Identifying Hereditary Breast and Ovarian Cancer Syndrome With The Help of Primary Care Providers In North Dakota

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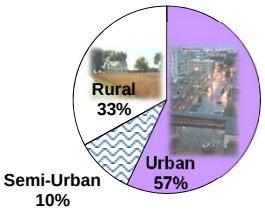
Where People Live in North Dakota



Source: U.S. Bureau of the Census, ND Department of Health

Genetic Services in ND

- In larger cities
  Fargo, Grand Forks, Bismarck, Minot

  Focus on newborn and pediatric

  Increased awareness and research on cancer genetic syndromes

  How can the rural primary care provider assess patients for inherited cancer syndromes?

Breast Cancer

Background and facts:

- Each year more than 226,000 women in the US are diagnosed with Breast Cancer and 46,000 women are diagnosed with Ovarian Cancer.
- Currently 1:8 women at risk for breast cancer 12.2%
- Breast Cancer is the most common type of cancer in women
- Second leading cause of cancer deaths for American women.

Who Gets Cancer?

- Children < 2 years of age
- People > 60 years of age
- People with AIDS
- People on long-term immunosuppressive drugs

Introduction

- **Sporadic cancer**

- **Familial cancer**
  - Grouping or clustering in families

Hereditary Cancer

What is hereditary cancer?

North Dakota Cancer Cases 1998-2007

		Men 18,058	Women 16,189		
Prostate	32%			32%	Breast
Colorectal	13%			12%	Colorectal
Lung/Bronchus	13%			10%	Lung/Bronchus
Urinary bladder	7%			6%	Corpus/Uterus
Non-Hodgkin Lymphoma	4%			4%	Non-Hodgkin Lymphoma

Source: ND Cancer Registry

Breast Cancer

- ✓ About 525 new cases each year in North Dakota
- ✓ Most commonly diagnosed cancer among women
- ✓ Mammography is highly accurate, but not perfect.
- ✓ Mammography detects 80%-90% of breast cancers in women without symptoms.
- ✓ Second leading cause of cancer deaths in women
- ✓ About 5,102 breast cancer survivors in 2005

Sources: ND Cancer Registry, American Cancer Society, 2008

BRCA 1 and BRCA 2

- Hereditary breast and ovarian cancer syndrome or HBOC is a type of hereditary cancer.
- Majority of hereditary breast cancers are caused by an alteration in either the BRCA 1 or BRCA 2 genes.
- There are other rare forms of hereditary breast cancer.
- In 1996 genetic testing became clinical available.

Several professional societies have set guidelines for testing

- ASCO
- NCCN
- ACS
- ISONG
  - USPTF**
- We use these guidelines to determine who should be offered education and counseling so that they can make informed decisions about genetic testing.

Personal or family history

- Who fits into the 10%?

- Breast Cancer before the age of 50
- Ovarian cancer at any age
- Male breast cancer
- Bilateral breast cancer
- Both breast and ovarian cancer
- Relative with a BRCA mutation
- Ashkenazi/Eastern European Jewish descent
- Triple Negative Breast Cancer
- Breast cancer after the age 50 (In addition to one of the other risk factors above)

BRCA1 and BRCA2

- Lifetime cancer risks:
- Breast cancer 40-87%
- Ovarian caner 15-44%
- Male Breast Cancer 7% vs. <.05%
- Prostate, Colon, Melanoma and pancreatic

Risk Assessment

- If a patient has red flag criteria they should consider a risk assessment evaluation.
- Provides education about risks and benefits of testing
- Provides a personalized cancer risk assessment
- Allows the patient and family to make an informed decision

Tools for Primary Care

- Family History Risk Assessment Tool (FHAT)
- Manchester scoring system
- Risk Assessment in Genetics (RAGs tool)

Autosomal Dominant

- Mutations are inherited by mother or father and it is autosomal dominant.
- Autosomal dominant: family members have a 50/50 chance on inheritance of mutation.
- It is best to test the individual who has had cancer if possible.

Male Carriers

- Don't forget male breast cancer!

Benefits

- Identifies high risk individuals
- Identifies non carriers in families with known mutation
- Allows early detection and risk reduction strategies
- May relieve anxiety and stress

Limitations

- Does not detect all mutations; may not rule out hereditary risk
- Continued risk of sporadic
- Efficacy of some interventions not well established
- May result in distress; survivor guilt
- May give a false sense of security

- HIPAA law
- GINA law (passed in 2009).

Insurance Fears

- Health Insurance
- Life Insurance
- Disability Insurance

Summary

- Increase role for primary care providers to assess patients for red flag criteria
- Genetic testing in appropriate population
- Need for education among health care providers
- Proactive role for BRCA mutation carriers and support in their treatment decisions.

Summary

- More data is needed to determine if intervention in BRCA carriers decreases mortality
- Need for more health professionals to be interested in genetics!

Questions?