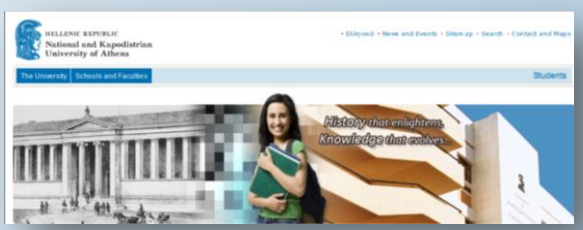
Interventions Breast Cancer Genetics Young Breast Cancer Survivors and their At-Risk Relatives

Maria C. Katapodi, PhD, RN, FAAN
Professor of Nursing
Faculty of Medicine, University of Basel, Switzerland
Robert Wood Johnson Foundation – Nurse Faculty Scholar 2010

BACKGROUND

1998 National and Kapodistrian University Athens, Greece Fulbright scholar



2004 Master's and PhD at UCSF

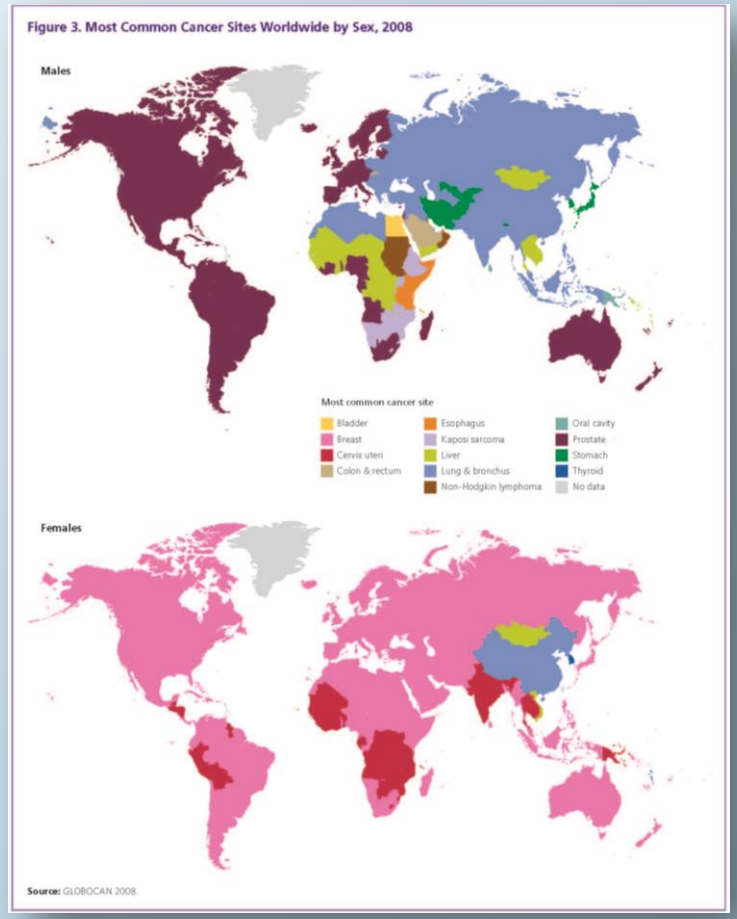
- Breast cancer prevention and early detection
- Minor in Adult Education and in Cancer Genetics

2006 University of Michigan

2010 Summer Genetics Institute (NIH)

- Molecular genetic/genomic research

Breast Cancer Global Burden



Sporadic 70%

- No known risk factors

Familial 20% - 25%

- Family history and genetic predisposition

Hereditary Breast - Ovarian Cancer (HBOC) 5%-10%

- *BRCA1*, *BRCA2*, *PTEN*, *p53*, *Chek2*, *STK11*, and *CDH1*

Genetic Predisposition Breast and Ovarian Cancer

Personal health history

- Age of breast cancer onset ≤50 years
- Two primary breast cancers in the same woman
- Breast and ovarian cancer in the same woman

Family health history

- 3+ cases of breast or ovarian cancer
- Breast and ovarian cancer in same side of family
- Breast and other cancers in same side of family
- Male breast cancer

High-risk populations

- Ashkenazi, French-Canadian, Hungarian, Icelandic, Swedish

Cancer Risks for Mutation Carriers

60%–80% lifetime breast cancer risk

- vs.12% population risk

40%-50% lifetime ovarian cancer risk

- vs. 1.8% population risk

3 - 4 fold risk pancreatic and prostate cancer, melanoma

Risk Management Strategies

Average-Risk Women (12% or 1 in 8)

- ***Routine Screening***
  - CBEs, mammograms, BSE

Mutation Carriers and High-Risk Women

- ***Intensive Surveillance***
  - CBEs, mammograms, breast MRI
- ***Prophylactic Risk Reduction Surgery***
  - Mastectomy and/or salphingo-oophorectomy
- ***Chemoprevention***
  - Tamoxifen, Raloxifen, Aromatase Inhibitors

Women's Breast Health Study

US Department of Defense 2003

- Descriptive, cross-sectional survey
- San Francisco Bay Area
- Community-dwelling, multicultural sample
- 184 cancer-free women
- Perceptions of breast cancer risk and screening
  - 15% higher risk – family history or personal factors

Information Dissemination

- Providers do not have direct contact with at-risk family members
- «Trickle down of information» from probands to relatives
- About 50% of at-risk family members unaware

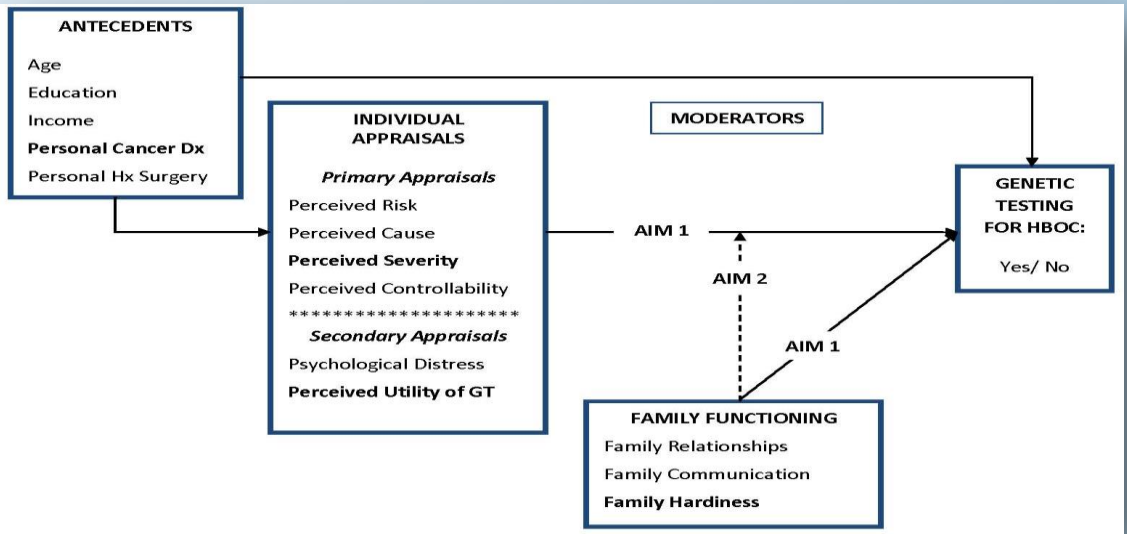
Hereditary cancer risk, family functioning, and decision-making:

Oncology Nursing Foundation, 2007

- Descriptive, cross-sectional survey
- 168 dyads (proband-female relative)
- Genetic clinic

  BOCRE program

  UMCCC



Barriers in Knowledge Dissemination

- Lay people find genetic information difficult
  - Understand and explain
  - FDRs are informed first and more often
- Existing challenges in family relationships, cohesiveness, and coping
  - Probands may want to protect family members, avoid blame and conflict, come to terms with own diagnosis

Robert Wood Johnson Foundation
Nurse Faculty Scholars

THE FAMILY GENE TOOLKIT:

Talking and Thriving after Genetic Testing for Hereditary Cancer

Robert Wood Johnson Foundation – Nurse Faculty Scholar, 2010

Screening and genetic testing in young breast cancer survivors and at-risk female relatives

Centers for Disease Control and Prevention 2011

CDC

PRC MI Prevention RESEARCH CENTER of MICHIGAN
Improving Health in Partnership with Families and Communities

MDCH Department of Community Health

University of Michigan SCHOOL OF NURSING

MCC Michigan Cancer Consortium

M SPH

University of Michigan Medical School

STUDY AIMS

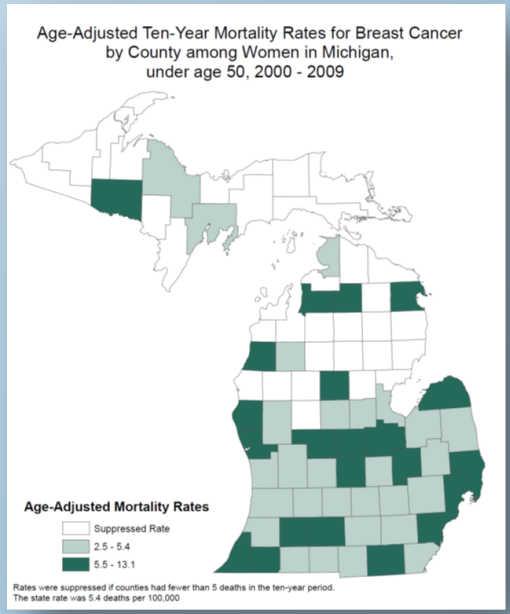
Aim 1: Identify and survey YBCS and high-risk female relatives about use of genetic services and breast cancer screening

Aim 2: Test the efficacy of two versions of an intervention (Targeted vs. Enhanced Tailored) to increase use of these services

SETTING

Michigan Cancer Surveillance Program

- Public database for cancer surveillance
- Established 1984
- 7,864 cases of young breast cancer survivors state-wide



SAMPLE

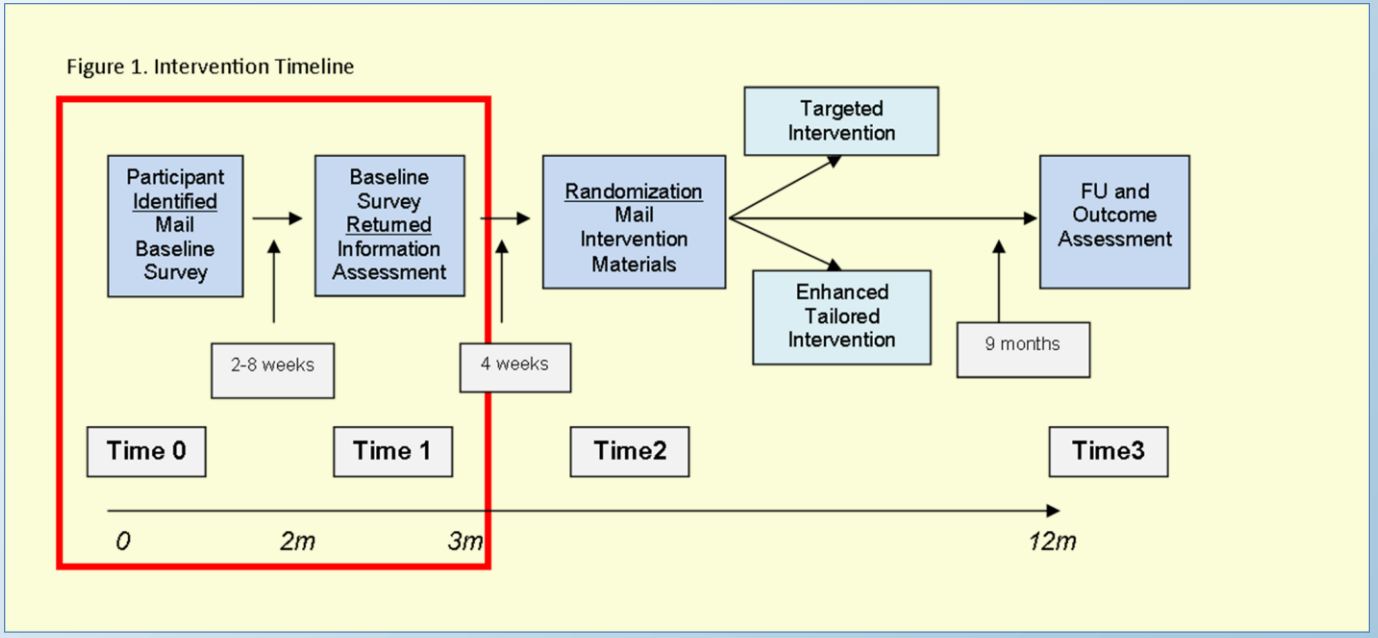
- Random sample of 3000 YBCS
- Stratified by race (Black vs. White/Other)
- Purposeful sample of 2 female relatives per YBCS

Young Breast Cancer Survivors:	Female Relatives:
Female, 25–64 years of age	Female, 25–64 years of age
Unilateral or bilateral ***invasive breast cancer or DCIS*** between ***20-45 years old***	***Unaffected*** with any type of cancer ***FDR- or SDR*** of the YBCS
Michigan resident at time of diagnosis	US resident
Able to read English	Able to read English
Not currently pregnant, incarcerated, or institutionalized	Not currently pregnant, incarcerated, or institutionalized
	YBCS is willing to contact

Design

Randomized Trial

- Unit of Randomization: Family
- Targeted vs. Enhanced Tailored



INTERVENTION: TARGETED

MARIA KATAPODI, Ph.D., R.N., FAAN
Assistant Professor
Robert Wood Johnson Foundation – Nurse Faculty Scholar 2010
400 North Ingalls, Room 2158
Ann Arbor, Michigan 48109-5482
Tel: 734.647.0178
email: mkatapo@umich.edu

April 2

Name: YBCS
Address
City, MI Zip

Dear _____,

Thank you for taking part in our study. Our goal is to help young b
relatives take the best possible care of their health.

It is important for you to know that having **breast c**
woman is in a high-risk group. **High-risk wom**
cancer than other women. One reason is
changes in genes that are inherited

High-risk women may be
the chances that y
may help find
your chances
family have hig

Follow-up health
look over the mate
genetic specialist and

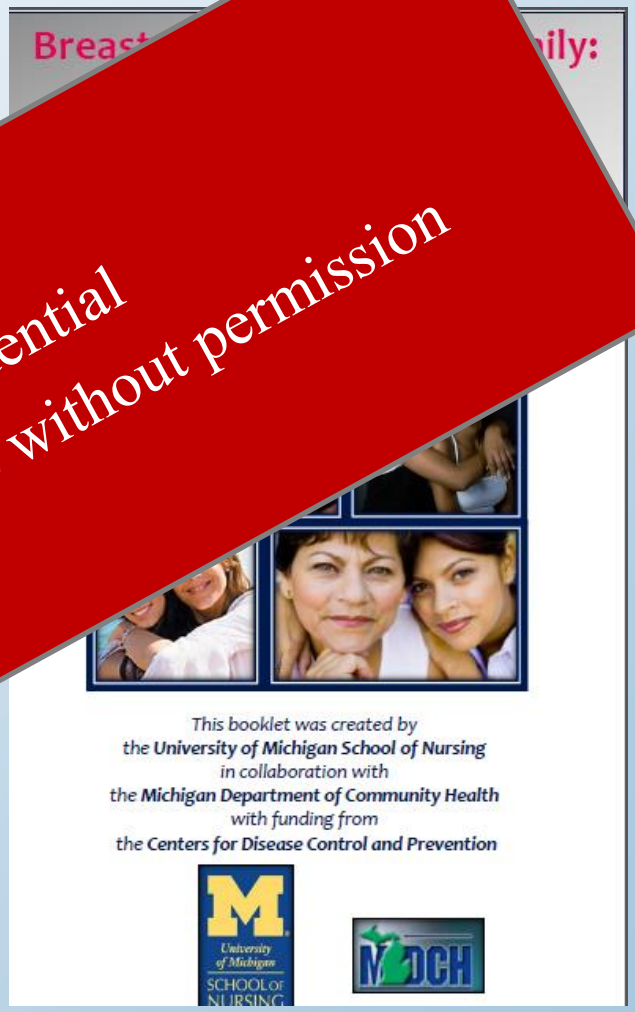
Please talk with your he
care that is right for you.
www.cdc.gov/cancer/breas

Thank you once again for takin
Your answers will help us learn
cancer screenings and follow-up

Sincerely,

Maria C. Katapodi, PhD, RN, FAAN
Assistant Professor of Nursing

www.nursing.umich.edu



Breast ... ily:

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*the **University of Michigan School of Nursing***
in collaboration with
*the **Michigan Department of Community Health***
with funding from
*the **Centers for Disease Control and Prevention***

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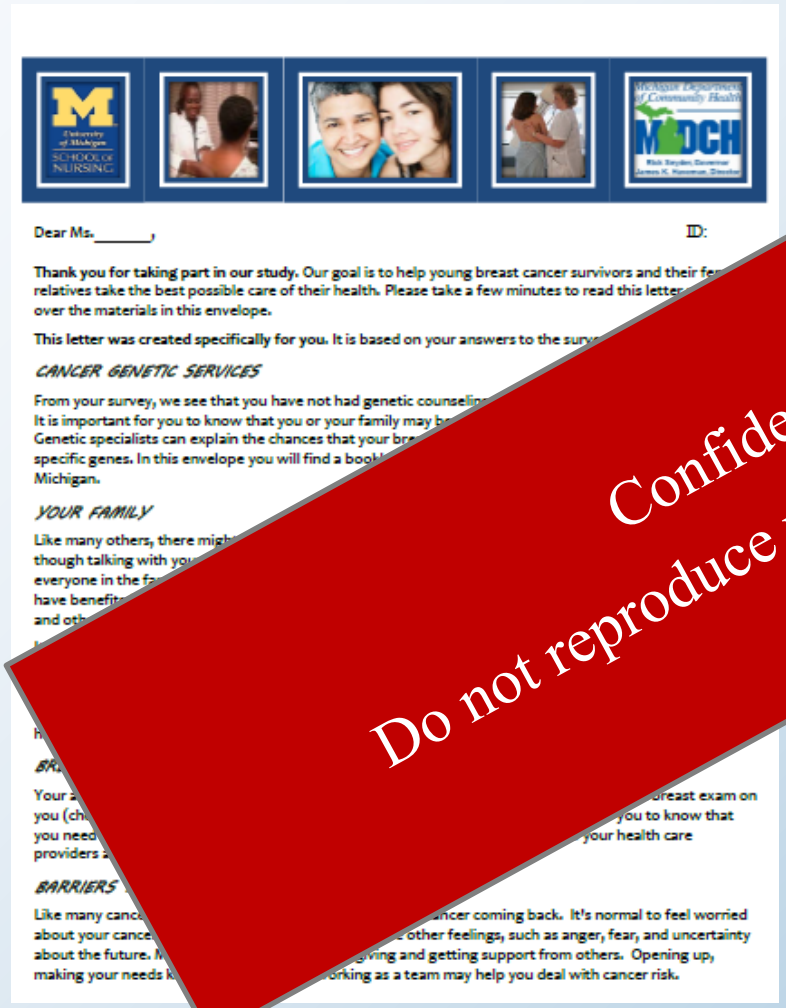
INTERVENTION: ENHANCED TAILORED



Dear Ms._____, ID:

Thank you for taking part in our study. Our goal is to help young breast cancer survivors and their fe
relatives take the best possible care of their health. Please take a few minutes to read this letter
over the materials in this envelope.

This letter was created specifically for you. It is based on your answers to the surv

CANCER GENETIC SERVICES

From your survey, we see that you have not had genetic counselin
It is important for you to know that you or your family may b
Genetic specialists can explain the chances that your br
specific genes. In this envelope you will find a book
Michigan.

YOUR FAMILY

Like many others, there migh
though talking with you
everyone in the fa
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Your
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providers

BARRIERS

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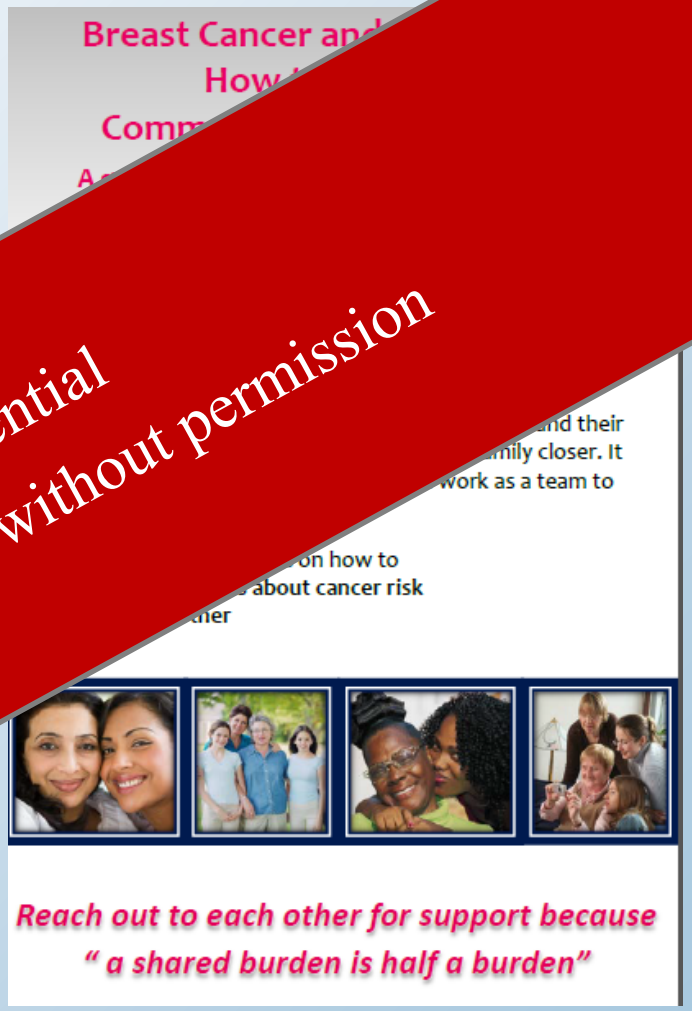
about the future.
making your needs k

breast exam on
you to know that
your health care

ncer coming back. It's normal to feel worried
other feelings, such as anger, fear, and uncertainty
ving and getting support from others. Opening up,
orking as a team may help you deal with cancer risk.

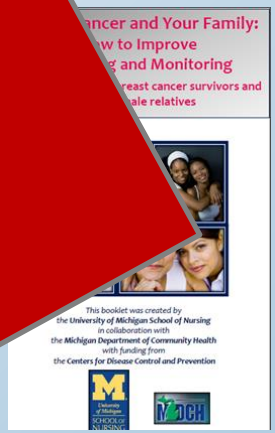


Breast Cancer and
How
Comm

and their
mily closer. It
work as a team to

on how to
about cancer risk
ner

Reach out to each other for support because
" a shared burden is half a burden"



ncer and Your Family:
w to Improve
g and Monitoring
reast cancer survivors and
ale relatives

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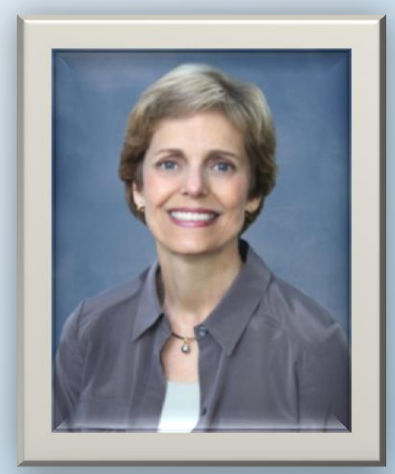
LESSONS LEARNED:
People Matter

- Mentoring
- Collaborations
- Project Manager



LESSONS LEARNED:
The Environment Creates Efficacy

- Infrastructure and Support
- Organizational Culture
- Values Clarification

LESSONS LEARNED:
The Project

- Recruitment
- Follow the data
- Openness to opportunities
- Scaling up

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Thank you for your attention!

Questions?

Faculty of Medicine,
University of Basel, Switzerland