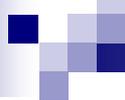


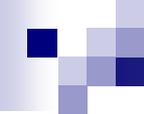
Role of the Genetic Counselor on Your Cancer Center Team

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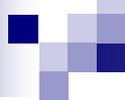
Objectives

- By the end of this talk, you will be:
 - Able to identify the clinical characteristics of patients who should be referred for cancer genetic counseling.
 - Familiar with the components of a genetic counseling consultation.
 - Familiar with the administrative considerations for starting a genetic counseling program.



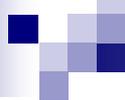
Purpose

- The purpose of cancer genetic counseling is to:
 - Educate clients about their chance of developing cancer.
 - Help them derive personal meaning from cancer genetic information.
 - Empower them to make educated, informed decisions about genetic testing, cancer screening, and cancer prevention.



Why is genetic counseling important? For patients...

- Cancer risks in hereditary cancer families are much higher than the general population.
- Hereditary cancers tend to develop at a younger age than expected, often prior to the time at which general population screening would be initiated.
- Clinical management may be altered.
- Identify individuals in the family who are at risk. Psychosocial impact on patient and family.

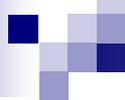


Why is genetic counseling important? For physicians...

- Complex hereditary syndromes
- Changing information on diagnosis and testing
- Psychosocial impact on patient and family
- Long-term follow-up

Why is genetic counseling important? For the practice...

- Ann Chadwick, RN at the University of Washington
- Died at age 41 of ovarian cancer.
 - Breast cancer at 28.
 - Contralateral breast cancer at 37.
- Lawsuit asserting that doctors should have warned a woman to have her ovaries removed because she had a high risk of ovarian cancer was settled in 2001 for \$1.6 million.



Who should be referred?

- A referral for cancer genetic risk assessment and counseling should be considered for clients with personal or family history features suggestive of familial or hereditary cancer.
- Should not be limited to just those individuals who are potential candidates for genetic testing.

Features

■ Individual Patient

- Multiple primary tumors.
- Bilateral primary tumors in paired organs.
- Younger-than-usual age at tumor diagnosis
- In the sex not usually affected.

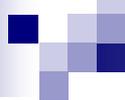
■ Patient's Family

- One first degree relative with the same or a related tumor.
- \geq two 1st degree relatives with tumors at the same site or related tumors.
- \geq two relatives in two generations with tumors of the same site or related tumors.
- Known genetic mutation in the family.



Making a Referral

- Referral Form
 - Patient demographics
 - Indication
 - Patient Signature
- Who introduced the idea?
- Is the patient still in the clinic?
- Schedule the consultation.



The Initial Consultation

- Psychosocial Assessment
- Personal medical history
- Family medical history
- Risk Assessment
 - Classify
 - Calculate
 - Counsel
- Molecular Testing
- Pretest Counseling
- Informed Consent
- Sample Collection

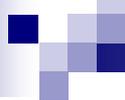


Psychosocial Assessment

- Motivations for seeking a cancer risk consultation.
- Beliefs about cancer etiology and perception of risk.
- Ethnocultural information.
- Socioeconomic and demographic information.
- Psychosocial factors.
- Current cancer screening.
- Health behaviors.
- Coping strategies.

Personal Medical History

- Age
- Personal history
- Major illnesses
- Hospitalizations
- Surgeries
- Biopsy history
- Reproductive history
- **Organ in which tumor developed**
- **Age at time of diagnosis**
- **Number of tumors**
- **Pathology, stage, and grade of malignant tumor**
- **Pathology of benign tumors**
- **Treatment regimen**

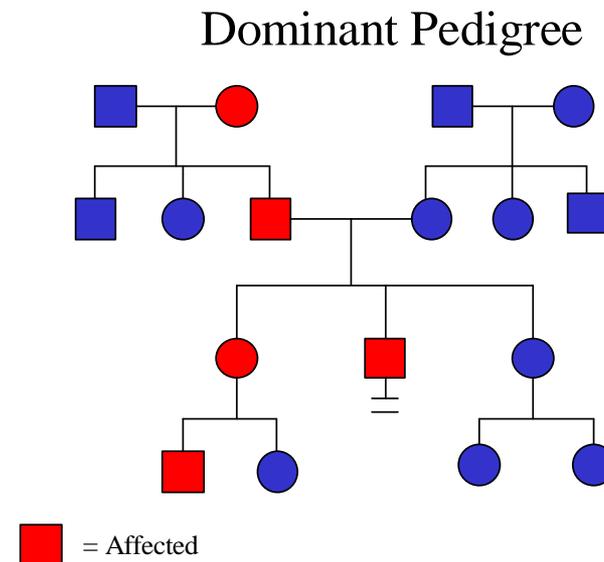


Family History

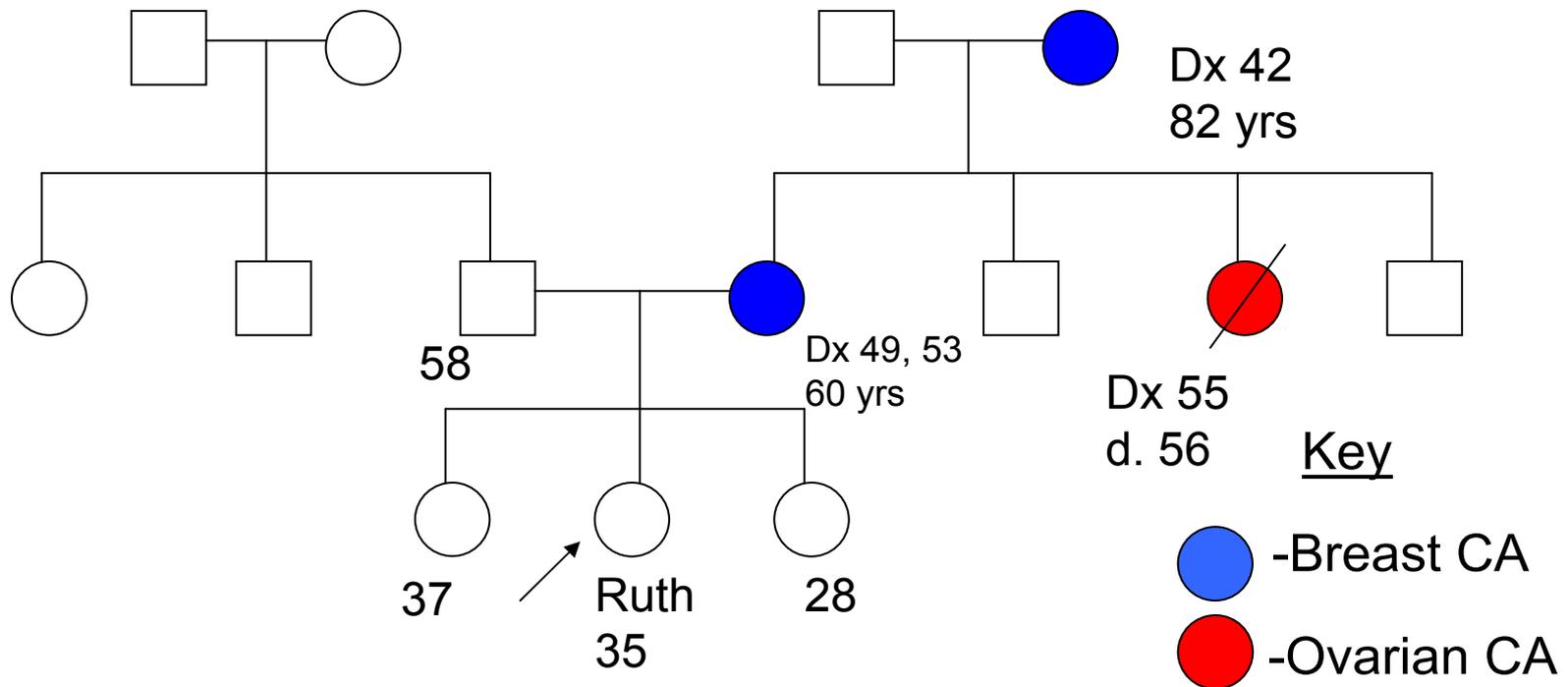
- Cornerstone of cancer genetic risk assessment.
- Minimum three to four-generation pedigree
- Standardized pedigree nomenclature
- Paternal and maternal history
- Ancestry/Ethnicity
- Consanguinity

Taking a Family History

- Organ in which tumor developed
- Age at time of diagnosis
- Number of tumors
- Pathology, stage, and grade of malignant tumors
- Pathology of benign tumors
- Treatment regimen
- Environmental exposures
- Surgeries
- Current screening
- If deceased, age and cause



Cancer Family History



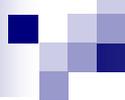


Risk Assessment - Classify

- Hereditary Cancer (5-10%)
 - Families with known cancer syndromes or histories that exhibit the classic features of hereditary cancer.
- Familial Cancer (10-15%)
 - More cases of a specific type of cancer than expected, but not necessarily exhibiting the classic features of hereditary cancers.
- Sporadic Cancer (75-80%)
 - Cancer in the family is mainly due to nonhereditary causes.

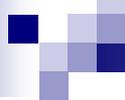
Risk Assessment - Calculate

- Develop differential diagnosis
- Utilize model that estimates risk of carrying a mutation in a cancer predisposition gene. (e.g. BRCAPro)
- Utilize model that estimates absolute risk of developing specific cancers in the absence of a mutation in a known gene. (e.g. Gail or Claus model)



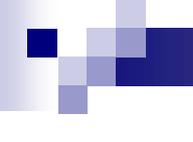
Risk Assessment - Counsel

- Risk of having mutation in susceptibility gene vs. risk of developing cancer
- Patient's perception of risk
- Risk for patient's children / other family members
- Assess patient understanding.



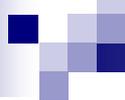
Molecular Testing

- Client has significant personal and/or family history of cancer.
- Test can be adequately interpreted.
- Results will affect medical management.
- Client can provide informed consent.



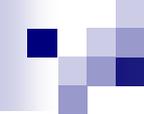
Molecular Testing (cont.)

- Clinical testing
 - Available on a clinical, fee-for service basis.
 - CLIA-approved laboratory.
 - Note: Not all labs offer same clinical testing.
- Research testing
 - Available in the context of a research study.
 - IRB-approved.
- Both available?
 - Discuss pros and cons with the patient.



Informed Consent

- Purpose of the test and who to test.
- General information about the gene(s).
- Possible test results.
 - Positive result
 - Negative result
 - Variant
- Likelihood of a positive result.



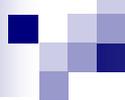
Informed Consent (cont.)

- Technical aspects and accuracy of the test.
 - False-positive or false-negative result
- Economic considerations
- Risk of genetic discrimination
- Psychosocial aspects
- Confidentiality issues



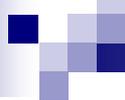
Informed Consent (cont.)

- Utilization of test results: Medical surveillance and preventive measures.
- Alternatives to genetic testing.
- Storage and potential reuse of genetic material.



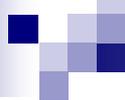
Sample Collection

- Coordinate sample collection and shipment.
- Preauthorize with insurance company?
- Provide client with estimated turnaround time.
- Establish a plan for disclosing results.



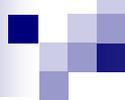
The Second Consultation - Result Disclosure

- Combine with an MD visit
- Results disclosure
- Significance of test results (e.g. cancer risk)
- Assess emotional impact of test results
- Medical management
- Informing other relatives
- Future contact
- Resources



Program Infrastructure

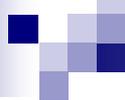
- Space (sites, staffing, equipment needs)
- Human Resources
- Other Resources
 - Budgets
 - Billing structure (96040 – Genetic Counseling)
 - Information Management
 - **Patient Confidentiality**



Program Development

■ Structure and Function

- What clinic model will be used?
- Team meetings
- Scheduling
- Patient flow and patient communication policies
- Development of forms



Additional Considerations

- Genetic Testing Fees (\$400 - \$4000)
 - Clinic pays for testing and seek reimbursement from patient.
 - Patient seeks pre-approval from insurance company.
 - Seek reimbursement from insurance company.
 - Patient pays out of pocket.

Resources

http://www.nsgc.org/

National Society of Genetic Counselors
The leading voice, authority and advocate for the genetic counseling profession

Home | Consumer Info | Career | News Room | **For Healthcare Providers** | Members Only

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velopment of consensus document around prenatal screening and diagnosis as
occurrence: Understanding Prenatal Screening and Diagnosis of Down
ditional and Advocacy Community Perspectives
res in Genetic Counseling is now available. Click [here](#) to view the newsletter!
[ler](#)
ailable!
to announce the Student Research Project Award is now Available! Click [here](#)
seling. Created in collaboration with [Genetic Alliance](#), this guide to genetic
eling is, what to expect from a genetic counseling visit, and the different types
arv and other emails? [Download](#) instructions on how to set your email to
cs and Genetic Counseling Services" - Frequently Asked Questions
ation

Journal of Genetic Counseling

Family History Tool

Practice Guidelines

State Licensing and Federal Advocacy

Perspectives in Genetic Counseling

Resources (cont.)

The screenshot shows a Mozilla Firefox browser window displaying the NSGC Cancer Genetics Healthcare Provider Link. The browser's address bar shows the URL: http://www.nsgc.org/providers/cancer/cancer_genetics_provider.cfm. The page title is "NSGC: Welcome to the NSGC Cancer Ge...".

The website header features the NSGC logo (National Society of Genetic Counselors) and a navigation menu with links: [About Us](#) | [Education](#) | [Resources & Publications](#) | [Consumer Info](#) | [Career](#) | [News Room](#) | [For Healthcare Pr...](#)

A search bar is located on the left side of the page, with the text "Search:" and a "Go" button.

The main content area is titled "Welcome to the NSGC Cancer Genetics Healthcare Provider Link" and contains a list of resources:

- Fact Sheets about Hereditary Cancers (*Under Construction*)
- [What can a Genetic Counselor do for you?](#)
- [Pocket Referral Guidelines](#)
- [Find a Genetic Counselor](#)
- [What should I tell my patients about genetic discrimination?](#)
- Who needs genetic counseling and genetic testing? (*Under Construction*)
- [Clinical Genetic Testing vs. Research Genetic Testing Fact Sheet](#)
- [DNA Banking](#)
- NSGC Practice Guidelines
 - [Hereditary Cancer Risks](#)
 - [Hereditary Breast Ovarian Cancer Syndrome](#)
- [NSGC Position Statements](#)
- Need a SPEAKER for an educational event? Go to the [NSGC Speaker's Bureau!](#)
- [Additional Cancer Genetics Resources](#)
- Resources for your Patients (*Under Construction*)

At the bottom of the page, there is a link: [Back to Cancer Genetics Healthcare Providers Main Page](#)