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# Adults' perceptions of genetic counseling and genetic testing

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ABSTRACT

*Purpose:* This study described the perceptions of genetic counseling and testing of adults ($N = 116$) attending a genetic education program. Understanding perceptions of genetic counseling, including the importance of counseling topics, will contribute to patient-focused care as clinical genetic applications for common, complex disorders evolve.
*Methods:* Participants completed a survey addressing: the importance of genetic counseling topics, benefits and negative effects of genetic testing, and sharing test results.
*Results:* Topics addressing practical information about genetic conditions were rated most important; topics involving conceptual genetic/genomic principles were rated least important. The most frequently identified benefit and negative effect of testing were prevention/early detection/treatment and psychological distress. Participants perceived that they were more likely to share test results with first-degree than other relatives.
*Conclusions:* Findings suggest providing patients with practical information about genetic testing and genetic contributions to disease, while also determining whether their self-care abilities would be enhanced by teaching genetic/genomic principles.

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## 1. Introduction

Scientific knowledge about the contributions of genomic variation to both rare and common diseases is growing at a rapid pace. This knowledge plus the technological advances in DNA sequencing will result in increased clinical applications (Green & Guyer, 2011). People will have unprecedented opportunities to learn about their genetic susceptibility to common diseases and how gene-environment interactions can affect their health (Feero et al., 2010). Nurses have a key role in helping patients understand and use health-related genetic and genomic information (Greco & Salveson, 2009). An identified gap in genomic nursing science, which will help nurses fulfill this role, is knowledge about individuals' expectations of providers and their self-management strategies when encountering genomic-based health care for common, complex disorders (Calzone et al., 2013). Research about adults' perceptions of genetic counseling and their expectations for genetic testing will help address this gap. A relevant group for study is adults who express an interest in genetics because they will likely be early adopters of genetic testing, whether ordered by their health-care provider or through direct-to-consumer marketing. An educational program for the public about genetics and health provided an opportunity to survey attendees about their perceptions of genetic counseling and testing.

## 2. Perceptions of genetic counseling and testing

Research suggests that individuals' perceptions of genetic disease susceptibility influence their use of risk reduction behaviors (Vos et al., 2012). Considering patients' perceptions of genetic conditions and services during genetic counseling also facilitated their understanding of the information provided and satisfaction with the counseling experience (Skirton & Eiser, 2003). Research addressing perceptions of genetic information and services has focused on three groups: (a) adults in the general population; (b) patients with chronic illnesses, and (c) adults at high-risk for hereditary cancers. No published studies were found that addressed the perceptions about genetic counseling and testing among

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adults who express an interest in genetics, but had not participated in genetic counseling or testing.

Studies about perceptions of genetics among adults in the general population found that although they lacked scientific genetic knowledge, they recognized the potential benefits and limitations of genetic testing (Catz et al., 2005; Frazier et al., 2006; Rew et al., 2010; Rose et al., 2005; Skirton et al., 2006). Benefits of testing included increasing control over one's life (Rose et al.), preventing disease (Catz et al.), and providing information for future generations (Frazier et al., Skirton et al.). Limitations of testing included emotional distress about results, discrimination, test credibility, treatment expense, and confidentiality breaches. Older adults wanted professional support when sharing results and indicated they would disclose results selectively to family members based on ability to take preventive action (Skirton et al.). They were concerned that communicating results to family members might cause psychological distress or actual physical illness (Frazier et al., Skirton et al.). These studies did not address adults' perceptions of specific genetic topics or issues that may be discussed during counseling.

Dutch patients with common, chronic diseases had positive attitudes about genetic testing (Morren et al., 2007). Females reported significantly more perceived genetic knowledge. However, they were less interested in testing if treatment was not available. Females were also more likely to indicate they would inform siblings of test results. Specific reasons for disclosing or withholding results with family were not explored. A follow-up survey found that a less favorable attitude towards genetic testing was related to less perceived medical knowledge and greater perceived psychosocial knowledge about genetics (Calsbeek et al., 2007). Factual genetic knowledge was positively related to education and perceived heredity of one's illness.

The importance or emphasis placed on genetic counseling topics has been studied among adults at high-risk for hereditary cancers. Scandinavian patients referred for cancer genetics counseling rated medical facts and practical care, such as surveillance recommendations, as most important and placed less emphasis on basic genetic information and supportive care (Roshanai et al., 2012). However, older, female cancer patients also rated the need for information and support in sharing genetic information high in importance when compared to other participants. Among young women with breast cancer, the most frequently identified need for information related to genetics was the impact of their diagnosis on their children's risk followed by impact on other family member's risk (Cohn et al., 2003). Fewer participants identified a need for information about genetic counseling or testing. Australian Jewish women at risk for hereditary breast–ovarian cancer ranked the following genetic counseling topics from highest to lowest based on preference: cancer and genetic risk, breast–ovarian cancer surveillance, preparation for testing, and help with making testing decisions (Apicella et al., 2006). American women at risk for a genetic mutation for breast–ovarian cancer sought information support from their health-care provider about the meaning of a genetic mutation in their family and risk reduction strategies (Crotser & Dickerson, 2010). They advised health-care providers to explain issues related to genetic testing (e.g., the meaning of test results, emotions associated with testing, and risk-reduction options) during pretest counseling.

Because the concept of importance signals a quality of significance and a value judgment of worth, inquiry about adults' perceptions about the importance of genetic counseling topics will help providers consider relevant information from the patient perspective as genetic testing for common, complex disorders evolves. Likewise, knowledge about adults' expectations for the benefits and negative effects of testing and sharing of test results provides a consumer-focused view of the genetic counseling/testing process that providers can use when discussing the genetic testing process with their patients.

### 2.1. Purpose of the study

The purpose of this study was to describe perceptions of the importance of selected genetic counseling topics and expectations about the genetic testing among adults who expressed an interest in genetics by attending a public genetic education program. Based on the literature review, gender and genetic knowledge were chosen to explore group differences in perceptions. The research questions were: (1) How important are selected topics that may be discussed during genetic counseling?; (2) What are perceived benefits and negative effects of genetic testing?; (3) With which relatives would participants share genetic test results?, and (4) What are potential reasons for not sharing genetic test results with relatives?

## 3. Methods

### 3.1. Design and sample

A cross-sectional, descriptive design was used. Coordinators at a public education program addressing the health implications of advances in genetic knowledge invited 241 attendees to complete an investigator-developed, anonymous written survey. Invitation letters and survey packets were given to adults at the registration desk when they attended for the first time at either the first or second week of a 4-week program. The program was sponsored by and held at a U.S. mid-western university medical center, with satellite broadcast and telephone communication to six designated community sites resulting in two urban and five rural locations. Of those invited, 166 (68%) accepted a packet. Half ($n = 123$; 51%) returned a completed survey at their first session or afterward by postage-paid mail. The Institutional review board of the university that sponsored the program approved the study. Completion of a survey was considered consent to participate. Surveys from seven participants reporting previous genetic counseling were excluded, leaving 116 (48%) for analysis.

### 3.2. Survey development

The survey consisted of three quantitative and two qualitative components. Quantitative components, described below, addressed the importance of genetic topics, sharing genetic information, and background characteristics. Qualitative questions addressed the benefits and negative effects of genetic testing and reasons for not sharing genetic information with relatives. All questions were based on published literature for face validity and were reviewed by a medical geneticist, a genetic counselor, and a nurse researcher. Consensus was either achieved initially or reviewers' suggestions were used for item revisions.

#### 3.2.1. Importance of genetic topics

Twelve items addressed the importance of selected genetic topics (see Table 1). Response options ranged from 1 (not at all important) to 5 (extremely important). Descriptive statistics were calculated to examine responses to individual items. The items were also summed into a composite score to explore group differences. A principal components analysis indicated three eigenvalues greater than one, with a distinct “elbow” at the second eigenvalue, supporting one factor and a composite score. The Cronbach alpha coefficient for the summed items was .82.

#### 3.2.2. Sharing of genetic information

Eleven items addressed the likelihood of sharing genetic information with first-degree and other relatives. Response options ranged from 1 (not at all likely) to 4 (extremely likely). The six conceptually-related items addressing first-degree relatives (adult children, adolescent children, mother, father, brothers, sisters) and the five items addressing other relatives (aunts, uncles, nieces/nephews, cousins, other relatives)

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