

REVISED GENETICS RESEARCH QUESTIONS

KNOWLEDGE, BEHAVIOR, ATTITUDES QUESTIONS

I. KNOWLEDGE

- A. What is the knowledge level of EOC in
 - 1. Women in the general community
 - 2. Women diagnosed with EOC
 - 3. Women relatives of women diagnosed with EOC
 - 4. Women with EOC of different ethnic backgrounds (and their relatives)
 - 5. Primary care physicians
- B. Dimensions of knowledge
 - 1. Presenting symptoms
 - 2. Risk factors and genetics
 - 3. Diagnostic tests
 - 4. Genetic link with breast CA
 - 5. Course and prognosis
 - 6. Treatment options
 - 7. Prophylactic options
- C. What are prevalent knowledge misconceptions?

HYPOTHESES:

A. Knowledge of EOC will be greater in women diagnosed with EOC when compared to women in the general community and women with EOC from different ethnic background.

B. Knowledge of EOC between patients and relatives will be mediated by communication patterns, as will prevalence of knowledge misconceptions across family members. High communication families will demonstrate similar knowledge and similar misconceptions.

II. BEHAVIOR

- A. What are lifestyle and other behaviors (diet, exercise, screening, prayer) that women in the four groups specified engage in to reduce risks of EOC?
 - 1. Behaviors with some scientific/medical basis
 - 2. Behaviors with no known data to support risk reduction
 - 3. Behaviors with a cultural basis
- B. What factors mediate behavior?

HYPOTHESES:

A. A majority of patients will engage in behaviors with no known scientific basis for risk reduction.

B. Women from different ethnic backgrounds will engage in more folk behaviors and remedies than will women from the majority

culture.

C. Cultural, communication, and psychological variables will mediate patient behavior.

III. ATTITUDES

A. What are prevalent attitudes toward EOC?

1. Optimism/pessimism (in relation to breast, colon CA)
2. Control/lack of control/acceptance (in relation to breast, colon CA)

B. What factors mediate attitudes?

HYPOTHESES:

A. Attitudes toward EOC will be more negative than attitudes toward breast and colon CA.

B. Cultural, communication, and psychological variables will mediate patient attitudes.

COMMUNICATION QUESTIONS

I. FAMILY COMMUNICATION

A. What are communication patterns about disease (or disease risk) within the family? (Who talks to whom, about what?)

B. What types of information are communicated? (Diagnosis, prognosis, risk factors, genetics, treatment options)

C. What is nature of communication? (Informational, affective, problem-solving etc.)

HYPOTHESES:

A. Communication patterns will be related to family cohesion and conflict.

B. Communication patterns will be related to comprehension about the meaning of genetic testing; willingness among family members to agree to participate in genetic testing; and the operation of family processes of coercion, stigmatization, and isolation in regard to the possibility of genetic testing.

II. PATIENT-DOCTOR COMMUNICATION

A. What types of information are communicated between doctor and patient?

B. What is the nature of communication between doctor and patient? (Informational, affective, problem-solving etc.)

HYPOTHESES:

A. Communication between patient and physician will be related to positive adaptation to disease.

B. Communication between patient and physician will be related to interest in and comprehension about genetic testing.

QUESTIONS PERTAINING TO PSYCHOLOGICAL STATES

I. DEPRESSION/ANXIETY

A. What are depression/anxiety levels of EOC patients in comparison to:

1. Community sample (or national norms)
2. Female relatives
3. EOC patients and relatives of different ethnicities

B. Do depression/anxiety increase or decrease after

1. Family history and discussion of genetic risk
2. Disease progression (1 yr. post-diagnosis)
3. Participation in a support group

HYPOTHESES:

A. EOC patients will exhibit greater levels of depression/anxiety than the community sample and relatives.

B. Relatives will exhibit depression/anxiety greater than that of the community sample, but less than that of EOC patients.

C. Depression/anxiety will decrease after participation in a support group.

D. Depression/anxiety will increase with disease progression, but may be mediated by factors such as support, culture, and psychological variables.

II. BUFFERING FACTORS

A. Do prior beliefs, personality variables, coping strategies, family environment, and psychological factors influence adaptation to disease?

B. Do personality variables coping strategies, family environment, and psychological factors influence interest in genetic testing?

HYPOTHESES:

A. Study subjects who

1. are high in optimism and commitment
2. have a high sense of mastery and control
3. do not rely on denial and escape-avoidance coping
4. are members of families high on cohesion, low on conflict
5. have good informal support networks

will adapt more positively to diagnosis (depression/anxiety, quality of life, course of disease?)

B. Study subjects as described above will have more interest in and better comprehension of genetic testing.

QUESTIONS PERTAINING TO CULTURE

I. CULTURE AND ADAPTATION

A. How do different cultural elements influence patient response to disease?

1. Personalism, respect, and simpatia
2. Control over nature
3. Familism

HYPOTHESES:

A. Patients who are bicultural will exhibit the same or better adaptation to disease than patients from the majority culture and patients with a traditional cultural orientation, as measured by levels of depression, anxiety, and quality of life.

B. Patients who strongly endorse traditional cultural values that reflect harmony with the natural order will have a more accepting attitude toward disease than patients who evince a more active control over nature attitude.

C. Patients who highly value qualities of personalism and respect and who successfully identify these in their health care provider will have a better adaptation to disease than those who do not report such a relationship.

II. CULTURE AND GENETIC TESTING

A. How do different cultural elements influence patient interest in and comprehension of genetic testing?

HYPOTHESES:

A. Bicultural patients will show the same interest in genetic testing as patients from the majority culture and more interest than patients with a traditional cultural orientation.

B. Patients whose attitudes reflect harmony with the natural order will be less interested in genetic testing, but will have a more accepting attitude in contemplating hypothetical reported results, whether or not they might place the patient at increased risk.

C. Patients who highly value qualities of personalism and respect and who successfully identify these in their health care provider will be more interested in genetic testing than those who do not; and will demonstrate better comprehension of the

implications of genetic testing.

D. Patients who score high on values of familism, and whose families are included in the explanation of genetic testing, will be more interested in testing; and will demonstrate better comprehension than those whose families are not included in the counseling process.

E. Cultural explanatory models of cancer will be related to perceived value of genetic testing.