Identifying Public Health Opportunities to Reduce the Burden of Ovarian Cancer

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Introduction

The Centers for Disease Control and Prevention (CDC) serves as a leader for nationwide cancer prevention and control activities. The CDC often partners with state health agencies and other key groups to identify problems, needs, and opportunities related to modifiable risk factors and to implement health promotion and cancer reduction activities. New categorical funding from Congress for FY 2000 and FY 2001 has provided the CDC with an opportunity to conduct public health activities targeted towards reducing ovarian cancer morbidity and mortality.

The American Cancer Society has estimated that in 2001 there will be 23,400 new cases of ovarian cancer and 13,900 deaths in the United States. According to information presented at a 1994 National Institutes of Health consensus conference on ovarian cancer, survival rates among women with early-stage disease are significantly higher than rates observed among women with advanced-stage disease, but only about 25% of all ovarian cancers are detected at Stage 1. Unfortunately, the etiology of ovarian cancer is not well understood, and there are no screening tests that have been shown to be effective in reducing ovarian cancer mortality.

To explore a broad spectrum of potential ovarian cancer prevention and control activities, the CDC's Division of Cancer Prevention and Control convened a workshop that included leaders from state health departments and ovarian cancer advocacy groups, as well as physicians and scientists from federal agencies, academic medical centers, and cancer treatment programs. Representatives from two state health departments were included in the planning of the workshop to ensure that the discussion would be focused on public health oriented activities and research.

The workshop, "Public Health Opportunities for Reducing the Burden of Ovarian Cancer," was held November 1–3, 2000, in Atlanta, Georgia. The workshop included three workgroups, each focusing on different aspects of ovarian cancer:

1. Surveillance and Prevention
2. Early Detection
3. Treatment

Each of the three workgroups covered a wide range of potential programmatic and research areas. Only those public health activities that had broad support among workgroup participants are summarized here. In addition, activities that traditionally occur in laboratory settings are not

included in this report. For example, although there was considerable interest in experimental and clinical chemo prevention research, this type of clinical research is not a public health activity and is not included in this report.

The importance of developing partnerships with other agencies and organizations to facilitate research and implement public health activities was emphasized during the workshop. However, all of the potential partners and all potential public health activities discussed during the workshop could not be summarized in this short report but were captured in another form.

A number of topics or proposed activities emerged as part of the discussion in more than one workgroup. These topics were included under the workgroup that seemed most relevant to the particular issue. A list of workshop participants is at the end of this report.

Public Health Priorities from the Surveillance and Prevention Workgroup

Collect data on women's knowledge about ovarian cancer, their behaviors that may impact ovarian cancer risk, and how they make decisions about seeking medical care. The possibility that women could reduce their risk of mortality from ovarian cancer by learning more about ovarian cancer, including risk factors and symptoms, is appealing. However, little is known about what health or risk messages are appropriate, how to deliver the messages effectively, and how women decide to seek medical care for non-specific symptoms such as those often associated with ovarian cancer.

Workgroup participants felt that additional research was needed to lay the foundation for future communications activities. For example, a number of national and state surveys exist such as the National Health Interview Survey that could be used to evaluate knowledge and health-related behaviors in women if appropriate questions could be developed. However, the group acknowledged that collecting medical information such as family history of cancer, detailed history of oral contraceptive use, and whether or not a woman had an oophorectomy may be difficult using current surveys.

In addition, the development of models to assess how women make decisions about seeking health care was viewed as an important but complicated process that could not be addressed using current data or existing surveys.

Develop a mathematical model, like the Gail model for breast cancer risk, to identify women at high risk for ovarian cancer. The Gail model[1] was developed to estimate the risk of breast cancer based on important risk factors such as age, family history of breast cancer, parity, and history of breast biopsies. The model was developed based on the experience of a cohort of women who received annual screening with mammograms.

Workgroup participants were interested in pooling existing information to design a model that would be widely accepted for identifying women at high risk of ovarian cancer.

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[1] Gail MH, et al. J Natl Cancer Inst. 81(24):1879-86,1989.

Screening for ovarian cancer in the general population of asymptomatic women has not been proven to reduce mortality. However, the report from a 1995 consensus conference sponsored by the National Institutes of Health indicated that there are high risk women who might benefit from periodic medical evaluation. High risk women may also wish to participate in screening trials or other types of research studies.

Developing a model should involve researchers from a number of different fields and different research institutions. Based on comments from researchers who participated in the meeting, there are a number of ongoing epidemiologic and genetic studies that might contribute significantly towards developing a risk prediction model. For this reason, developing a model would likely take several years to complete.

Although identifying high risk women was viewed as a worthwhile goal, some participants noted that most ovarian cancers occur in women who are not currently considered high risk.

Use available data from cancer surveillance systems to enhance knowledge about ovarian cancer incidence, staging, and treatment patterns. Data from population-based cancer registries are used to estimate the annual incidence of ovarian cancer. These estimates are calculated without removing women who have had their ovaries surgically removed from the denominator and are therefore at low risk.

Since hysterectomy/oophorectomy rates vary between different populations, the reported differences in incidence rates between socioeconomic and ethnic groups may, in part, because of differences in the proportion of women who may have had a bilateral oophorectomy. Workgroup participants noted that accurate data on the rate of oophorectomies are difficult to obtain because women may not know if their ovaries were removed during a hysterectomy and existing medical databases are probably inadequate to quantify oophorectomy rates in different populations of women.

Participants also noted that data from population-based cancer registries could be used to identify women diagnosed with ovarian cancer who could be enrolled in new studies addressing other issues related to treatment patterns and accuracy of staging.

Priority Recommendations from the Early Detection Workgroup

Identify potential early symptoms of ovarian cancer and evaluate sources of delay from the appearance of these symptoms to diagnosis. It is not clear whether distinct symptoms of ovarian cancer consistently appear at the early stages of the disease, or whether these symptoms are recognizable by a woman or her physician. The workgroup identified a need to define the role of symptoms for both a woman and her physician in the earlier diagnosis of ovarian cancer. Two possible approaches were discussed to address this issue:

1. A retrospective evaluation of women who presented with symptomatic disease to collect data on what symptoms were present, when the symptoms began, what diagnostic approaches were used, and whether diagnostic tests were appropriate and well-timed;

2. A case series comparison of ovarian cancer symptom profiles with profiles from other diseases in an attempt to identify the constellation of symptoms that may differentiate ovarian cancer from other diseases. A number of studies are currently underway or planned that should increase our understanding of potential early symptoms and the delays that occur in the path to diagnosis.

Develop "best practice" guidelines for primary care providers on the recommended cascade of diagnostic tests necessary for optimal management of women who present with symptoms suspicious for ovarian cancer. Many health care providers, particularly those in community health settings, may not be familiar with ovarian cancer symptoms, the most appropriate methods for diagnosis, and the importance of referral to appropriate specialists. This lack of information may lead to a delay in diagnosis, incorrect staging, and less-than-optimum early treatment.

The workgroup identified a need to develop messages for many types and specialties of health care providers about topics such as potential early symptoms and referral to appropriate specialists for diagnosis and treatment. Developing recommended diagnostic procedures and referral guidelines that will be adopted by physicians will require involvement and agreement across the various medical specialties that provide primary care, diagnostic services, and treatment.

Develop a method for clinicians to collect more accurate information on family history of cancer. Family history of ovarian or breast cancer and a personal history of breast cancer may increase a woman's risk of ovarian cancer. Workgroup participants expressed concern about the limited family history of cancer routinely collected by providers. Participants encouraged development of a method to better collect family history of ovarian, breast, and other cancers.

Develop methods or standards to improve the quality of ultrasound examinations. Because ultrasound is so often used in the pathway to diagnosis of ovarian cancer, the quality and interpretation of ultrasound images is important. The poor quality of current ultrasound equipment in some settings; the expertise of individuals conducting, reading, and evaluating the ultrasound exam; and the methods used to report results were raised as potential areas of concern that could affect the accurate diagnosis of ovarian cancer. For example, test results produced from outdated equipment may lead to unnecessary surgery or delayed diagnosis of cancer. Standards for mammography that evolved from a voluntary program for facilities and providers could serve as a possible model for improving ultrasound quality.

Priority Recommendations from the Treatment Workgroup

Support research on quality of life issues. Quality of life for ovarian cancer patients was considered an important and multifaceted issue. Related topics that workshop participants believed warranted additional research include access to centers of excellent care, co-morbidity, pain management, availability of information needed to make decisions, and possible overuse of expensive, high risk treatment with little benefit in women with refractory disease. Possible first steps include:

1. Identifying co-morbid conditions and long-term sequelae in survivors and

2. Quantifying over-treatment of patients with refractory ovarian cancer with the use of costly, high-risk, low-benefit interventions. Participants suggested that this could be done using Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration) and cancer registry data to look at the number of treatment regimens used and overall time from third-line treatments to death. Limited access to high quality clinical trials was also seen as a potential problem for many patients.

Establish and disseminate guidelines to primary care providers on the importance of timely referral of ovarian cancer patients to gynecologic oncologists. Timely referral of ovarian cancer patients to specialists, typically gynecologic oncologists, with experience in staging and treatment of this disease is considered to have a significant impact on survival. The establishment and dissemination of best practice guidelines for referral to appropriate specialists, and treatment regimens was seen as an important unmet need.

Information is also needed about current referral patterns and about women with ovarian cancer who do not currently receive care from such specialists. Involvement and agreement among a number of medical specialty societies would be needed to develop a consensus on referral guidelines.

Develop and disseminate a guidance manual for ovarian cancer patients. The development and dissemination of information in the form of a manual of care for ovarian cancer patients about treatment options and issues was considered an important task. Participants outlined issues that the manual should include such as best practice guidelines for treatment, follow-up, and long-term care; questions and answers to/from providers and insurers; and a basic educational component.

A number of specific points that patients should be encouraged to discuss with their physicians were also identified: access to clinical trials, pain management, symptom management, hospice referral, and psychological / psychiatric / social support counseling for the patient and family members.

Assess needs related to insured and uninsured patients' access to information about ovarian cancer and treatment, access to high quality treatment, and access to resources needed to improve quality of life. Access to the information or resources needed during treatment and follow-up care was identified as a prominent area of concern for ovarian cancer patients. Access to quality treatment can be affected by insurance status, geographic location, availability of transportation and housing near treatment centers, and availability and completeness of information about treatment options and resources for the patient.

The type of care and services needed include referral to appropriate specialists, chemotherapy, surgery, supportive drugs, home health care, physical therapy, ambulance services, support for family care givers, and extended services during recurrence (hospice and palliative care).

A need for psychosocial services for patients through community-based support groups was also identified. A variety of epidemiological and public health activities will be required to identify, evaluate, and address specific gaps related to access to information or resources among women with ovarian cancer.

Support efforts to ensure equitable opportunities for patient enrollment in clinical trials. Historically, clinical trials have played a crucial role in the evaluation of new therapies, some of which have, in turn, decreased morbidity and increased survival. Participation in clinical trials has also given many women an opportunity to receive state-of-the-art care that might not otherwise have been available to them.

Ovarian cancer treatment is expensive, and many insurance programs limit or prohibit access to new therapies. Public health interventions could increase the number of women who have an opportunity to consider participating in a clinical trial.

First, efforts could be undertaken to encourage availability of comprehensive, up-to-date, readily accessible listings of ongoing phase III clinical trials related to ovarian cancer treatment. Second, patient materials could be developed to inform women of the potential benefits and risks of clinical trial enrollment. Such materials could also include guidance on questions women should ask and issues they should consider before deciding to enroll in a particular clinical trial.

Conclusion

The experience and background of the workshop participants was diverse and led to the identifying of many complex and important issues to be addressed by the public health community in the effort to reduce morbidity and mortality from ovarian cancer. However, certain areas of interest were common among many of the participants and are summarized in this report. All of the potential public health activities that were discussed during the workshop could not be included in this short report.

The Division of Cancer Prevention and Control appreciates the interest and effort put into this workshop by those who participated and looks forward to continued collaboration on this important public health issue.

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