



Breast/Ovarian Cancer: Counseling Protocol Checklist

University of Iowa
Division of Medical Genetics
Testing Protocols

Patient's Name _____

Hospital Number _____

I. PATIENT'S PRECONCEIVED IDEAS ABOUT PERSONAL CANCER RISK AND ETIOLOGY

Dates and Initials:

- A. General population risk for breast cancer
- B. Self perceived cancer risk and etiology
- C. Personal experience with cancer

II. PSYCHOSOCIAL ASSESSMENT

- A. Coping style
- B. Mental health conditions
- C. Life crisis
- D. Insurance status
- E. Career status of self and /or spouse

III. RISK ASSESSMENT

- A. Pedigree history
- B. Reproductive history
- C. Breast history
- D. Pedigree analysis of risk
- E. GAIL model analysis of risk *
- F. Claus tables analysis of risk *
- G. Risk for ovarian cancer

IV. GENERAL INFORMATION

- A. Risk factors for breast cancer
- B. How breast cancer is inherited
- C. General cancer screening recommendations

V. INDIVIDUALIZED SCREENING/TREATMENT PLAN

- A. Surveillance and prophylactic treatment
- B. Gene testing (high risk individuals)
- C. Follow up plan

VI. PSYCHOLOGICAL SUPPORT

- A. Support person
- B. Professional counseling services-UIHC or local
- C. Support groups

Initials/Signatures of Counselor(s)

GENETIC COUNSELING _____ date

OUTSIDE RECORDS SENT FOR _____ date/patient name

EXAMINATION _____ date/where/results

DNA TEST RESULTS _____ date/results/lab

FOLLOW-UP PLAN _____

REFERRALS _____

BREAST/OVARIAN CANCER COUNSELING OUTLINE

I. PATIENT'S PRECONCEIVED IDEAS ABOUT PERSONAL CANCER RISK AND ETIOLOGY (beliefs patient has prior to counseling)

A. General population risk for breast cancer

Breast cancer - 2% by the age of 20 and 11% (or 1 in 9) by the age of 85

Ovarian cancer - 1.4% by the age of 80

B. Self perceived cancer risk and etiology

What do you believe your risk for cancer to be? Do you believe it to be higher, just the same or lower than the general populations risk to develop cancer?

C. Personal experience with cancer

Have you or anyone you know ever been diagnosed with cancer? What was this like for you?

II. PSYCHOSOCIAL ASSESSMENT

A. Coping style

How do you handle stress or crisis?

B. Mental health conditions

Are you now or have you ever been treated for a mental illness, had psychological therapy?

C. Life crisis

Divorce, birth, family member just diagnosed with cancer, death of someone close to you, any major changes in your life?

D. Insurance status

Life, health, disability

C. Career status of self and /or spouse

Are you or the insurance policy holder in your family considering a change in career?

III. RISK ASSESSMENT**High risk**

High risk has been defined as a cumulative risk of > 35%. Others define high risk as individuals who are at 50% risk to inherit breast cancer. Families in which 3 or more affected individuals are known, in at least 2 consecutive generations, with at least one affected individual diagnosed before the age 50 has been defined by the task force of the Cancer Study Consortium, ELSI branch of the Human Genome Research office as high risk (50%) pedigrees. There is no consensus concerning minimum criteria for identification of a high risk, AD pedigree. Characteristics of high risk cases include:

- positive family history of breast and/or ovarian cancer in 3 or more individuals in 2 consecutive generations
- AD pattern of inheritance
- one blood relative with either breast or ovarian cancer under the age of 45
- individual who has or had bilateral or multi focal breast cancer
- Individual who has or had breast or ovarian cancer under the age of 45, or pre menopausal onset of cancer

- male breast cancer relative
- the relative of someone with a documented mutation in a familial cancer gene.

Moderate risk

Moderate risk has been defined as a cumulative risk between 15 and 35 %. Characteristics of moderate risk cases include:

- less striking family history
- absence of ovarian and other non-breast cancers
- older age and postmenopausal onset of breast cancer

A. Pedigree history

Include the following information:

1. At least a 3 generation pedigree
2. Age at diagnosis of cancer (all individuals with cancer)
3. Current age and/or DOB of all family members
4. Age at death for all deceased relatives
5. Document hysterectomy, oophorectomy, surgical removal of any organs or tissue in any relative and reason for removal - may need to obtain pathology reports, histology reports or other records
6. Document reasons for no biological children

7. Genetic syndrome (some are associated with increase cancer risks)
8. Document laterality of primary tumor
9. Document metastatic disease

B. Reproductive history

1. Patient's age at menarche
2. Patient's age at the birth of first child
3. Patient's age at menopause
4. History of birth control pill use
5. Document other hormone therapy

C. Breast History

1. SBE (self breast exam)-document knowledge of & how often it is done
2. Has the patient ever had a lump in her breast? If yes when, which breast, was it biopsied, where was biopsy done and what were the results.
3. Has the patient ever had a mammogram? If yes when, why & what were the results

D. Pedigree analysis of risk

Enter risk on counseling checklist

E. GAIL model analysis of risk

Enter risk on counseling checklist

F. Claus tables analysis of risk

Enter risk on counseling checklist

G. Risk for ovarian cancer

BRCA 1 carriers have a 20-60% risk by the age of 80 to develop ovarian cancer

IV. GENERAL INFORMATION

A. Risk factors for breast cancer

1. Positive family history is the strongest risk factor
2. Others may include:
 - hereditary factors
 - dietary factors
 - environmental factors

3. Specific factors for individual cases of cancer are generally not known

B. How breast cancer is inherited

1. Only about 5-10% of breast cancer is inherited or due to a mutation in a gene inherited from a parent
2. Autosomal dominance (use AD handout)
3. Tumor suppresser gene
4. Two hit hypothesis- the first hit is inherited in the germ cell, the second hit is acquired in the somatic cell
5. Stress that having an abnormal copy of one of the breast cancer genes predisposes an individual to cancer.

C. General cancer screening recommendations

Several agencies have screening recommendations, the following are ACS recommendations:

1. Breast cancer
 - 20 years and older: SBE monthly
 - 20-40: clinician breast exam every 3 yrs, initial mammogram between 35-40
 - 40-50: mammography every 1-2 yrs as determined by your clinician, annual clinical breast exam
 - 50 +: annual mammography and clinical breast exam
2. Ovarian cancer

- no specific recommendations exist for ovarian cancer screening in the general population except for annual pap smear and bimanual pelvic exam

V. INDIVIDUALIZED SCREENING/TREATMENT PLAN*

A. Surveillance and prophylactic treatment. STRESS no one method has proven to decrease morbidity or mortality. Options should be discussed with oncologist and/or surgeon

1. Options for high risk individuals for breast and ovarian cancer management include:

- a. SBE monthly beginning at age 18
- b. clinical breast exam every 6 months beginning at age 25
- c. mammography yearly beginning at age 25-35, then every 6 months after age 50 (should be done at a consistent location when possible with prior films available for comparison)
- d. prophylactic mastectomy after consultation with an oncologist and surgeon
- e. chemoprevention (i.e. Tamoxifen)
- f. ovarian cancer screening (there is no proven benefit for screening) beginning at age 25-30 yr., rectovaginal pelvic exam, CA 125, and transvaginal ultrasound every 6 mo.- 1 yr.; prophylactic bilateral oophorectomy by age 35 or earlier if childbearing is complete
- g. prostate cancer screening ACS guidelines;digital rectal examination (DRE) and serum prostate-specific antigen (PSA) yearly, beginning at age 50
- h. colon cancer ACS guidelines; DRE yearly beginning at age 40; stool slide test every year after age 50; procto exam-after 2 initial negative tests 1 year apart every 3-5 years after the age of 50

2. Provide literature: document teaching material given to patient

3. Refer to other services (oncologist, surgeon, wellness/ health promotion clinic) as needed

* The guidelines for screening will change as more is learned about effectiveness. It is important for the counselor to be familiar with what is currently recommended. This protocol may not reflect changes in screening recommendations. Prostate and colon cancer screening in BRCA 1 families are the same for sporadic prostate and colon cancer. While there is an increase risk for BRCA 1 carriers to develop these cancers, the age of onset is similar to that of sporadic prostate and colon cancer.

B. Gene Testing (high risk individuals)

1. DNA abnormality

2. Limitations of gene test:

- mutations indicate an increased risk for cancer
- no proven prevention strategies to decrease mortality
- mutations may not be detected
- ambiguous results may be obtained. Another affected member may need to be tested
- mutations may exist in a different cancer gene which was not screened for in this test
- not detecting a mutation does not mean cancer will not develop
- sporadic cancer may exist in an inherited breast cancer family

3. Benefits of testing:

- could provide an explanation for cancer in the family

- relief from uncertainty
- could change surveillance programs
- clarify risk for family members

4. Impact of testing on insurance

5. Impact of testing on career/employment

6. Psychological consequences of positive and negative results

(anger, shock, denial, anxiety, depression, guilt, change in self image, change in relationships, worry, relief)

7. Confidentiality issues in a family

8. Cost of testing/time table (will depend on the lab that is used)

9. Informed consent

10. DNA banking

11. Others' access to medical records

12. Withdrawal from testing

C. Devise follow up plan individualized according to risk and personal preference

VI. PSYCHOLOGICAL SUPPORT

A. Support person

1. Should the individual decide to have gene testing, identification of a specific support person to accompany her/him through the protocol is recommended. This person may be a spouse or a relative who is not at risk for familial cancer, or a close friend.

B. Professional counseling services-UIHC or local

1. Is he or she aware of what is available locally
2. Referral to professional counseling service as needed
3. UIHC Clinical Cancer Center 391-356-4422 (Dr. Susan Kambhu)

C. Support groups

1. National Alliance of Breast Cancer 1-800-719-9154
2. National Coalition for Cancer Survivorship 301-656-8868
3. National Breast Cancer Coalition 202-296-7477
4. The American Cancer Society 1-800-ACS-2345
5. National Cancer Institute 1-800-4-CANCE

VII. PATIENT OUTCOMES

A. The patient will:

1. Convey knowledge of risk factors involved in cancer, how cancer is inherited, and general screening recommendations
2. Identify their risk and the risk of others in their family for cancer
3. Convey knowledge of resources, other professionals to talk with regarding their risk and risk management
4. Take action to promote wellness as recommended by a health professional (follow through with referral services)
5. Identify social support system such as: support groups, other health care professionals, and personal friends
6. Make a decision regarding whether to pursue DNA testing/banking.

Copyright 1997, University of Iowa, Division of Medical Genetics