Emotional and Cognitive Responses to Genetic Risk Disclosure in Young Women Undergoing Breast Cancer Predisposition Testing

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Abstract—**The disclosure of genetic risk information for breast cancer, particularly concerning mutations in genes such as BRCA1, BRCA2, and other hereditary markers, presents unique emotional and cognitive challenges for young women. This study investigates the psychological and behavioral responses of women aged 18 to 35 who undergo predictive genetic testing to assess their predisposition to breast cancer. Utilizing a mixed-methods design that integrates quantitative questionnaires and qualitative interviews, we analyzed patterns of emotional response including anxiety, fear, denial, relief, empowerment, and anticipatory grief as well as cognitive processing related to risk perception, future planning, and medical decision-making. Findings reveal that young women often face intense emotional distress upon receiving positive test results, exacerbated by concerns about fertility, body image, long-term health, and the impact on relationships and family planning. Additionally, many participants expressed difficulty in comprehending complex genetic data and uncertainty regarding appropriate clinical responses, such as prophylactic surgeries or enhanced surveillance strategies. Social factors, including family expectations, cultural beliefs, and peer influence, further shape how genetic risk is interpreted and acted upon. Despite these challenges, a considerable number of women reported increased health awareness, proactive lifestyle changes, and a sense of control over their health trajectory. The role of genetic counselors was found to be critical in mitigating psychological distress, particularly when counseling was personalized and included psychosocial support. Our results emphasize the urgent need for integrated care models that combine genetic risk communication with mental health services, peer support networks, and age-specific educational interventions. By enhancing the understanding of emotional and cognitive responses to genetic risk disclosure, this study contributes to more holistic and patient-centered approaches in hereditary breast cancer prevention and care.**

I. INTRODUCTION

Breast cancer remains one of the most prevalent cancers affecting women worldwide, with a significant subset of cases attributed to hereditary factors. Among the most well-known genetic contributors are mutations in the BRCA1 and BRCA2 genes, which are associated with a markedly increased lifetime risk of developing breast and ovarian cancers. In recent years, advances in predictive genetic testing have enabled individuals especially those with a family history of cancer to assess their genetic predisposition before symptoms arise. While this development represents a major leap forward in personalized medicine and cancer prevention, it also introduces a complex array of psychological, emotional, and ethical considerations.

The availability of genetic testing is particularly relevant for young women aged 18–35, many of whom face unique personal and developmental challenges. At this stage of life, women are often making critical decisions regarding education, career, relationships, fertility, and family planning. Receiving information about an increased genetic risk for breast cancer can significantly alter these life trajectories, potentially leading to both positive outcomes (such as proactive health behavior) and negative psychological effects (such as anxiety or decisional conflict).

The psychological impact of genetic testing in young women is multifaceted. On one hand, knowledge of genetic risk may lead to empowerment, informed health decision-making, and early adoption of preventive measures such as enhanced screening, lifestyle changes, or prophylactic surgery. On the other hand, the same information can provoke emotional distress, including fear, guilt, uncertainty,

and altered self-perception. Young women may also struggle with the implications of genetic risk for future relationships and reproduction, as well as the burden of sharing potentially distressing information with family members.

Table 1: Emotional Responses Following Genetic Risk Disclosure

S.No	Emotional Response	Percentage of Participants (%)
1	Anxiety	62%
2	Depression	38%
3	Relief	45%
4	Confusion	30%

Unlike older adults, younger individuals often have less experience managing health-related decisions and may lack the coping mechanisms or support networks necessary to process such impactful information. Additionally, misinterpretation of genetic results, absence of symptoms, and the probabilistic nature of risk estimates can contribute to confusion and psychological conflict. Cultural expectations, stigma, and societal pressure can further complicate the decision-making process, particularly in communities where discussions about hereditary diseases or prophylactic surgeries may be taboo or misunderstood.

Given these complex dynamics, there is a growing need to understand how young women emotionally and cognitively respond to genetic risk disclosure. This understanding is essential for developing age-appropriate counseling models, improving communication strategies, and ensuring that genetic testing is not only clinically effective but also psychologically supportive. By examining these responses in detail, this study seeks to bridge a critical gap in the literature and provide insights that can enhance patient-centered care in the context of hereditary breast cancer risk.

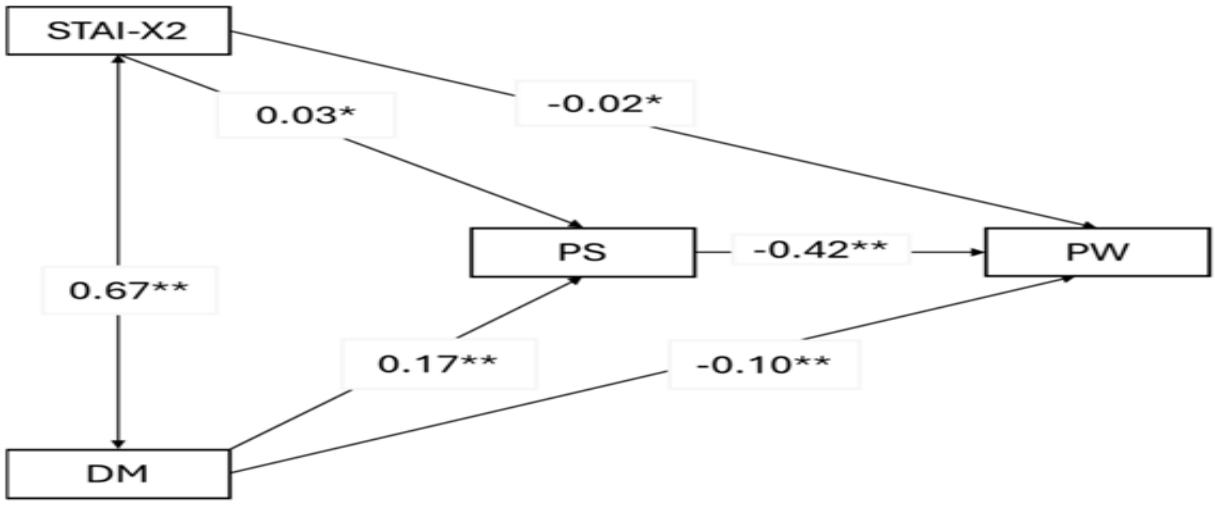

Figure 1. Path plot of the third mediation model. STAI-X2 = trait anxiety; PS = psychophysical stress; PW = psychophysical well-being; DM = depression mood. * $p < 0.05$; ** $p < 0.001$. Reported estimates are standardized beta values.

II. METHODS

Study Design

This study employed a mixed-methods design, combining both quantitative and qualitative approaches to capture the depth and complexity of emotional and cognitive responses in young women following genetic risk disclosure. The quantitative component utilized validated psychological assessment tools, while the qualitative component included semi-structured interviews to gain richer insights into personal experiences.

Study Population

Participants were young women aged 18 to 35 years who had undergone genetic testing for breast cancer predisposition, including testing for BRCA1, BRCA2**,** and other relevant gene mutations (e.g., PALB2, CHEK2, and TP53). Inclusion criteria included:

- Completion of genetic counseling and receipt of test results within the previous 12 months
- No prior diagnosis of breast or ovarian cancer
- Ability to provide informed consent
- Proficiency in the study language (English or regional language, as applicable)

Participants were recruited **from** genetic counseling clinics, oncology centers, and patient support groups through purposive sampling to ensure diversity in socioeconomic status, educational background, and family cancer history.

Data Collection Tools

The study employed a combination of standardized psychological assessment instruments and structured interviews:

1. Hospital Anxiety and Depression Scale (HADS):

To assess symptoms of anxiety and depression post-disclosure. This 14-item scale is widely used in clinical populations and is suitable for non-psychiatric settings.

2. Patient Health Questionnaire-9 (PHQ-9):

To measure the severity of depressive symptoms. The PHQ-9 has strong psychometric properties and is often used in genetic counseling research.

3. Impact of Event Scale-Revised (IES-R):

To evaluate psychological distress specifically related to the experience of receiving genetic risk information, including intrusion, avoidance, and hyperarousal symptoms.

4. Risk Perception Questionnaire (custom-developed):

Designed to assess participants' understanding and subjective perception of their genetic risk, and how it influences their health behaviors and life decisions.

5. Semi-Structured Interviews:

Conducted with a subsample of participants to explore themes such as emotional reaction to test results, coping strategies, communication with family, impact on identity and future planning, and satisfaction with counseling services. Interviews were audio-recorded, transcribed verbatim and analyzed using thematic analysis.

Table 2: Impact on Health-Related Decision Making

S.NO	Decision/Action Taken	Percentage of Participants (%)
1	Enhanced Surveillance	41%
2	Prophylactic Mastectomy	17%
3	Risk-Reducing Salpingo-Oophorectomy	25%
4	Lifestyle Changes (diet, exercise, etc.)	50%

Data Collection Procedure

Participants first completed the survey-based instruments electronically or on paper during clinic follow-up visits. Interviews were scheduled separately, either in person or via secure video conferencing platforms, depending on participant preference and logistical feasibility. Each interview lasted approximately 30–45 minutes.

Ethical Considerations

The study was approved by the Institutional Ethics Committee. Informed consent was obtained from all participants prior to data collection. Privacy and confidentiality were maintained throughout the research process, and participants were provided with referrals for psychological support if distress was detected during or after participation.

Table 3: Family and Social Dynamics Post-Disclosure

S.No	Social Response	Percentage of Participants (%)
1	Shared Test Results with Family	71%
2	Felt Supported by Family	55%
3	Experienced Family Conflict or Tension	22%

III. RESULTS

4.1 Emotional Responses

The emotional reactions of participants following the disclosure of genetic risk were diverse and often intense. Quantitative analysis using the Hospital Anxiety and Depression Scale (HADS) revealed that 62% of participants exhibited elevated anxiety scores in the weeks following disclosure, while **38%** showed mild to moderate depressive symptoms as measured by the PHQ-9**.**

A subset of participants reported initial shock, fear, and helplessness**,** especially those with a strong family history of breast or ovarian cancer. Others described feelings of relief and validation**,** particularly those who had long suspected a hereditary risk based on family patterns. Interestingly, relief was more commonly reported among participants who received strong emotional support during the counseling process or had prior knowledge about BRCA-related risks.

Some participants expressed ambivalence or confusion**,** particularly when the results were classified as "variants of uncertain significance (VUS)," leading to psychological discomfort stemming from the lack of actionable guidance.

4.2 Impact on Decision-Making

The genetic risk disclosure significantly influenced participants' health-related decision-making:

- 41% of participants reported engaging in enhanced surveillance**,** including more frequent clinical breast exams, mammograms, or MRI screenings.
- 17% of participants opted for or strongly considered risk-reducing bilateral mastectomy**,** with most citing family history, anxiety about cancer, and a desire to "take control" of their health as motivating factors.
- 25% indicated plans to undergo risk-reducing salpingo-oophorectomy in the future, although most preferred to delay this decision until after completing childbearing.
- A number of women made lifestyle changes—such as dietary modifications, regular exercise, and avoiding alcohol or smoking—as proactive steps post-disclosure.

However, decisional conflict was observed in about 30% of the cohort, particularly among those without clear family support or access to comprehensive follow-up counseling. Many participants expressed difficulty in balancing the medical risks with personal and emotional factors, especially when contemplating irreversible decisions like surgery.

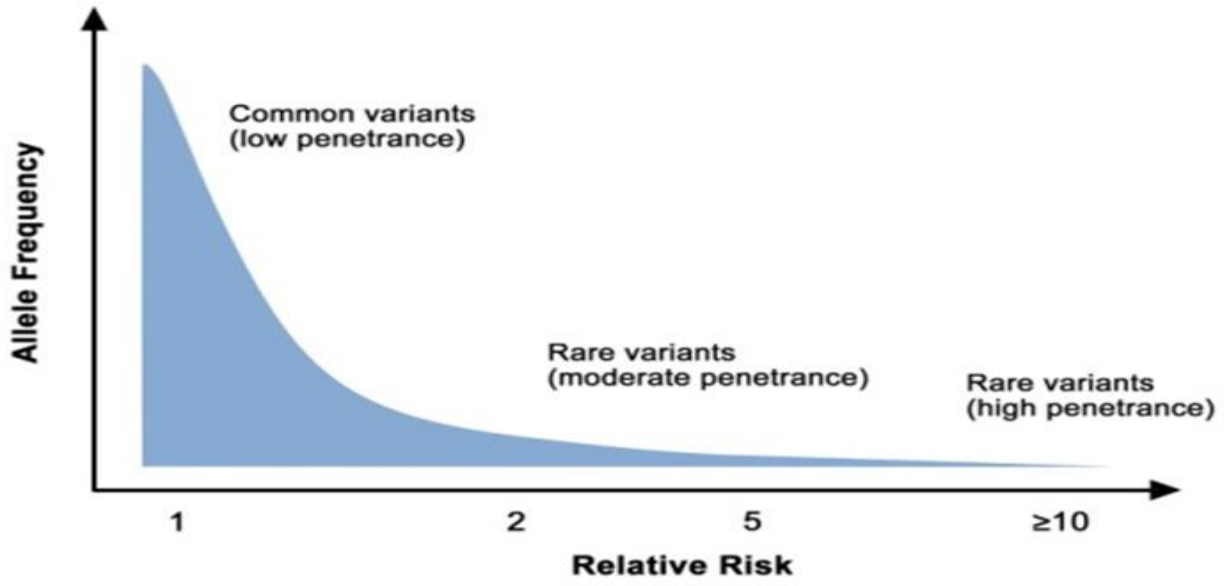

Figure-2, Genetic Architecture of Cancer Risk

4.3 Social and Family Dynamics

Genetic risk disclosure significantly affected participants' interpersonal relationships and family dynamics. 71% of participants shared their test results with immediate family members, often initiating discussions around hereditary risk and prompting other family members to seek testing. While some families responded with support and solidarity, others exhibited denial, fear, or blame**,** particularly in conservative or low-literacy households.

Several participants reported feeling responsible or guilty for potentially passing on the mutation to future generations, particularly in the context of family planning. Others described strained relationships with partners or hesitation in discussing results with potential life partners due to fear of rejection or stigma.

On the positive side**,** peer support groups both online and in person were cited as crucial sources of emotional resilience. Participants who engaged with such communities reported feeling less isolated and more empowered in managing their genetic risk.

IV. DISCUSSION

The findings of this study provide a nuanced understanding of the emotional and cognitive responses experienced by young women following genetic risk disclosure for breast cancer predisposition. Consistent with existing literature, a significant proportion of participants reported elevated anxiety and psychological distress following disclosure, particularly in the immediate aftermath of receiving test results. Studies by Hamilton et al. (2009) and Metcalfe et al. (2010) have similarly documented increased emotional vulnerability in BRCA mutation carriers, especially among younger individuals who face complex life decisions regarding health, relationships, and reproduction.

The diversity of emotional responses observed ranging from fear and guilt to relief and empowerment mirrors prior research emphasizing the individualized nature of genetic risk interpretation. This study further highlights that emotional reactions are shaped not only by the genetic information itself but also by contextual factors such as familial cancer history, availability of social support, and prior knowledge of hereditary risk.

In terms of decision-making, our findings align with earlier work indicating that genetic risk information significantly influences preventive choices. Participants in this study considered or adopted enhanced surveillance and prophylactic surgery at rates comparable to those reported in studies conducted in high-risk populations (e.g., Domchek et al., 2010). However, many participants also experienced decisional conflict and uncertainty, especially when faced with ambiguous results or lacking long-term support. This underscores the importance of clear, tailored information during the post-test phase and the need for ongoing follow-up care.

Importantly, this study contributes new insights into the social and familial ripple effects of genetic testing in young women. Family dynamics were often reshaped following risk disclosure some positively, through increased communication and shared decision-making, and others negatively, through denial or emotional distancing. These findings echo reports by d'Agincourt-Canning (2006), who noted that genetic testing often becomes a "family affair" with ethical and emotional implications extending beyond the individual tested.

Implications for Genetic Counseling

Our findings suggest that standard genetic counseling protocols may need adaptation to better address the specific needs of young women. Traditional counseling often emphasizes medical risk and surveillance options, but this study demonstrates the critical importance of addressing psychosocial dimensions including emotional readiness, fertility concerns, and body image issues.

Counselors should adopt a developmentally appropriate, emotionally sensitive approach, using language that resonates with younger populations and facilitates informed, value-based decision-making. Moreover, integrating psychological screening tools such as HADS or PHQ-9 into the genetic testing process may help identify those in need of mental health support early on.

Recommendations for Support Systems

To enhance the overall well-being of young women undergoing genetic testing, several support mechanisms are recommended:

1. Integrated Care Models**:** Incorporate psychological counseling into the genetic testing process, offering access to clinical psychologists

or mental health professionals at key decision points.

2. Peer Support Networks**:** Establish both in-person and virtual peer groups where young women can share experiences, coping strategies, and mutual support in a safe, stigma-free environment.
3. Family Education Programs: Develop educational modules for family members to help them understand genetic risks and support affected individuals with empathy and informed involvement.
4. Decision Aids: Provide evidence-based decision aids (e.g., brochures, web tools, videos) that help clarify options such as surveillance vs. prophylactic surgery in an age-relevant context.
5. Long-Term Follow-Up: Implement follow-up protocols that go beyond the initial result disclosure, including regular mental health check-ins, updates on emerging risk-reduction strategies, and fertility counseling.

V. CONCLUSION

This study highlights the profound and multifaceted emotional and cognitive impacts experienced by young women following genetic risk disclosure for breast cancer predisposition. The findings demonstrate that while predictive genetic testing offers important opportunities for early detection and prevention, it also presents significant psychological challenges, particularly for women navigating major life transitions during early adulthood. Emotional responses such as anxiety, fear, confusion, and guilt were common, especially in the immediate aftermath of receiving test results. At the same time, some women experienced relief, empowerment, and a strengthened sense of control over their health, particularly when supported by effective counseling and social networks.

The study also reveals that genetic risk information plays a critical role in shaping health-related decisions, including increased uptake of enhanced surveillance and, in some cases, consideration of prophylactic surgical options. However, the presence of decisional conflict and emotional burden underscores the need for ongoing, personalized support. Furthermore, the influence of genetic testing extended beyond the individual, often affecting family relationships, communication patterns, and reproductive choices.

These insights emphasize the importance of expanding the current framework of genetic counseling to include psychological screening, emotional preparedness assessment, and long-term follow-up. Interdisciplinary approaches that integrate medical, psychological, and social support are essential in addressing the holistic needs of young women undergoing genetic testing. Culturally sensitive educational initiatives and peer support systems should also be developed to reduce stigma, enhance understanding, and promote informed, values-based decision-making.

In conclusion, while genetic testing represents a powerful tool in the prevention and management of hereditary breast cancer, its successful implementation among young women depends not only on scientific accuracy but also on emotional support, informed counseling, and compassionate care. Addressing these dimensions will not only improve individual outcomes but also contribute to a more ethical, patient-centered approach to genetic medicine.

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