Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course

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Epidemiology and Applied Research Branch

Federal Advisory Committee on Breast Cancer in Young Women Meeting
September 22, 2011
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- Project components:
  - Review of the scientific literature
  - Environmental Scan
  - Media Review
  - Expert Panel
Part 1:

LITERATURE REVIEW & ENVIRONMENTAL SCAN
Review of the Scientific Literature

- **Review of the scientific literature**
  - **Areas of Focus:**
    - Epidemiology
    - Family History and Genomics
    - Risk and Prevention
    - Screening
    - Diagnosis and Treatment
    - Survivorship
    - Social Disparities
    - Patient and Provider Communication

- **Methodology:**
  - Peer-reviewed literature from US, Canada, and/or UK published between January 1, 2000 and December 31, 2010
  - Focus on women aged 50 years or younger
Risk and protective factors discussed in the literature

- Family history and ethnicity
- Hormones/estrogen/OC use
- Age of menarche/onset of puberty
- Age at first full-term pregnancy
- Birth characteristics
- Parity
- Breast density
- Breast feeding
- Induced abortion/miscarriage
- Diet/ Nutrition
- Vitamins/dietary supplements
- Physical activity
- Obesity/Overweight/BMI
- Alcohol use
- Smoking/ Second hand smoke
- Radiation exposure
- Environmental exposures, traffic emissions
- Prophylactic surgery
Early Detection discussed in the literature

- **Guidelines**
  - Screening
  - Family History/ High Risk Women
  - Genetic Counseling/ Testing

- **Screening Methods**
  - Breast Self Exam
  - Clinical Breast Exam
  - Mammography
  - MRI
  - Ultrasound

- **Family history (FH)**
  - Using FH to determine risk
  - Assessing FH in clinical settings

- **Special Populations**
  - Ashkenazi Jewish women
  - African American Women
  - Survivors of Hodgkin’s Lymphoma (due to chest irradiation)

- **Genetic Counseling / Genetic Testing**
  - Risk Assessment
  - Referral and providers
  - Receipt of genetic testing/ counseling
  - Testing and clinical management decisions
Survivorship discussed in the literature

- **Treatment and related Side Effects/Late Effects**
  - Chemotherapy
  - Radiation
  - Surgery
  - Amenorrhea
  - Fatigue
  - Cognitive Function
  - Infertility
  - Treatment during pregnancy
  - Bone Mineral Density

- **Fertility preservation and family planning options**
  - Referrals/Decision Making

- **Prevention and management of secondary malignancies**
  - Reoccurrence
  - Regional and Metastatic Spread
  - breast-conserving therapy
  - mastectomy

- **Psychosocial effects and quality of life issues (QOL)**
  - Anxiety
  - Depression
  - Sexuality/Body Image
  - Occupational Functioning
  - Coping and Support
  - Social functioning
  - Financial concerns
Environmental Scan

- Scan of organizations and their websites
- Review of patient and provider educational materials
Part 2:

MEDIA REVIEW
Media Review

- Scan conducted from June 1, 2009-May 31, 2011
- Review of messages from a sample of 17,070 hits from US based print, press, and internet sources
  - Print (e.g. magazines, newspapers)
  - Press (e.g. television and radio news reports, press releases)
    - ABC, FOX, NBC, Today Show, NY Times, CNN, Daily News
  - Audience/Readership: 1 to 25,234,573
How Media Has Been Used to Disseminate Information

- Disseminating Research Findings
- Providing public and expert commentary on:
  - Agency, task force, federal, and organizational guidelines
  - Policies which have economic and health care practice and coverage implications
  - New technology
  - Risk and Protective factors for breast cancer
  - Epidemiology of breast cancer
  - Medical Decision Making between providers and patients
- Presenting personal survivorship stories
What events have molded the focus of media messages from 2009-2011

- Policy
- Guideline introduction and discussion
- Introduction of new technologies
- Emerging Research
- Advocacy Discussion/ Conferences/ Fundraising Events
What Topic Areas and Messages Are Younger Women Reading About Concerning Breast Cancer?

- Risk and Prevention
  - Early Detection
  - Survivorship
Media From 2009-2011

RISK AND PREVENTION
Risk and Prevention in the Media (2009-2011)

- Obesity
- Physical Activity/Exercise/Non-Active Lifestyles
- Nutrition/Dietary Intake
- Alcohol
- Smoking/Second-Hand Smoke
- Hormone Replacement Therapy
- Vitamin D
- Oral Contraceptives
- Family History/Genetic Risk
- Demographics: Race, Ethnicity, Gender, Age
- Radiation

- Breast Implants
- Chemicals (cleaning, cosmetics, personal care products)
- Air pollutants
- Medications used to treat other Chronic Illnesses
- Menstruation/Puberty
- Child Bearing/Pregnancy
- Estrogen
- Hot Flashes
- Preventive Mastectomy
- Emotional/Psychological
Obesity/ Physical Activity/ Nutrition

- **Obesity:**
  - Obese women are at greater risk of developing breast cancer
  - There is an association between weight gain and breast cancer recurrence risk.

- **Physical Activity/Exercise**
  - A “non-active lifestyle” increases one's risk to a rare aggressive breast cancer (triple-negative breast cancer).
  - “Exercise” can help maintain a healthy weight, which in turn can reduce breast cancer risk.

- **Nutrition/ Dietary Intake**
  - Risk reduction:
    - Drinking filtered water
    - Having a diet high in fiber
    - Reducing hormone intake through eating hormone free food
    - Benefits and Risk associated with soy intake:
Alcohol

- Numerous reports in print and press media about a study which followed nearly 6,900 girls from ages 9-16 into their 20s.
  - Those who drank heavily/often are at higher risk of benign breast disease, which is associated with higher rates of breast cancer.

- Cutting back on alcohol by keeping within government recommended limits of no more than 14 units a week ("a small drink a day") may help to reduce BC risk.
Smoking/Second Hand Smoke

- **Smoking**
  - “Increased, Elevated, or Likely Risk” for developing pre and post menopausal breast cancer:
    - Women who started smoking as teenagers and/or before their first full-term pregnancy
      - The risk is higher for people who continued to smoke than for people who smoked and then quit.
    - Those exposed to decades of passive smoking but this data is contested by other studies and the relationship if any, is unclear.
  - “Lower rates” of pre and post menopausal breast cancer development has been associated with:
    - Living and working in smoke free environments
    - States who have higher rates of smoke-free homes and offices (especially among younger women).
Non-Modifiable Risk Factors

- **Genomic/ FH**
  - Radiologists interviewed stated that the “most important known risk factors” include family history, radiation, and known genetic factors.
  - Women are at high risk of developing breast cancer or ovarian cancer due to family history and BRCA1/2 mutations

- **Racial/ Ethnic Risk**
  - African American and Ashkenazi Jewish women are at risk for developing breast cancer
  - African American and younger women are at greater risk for developing Triple-negative breast cancer
  - Cancer Spreads Faster In African Americans
Other Risk and Protective Factors

- **Vitamin D (D3)**
  - Low Vitamin D is potentially associated with more aggressive breast cancers
  - Vitamin D3 helps to prevent breast cancer
  - Low levels of Vitamin D have been found in black women and younger premenopausal women, populations that have a higher risk of aggressive triple negative breast cancers.

- **Oral contraceptives**
  - Women may be at risk for developing estrogen positive breast tumors after using birth control pills.
  - Taking birth control pills represent no greater risk for breast cancer development except potentially for those who are BRCA 1 or 2 positive.
Other Risk and Protective Factors

- **Radiation:**
  - Reducing radiation of the breast through less mammography can help prevent breast cancer.

- **Chemicals**
  - Risks are associated with exposure to chemicals found in cleaning, cosmetics and personal care products
  - Media does outlines ways women can avoid exposure which can be linked to breast cancer, endometriosis, infertility and osteoporosis

- **Air Pollutants**
  - Possible connection between exposure to air pollution and premenopausal breast cancer
  - Additional research is required to confirm this proposed connection between air pollution and breast cancer.
Other Risk and Protective Factors

- **Drugs to treat other Illnesses**
  - Link between use of antidepressant drugs and an increased risk for breast cancer
    - The media has indicated that the evidence is “unclear and conflicting.”
    - “Women in their 40s may want to think about getting mammograms if they are on antidepressants”
  - Drugs used to treat high blood pressure and cardiac disease have an impact on the risk of breast cancer recurrence.

- **Child Bearing/ Pregnancy**
  - Having babies at an older age increases risk of BC
  - Women tend to have fewer children later in life and this too increases risk.
Other Risk and Protective Factors

- Preventive Mastectomy
  - “Ever since a gene mutation tied to ovarian and breast cancer was discovered, women who have found they have it must consider whether to have their own breasts removed, even with no sign of cancer present.”
Media From 2009-2011

EARLY DETECTION
Media: Common Themes on Early Detection

- **Screening**
  - Mammography
    - Breast Density and Mammography
    - Adherence and Mammography
    - Traditional Mammography
    - Molecular Breast Imaging
    - Digital and 3D mammography
    - Effectiveness and frequency of mammography
    - Budget cuts, confusion, and concerns with state programs and nonprofit organizations offering mammography.
  - Breast Self-Exams
  - Screening Guidelines
    - Release or updates of guidelines
    - Confusion around guidelines
      - More than 3/4 of US women are confused by US mammography recommendations
Media: Common Themes on Early Detection

- Genetic Counseling/Testing
  - Whole-genome testing as a diagnostic tool
  - Genome sequencing detecting women with high genetic risk
  - Genetic testing for young women with family history of cancer
  - Testing for genetic mutations and employer and insurance discrimination

- Patient and Provider Information Sharing
  - Preparing questions to ask your provider prior to mammography
  - Talking to provider about how long it takes for screening results to be available and next steps if mammography is abnormal
  - Information about the types of providers who read and interpret screening tests
Media From 2009-2011

SURVIVORSHIP
Media: Common Themes on Survivorship

- **Treatment and Treatment Side Effects:**
  - Breast cancer treatment lowers sex drive
  - Treatment Drugs:
    - Tamoxifen
    - Avastin
  - Surgery
Media: Common Themes on Survivorship

- **Sexuality:**
  - Sexual Issues are often unaddressed in women who survive cancer.

- **Fertility:**
  - Insurance coverage
  - Women’s knowledge about fertility-related treatment issues
  - Timing of patient and provider discussions about fertility options

- **Psychosocial:**
  - Worry and Reoccurrence
  - Anxiety /Stress
  - Support Group
  - Family and Social Relationships
  - Humor/ Laughter
Media: Common Themes on Survivorship

- Disparities in Cancer Care
  - Insurance, Race and Poverty Affect Breast Cancer Care

- Discussion about Generalized Breast Cancer Campaigns/Messaging:
  - Disputes about whether current breast cancer campaigns are “crewd” and whether they “stereotype” or “objectify” women.
  - State based messaging (e.g. Utah) encouraging women to “take the time to get screened” for breast cancer.
September 12-14, 2011

EXPERT PANEL MEETING
Expert Panel Meeting

- **Expert Panel Meeting**
  - 3 day meeting at the Crown Plaza Ravinia in Atlanta, GA on September 12-14, 2011
  - 18 nationally recognized experts and advocates from several relevant disciplines

- **Objectives:**
  - Examine where scientific evidence indicates an opportunity for public health intervention, communication efforts, or a strong need for further research.
  - Review messages about risk and prevention, early detection and survivorship issues
DAY 1: Expert Panel Meeting/ Risk and Prevention

- **Focus/ Tasks:**
  - Scientific research and gaps in research concerning risk (modifiable and non-modifiable), prevention and protective factors associated with breast cancer among younger and premenopausal women.
  - Addressing which risk and prevention factors had strong, promising, or limited scientific evidence available for translation into public health messages.

- **Presentations:**
  - Hormone Therapy and breast cancer risk
  - Environmental chemicals affecting breast cancer risk
  - Breast cancer risk related to genetic mutations
  - Physical activity, nutrition, obesity, smoking and other behavioral factors related to risk and prevention of breast cancer.
DAY 2: Expert Panel Meeting/ Early Detection

Focus/Tasks:
- Early detection: screening guidelines, genetic counseling and testing, and provider education and the identification of high risk women.
- Small and large group discussion focused on;
  - Which early detection guidelines are being used in practice
  - Messages for average and high risk younger women
  - Insurance coverage and access
  - Provider identification of high risk populations?
  - Provider knowledge regarding genetic testing and referrals
  - Reviewing tools and resources for risk assessment

Presentations:
- A review of guidelines for breast cancer screening
- Communicating genetics research to the general public
- Ethical issues related to genetic testing
- Implementing genomics in practice and insuring quality testing
- Medical decision making after genetic testing
DAY 2/3: Expert Panel Meeting/ Survivorship

- **Focus/Tasks:**
  - Scientific literature and media messages concerning survivorship issues, with a focus on:
    - Guidelines and Best Practices for service delivery, referrals, patient and provider communication, information sharing and decision making for each stage of the cancer continuum.
    - Fertility/Infertility affecting younger breast cancer survivors
    - Psychosocial care and Quality of Life for younger breast cancer survivors

- **Presentations:**
  - Adherence, decision making and provider choice regarding follow-up care
  - Quality of Life issues
  - Psychosocial concerns
  - Infertility, fertility preservation and sexuality
  - Cancer disparities
Expert Panel Meeting Findings

- **Risk and Prevention**
  - Women and providers may struggle with “numeracy and health literacy” when discussing breast cancer risk
  - Risk Factors with “Sufficient” Research Evidence
    - Family History and Genomics
    - Demographics: Age, race/ethnicity
    - Breast Density
    - Parity
  - Risk Factors with Promising Evidence, but requiring additional research
    - Age of Menarche
    - Onset of Puberty
    - Age of 1st birth
    - Radiation Exposure
    - Birth Weight
    - Gestational Age
    - Stress, Sleep
    - Exposure to Chemicals
Expert Panel Meeting Findings

- **Risk and Prevention**
  - Communication/ Messaging:
    - Know your…. 
      - Body
      - Health History
      - Family History of breast and ovarian cancer
Expert Panel Meeting Findings

- Early Detection
  - Guidelines/Screening:
    - Clear statement about what guidelines exist and similarity and differences between them
    - Guidelines may be outdated before they are updated
    - Reconciling differences between guidelines and what doctors recommend in practice about self breast exams.
    - MRI as a part of screening for high risk women
    - Need to enhance reminder systems from physicians to patients about the need for screening
Expert Panel Meeting Findings

- Early Detection
  - Risk Assessment
    - There needs to be an adequate assessment of risk for younger women including capturing good family history and periodically thereafter.
    - Having automated risk assessment at the time of mammography
  - Genetic Counseling/Testing
    - Issues with insurance coverage of genetic testing
    - Training and licensing of genetic counselors
    - Women need to be empowered with ways of gaining access to genetic counseling services
Expert Panel Meeting Findings

- **Survivorship**
  - **Research:**
    - Survivorship issues have been well studied, but analyses for women under 50 has not been widely conducted.
    - Overlapping concerns for pre and post menopausal survivors of breast cancer, but there are unique needs for younger women.
    - Some issues that are especially important for younger women are:
      - Work and re-entry into work force after treatment
      - Infertility/ Fertility Counseling before treatment
      - Cognitive Effects
      - Psychosocial Adjustment and Support
      - Decision Making and Communication Strategies
      - Side Effect and Quality of Life (e.g. lymphedema, osteoporosis)
Expert Panel Meeting Findings

- **Survivorship**
  - **Guidelines:**
    - Lack of guidelines on what the minimum standard of care should be **BUT** there are best practices and interventions
      - Guidelines should outline services unique to younger women that should be received by current provider or by way of referral
      - Guidelines would empower women to ask about optimal services early on or as a survivor
      - Guidelines would help providers offer more personalized care
  - **Awareness of state based breast cancer directories**
    - (e.g. North Carolina BC Directory: [http://bcresourcedirectory.org](http://bcresourcedirectory.org))
  - **Special Populations**
    - Monitoring of inclusion of ethnic minorities and disparate populations in research trials
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