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Opportunities for Public Health Communication, Intervention, and Future Research on Breast Cancer in Younger Women

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Abstract

Background—Approximately 6% of breast cancers in the United States occur in women under the age of 40 years. Compared with women 40 years of age, younger women are diagnosed at later stages, have higher rates of recurrence and death, and may be predisposed to secondary breast or ovarian cancer. An informal meeting of experts discussed opportunities for research and public health communication related to breast cancer among young (< 40 and/or premenopausal) women.

Methods—In September 2011, the Centers for Disease Control and Prevention hosted 18 experts in oncology, genetics, behavioral science, survivorship and advocacy, public health, communication, ethics, nutrition, physical activity, and environmental health. They (1) reviewed research and programmatic knowledge on risk and preventive factors, early detection, and survivorship; and (2) discussed ideas for research, communication, and programmatic efforts related to young women diagnosed with or at risk for early onset breast cancer.

Results—Levels of evidence and themes for future research regarding risk and preventive factors, including exposures, were discussed. Early detection strategies, including screening, risk assessment, and genetic counseling, as well as survivorship issues, follow-up care, fertility and reproductive health, and psychosocial care were highlighted.

Conclusion—Community and academic researchers, providers, advocates, and the federal public health community discussed strategies and opportunities for this unique population. Although the evidence is limited, future research and communication activities may be useful to organize future public health initiatives.

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Introduction

WITH WELL OVER 210,000 new cases occurring every year, breast cancer is the most common cancer diagnosis among women in the United States other than non-melanoma skin cancer.^{1,2} Despite significant advances in prevention and treatment, approximately 40,000 women die each year from breast cancer.² While the majority of breast cancers are diagnosed in women over the age of 50 and often at an early stage,^{1,2} breast cancer in women under 40 raises some unique concerns that have not been well studied.

Young women (under the age of 40 years) account for approximately 5% to 6% of all newly diagnosed cases of breast cancer in the United States.² While it is a rare to be diagnosed with breast cancer at a young age, younger women compared to older women (40 years), face higher rates of recurrence and death, are diagnosed at later stages, and have tumors that are higher grade and larger in size.² Also, being diagnosed with breast cancer at a young age could be indicative of a genetic mutation making women more susceptible to a secondary breast cancer or ovarian cancer.^{3,4} Additionally, unlike diagnoses among older women with breast cancer, African American women under 40 years of age are diagnosed more frequently and with more aggressive forms of breast cancer than white women.⁵ Early detection practices, like mammography, are not regularly recommended for women under 40 years of age.^{6,7} In addition, these younger women face significant long-term treatment related side effects (such as infertility, cognitive dysfunction, muscular and skeletal issues, and cardiac and vascular concerns) and an increased risk for several comorbidities.^{2,4,8-15}

In recognition of the need to increase prevention and health promotion research and support of this population, the Division of Cancer Prevention and Control (DCPC) at the Centers for Disease Control and Prevention (CDC) hosted an informal meeting of recognized experts to (a) review published research and programmatic knowledge on risk and preventive factors, early detection and survivorship issues related to young women diagnosed with or at risk for breast cancer; and (b) discuss areas where the field of public health might have the greatest research and communication impact in responding to the needs of this population. The objective of this report is to present the key discussion themes and ideas for future research and communication efforts discussed during the meeting.

Methods

In September 2011, the CDC/DCPC hosted 18 recognized breast cancer experts in Atlanta, Georgia for a 3-day meeting to examine opportunities for research and health communication regarding risk and prevention, early detection, and survivorship issues related to breast cancer in young women (BCYW; defined as < 40 years of age and/or premenopausal).

The participating experts represented government organizations, nongovernmental organizations, academic institutions, and recognized community breast cancer advocacy organizations. They also represented diverse and unique backgrounds and expertise in the following areas: medical oncology, genetics, behavioral science, health psychology, oncology nursing, breast cancer survivorship, advocacy, public health, health policy,

epidemiology, molecular biology, communication sciences, ethics, nutrition, physical activity, and environmental health. Participants were identified based on the number of peer-reviewed manuscripts they published as a first author since 2000 on topics related to breast cancer in young women, their specific area of expertise, and prominence in their area of expertise.

A core committee of CDC/DCPC staff, in collaboration with The Cloudburst Consulting Group, Inc. (CCG), prepared and reviewed materials (e.g., overview of meeting objectives, discussion questions, a review of scientific literature published between January 2000 and December 2010) for each participant to consider prior to the meeting. A 1-hour conference call with CDC, Strategic Health Concepts, Inc. (SHC) and CCG staff prior to the in-person meeting in Atlanta, Georgia was held to answer any questions about the provided materials or meeting logistics.

The meeting was facilitated and transcribed by CCG sub-contractors and all meeting logistics including; travel and meeting facilities, were arranged by CCG. An ad hoc committee of CDC/ DCPC staff served as observers of the meeting and provided clarification on CDC related activities.

The first day of the meeting focused on examining existing scientific research gaps concerning risk (modifiable and nonmodifiable), prevention, and protective factors for breast cancer among young women. For the purposes of this meeting only, participants categorized these factors into three categories (those with “strong,” “promising,” or “limited or insufficient” scientific evidence) to facilitate the discussion and identified factors for public health communication tools and resources. The second day of the meeting focused on early detection with a specific emphasis on screening guidelines, genetic counseling and testing, provider education, and the identification of high-risk women. The third day of the meeting focused on scientific literature and media messages concerning survivorship issues and concluded with discussions on social media messaging and communication support interventions.

All ideas and suggestions offered regarding risk and prevention, early detection, and survivorship issues for breast cancer in younger women were summarized by CCG facilitators and participants were given additional time to discuss ideas for future research, programmatic and communication efforts at the end of the meeting.

Scientific research gaps: Risk, prevention, and protective factors

To formulate ideas about areas for future research and public health communication, participants discussed areas with “strong evidence,” “promising evidence, but not enough for significant public health action,” and “limited or insufficient evidence” for modifiable risk factors, nonmodifiable risk factors, and protective factors associated with breast cancer in young women.

“Strong” evidence—The participants discussed several modifiable and nonmodifiable factors and breast cancer risk. The modifiable factors included physical activity, duration of breast-feeding, chemoprevention, and alcohol overuse. The nonmodifiable risk factors

included, but were not limited to family history (e.g., BRCA1/BRCA genetic mutations), age, age at first menarche and onset of puberty, birth characteristics (e.g., birth weight and birth order), radiation exposure from previous cancer treatment, breast density, race/ethnicity (e.g., Ashkenazi Jewish, Hispanic and younger African American women), and previous diagnosis and treatment of ovarian, breast, or colon cancer. The classification of these factors as “modifiable” versus “nonmodifiable” was varied depending on cultural and sociodemographic characteristics: environmental exposures associated with socioeconomic status, exposure to second-hand smoke, older age at birth of first child (> 30 years of age), and ever breast-feeding. Panelists had diverse opinions on the strength of the evidence for parity and oral contraceptive use as modifiable risk factors.

“Promising” evidence—Several modifiable and nonmodifiable factors were discussed as having “promising” evidence, but not enough for significant public health action. While participants discussed some of the research linking body mass index (BMI) as a modifiable risk factor for breast cancer among premenopausal women depending on age, additional knowledge is needed on different racial/ethnic groups in pre versus postmenopausal women. Another modifiable risk factor that was discussed was the evidence regarding the protective qualities of moderate or less than moderate alcohol use in decreasing breast cancer risk among premenopausal women. The participants mentioned that nonmodifiable risk factors that need additional research include premature birth weight and preterm birth, benign breast disease (e.g., atypical hyperplasia), genetic (e.g., BRCA 1/2) and ethnic background factors contributing to risk for triple-negative breast cancer, and exposure to pesticides and certain other chemicals.

“Insufficient” evidence—The experts discussed several modifiable, nonmodifiable, and protective factors for which the evidence is less clear regarding the relationship of each with breast cancer in premenopausal women and may be potential areas for future research.

Nutrition, diet, and alcohol consumption—The participants discussed the role of organic, vegetarian, and vegan food diets in changing breast cancer risk, the specific type of fats (e.g., saturated, unsaturated, polyunsaturated, or monounsaturated) that are protective against breast cancer, and the impact of binge drinking on breast cancer risk among young women. Despite the potential methodological challenges such as follow-up, retention, and accuracy of dietary reporting, participants proposed that a longitudinal study to follow a cohort of individuals and document their diets from birth throughout the lifespan may be necessary to understand the role of diet in altering the timing of breast development in early life.

Reproductive health—Participants stated that examining granddaughters of women exposed in utero to diethylstilbestrol, and the association between fertility drugs and breast cancer risk.

Oral contraceptive use—Participants discussed the larger sample sizes of women < 50 years of age to study the possible link between oral contraceptives as a protective factor for premenopausal breast cancer.

Lactation impairment—Some participants discussed that the current measures of insufficient weight gain and death of the infant due to maternal lactation impairment are insensitive and have poor end points.

Hair chemicals for African American women—Participants discussed that endocrine disruptors, such as hair products with placental extracts, may cause fairly severe premature puberty in African American girls as young as four or five years of age. It was noted that pubertal progression may stop and reverted back to normal levels if girls discontinued use of these products.

Other factors with insufficient evidence—The participants discussed the use of tamoxifen, raloxifene, and aromatase inhibitors to decrease breast cancer risk among women with a known increased risk for breast cancer; however, it is unclear how these risks vary for premenopausal women. Participants stated that the effects of modifiable risk factors like environmental and toxin exposures, and stress are considered to have limited evidence for premenopausal breast cancer risk. More research is also needed in understanding risk and protective qualities of circadian rhythms (e.g., night shift work) and chemoprevention as a preventive measure for women at high risk of premenopausal breast cancer.

Public health communication

Knowledge and awareness—Participants offered that communication efforts may needed to increase knowledge and awareness among young women who are, or might be, at risk for premenopausal breast cancer. Participants discussed that communication efforts should be careful not to give women an exaggerated sense of their risk for breast cancer. Instead, information should accurately convey the “concepts” of breast cancer risk to the public. Women may be educated to (a) know their individual risk, (b) know their family’s cancer history and genetic risk, (c) be aware that a women can develop breast cancer even at a young age and in the absence of a family history, and (d) be aware that a women can develop breast cancer even if a family member tested negative for a genetic mutation. Participants also stated that the public health community may need to ensure that communication efforts be tailored and clearly defined based on a woman’s level of risk, taking special consideration for African American and Ashkenazi Jewish women and those with increased genetic risk.

Patient and provider communication—Participants discussed the vast opportunities for improving patient and provider communication. Discussions about family history, genetic information, and breast cancer risk between providers and patients were suggested since they would inform decision-making regarding referral to genetic counseling. Educational resource tools may be made available and new applications may be developed to help patients and providers estimate patient risk, and primary care providers may need education on how to communicate risk factors for premenopausal breast cancer to their patients.

Early detection—Participants discussed the need for improved communication regarding screening modalities, screening guidelines, risk assessment tools, and genetic testing regarding early detection of breast cancer among young women.

Screening and screening guidelines—The participants mentioned that clear information for younger women and the general public about what early detection guidelines exist and the similarities between them may be a priority. Participants discussed Magnetic Resonance Imaging (MRI) as a method for screening women identified to be at high risk, such as BRCA1/2 positive women or women with history of radiation to treat childhood cancer, needed further examined. Additionally, participants reported the need for certain guidelines to address women with a personal history of breast cancer, women at high risk for breast cancer, and women at average risk for breast cancer. These guidelines may emphasize the importance of providers understanding delays in diagnosis, the link between awareness and delays in diagnosis, and the need for a prompt response to symptoms in the absence of screening is recommended. Enhanced physician and patient reminder systems about timing of screening were also suggested for young women (< 40 years).

Risk assessment—Participants discussed the need for a clear definition of “high-risk” women before new screening recommendations are developed. Participants acknowledged difficulties with determining risk in young women, but without a clear definition, an adequate assessment of breast cancer risk conducted by providers could not be done. While several participants suggested that providers conduct assessments of their patients to identify breast cancer risk beginning at 25 years of age, others suggested that these assessments could be performed earlier. One suggestion was to conduct risk assessments during initial medical visits and include periodic evaluation of family history and automated risk assessment at the time of mammography.

Genetic counseling/testing—Participants discussed that women may need to be empowered with ways of gaining access to genetic counseling services. They suggested that a centralized resource for providing information on genetic testing be made available to individuals and local organizations to find local, competent genetic counselors and centers targeting women at high risk for breast cancer. The participants discussed the need for provider education for physicians, nurse practitioners, and physician assistants on appropriate referral to genetic counseling. They discussed that in order for increased referral and uptake of genetic counseling and testing to occur, inconsistencies with insurance coverage of genetic counseling and testing may need to be resolved, and increased training and licensing of genetic counselors may be necessary to improve service provision.

Survivorship concerns of young breast cancer survivors

Improving follow-up care—Participants stated that there is a dearth of research regarding follow-up care for breast cancer survivors under the age of 40 years, and that there are currently no guidelines to address the survivorship concerns of this population. Participants suggested that organizations involved in cancer care might jointly develop survivorship guidelines, which focus on premenopausal women < 40 years of age. They also suggested that those who develop survivorship guidelines consider placing a stronger

emphasis on patient-centered care and the critical role of nurses and other providers. Suggestions on other points to address during the guideline development process were bone health and density, lymphedema, weight gain, sexuality and fertility, fatigue, neuropathy, weakness, genetic risk, mental health, upper extremity dysfunction, and breast reconstruction. Some other suggested guideline topics may be tailored to address various effects from different types of tumors and cancer treatment.

In addition to formulating appropriate guidelines for breast cancer survivors under the age of 40 years, participants also suggested the need for educational resources for providers and survivors to increase “good survivorship care” and inform survivors about accessible and comprehensive cancer services. Participants discussed that different mechanisms may be used to improve patient and provider education, which might include on-demand streaming of educational materials, and telemedicine service delivery.

Several suggestions were also offered about ways of improving follow-up care service delivery. Participants reported that service delivery mechanisms like telemedicine might be used to ensure that providers maintain good communication and to assist survivors in achieving access to survivorship services and care plans, particularly in rural areas. Participants also stated the widespread publication and dissemination of best practices and other published models of survivorship care programs offered in variety of settings and with varied resources may be considered. Participants also discussed that existing state-based directories of specialists (e.g., lymphedema therapists, certified genetic counselors) and other follow-up care information may be organized at the national level to encourage national coverage of such directories.

Fertility and reproductive health—Fertility concerns experienced by young women with breast cancer were recognized by several participants as a topic of great importance. They mentioned that young breast cancer survivors are of reproductive age; treatment and care decisions might affect their fertility outcomes. Specifically, fertility issues related to recurrence, new cancers, general health perception, general health promotion, treatment, side effects, premature aging, and continuity of care may be addressed in the medical care context of breast cancer diagnosis and treatment. Participants stated that providers might consider addressing fertility issues as part of the survivors’ comprehensive medical sequelae. In addition, providers consider having realistic and honest discussions with their patients regarding the success rates of Assisted Reproductive Technology (ART) and less expensive or alternative options (e.g., gestational surrogacy, adoption).

Participants acknowledged that provider adherence to fertility counseling and treatment guidelines may be problematic. They suggested reviewing successful models and lessons learned (e.g., adult men with testicular cancer who bank their sperm prior to undergoing treatment and specialized care to address the effect of treatment on fertility in male and female pediatric and adolescent populations with cancer) to address fertility issues of young breast cancer survivors. Participants proposed that recommendations define an appropriate time frame for providers to offer referral for reproductive services since women may not be sufficiently referred to reproductive endocrinologists prior to initiation of chemotherapy. Participants proposed conducting a comprehensive literature review to identify gaps in

fertility issues of young women with breast cancer, and to determine the extent to which oncologists follow and adopt guidelines. In addition, they discussed that fertility counseling and treatment are generally not covered by insurance, which is one of the concerns of young breast cancer survivors. Overall, the participants summarized that the lack of insurance coverage for fertility treatment has not been adequately addressed to date as a public health problem.

Participants stated that culturally tailored education materials and support may be offered to husbands and partners, other family members and friends, and young breast cancer survivors who may feel uncomfortable in meeting with a reproductive endocrinologist. In addition, they discussed that education may be offered to health care providers on issues related to the stigma and discrimination among young women with breast cancer who express an interest in preserving their fertility, but are unmarried or not in a stable or committed relationship.

Psychosocial care—Emotional, behavioral, and social concerns affecting young breast cancer survivors were discussed, and participants stated that the public health community may have a vital role in improving upon on several areas of psychosocial health affecting young breast cancer survivors. First, participants agreed that clinical practice guidelines for psychosocial care of young breast cancer survivors are needed after review of existing publications.^{16,17}

Participants discussed that improvement in clinical practice to address psychosocial needs of young breast cancer survivors could be made by

- (a) conducting psychosocial assessments at the initiation and completion of cancer treatment (especially for assessing distress),
- (b) ensuring that psychosocial issues specific to young women with breast cancer are built into survivorship care plans (e.g., birth control, fertility, early stage in their careers, sexual functioning, the financial impact of treatment, premature menopause), and
- (c) integrating patient navigators and trained health advisors in both community and healthcare settings to assist young breast cancer survivors in finding and receiving psychosocial services.

Opportunities to partner with community-based organizations, health ministries, and cancer ministries in faith-based institutions to address the psychosocial needs of young breast cancer survivors were also discussed. Participants suggested that peer counseling and other models of community based counseling may be reviewed, because many cancer centers and hospitals are not currently staffed to provided adequate psychosocial care to the number of survivors that request or need it. Additional suggestions from the participants included community based services that may be particularly helpful to those who are low income and do not have access to psycho-oncology care due to cost or geographic location. Community-based programs and organizations are well positioned to disseminate education information to providers on the need to address psychosocial issues in their young patients, perform baseline assessments, and inform their patients of available resources (e.g., support groups, family and partner supportive services). While the need for disseminating information about

current resources was broadly discussed, psychosocial supportive services tailored to meet the needs of young breast cancer survivors are sparse. Participants stated that comprehensive list of available services at regional, state and national levels are needed and may include traditional psychological services, peer and family support groups, financial and legal services and other important outreach resources that are free or have a reduced cost. Providers would optimally give the list of resources to their young breast cancer patients during the initial assessment and engage their patients in a follow-up discussions regarding available support services at various points across their cancer trajectory (e.g., at the conclusion of treatment, during follow-up care).

Lastly, participants discussed that there were several opportunities for additional research on the psychosocial needs of young breast cancer survivors. The participants suggested the following areas for further exploration:

- (a) the role of spirituality in receipt of psychosocial care,
- (b) the efficacy and usability of internet-based social networking sites versus traditional supportive services, especially for underserved populations,
- (c) a systematic review of existing supportive services tailored to meet the needs of young breast cancer survivors in ethnic and linguistic minority populations,
- (d) the lifelong impact of breast cancer morbidity and mortality on spouses/partners and children of younger women, and
- (e) the emotional needs of young women who are struggling with decisions and choices made regarding fertility and reproductive health.

Conclusions

CDC/DCPC hosted an informal meeting to examine opportunities for breast cancer research and health communication surrounding risk and prevention, early detection and survivorship for young women. The ideas discussed by these participants provided a strong foundation for work underway at CDC to address public health issues related to breast cancer in young women. This report describes the expertise offered by subject matter experts for public health action, and elucidates future research and communication opportunities.

These participants noted that while there are some risk and protective factors with “sufficient” evidence to encourage public health action regarding breast cancer in young women, the overall evidence base to support widespread action is still quite limited. This provides both opportunities and challenges especially for communicating risk to young breast cancer survivors. Likewise, participants noted that early detection for young women remains a controversial area in need of further clarification of existing screening guidelines, appropriate definitions of risk, accurate risk assessment, and improved access and communication about genetic counseling. While several programmatic and research efforts are directed at improving the needs of cancer survivors, the participants noted that these efforts are not often tailored for young breast cancer survivors, especially for those who come from ethnic and linguistic minority populations, and those who are socially and economically disadvantaged. The participants suggested that survivorship research and

programmatic efforts continue to focus on improving the provision of quality health care and recognize opportunities for public health action regarding fertility issues and reproductive and psychosocial health.

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