culturally and racially appropriate. The results from this assessment served as a building block for the TOCP to ensure communication, education and support processes meet the needs of healthcare providers, hospital systems, and other stakeholders to promote early ovarian cancer detection, provide access to treatment for all women and provide an effective survivor support structure.

Although the TOCP developed a “Learn and Live” ovarian cancer educational program for healthcare providers, future plans are to develop a series of in-person/online ovarian cancer learning events for healthcare professionals and educators in rural communities with the help of colleges and universities with medical related programs that will provide CME’s/CEU’s for attendees. The purpose of this training is to help clinicians recognize the risk factors and clinical features of ovarian cancer to diagnose women as early as possible and provide the most optimal patient care, education, and support.



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The following chart was developed based on the needs assessment to depict levels of engagement for TOCP participants to select activities commensurate with particular needs and staffing/budget limitations to promote ovarian cancer awareness.



KEY FINDINGS

The following key findings were found in the Southern Seven Health Department counties:

- No gynecologic specialists.
- No gynecologic oncologists.
- No genetic counselors.
- No ovarian cancer awareness organization serving the area.
- No ovarian nor cancer support groups.
- Lack of knowledge of ovarian cancer signs and symptoms among residents and healthcare workers.
- Lack of ovarian cancer awareness materials.
- Lack of adequate broadband services in area to accommodate ovarian cancer-related telehealth and genetic counseling programs.
- Lack of adequate transportation for residents to visit healthcare providers.



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CONTACTS

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