

TORONTO STAFF REPORT

October 7, 2002

To: Board of Health

From: Dr. Sheela V. Basrur, Medical Officer of Health

Subject: Toronto Cancer Prevention Coalition Position Paper on the Primary Prevention and Early Detection and Screening of Breast, Ovarian and Cervical Cancer

Purpose:

This report presents to the Board of Health, the Position Paper on the Primary Prevention and Early Detection and Screening of Breast, Ovarian and Cervical Cancer. The position paper provides a current overview of primary prevention and early detection and screening of breast, ovarian and cervical cancers.

Financial Implications and Impact Statement:

There are no direct financial implications for the City of Toronto stemming from this report.

Recommendation:

It is recommended that the position paper be received for information.

Background:

The Early Detection and Screening Working Group of the Toronto Cancer Prevention Coalition is made up of representatives of agencies across the Greater Toronto Area, with a mandate to decrease the incidence and mortality from breast, cervical and ovarian cancer. The working group also includes citizens with knowledge and experience of women's cancers and the cancer control system.

In November 1999, the Early Detection/Screening Working Group commissioned research with funds from the Province and Cancer Care Ontario, Central East Region to identify barriers to screening for women's cancers among the diverse population of Central East Region, along with best practices from the literature. This working paper was not ready for inclusion when the other six working papers from the Toronto Cancer Prevention Coalition were submitted as part of the Action Plan to the Board of Health in May 2001.

Comments:

The attached position paper is based on the premise that while there are uncertainties about both the primary and secondary prevention of breast, ovarian and cervical cancer, there is enough evidence to make substantive recommendations towards preventing these cancers from occurring, as well as reducing the barriers which prevent early detection and treatment for women.

Breast Cancer:

Breast cancer is the most common cancer diagnosis in women and in Canada accounts for 30% of all new cancer cases each year. In the past 25 years, the incidence rate of breast cancer in Canada has increased by 28%. Mortality rates, by contrast, are declining in Canada, possibly as a result of earlier detection and some improvements in treatment. It is estimated that 1 in 9.5 Canadian women will develop breast cancer in their lifetimes and one in 26 women who live to 85 years of age, will die from it. International differences have been noted, with a higher incidence of breast cancer in industrialized countries than in developing countries. This may point to the role played by diet as well as environmental and occupational carcinogens in cancer development.

The current conflicting data on the efficacy of mammography as well as breast self-examination (BSE), have left many women wondering what to make of the latest research. This position paper addresses the need to ensure that women are aware of the debate surrounding mammography and that they are provided with the full range of information on which to base their decisions.

While a thoughtful analysis of these conflicting statements and positions is underway, the Toronto Cancer Prevention Coalition recommends that Toronto Public Health continue to educate women about the recommended guidelines for breast screening including information about monthly BSE.

In addition, the Toronto Cancer Prevention Coalition recognizes that clear-language materials in the key languages of the GTA, as well as cultural sensitivity, are essential for any communication efforts.

Ovarian Cancer:

Referred to as “the disease that whispers”, ovarian cancer is difficult to manage because it is most often diagnosed at an advanced stage when survival chances are diminished. When ovarian cancer is diagnosed and treated early, the survival rate after five years is 85 to 90 per cent. But 60 to 70 percent of women are diagnosed with late-stage disease and die within five years, making ovarian cancer the leading cause of gynecologic cancer mortality in North America. There currently exists no systematic screening program for ovarian cancer in Ontario. Long-term

studies in both North America and the U.K are examining the effectiveness of screening programs for ovarian cancer but in most cases, the results are years away. There are, however, a number of efforts underway to promote awareness and early detection of the disease.

Cervical Cancer:

In Ontario, cervical cancer ranks as the second most common cancer in women ages 35-49 and third among women ages 20-34. It is also one of the most preventable forms of cancer, due to the success of cervical cancer screening with the Pap test. In most cases, the disease is slow to progress, so early treatment and follow-up care provide a good chance of eradicating the disease.

Toronto Public Health and other health departments in the GTA have recognized the importance of developing programs to address cultural and linguistic barriers and to make efforts to reach these diverse populations. There is still much work to be done in this area to address barriers to accessing screening. This can only be achieved through the combined efforts of many community groups, health care agencies and key stakeholders.

Conclusion:

In the Greater Toronto Area, women's cancers are an important public health issue. Improved awareness about primary prevention is critical to reduce in the incidence of women's cancers, and secondary prevention efforts must be enhanced to improve quality of life and mortality rates.

The Ministry of Health has mandated Boards of Health to increase the number of women aged 50 to 69 who receive screening mammography through the Ontario Breast Screening Program and to increase the proportion of women who receive cervical screening according to the guidelines set by the Ontario Cervical Screening Program. Toronto Public Health, in collaboration with the Ontario Cervical Screening Program is developing key strategies for reaching priority populations for cervical screening.

In sum, Toronto Public Health is well-positioned to support a variety of health promotion strategies that could enhance the prevention, screening and early detection of women's cancers. Such strategies, in keeping with the philosophy of the Toronto Cancer Prevention Coalition, include awareness-raising and education about the importance of health-related behaviours (e.g. smoking, alcohol consumption, nutrition, safe sex practices, physical activity and screening) as well as exposure to environmental and occupational carcinogens which may threaten their health.

The position paper of the Early Detection and Screening Working Group of the Toronto Cancer Prevention Coalition will be printed and distributed widely within Central East Region.

The final document will be posted on the websites of the Toronto Cancer Prevention Coalition and Cancer Care Ontario - Central East Cancer Prevention and Screening Network.

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List of Attachments:

- Attachment A: Position Paper on the Primary Prevention and Early Detection and Screening of Breast, Ovarian and Cervical Cancer
- Attachment B: Membership of the Early Detection and Screening Working Group of the Toronto Cancer Prevention Coalition – 1999

Attachment A

**Toronto Cancer Prevention Coalition Position Paper on the
Primary Prevention and Early Detection and Screening
of Breast, Ovarian and Cervical Cancer**

prepared for the Early Detection/Screening Working Group

by Anne Rochon Ford

August 2002

"Our decision making must be informed by science, to the extent that we have or can plausibly expect to have scientific evidence; but where the evidence is unlikely to be forthcoming our decision making must be informed by our values, chief among which is the need to err on the side of caution."

Hancock (1989) cited in Report of the Ontario Task Force on the Primary Prevention of Cancer, p. 33

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The Working Group wishes to acknowledge the original work on early detection and screening carried out by Judith MacPhail in 1999-2000 which has enriched the “Women’s Cancers and Secondary Prevention” section of this paper in particular.

Introduction

This paper considers prevention measures relating to 3 types of cancer – 2 found only in women (cervical and ovarian cancer) and one found primarily but not exclusively in women (breast cancer). The Toronto Cancer Prevention Coalition is committed to the **primary prevention** of cancer and additionally recognizes the importance of screening and early detection, known as **secondary prevention**. Screening can reduce mortality and morbidity but it can not decrease the occurrence of cancers.

The orientation of this paper is based on the premise that while there are uncertainties about both the primary and secondary prevention of breast, ovarian and cervical cancer, there is enough known to make substantive recommendations towards preventing these cancers from occurring, and reducing the barriers which prevent women from having them detected and treated as soon as possible.

This paper has been written for its applicability to the Greater Toronto Area (GTA). With the largest urban population in Canada, the area contains approximately 50 per cent of the population of the province and is a complex mix of urban and semi-urban populations, as well as economic disparities and a strong multicultural mix. More than 200,000 immigrants come to Canada each year and almost 60% of these newcomers settle in the GTA where more than 100 languages are spoken.

Toronto Public Health's 2000 paper profiling the incidence and mortality of cancer in the GTA¹ unearthed the following salient points about these three women's cancers amongst residents in this geographical area:

- Breast cancer made up 28.5% of new cancers between 1991 and 1995.
- Breast cancer was the leading cause of cancer mortality between 1991 and 1995, accounting for one fifth (19.7%) of all cancer deaths (annual average of 435 deaths).
- Breast cancer rates have risen steadily for 30 years though the rate of mortality from breast cancer has declined.
- Breast cancer was the top contributor to potential years of life lost (24.8%), along with ovarian cancer (7.4%) and cervical cancer (4.1%).
- Overall, incidence rates for ovarian cancer showed no change, and the mortality rate decreased gradually between 1986 and 1995 at an average annual rate of 1.1%.
- Cervical cancer incidence decreased between 1986 and 1995 at an average annual rate of 2.1%. This decrease could be related to increasing early detection of precancerous cells through Pap tests.

Background: A Review of Three Cancers in Women

Ovarian Cancer

Referred to as “the disease that whispers”, ovarian cancer is difficult to manage because it is most often diagnosed at an advanced stage when survival chances are diminished. When ovarian cancer is diagnosed and treated early (i.e. a Stage 1 tumour), the survival rate after five years is 85 to 90 per cent. But 60 to 70 percent of women diagnosed have late-stage disease and die

¹ Meera, Jain, Fleischer, Paul and Sheela V. Basrur, *Toronto's Health Status: A Profile of Cancer*, Toronto Public Health, June 2000

within five years, which means that ovarian cancer is the leading cause of gynecologic cancer mortality in North America.²

Risk factors include having one or more first-degree relatives with ovarian cancer, age, low parity, a diagnosis of breast, endometrial or colorectal cancer, early onset of menstruation and obesity. There is conflicting evidence as to whether the use of fertility drugs, or infertility itself pose risk factors for ovarian cancer.³

Symptoms are considered vague and, consequently, incorrect diagnosis of ovarian cancer is a frequent problem. Symptoms include abdominal bloating, distension and discomfort, changes in bowel habits, nausea, unexplained weight gain and lower back pain. Since there is presently little consensus around the causes of ovarian cancer, it is critical that women and health care providers become more aware of early symptoms of the disease.

Methods of detection of ovarian cancer available thus far are unfortunately not as sensitive as those for other women's cancers such as cervical cancer. Current methods include abdominal ultrasound, transvaginal sonography, bi-manual recto-vaginal pelvic examination, and a blood test for an antigen in the blood known as CA125. Ideally, a combination of more than one of these procedures is required for the best chances of detection. The National Ovarian Cancer Association (NOCA) recommends that "women who are at a high risk of ovarian cancer, based on family history, should be screened twice yearly with transvaginal ultrasounds and CA 125 testing. Women who are at lower risk for ovarian cancer are encouraged to be aware of the symptoms of ovarian cancer and to communicate any changes to their family doctor during annual check-ups."⁴

² From the Canadian Task Force on Preventive Health Care Website, "Screening for Ovarian Cancer", <http://www.ctfph.org> , accessed February 14, 2002

³From the National Ovarian Cancer Association Website, www.ovariancanada.org – FAQ – accessed February 12, 2002

⁴ From the Website of the National Ovarian Cancer Association, <http://www.ovariancanada.org>, accessed February 3, 2002

The Canadian Task Force on Preventive Health Care recommends for all women that "it would be prudent to examine the ovaries at the time of cervical screening", and "to refer women with a family history of ovarian cancer to an academic research centre for follow-up". (CTFPH website)

We do not presently have a system for widespread population based screening to reduce mortality from ovarian cancer, or evidence that routine screening would result in decreased rather than increased morbidity and mortality. (Canadian Task Force on Preventive Health Care, guidelines last updated January 1994). The National Cancer Institute in the United States is currently undertaking a large-scale study to determine if certain screening tests reduce mortality from lung, colorectal, ovarian and prostate cancers.

Cervical Cancer

In Ontario, cervical cancer ranks as the second most common cancer in women ages 35-49 and third among women ages 20-34. It is also one of the most preventable forms of cancer, due to the success of cervical cancer screening with the Pap test. The Pap test can identify cellular changes in the cervix before they progress to the cancerous stage. In most cases, the disease is slow to progress, so early treatment and follow-up care provide a good chance of eradicating the disease. The slow progression of the disease supports the importance of screening even if a woman is not currently sexually active. This makes well-run recruitment and follow-up programs essential in the campaign to control cervical cancer.

Provincial screening guidelines for cervical cancer note:

- 1) Women of all ages who are, or ever have been, sexually active should be screened.
- 2) After three normal Pap tests at one-year intervals, screening should be continued every two years.
- 3) If there have been four normal Pap tests in the previous ten years, screening may be discontinued after the age of 70. ⁵

Interpretation and application of these guidelines varies nonetheless. For example, many doctors in Ontario do annual Pap tests in cases where it may not be necessary. The result is that some women are seldom or never screened while others are over-screened.

In June 2000, Cancer Care Ontario and the Ontario Ministry of Health launched the Ontario Cervical Screening Program “to reduce the number of deaths from what is essentially a preventable disease”⁶. The Program is intended to reach women who are not having regular Pap tests, to ensure that women having Pap tests are receiving proper follow-up care, and to monitor and improve the quality of cervical screening services.

The OCSP has identified five priority populations as target groups for cervical health messages: women 50 and over, low income women, women with low literacy skills, newcomers to Canada, and Aboriginal women.

Cervical cancer has been directly linked to human papillomavirus (HPV), a sexually transmitted disease (STD), often manifesting as genital warts. The use of particular barrier methods of contraception may lower the possibility of transmitting the virus and putting a woman at higher risk for cervical cancer⁷. It should be noted that the types of HPV which usually cause genital warts are not the ones that primarily lead to cancer of the cervix. However, certain strains of the human papillomavirus (16 and 18) are associated with cervical cancer.

Early age of first intercourse (18 years or younger) is also a risk factor as the maturing cervix is more susceptible to disease transmission. Although multiple sexual partners is identified as a co-factor for putting a women at higher risk, it is important to remember that transmission can happen with only one partner who is carrying the virus. A weakened immune system (e.g. through HIV or AIDS) is also a recognized risk factor for cervical cancer. Smoking has been

⁵ *1996 Ontario Cervical Screening Guidelines*, Cancer Care Ontario - www.cancercare.on.ca/cervical/guidelines.html#recommendations - accessed August 20, 2002

⁶ From CCO press release, “Cancer Care Ontario Launches the Ontario Cervical Screening Program”, June 15, 2000.

identified as putting a woman at risk for cervical cancer and is related to the amount smoked and the number of years a woman has been smoking.⁸ The use of oral contraceptives have been associated with cervical cancer although the data are conflicting. All told, perhaps the single greatest risk factor for cervical cancer is not having regular Pap tests.

Cervical cancer statistics in Ontario in the 1990s show that most Pap tests are done on women under 50, while most of the women dying of cervical cancer are over 50. The introduction of the Pap test in Ontario in the 1960s reduced mortality significantly, but over the last 15 years the number of older women dying from cervical cancer has not changed significantly. This situation is due to older women not having regular Pap tests. Many older women do not feel they need to continue to have regular Pap tests after their child-bearing years. However, it can take 10 years or more for precancerous lesions to become cancerous. Finally, with increasing age, the immune system offers less protection against the virus and other factors that cause cervical cancer.⁹

The Canadian Task Force for Preventive Health Care recommends that women should be screened up to the age of 69. Women under this age who are not sexually active should discuss their need for screening with their doctor or nurse.

Because of its association with sexual transmission through vaginal intercourse, lesbian women may not realize that they should be screened for cervical cancer just as heterosexual women should be. Any woman who has been sexually intimate with another woman or man may still need to be screened, even if there has not been vaginal/penile penetration.

Women whose mothers were given the drug *diethylstilbestrol* (DES) during their pregnancy are also at higher risk for cervical cancer and other rare forms of gynecologic cancers. Given to hundreds of thousands of women to ostensibly prevent miscarriage, primarily in the 1940s, 50s

⁷ While condom use is to be encouraged for a range of reasons, it does have a limitation in the protection against HPV since the warts may appear in other parts of the male genitalia which are not protected by the condom.

⁸ From the Website of the National Cancer Institute, "What You Need to Know About Cancer of the Cervix", www.nci.nih.gov, last accessed Jan 29, 2002.

and 60s, the children of women who were prescribed the drug have a range of reproductive health problems including cervical and vaginal cancer and higher rates of dysplasia. Women who are DES-exposed should have both a yearly Pap smear as well as a more detailed pelvic exam (including colposcopy) to check for abnormal cell activity. It is estimated the tens of thousands of women in the GTA were exposed to DES *in utero*.¹⁰

Breast Cancer

Breast cancer is the most common cancer diagnosis in women and in Canada accounts for 30% of all new cancer cases each year. In the past 25 years, the incidence rate of breast cancer in Canada has increased by 28%. Early detection through mammography screening has been suggested as a reason for the increase in incidence rates. Mortality rates, by contrast, are declining in Canada, also possibly the result of earlier detection and some improvements in treatment. It is estimated that 1 in 9.5 Canadian women will develop breast cancer in their lifetimes and one in 26 women who live to 85 years of age will die from it¹¹. International differences have been noted with a higher incidence of breast cancer in industrialized, versus developing, countries. This may point to a role played by diet as well as environmental and occupational carcinogens in cancer development.

Factors which put a woman at risk for breast cancer include: a family history of the disease (hereditary breast cancer makes up approximately 5% to 10% of all breast cancer cases), a history of primary cancer of the ovaries or endometrium, having had no children (nulliparity) or having had children after age 30, use of exogenous (not produced within the body) hormones, early onset of menstruation and late onset of menopause (after 50), extensive exposure to ionizing radiation through the childbearing years, alcohol consumption, exposure to certain occupational and environmental chemicals (particularly organic solvents and chemicals that mimic estrogen), a high-caloric and low-fibre diet and one high in saturated fats (particularly in

⁹ Krauser J. Cervical cancer and older women. Bulletin/Newsletter (published by the Ontario Gerontology Association - phone 416-535-6034) February 1998 14(3): 13-14.

¹⁰ For more information on DES, see the Website of DES Action Canada, www.web.net/~desact.

¹¹ Working Group on the Primary Prevention of Breast Cancer (Canadian Breast Cancer Initiative), *Summary Report: Review of Lifestyle and Environmental Risk Factors for Breast Cancer*, Health Canada, 2001.

the post-menopausal years), obesity and lack of physical activity, and exposure to electromagnetic fields in the premenopausal years.¹²

The Ontario Breast Screening Program (OBSP) was established in Ontario in 1990 "to reduce mortality from breast cancer through early detection", using mammography as the screening device. Through dedicated screening centres, affiliated sites around the province along with a mobile unit, the programme targets women age 50-69 with no current symptoms of breast cancer. To date, participation rates in the program have not met targeted goals of reaching 70% of Ontario women between the ages of 50 and 69¹³, with the greatest problem reaching this goal being in the GTA. It is widely acknowledged that more resources are needed for outreach to hard-to-reach populations.

Awareness about breast cancer has increased exponentially in Canada since the mid 1990s, largely as a result of lobbying efforts by breast cancer survivors, which brought attention to the disease at the federal government level. The National Forum on Breast Cancer in Montreal in 1993, sponsored by the federal Dept of Health and the Canadian Breast Cancer Foundation, led to or coincided with the creation of a number of national organizations dedicated to research, fundraising and support related to breast cancer, most notably the Canadian Breast Cancer Research Initiative (CBCRI), the Canadian Breast Cancer Network (CBCN). A host of provincial and local organizations have formed in the past decade serving more focussed needs. Breast cancer support and resource services in the GTA include Willow (Breast Cancer Support and Resource Centre), the Ontario Breast Cancer Information Exchange Project, and the Ontario Breast Cancer Support Network.

Prevention: Definitions

¹² Working Group on the Primary Prevention of Breast Cancer (Canadian Breast Cancer Initiative), *Summary Report: Review of Lifestyle and Environmental Risk Factors for Breast Cancer*, Health Canada, 2001

¹³ Newsletter of the OBSP, January 2002.

In this paper, we make a distinction between primary and secondary prevention of cancer to discuss different approaches to cancer prevention and control. Distinctions are made in public health literature between primary, secondary and tertiary prevention. The Surgeon General of the United States defines the three levels of prevention as follows:

“Primary prevention generally refers to the elimination of risk factors for disease in asymptomatic persons. Secondary prevention is defined as the early detection and treatment of disease, and is practiced using tools such as Pap smears and blood pressure screening. Tertiary prevention consists of measures to reduce impairment, disability, and suffering in people with existing disease.”¹⁴

In an earlier paper (1979) by Dr. Quentin Rae-Grant called "The State of the Art: A Background Paper on Prevention", his definition of primary prevention encompassed a health promotion approach:

“Primary prevention aims at reducing the incidence of new cases in a population. It refers to activities, both of proved and presumed efficacy, that are intended to prevent certain disorders and dysfunctions. Its two different aspects are (a) efforts that concentrate on modifying the stressful environment, ie. specific protection; and (b) strengthening the ability of the individual to cope with stress, ie. promoting health or competence.”¹⁵

The Canadian Task Force on Preventive Health Care’s on-line medical dictionary defines primary prevention as “The prevention of disease or mental disorders in susceptible individuals or populations through the promotion of health, including mental health, and specific protection

¹⁴ <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001799.htm>

¹⁵ Hayday, Bryan, talk delivered in 1987: "Prevention: Hype or Hope: The Ontario Experience"; cited in personal correspondence with the Ontario Prevention Clearinghouse, April 2001

such as immunization, as distinguished from the prevention of complications or after-effects of existing disease.”

Cancer Care Ontario’s Prevention Blueprint (2000) notes that “Cancer prevention includes two main strategies:

- Eliminating the causes of cancer and preventing the disease from getting started in the first place and
- Screening to find cancer or its precursors so that it can be treated easily and effectively.”¹⁶

By contrast, in a deputation to the Board of Health for the City of Toronto Health Unit in May of 1995 on *Recommendations for the Primary Prevention of Cancer*, the Women’s Network on Health and the Environment noted emphatically, “Cancer prevention means reducing carcinogen exposure. **Early detection does not mean prevention.**” (original text in bold)

It is clear from even this brief overview of descriptions of primary prevention that there is no consensus on a definition and the subjective bias of each author is at play. Even the frequently quoted *Report of the Ontario Task Force on the Primary Prevention of Cancer* does not give a definition of the term. In light of this ambiguity, it seems safe to err on the side of caution and include both efforts of primary prevention – eliminating the causes and preventing the disease from developing in the first place, and secondary prevention – early diagnosis and screening of cancers so that they may be treated early where appropriate.

Women’s Cancers and Primary Prevention

“Failure to prevent cancer is the most important factor affecting Ontario’s cancer death rate...Fortunately we now have a reasonably good understanding of some

¹⁶ Cancer Care Ontario, *Ontario’s Cancer Prevention Blueprint 2000: An Ounce of Prevention*, May 2000, p 1

*of the most important causes of cancer. We certainly don't have all the answers but we know enough to make major improvements.”*¹⁷

This dictum from Ontario's provincial cancer agency should provide substantiation for the defence of primary prevention. And yet those who have been advocating for primary prevention continually remind us that the lion's share of cancer dollars go to screening and treatment, not to research into primary prevention. This limitation becomes particularly frustrating in light of the fact that there are additional beneficial reasons for focussing on primary prevention as well as secondary prevention in the efforts to reduce cancer in Ontario: **In addition to cancer prevention benefits, efforts to enhance healthy eating, tobacco reduction, alcohol moderation, increased physical activity and the elimination of carcinogens in the environment and the workplace lead to many positive and quantifiable health benefits for the population through reduced incidence of chronic diseases such as diabetes, arthritis and hypertension.**

Primary prevention strategies generally fall into two categories – those that are aimed at changing individual behaviour and those that are aimed at improving environmental conditions. Public health campaigns over the past several decades have tended to favour the former strategies focussed on an ethic of individuals taking personal responsibility for their health. However, with relatively little progress in improvements in mortality rates of some cancers, it is increasingly recognized that a broader environmental approach must also be adopted.¹⁸ To cite the Breast Cancer Prevention Coalition, “...aside from tobacco-induced tumours, which can be prevented by stopping smoking - we've bought the idea that the only way to grapple with cancer is to 'beat' it with early detection and treatment. But after nearly three decades of the 'war' on cancer (declared by U.S. President Richard Nixon in 1971) and billions of dollars spent, overall

¹⁷ Cancer Care Ontario, *Ontario's Cancer Prevention Blueprint 2000: An Ounce of Prevention*, May 2000, p.4

¹⁸ For more on this see another background paper of the Toronto Cancer Prevention Coalition, “Preventing Occupational and Environmental Cancer: A Strategy for Toronto”, prepared by the Occupational and Environmental Carcinogens Working Group, May 2001, available on the Toronto Cancer Prevention Coalition Website, <http://www.city.toronto.on.ca/health/resources/tcpc/>

mortality and incidence rates continue to rise”.¹⁹ (Note that, in fact, mortality is declining with some cancers.)

Because of the comparatively small amount of research funding that goes to all facets of primary prevention, the current state of knowledge in these three cancers in women is uneven. Due largely to the extent of lobbying and awareness-raising around breast cancer that has taken place over the past decade (a phenomenon that is only just beginning with ovarian cancer and which some would say has yet to begin with cervical cancer²⁰) our knowledge of primary prevention of breast cancer surpasses what we know about ovarian and cervical cancer.

Cancer Care Ontario’s *Blueprint for Prevention*, for example, only specifically refers to secondary methods of prevention of cervical cancer (the Ontario Cervical Screening Program) and makes only general statements applying to all cancers for measures such as improving diet: “Between 30% and 40% of all cases of cancer are preventable by feasible and appropriate diets and related factors”.²¹ They are able to be more specific with respect to alcohol intake: “Keeping alcohol intake within the recommended limits will prevent up to 20% of cases of cancers of the aerodigestive tract, the colon and rectum, and breast”.²²

The distinctions between general statements about overall primary cancer prevention and statements specific to certain cancers are in a constant state of evolution, reflecting in broad historical terms, the relatively new state of this field of research.

Sometimes, substantive information about the causes of certain women’s cancers can lead to uncertainty as to whether primary prevention measures should necessarily be recommended. For example, ovarian and breast cancer share the risk factor of nulliparity (having never had a full-term pregnancy). Does this mean that we advocate for women having children in their twenties

¹⁹ From the Website of the Breast Cancer Prevention Coalition, www.stopcancer.org .

²⁰ Some breast cancer advocates have noted that now that it has become more "acceptable" to talk publicly about breast cancer, it will become easier for women to talk about the other two cancers.

²¹ “Ontario’s Cancer Prevention Blueprint 2000: An Ounce of Prevention”, Cancer Care Ontario, p. 12.

²² “Ontario’s Cancer Prevention Blueprint 2000: An Ounce of Prevention”, Cancer Care Ontario, p. 13.

in order to improve their chances of not getting breast cancer? Similarly, the use of oral contraceptives may put one woman at higher risk for breast cancer while possibly protecting that same woman from ovarian cancer. Does this mean we advocate for or against the use of oral contraceptives? Early age at first intercourse has been associated with a higher risk of cervical cancer. Should this be a reason to advocate for abstinence?²³ Rather, perhaps these factors should be seen as information that women must be offered so that they can make informed decisions. Just as appropriate messages must be found to reach teens regarding tobacco cessation, similarly creative measures are needed to reach teens and young adults about these choices.

The report "Ten Key Carcinogens in Toronto Workplaces and Environment", recently commissioned by Toronto's Medical Officer of Health, Dr. Sheela Basrur, notes that for nine of the ten carcinogens studied, "there is strong evidence to indicate that they induce cancer in humans and strong agreement among regulatory agencies that they should be treated as known or probable human carcinogens".²⁴ It is further noted that "these contaminants tend to be present in Toronto's outdoor air at levels that approach or exceed the air levels deemed "tolerable"..."²⁵ With this report comes a clear recognition of the need to be looking much more closely at the environmental factors that are leading to increased rates of certain cancers. It is only with a shift in focus to research such as this, and when the ensuing policy changes are implemented, that the *primary* prevention of many cancers will occur. Toronto Public Health's Healthy Environments Program is presently examining the issues raised in the "Ten Key Carcinogens" paper.

The Need to Invoke the Precautionary Principle

²³ The Toronto Public Health Department has produced a brochure called "Wait for Sex? Why Should I?" which advises young women and men of the advantages of abstaining from sexual intercourse (and gaining sexual pleasure in other ways) which is used in sexual health programs in schools throughout the city. There is no consensus amongst departments of public health throughout the country as to whether this is the approach to take.

²⁴ Kim Perrotta and Ronald Macfarlane, *Ten Key Carcinogens in Toronto Workplaces and Environment: Assessing the Potential for Exposure*, Toronto: Toronto Public Health, March 2002, p.i of Executive Summary.

²⁵ *ibid*, p.ii of Executive Summary.

“The presence of toxic substances in the ecosystem has been linked to a number of adverse health effects, including cancer in animals and humans. A number of methodological barriers...hinder the acquisition of conclusive evidence, however, which has led to uncertainty about the extent to which environmental contaminants contribute to cancer...In the face of this uncertainty, the Task Force considers that the only prudent approach to safeguarding the health of the public from known and suspected environmental carcinogens is to be **precautionary** while the necessary research efforts are being made to resolve the uncertainty.”
(Task Force on the Primary Prevention of Cancer, p. 29)

Ovarian Cancer

The Ontario Task Force on the Primary Prevention of Cancer noted that ecological studies have shown a positive correlation between levels of dietary fat and meat consumption and cancer of the ovaries. The hypothesis has not been sufficiently tested in individuals with case control and cohort studies. More specific dietary elements point to more focussed recommendations. They note that “there is fairly consistent evidence of an association of dietary fat consumption, especially saturated fat, with...ovarian cancer”.²⁶

Since this information is consistent with overall healthy eating recommendations in Canada's Food Guide to Healthy Eating, it could be added to existing information packages and advertising campaigns aimed at raising awareness about ovarian cancer and the need for early detection.

Recent research conducted on the role of antioxidant vitamins C and E (taken as supplements) in relation to ovarian cancer found that they contributed to a reduced risk of ovarian cancer.²⁷

²⁶ “Report of the Task Force on the Primary Prevention of Cancer”, p 17.

²⁷ Aaron T. Fleischauer et al, "Dietary antioxidants, supplements and risk of epithelial ovarian cancer", *Nutrition and Cancer* 40(2), 2002, pp92-98.

Research on fertility drugs (drugs that cause women to ovulate) has determined that this class of drugs may slightly increase a woman's chance of developing ovarian cancer²⁸. Further research is underway in this area.

Cervical Cancer

The association between smoking and cancer of the cervix has been established.²⁹ The carcinogens in cigarette smoke have been found to be highly concentrated in cervical mucus at levels 10 to 20 times higher than in the blood. Primary prevention efforts must therefore include targeted anti-smoking campaigns to women. **Current anti-smoking campaigns could begin to include messages about this particular association with another form of cancer other than lung cancer, particularly where the target audience is young women.**

While a direct link between oral contraceptive use and cervical cancer has not been established, recent research has found that women who are infected with HPV and use oral contraceptives over an extended number of years (more than 5) are more likely to develop cervical cancer compared with HPV-positive women who do not take oral contraceptives.³⁰

The National Cancer Institute (U.S.) notes that Vitamin A may also play a role in stopping or preventing cancerous changes in cells on the cervix. There is also growing evidence to support a link between stress and the development of cervical cancer.

Breast Cancer

A study funded by the Canadian Breast Cancer Research Initiative in 2001 revealed that a reduction in breast cancer risk can be achieved through physical activity. In particular they found that physical activity undertaken after menopause had the most beneficial effect. Postmenopausal

²⁸ Fact Sheet of the National Cancer Institute (US Government), "What You need to Know About Ovarian Cancer", Website <http://www.nci.nih.gov> , accessed Feb 13, 2002.

²⁹ Fact Sheet of the National Cancer Institute (US Government), "What You Need to Know About Cancer of the Cervix", Website <http://www.nci.nih.gov> , accessed Feb 13, 2002.

³⁰ Findings reported in the March 27, 2002 issue of *The Lancet*, noted in a release from Kaisernetwork.org (http://www.kaisernetwork.org/daily_reports) of the same date.

women who have been physically active throughout their lives can reduce risk by up to 42%.³¹ The Ontario Task Force on the Primary Prevention of Cancer noted that lifelong habits of physical activity need to be established throughout the school-age years. In light of the fact that physical education programs have been amongst the first courses to be cut or reduced in Ontario schools, **the Toronto Cancer Prevention Coalition recommends that school boards in the GTA re-instate earlier levels of physical education programs at both the elementary and secondary levels.**

Sufficient evidence exists to confirm the carcinogenicity of hormone replacement therapy in women.³² This risk increases with the length of time the medication has been taken. The Ontario Task Force on the Primary Prevention of Cancer reported that “if half of all women in Canada were to take prolonged courses of estrogen at the time of menopause...9% of breast cancer would be attributable to this cause”. (Task Force on the Primary Prevention of Cancer, p, 46) Recent research in the U.S. (2002) found the risk was greater with prolonged use of hormone replacement therapy and specifically contributed to the development of lobular tumours of the breast.³³ In July 2002, a large clinical trial of the Women's Health Initiative examining the risks and benefits of HRT was halted because the medication's long-term risks were found to outweigh its benefits. The trial confirmed that HRT alleviates hot flashes and night sweats and helps prevent bone fractures, but found that estrogen and progestin supplements increase the risk of invasive breast cancer when used for five years or more.³⁴

Carcinogens in the environment and in occupational settings are slowly becoming the focus of more research on the primary prevention of cancer.

³¹ Canadian Breast Cancer Research Initiative, “*Guidelines for physical activity to reduce breast cancer risk at any age*”, press release, October 15, 2001

³² Fact Sheet of the National Cancer Institute (US Government), "Questions and Answers About Hormone Replacement Therapy", revised August 23, 2001. http://newscenter.cancer.gov/pressreleases/hormone_qa.html .

³³ Chen C-L, Weiss NS, Newcomb P, Barlow W, White E., "Hormone replacement therapy in relation to breast cancer", *JAMA* 2002 (Feb 13); 287:734-741.

³⁴ Writing Group for the Women's Health Initiative Investigators. "Risks and Benefits of Estrogen Plus Progestin in Healthy Postmenopausal Women." *JAMA* 2002 (July 17); 288: 321-333.

- An association was reported between sulphur dioxide and ground level ozone emissions and breast cancer. (Task Force, p. 29)
- Proximity of residence to hazardous waste sites has been associated with increased risk of breast cancer. (Task Force, p. 29)
- There is a plausible association between organochlorines and breast cancer (note that main route of entry to humans is through pesticides in the food chain). (Task Force, p. 29)
- “Certain types of chemicals, namely organic solvents, concentrate in the non-lactating breast and stagnate in the milk ducts, where they are then transformed into reactive metabolites that exert detrimental effects.” (CBCI Working Group Report, p. 26)
- Exposure to electromagnetic fields may increase breast cancer risk in premenopausal women, by indirectly affecting hormone secretions. (CBCI Working Group Report, p. 26-28)

In light of this information, the Toronto Cancer Prevention Coalition urges appropriate measures to inform citizens of the presence of toxins in the environment and advocates that workers should be made aware of the presence of toxins in their workplace. Further, the Toronto Cancer Prevention Coalition supports tighter workplace health and safety regulations to safeguard against further exposure to toxins.

With respect to the role of diet in breast cancer prevention, epidemiological studies reviewed by the Working Group on the Primary Prevention of Breast Cancer of the CBCRI found that

- total fat - mainly saturated fats - possibly increases risk
- Omega-3 fatty acids, found in fish oils, may decrease breast cancer risk
- there was a suggestion of increased risk with animal protein intake
- there is a possible decrease in risk from non-starch polysaccharides/dietary fibre intake
- Vitamin A (beta-carotene) and Vitamin C intake may decrease risk
- Vitamin D may provide a protective effect (from diet, supplementation and sunlight exposure)
- iodine and selenium may provide protective effects

- there is strong evidence for a decreased risk with high vegetable and fruit intake - particularly vegetables
- preliminary indirect evidence suggests a protective effect from phytoestrogens (a major component of soy-based foods)
- meat intake possibly increases risk; poultry consumption possibly not related; fish intake may decrease risk ³⁵

The Toronto Cancer Prevention Coalition urges a broad diffusion of positive dietary messages and their link to cancer prevention.

Controversies in the Primary Prevention of Breast Cancer

“Chemoprevention”

Chemoprevention in breast cancer management is the use of drugs to block the action of estrogen in the development of the disease.

For the past few years, the pharmaceutical company AstraZeneca has been marketing its drug Nolvadex (tamoxifen) for the prevention of cancer in healthy women³⁶ in the United States. Through a change in American drug laws, companies can advertise prescription drugs directly to the public on television, print, and radio – known as direct-to-consumer advertising or DTCA. Although it is not legal to advertise prescription drugs directly to the public in Canada, Canadian women and their doctors are exposed to the ads for tamoxifen for breast cancer risk reduction through American television and magazines.

³⁵ Working Group on Primary Prevention of Breast Cancer (CBCRI), *Summary Report: Review of Lifestyle and Environmental Risk Factors for Breast Cancer*, Health Canada 2001, pp 15-16.

Although Health Canada has not approved the use of tamoxifen for breast cancer risk reduction, it is on the market in this country for the treatment of breast cancer and, through a loophole in Canadian drug laws (known as “off-label prescribing”), physicians are free to prescribe it to healthy women at their discretion. Some Canadian physicians and consumer groups, such as the Canadian Breast Cancer Network³⁷, the Working Group on Women and Health Protection³⁸ and Breast Cancer Action Montreal, have taken positions against the use of tamoxifen on healthy women, arguing that not only can its use in healthy women create other serious health problems³⁹, but the move to the use of drugs for prevention is a dangerous precedent which takes attention and resources away from safer means of prevention. Others argue that chemoprevention is our best hope for the future of breast cancer research .

Again, it is not the position of the Toronto Cancer Prevention Coalition to take a stand “for” or “against” chemoprevention. Rather **the Toronto Cancer Prevention Coalition wants to ensure that the relevant intermediaries are providing women with the full range of information they need to be making informed decisions.** (This statement recognizes that such decisions can be complicated by pressures from family, friends and health care providers who have their own biases. Decisions can be further compounded by language barriers and cultural differences. Service organizations such as Willow and CancerConnection can help women in their decision-making.)

Women’s Cancers and Secondary Prevention

³⁶ The phrasing that was permitted by the FDA was that tamoxifen could “reduce the risk of breast cancer in the short term but could not prevent it”.

³⁷ The position put forward by the Canadian Breast Cancer Network and endorsed by a number of organizations, is available on the Website of the Breast Cancer Prevention Coalition at http://www.stopcancer.org/ca_env/pg15.html.

³⁸ The Working Group’s position paper on chemoprevention, “Preventing Disease: Public Health versus Chemoprevention” by Sharon Batt, is forthcoming (Fall 2002) on their Website - <http://www.whp-apsf.ca>.

³⁹ Endometrial cancer, blood clotting and vision problems have been identified in the research done to date on tamoxifen.

The purpose of screening is the early detection of cancer in people without any symptoms such as a breast lump or cervical lesion. For screening to be effective, a cancer must be found early, before it spreads. For screening to be further effective, treatment must be dealt with in a timely way. Currently, population-based screening programs are used for breast cancer, because tumours can be detected early, and cancer of the cervix, because precancerous changes can be detected. The Ontario Breast Screening and Cervical Screening programs are province-wide initiatives funded by the Ministry of Health and administered by Cancer Care Ontario (CCO). Breast and cervical screening programs are considered cost effective because the costs of screening appropriate segments of the population and treating cancer in early stages are generally less than the health care costs associated with treating advanced cancers.⁴⁰

It is important to keep in mind that screening often detects cancers but it does not decrease their occurrence. It can, however, be effective in reducing mortality and morbidity.

Ovarian Cancer

There currently exists no systematic screening program for ovarian cancer in Ontario. Long-term studies in both North America and the U.K are examining the effectiveness of screening programs for ovarian cancer but in most cases, the results are years away. There are however a number of efforts underway to promote awareness and early detection of the disease.

Educating women about symptoms and risk factors of ovarian cancer is part of the role of the National Ovarian Cancer Association (NOCA - initially known as the Corinne Boyer Fund). The organization provided \$1-million to create an endowed chair in ovarian cancer research at the University of Ottawa's Faculty of Medicine. The Association also committed \$120,000 for the first phase of a national tumour bank network to store tissue for research purposes. Other activities include the formation of a consumer action group; "Listen to the Whispers", a public education project with audio-visual aids; Lunch and Learn, an educational programme for well women; the development of a website with lay and health professional information from across

⁴⁰ Office of the Provincial Auditor (Ontario) www.gov.on.ca/opa .

Canada; and linking women with ovarian cancer to support groups.
(<http://www.ovariancanada.org>).

The outcome of a federally funded national survey on ovarian cancer, sponsored by NOCA, was the Ovarian Cancer Forum '99, a national meeting held in Toronto. The forum highlighted such gaps in managing ovarian cancer as failure to detect the disease early, inattention to warning symptoms, lack of information, and poor physician-patient communication. A key goal of the forum was to develop an action plan for the future. Many forum delegates perceived a lack of awareness about signs and symptoms on the part of both women and health care practitioners, particularly family physicians.

Both of these initiatives demonstrated the need for effective educational materials written in understandable language that is sensitive to ethnicity, age and socio-economic status. This, in turn, led to the development of the Ovarian Cancer Information Project, modelled in part after the earlier Ontario Breast Cancer Information Exchange Project. The project is sponsored by NOCA, funded by the Lawson Foundation and administered at the Toronto-Sunnybrook Regional Cancer Centre.

The purpose of the Ovarian Cancer Information Project is to develop and disseminate information about ovarian cancer to four target groups: well women, women at risk, women living with the disease and their families; and health care professionals. National Advisory and Steering Committees have been established and in January 2002 the Project sponsored a stakeholders meeting in Toronto. The results of that meeting will be taken forward in the continued development of the project.

Cervical Cancer

As noted above, the Ontario Cervical Screening Program was launched in June 2000 by Cancer Care Ontario (CCO) and the Ontario Ministry of Health. The Program was a response to earlier recommendations of the Ontario Cervical Screening Collaborative Group (OCSCG). The OCSCG represents a partnership of both public and private sector organizations, including health

professional associations, consumer representatives, researchers, CCO, and the Ontario Ministry of Health. The OCSCG recognized that an organized cervical screening program was needed to achieve the desired reduction in cervical cancer. Its objective is to reduce the incidence of and mortality from cervical cancer by 50% between 1993 and 2005. The OCSCG continues to function since the inception of the program.

In 1997, the OCSCG decided to develop a computerized cervical screening database to enable it to measure program effectiveness. The initial purpose of the database was to provide physicians with access to women's cervical screening histories to help them properly interpret Pap smears; make informed recommendations for the follow-up of abnormalities; ensure detected abnormalities have been appropriately followed up; and ensure timely scheduling of women for subsequent tests.

However, the database effectiveness has been limited due to incomplete data. For the 1997 year, only approximately 50% of the estimated 1.5 million Pap smears taken in Ontario were registered on the database. This can be attributed to the following:

- Reporting information on Pap smears is voluntary.
- Some laboratories are either not computerized or have computerized data that is incompatible with the database.
- Tests are performed in hospital laboratories, which cannot release their results due to restrictions contained in the Public Hospitals Act.⁴¹

A survey of cervical screening promotion in Ontario Public Health Units (Cervical Screening Promotion in Ontario Public Health Units, June 1999) identified gaps to cervical cancer screening. Gaps identified by Toronto Public Health were lack of linguistic and cultural acceptance in educational materials; lack of material geared to older women; lack of standardized messages and commitment to promote screening among health care providers and other stakeholders. Hard-to-reach groups included immigrant women, older women of post

child-bearing age, low income women, and high risk teens. The absence of effective community-based promotion of cervical screening was a major barrier, as were lack of knowledge, transportation problems, lack of profile of peer role models, and language barriers and cultural norms and beliefs (CCO - Ontario Cervical Screening Program, 1999).

Unsatisfactory post-treatment follow-up of abnormal Pap tests has a lengthy history and is still an ongoing concern in Ontario. One large multi-center study, including four Canadian centers, found that up to 80% of women identified as having an abnormal Pap test failed to complete the recommended post-treatment follow-up of three consecutive negative tests and colposcopies, thus exposing themselves to risk of developing invasive carcinoma of the cervix.⁴² Because these services are free in Canada, one may hypothesize that fear and lack of knowledge play a role in failed follow-up.⁴³

Studies such as the 1994 National Population Health Survey (NPHS) consistently show that immigrant women, elderly women and women of low socioeconomic status tend to be under screened or never screened. Taken as a whole, these hard-to-reach candidates for cervical screening represent a small proportion of Canadian women. However, they form the majority in the very subgroups that are most at risk of cervical cancer, and their numbers are many in the GTA.

Toronto Public Health and other health departments in the GTA have recognized the importance of developing programs to address the acknowledged gaps and to reach these priority groups. There is still much work to be done in this area for all barriers to screening to be overcome. This is work that can only be achieved through the combined efforts of many community groups, health care agencies and key stakeholders.

⁴¹ Office of the Provincial Auditor, 1999

⁴² Richart RM, Townsend DE, Crisp W et al. "An analysis of longterm follow-up results in patients with cervical intraepithelial neoplasia treated with cryotherapy", Am J Obstet Gynecol 1980; 137: 823-6. (from Stewart et al., 1993)

⁴³ Stewart DE, Lickrish GM, Sierra S, Parkin H. The effect of educational brochures on knowledge and emotional distress in women with abnormal papanicolaou smears. Obstetric & Gynecology 1993; 81: 280-282.

Breast Cancer

The major initiative for breast screening serving women in the GTA is the Ontario Breast Screening Program (OBSP) of the Central East Region. Approximately one-third of the mammography facilities in Ontario participate in the OBSP. Participating sites offer the benefits of automatic recall, generation of statistical information for program evaluation, accreditation (quality assurance), and accommodation of existing physician referral patterns. The suggested screening period for women is once every two years, although some higher risk women are re-screened annually. Cancer Care Ontario estimated that there were approximately one million Ontario women in the OBSP's target population.

With the goal of a province-wide participation rate of 70% of women age 50-69 by the year 2010, there is considerable ground still to cover with the current rate at approximately 20%. The region with the lowest rate is that in which the GTA is found: Central East. With enormous demographic challenges, the region has nonetheless managed to open 10 new affiliate sites since April 2000.

The OBSP's ability to determine whether it is achieving its goal has been limited because the vast majority of mammograms performed in Ontario are done at non-OBSP facilities. Women in Ontario obtain a mammogram either at an OBSP facility or through a physician referral to a non-OBSP facility. Due to the confidentiality of medical records, the OBSP does not receive information on women who have had non-OBSP mammograms. Accordingly, for the target population, the OBSP cannot determine, for example, which women are high risk or who have never been screened. One of the greatest challenges to recruitment has been the fact that referral patterns to radiology clinics are stable. Thus, women who attend screening at a non-OBSP sites will continue to attend that site, regardless of how many OBSP sites open in the region.

Reduction of cultural and linguistic barriers is a constant challenge throughout the Central East region. More than 200,000 immigrants come to Canada each year and almost 60% of these newcomers settle in the GTA, where more than 100 languages are spoken. Sustained outreach

was conducted with the Ismaili community and a successful pilot with the Immigrant Woman's Health Centre. With regard to the latter, trained counselors are funded on a per screen basis to recruit women to the OBSP in different languages (Chinese, Italian, Spanish, Tamil, Urdu, Punjabi, Farsi and Vietnamese).

Numerous multicultural outreach programs have been offered by the OBSP - Central East Region from 1993 to present with supportive funding from the Canadian Breast Cancer Foundation, Ontario Chapter. For example, a Chinese Community Outreach Coordinator conducted group presentations, displays, coverage in the Chinese media, outreach to Chinese physicians and recruited and trained Chinese volunteers for presentations and group screening assistance (interpreters, escorts and coordination). An outcome of this initiative was that 1,110 Chinese women were screened. OBSP outreach is currently taking place in the Spanish, Somali and South Asian communities.

In addition to the outreach efforts of the OBSP, Toronto Public Health is mandated to raise awareness and to support OBSP in increasing the number of women accessing their sites for mammograms. To this end, TPH is involved in many health promotion strategies and joint community initiatives.

Controversies in the Secondary Prevention of Breast Cancer

i) Mammography

“Once you think you have the answer, you stop asking the questions. You can’t assume that pinning on a pink ribbon and having every woman get a mammogram is the solution.”

Fran Visco, National Breast Cancer Coalition, cited in New York Times, December 9, 2001

*“Mammograms are not an answer”
(Newsday.com Dec 28, 2001)*

"Questions grow over usefulness of some routine cancer tests"

(New York Times, Dec 30, 2001)

"It will be a long time before mammograms cease to be a crutch for women afraid of breast cancer."

Dr. Cornelia Baines, epidemiologist, Deputy Director, Canadian National Breast Screening Studies, speaking at McMaster University, January 31, 2002

"Mammography: Is there another side to the story?"

(Breast Cancer Action Montreal Bulletin, Winter 2002)

"Mammograms: Not perfect but necessary"

(New York Times, Feb 5, 2002)

"The mammography screening debate: time to move on"

Karen A. Gelmon & Ivo Olivetto, Commentary: The Lancet, Vol 359, March 2002, pp 904-5.

Recently, a heated debate, beset by intense emotional reactions, is waging in the press about the usefulness of mammography. Headlines and quotes like the ones noted above call out from newsstands, television screens and radios across the country. Women are caught. They are understandably confused and torn about what to make of the latest research. **This fear and confusion is creating a barrier to getting women in for screening.**

The genesis of the most recent debate is a study published in *The Lancet* in October 2001 that calls into question the long-held belief that if women have regular mammograms starting at age 50 (or younger, depending on the jurisdiction) they will reduce their chances of dying from breast cancer by roughly 30%. Women have also been told that if a tumour is detected earlier, they will have a much better chance of not having to have disfiguring surgery or other harsh treatments which might be needed for a larger or more invasive tumour found later. The study reported in *The Lancet*, undertaken by a group of researchers in Denmark, calls into question a range of studies on mammography on which these earlier statements of hope were based.

However, in March 2002, a lengthy defence of some of the studies in question (four studies in Sweden) was published in *The Lancet*, concluding that the previous critique was "misleading and scientifically unfounded"⁴⁴ An editorial in that same issue appropriately noted that, "The literature on screening mammography provides ample opportunity for confusion and dogma, and can be interpreted to prove both benefit and harm."⁴⁵ Further refutation of the Danish report came shortly afterwards from the International Agency for Research on Cancer (IARC), part of the World Health Organization, when its panel of experts claimed that "many of the Danish researchers' concerns were unfounded". It further noted that "Organised screening programmes are more effective in reducing the rate of death from breast cancer than sporadic screening of selected groups of women."⁴⁶

Additional concerns about mammography include evidence since the 1940s that the cumulative effect of the radiation generated from the mammogram testing over a number of years, may add to a woman's risk of breast cancer as she ages.⁴⁷

The point here, and for the Toronto Cancer Prevention Coalition, should not be to take a position "for" or "against" on this debate. It would seem more prudent **for the Toronto Cancer Prevention Coalition to make sure that women are aware of the debate surrounding mammography and to ensure – through the various local and provincial departments and programs which reach women on issues of health promotion and disease prevention – that they are provided with the full range of information on which to base a decision.** (The Toronto Cancer Prevention Coalition recognizes that because of the particular complexity of this debate, clear-language writing in the key languages of the GTA, as well as cultural sensitivity, is essential for any communication materials.)

⁴⁴ Nystrom, L et al, "Long-term effects of mammography screening: update overview of the Swedish randomised trials", *The Lancet*, March 2002, Vol 359, p. 919.

⁴⁵ Gelmon, Karen A. and Ivo Olivotto, "(Commentary) The mammography screening debate: time to move on", *The Lancet*, March 2002, Vol 359, p. 904.

⁴⁶ From a press release issued by IARC, March 19,2002, "Mammography screening can reduce deaths from breast cancer", <http://www.iarc.fr/pageroot/PRELEASES>.

Dr. Barnett Kramer, the associate director of disease prevention at the National Institutes of Health in the United States has noted that “Once a program has been highly promoted and advanced as a way to save lives, it can be difficult to suggest that guidelines be revised .”⁴⁸ As Ontario health policy makers struggle with this issue surrounding mammography, we would hope that guidelines would not be impossible to revise, should the conclusion be that this is the wisest course to follow.

ii) Breast Self-Examination

Manual breast self-exam (BSE) has long been thought to be an important tool in the fight against breast cancer. Advocated consistently since the post WWII era in Canada , BSE is premised on the belief that finding smaller tumours earlier dramatically improves a woman’s chances of survival.

In the summer of 2001, however, with the release of the results of a major Canadian report⁴⁹ in *the Canadian Medical Association Journal*, this thinking was turned on its head. Referred to as “The Baxter Report” after principal author, Dr. Nancy Baxter, the conclusion was that after reviewing the existing studies on the value of BSE, there was insufficient evidence to suggest that it lowers mortality and, in fact, could be harmful in that it creates unnecessary doctor visits and leads to unnecessary biopsies. Subsequently, the Canadian Task Force on Preventive Health Care, for whom the report was written, decided to no longer recommend the routine teaching of BSE for women of all ages.

⁴⁷ Epstein, Samuel, R. Bertell and B. Seaman, “Dangers and unreliability of mammography: Breast Examination is a Safe, Effective and Practical Alternative”, *International Journal of Health Services*, 31(3), pp 605-615, 2001.

⁴⁸ Cited in “Study sets off debate over mammograms’ value” *New York Times*, December 9, 2001.

⁴⁹ Baxter, Nancy, with the Canadian Task Force on Preventive Health Care, “Preventive Health Care, 2001 Update: Should Women be Routinely Taught Breast Self-examination to Screen for Breast Cancer?”, *Canadian Medical Association Journal* 164(13); 1837-46, June 26, 2001.

As with the latest research on mammography, the data are conflicting, and women are left wondering whether it is worth bothering to conduct a monthly procedure which they have long been told could save their lives. Despite the Canadian Task Force on Preventive Health Care's dictum not to recommend BSE, the Canadian Cancer Society and the Canadian Breast Cancer Foundation continue to recommend it. Dr. Barron Lerner of Columbia University has summarized that "the medical profession owes women the best scientific evaluation possible of breast self-examination. But it also owes them an understanding of the multiple reasons why BSE retains such powerful support despite the existing data."⁵⁰

Concern about BSE was heightened when the above-mentioned expert panel report from the International Agency for Research on Cancer stated that, "there is insufficient evidence that clinical breast examination or self-examination reduce mortality from breast cancer".⁵¹

While a thoughtful analysis of these conflicting statements and positions is underway, the Toronto Cancer Prevention Coalition recommends that Toronto Public Health continues to educate women about the recommended guidelines for breast screening including monthly BSE.

Future Considerations in the Secondary Prevention of Breast Cancer

In light of on-going concerns about the limitations of mammography for the early detection of breast cancer, investigations are underway of different methods for screening and early detection of the disease. A number of methods are currently under review in Canada and the United States, including both imaging technologies and biological methods. Methods already approved for use

⁵⁰ Lerner, Barron H., "When statistics provide unsatisfying answers: revisiting the breast self-examination controversy", *Canadian Medical Association Journal*; January 22, 2002, 166 (2), pp 199-201.

⁵¹ From a press release issued by IARC, March 19,2002, "Mammography screening can reduce deaths from breast cancer", <http://www.iarc.fr/pageroot/PRELEASES>.

include ultrasound, magnetic resonance imaging (MRI), computer aided detection and diagnosis (digital imaging) and thermography.

Thermography has been around since post WWII but fell out of favour for breast cancer diagnosis when mammography's benefits were becoming widely touted by the profession of radiology. Thermography measures heat in the form of infrared radiation coming off the body, with more blood circulation showing up as more heat. This method is able to show angiogenesis, the stage in the development of a cancer cell when it begins to create its own direct blood supply. It offers the promise of also being a form of primary prevention since it is able to detect cellular changes at their very earliest point in development. Some breast cancer organizations have expressed hope about thermography because it relies on heat, not radiation, which carries a cancer risk itself.⁵² Efforts are currently underway to establish a thermography clinic in Toronto. Some caution that thermography should not be viewed as an alternative to mammography but rather as an adjunct. (More information on thermography is available at www.breastinfrared.com.)

Ductal lavage is also being tested as a diagnostic tool for high risk women. This procedure is based on the understanding that breast cancer can begin with the presence of abnormal cells in the milk ducts. Fluid is drawn directly from the ducts using both a mild suction and a hair-thin catheter inserted into the nipple.⁵³

Additional research into alternative methods includes a blood test for detecting breast cancer.

⁵² "Some experts say mammogram controversy overdue", Cynthia Cooper, Women's e-News, (www.women'senews.org) Feb 3, 2002.

⁵³ "First clinical practice guidelines for ductal lavage issued", Reuters Medical News, January 15, 2002, www.womenshealth.medscape.com/reuters/prof/2002/01/01 (from *Cancer*, 2002, 94: 292-298).

Barriers Keeping Women from Early Detection and Screening

The majority of issues identified in the literature that appeared frequently and across screening protocols require solutions at the social or systemic level rather than at the level of programs directed at individuals. These issues include poverty, transportation, lack of support systems and access to information, child care, lack of time, organization of services (location, knowledge, skills and attitudes of staff, language in which services are available), having a regular health care provider, and priority given to preventive health care. Personal level issues that could be handled with public education or one-on-one by health care providers or volunteers include: fear of results, awareness and availability of tests and what they entail, shame and embarrassment, and taking an active role in pursuing screening.

The following is a brief summary of key systemic and personal barriers to screening and early detection found in a review of the literature.

Personal Barriers

- 1) *Risk Perception* – Women do not perceive themselves to be at risk (e.g. may think women's cancers are hereditary, or lack understanding about the link between HPV and cervical cancer.) Many women also don't understand that their risk is increased due to certain factors – e.g. a family history of breast cancer puts you at higher risk for both breast and ovarian cancer - and that risk of all these cancers increases with age.
- 2) *Too busy* – With double and triple workloads of family, home and career, women often do not make screening a priority.
- 3) *Misconceptions and fears about tests* – Women fear they will be diagnosed with cancer. Sometimes fear about revealing multiple sex partners keeps women from getting Pap tests.

- 4) *Fears of gynecologic procedures due to early trauma* – Women who have experienced sexual assault or abuse as children, adolescents or adults may be traumatized by the prospect of undergoing any gynecologic procedure.
- 5) *Women unaware that self-referral is an option.* It is not common knowledge that programs such as the OBSP do not require physician referral. Women are sometimes unaware that they don't need to wait for a crisis to develop to go for testing (e.g. bleeding or a lump).
- 6) *Lack of confidence.* Physicians do not routinely check for ovarian cancer, nor do all physicians routinely do clinical breast exams or encourage women over 50 to have mammograms. Knowing to ask for appropriate testing requires a certain level of confidence and body awareness that women are not routinely taught. A woman may simply lack the confidence to ask for testing that is not routinely offered.
- 7) *Embarrassment or modesty* – Feeling comfortable enough with a virtual stranger to undergo procedures which are very private in nature is something which may be widely accepted in North American society but is not necessarily so in the cultures of some immigrant groups to Canada.
- 8) *Discomfort with Pap test, mammogram or manual pelvic examination* – A woman may have had a previous experience with any one of these procedures which she found painful or uncomfortable. Fear of the unknown can also be a significant deterrent.
- 9) *Misconceptions relating to age and lifestyle* – Older women who are post childbearing years, and women who are not currently sexually active may feel it is no longer necessary to have certain procedures such as Pap tests and may be less inclined to see their family doctors in general.

Systemic Barriers

- 1) *Language* - The screening service or health care provider does not offer help in the woman's language or dialect.
- 2) *Cost* – Some family physicians charge an annual fee.
- 3) *Other economic considerations* – There is a \$25.00 fee payable for both CA125 blood testing and transvaginal ultrasound procedures. (If a woman is identified as being at high risk for ovarian cancer, OHIP will pay for the procedures.) Part-time or casual workers may have to forego wages to attend screening services during their work hours.
- 4) *Transportation* – For women who do not live close to where services are offered, transportation to the service can be a barrier (cost, lack of vehicle, etc.).
- 5) *Accessibility for women with disabilities* – Screening services are not always offered in fully wheelchair accessible buildings or offer sign language interpretation or TTY phone lines.
- 6) *Lack of long-term and predictable funding to establish continuity in screening programs* – This can be particularly true of cases of sporadic funding to immigrant women's health outreach programs and community-based care.
- 7) *Unfair distribution of resources* – In general, greater funding is allotted to high technology services such as mammography screening or genetic testing whereas community outreach and support services which may help to get women into screening tend to be underfunded.
- 8) *Low socioeconomic status and low literacy* – can prevent women from knowing about the importance of screening.

- 9) *No ongoing relationship with physician* – Women who have an on-going relationship with a physician are more likely to be aware of and to be referred for routine screening. Some clinics may also not offer Pap tests unless a woman is linked with a family doctor/general practitioner. In some areas it can be difficult finding a physician who is accepting new patients.
- 10) *Lack of cultural sensitivity on the part of physicians and other health practitioners* – This can make it difficult for women to discuss issues related to modesty and her cultural belief systems.
- 11) *Female genital mutilation* – Women from certain cultural communities who have undergone this procedure may face both physical and emotional difficulties in undergoing gynecologic examinations and other gynecologic procedures.
- 12) *Modesty on the part of some physicians* – Male physicians from some cultural communities may have difficulty offering any gynecologic procedures to women of that community due to cultural or religious beliefs. In addition, physicians educated outside of Canada may not be as familiar with screening guidelines (e.g. Pap tests) or may not have been trained to value the importance of such programs if they did not exist in their country of study.
- 13) *Incomplete information and inadequate dissemination of information* – Information that is available to women does not always contain the full range of what women need to know (e.g. that a female practitioner can be available for pelvic exams). Distribution of information is often conducted on an *ad hoc* basis with no information to accompany pamphlets handed out to health care providers.
- 14) *Sex of provider* - Some women want the option of a female health care provider to administer any testing.

- 15) *No centralized database* – There are insufficient databases with the information needed to track women who need to be reached or followed up with.
- 16) *Mobility* – There is a high degree of mobility amongst residents in the GTA, making follow-up and recall difficult.
- 17) *Privacy related to databases* – Some women may not be assured about confidentiality of the data they are giving which is entered in database registries.
- 18) *Lack of continuity of care* – This is particularly true for women who don't have family doctors and tend to rely on emergency rooms and walk-in clinics.
- 19) *Need for improved organization in approach to screening and early detection* – A systematic approach to screening of all women's cancers, rather than an opportunistic one, is needed.
- 20) *Perceived lack of importance of cervical screening* – Particularly in comparison with the attention to breast screening in the popular media, cervical screening does not receive adequate coverage.
- 21) *Lack of understanding of the OBSP approach by some family physicians* – This results in inadequate referrals for screening. (Some physicians are afraid to lose track of a patient once referred to the OBSP, due to a misunderstanding of how the system operates.)
- 22) *Lack of knowledge about early detection of ovarian cancer* – This is true of both health care providers and the general public, due to the vague nature of symptoms and the tendency to associate them with another condition. There is an additional lack of knowledge about the cluster of symptoms related to ovarian cancer, including abdominal pain, weight loss, anorexia, change in bowel habits, change in bladder functioning and weight gain.

- 23) *Lack of clinics* – This is particularly true of lack of familial ovarian cancer clinics in the GTA.
- 24) *Administrative barriers* – For example, clinic hours may not be convenient for shift workers or women with responsibilities that limit their mobility in standard operating hours.
- 25) *Communication and literacy* – There is a general lack of plain language information about screening and early detection for women with low literacy levels or who have English as a second language, although Toronto Public Health is making some progress on this front. Language is not the only issue, however - cultural sensitivity and adaptation of materials is equally important.
- 26) *Lack of social support* – Examples of this include the need for childcare for women to get to screening centres, or the need for a companion to accompany a woman for emotional support.
- 27) *Lack of clear and consistent strategies for the young, particularly in relation to cervical cancer* – Sexual health classes for both boys and girls that make clear links between HPV and cervical cancer need to be enhanced in the GTA.

Conclusion

Women's cancers are an important public health issue in the Greater Toronto Area. It is clear that improved awareness about primary prevention is critical for a reduction in the incidence of women's cancers, and secondary prevention efforts must be enhanced to improve quality of life and mortality rates.

It is additionally clear that cancer of the cervix is preventable, and yet the incidence continues to rise as key groups are not being screened; targetted goals for the provincial breast screening

program are not being met; ovarian cancer incidence is still rising as the disease continues to be misdiagnosed or diagnosed too late for early intervention measures to be useful.

Many efforts are underway at local, regional and provincial levels to break down the multiple barriers - both personal and systemic - which keep women from being screened or diagnosed. A concerted effort by all jurisdictions must be supported in order to better resource these efforts and effect meaningful change.

Recommendations

The Working Group on Early Detection and Screening of Women's Cancers wholeheartedly endorses the full set of recommendations put forward by its sister working groups of the Toronto Cancer Prevention Coalition towards an "Action Plan for Cancer Prevention in the City of Toronto" (May 2001). This Working Group recognizes that the implementation of these recommendations would make a substantial contribution to the reduction in incidence and mortality rates of women's cancers.

The Working Group on Early Detection and Screening further adds the following recommendations specific to the prevention of women's cancers:

- 1) A concerted effort is needed to link organizations and facilities to provide comprehensive multi-sectoral services for the early detection and screening of women's cancers. It is vital that such services take into consideration known priority populations as well as existing barriers for these groups. All community groups, health agencies and key stakeholders must work together to achieve these goals.
- 2) The Ministry of Health has mandated Boards of Health to increase the number of women aged 50 to 69 who receive screening mammography through OBSP and increase the proportion of all women who receive cervical screening according to the guidelines set by the OCSP. Toronto Public Health is well-positioned to support a variety of health promotion

strategies that could enhance the prevention, screening and early detection of women's cancers. Such strategies include awareness-raising and education about the importance of lifestyle choices (e.g. smoking, alcohol consumption, nutrition, safe sex practices, physical activity and screening) as well as exposure to environmental and occupational carcinogens which may threaten their health.

- 3) In keeping with the philosophy of the Toronto Cancer Prevention Coalition, this Working group will actively seek links with other relevant organizations who work on issues constituting risk factors for these three cancers (e.g. nutrition, tobacco, physical activity initiatives, environmental clean-up) and those organizations connected with identified target groups (e.g. Boards of Education).
- 4) To be effective, any efforts to implement the above recommendations and enhance primary and secondary prevention of women's cancers must *actively engage* the priority populations in their design and implementation. Particular sensitivity is required with respect to cultural diversity.

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