GAUGING THE PSYCHOLOGICAL IMPACT OF COUNSELING PATIENTS WITH
BRCA1/2, CDH1, TP53 AND LYNCH SYNDROME PATHOGENIC VARIANTS ON
GENETIC COUNSELORS IN THE CANCER SETTING

By

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Written under the direction of

Jessica Joines

And approved by

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ABSTRACT OF THE THESIS

Gauging the Psychological Impact of Counseling Patients with \textit{BRCA1/2, CDH1, TP53} and Lynch Syndrome Pathogenic Variants on Genetic Counselors in the Cancer Setting

By MATTHEW EMERY

Thesis Director:
Jessica Joines

Genetic counselors (GCs) in the cancer setting are involved to the repeat exposure of discussing life altering management recommendations for individuals who test positive for pathogenic mutations in cancer susceptibility genes. This study attempted to characterize the short- and long-term psychological impact GCs may experience as a result of repeat exposure to discussing management recommendations associated with pathogenic mutations in \textit{BRCA1/2, CDH1, TP53} and Lynch syndrome by surveying GCs in the cancer setting. Our study showed that GCs experience an increase in anxious feelings and sadness, and have concerns about variant penetrance prior to counseling patients with positive test results. We discovered that there are significantly increased levels of anxious feelings, sadness and penetrance concerns when counseling patients on pathogenic mutations in \textit{CDH1} and \textit{TP53} versus \textit{BRCA1/2} and Lynch syndrome. This effect appears to be tempered by time in practice as well as access to coping strategies including access to other GCs.
Dedication

I’d like to dedicate this thesis to my parents Kathleen and Peter Emery as well as my uncle James Smith. They have always encouraged me to follow my dreams and to appreciate the work it takes to achieve them.
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Introduction

Patients who seek genetic counseling (GC) in the cancer setting are counseled on their risk of carrying a mutation in a gene that could increase their lifetime risk of developing cancer. Additionally, they are educated on the management options that come with a positive test result. Examples of these genes include \textit{BRCA1/2}, \textit{CDH1}, \textit{TP53}, and the mismatch repair genes associated with Lynch Syndrome. While guidelines exist regarding screening and risk-reducing strategies for individuals with pathogenic variants in these genes, the degree and severity of invasiveness greatly vary between them.

Hereditary cancers are a rarity, 70% of cancers are thought to be sporadic, 20% familial and 10% hereditary where cancer risks can be linked to a specific gene. Mutations in \textit{BRCA1/2}, \textit{CDH1}, \textit{TP53} and the mismatch repair genes associated with LS are diagnostic of hereditary cancer syndromes. The prevalence of these mutations in the general population are estimated to be as follows; \textit{BRCA1/2} (1/400), \textit{CDH1} (<1% of Gastric Cancers), \textit{TP53} (1/5,000-20,000) and Lynch syndrome (1/279)(Plus, 2021).

Pathogenic mutations in \textit{BRCA1/2} confer a greatly increased lifetime risk for the development of breast cancer and ovarian cancer as well as an increase in risk for the development of pancreatic, prostate cancer and melanoma (Mavaddat et al., 2013). Management recommendations for those who carry a pathogenic variant in \textit{BRCA1/2} includes advanced breast screening, pancreatic screening and risk-reducing surgeries including frequent mammography/MRI of the breast, prophylactic mastectomy and bilateral salpingo-oophorectomy.

Pathogenic mutations in \textit{CDH1} confers a greatly increased lifetime risk for hereditary diffuse gastric cancer (HDGC) and lobular breast cancer (Benusiglio et al.,
Advanced screening for HDGC includes upper endoscopy with multiple random biopsies. Increased breast cancer surveillance for female *CDH1* carriers includes annual mammography and annual breast MRI with contrast. The recommended risk reduction for carriers of a pathogenic *CDH1* mutation is total gastrectomy between the ages of 18-40 (Network, 2020a).

Pathogenic mutations in *TP53* lead to the development of Li-Fraumeni Syndrome (LFS). LFS confers an increased lifetime risk for multiple primary cancers. The overall lifetime cancer risk for an individual with LFS is 95% for men and 100% for women. Additionally, there is a 50% lifetime risk for a second primary cancer. More targeted estimates include a greatly increased risk for the development of female breast cancer and colorectal cancer. Other common cancers seen with *TP53* mutations include: adrenocortical carcinoma, choroid plexus carcinoma, soft tissue sarcoma, bone sarcoma, brain cancer, ovarian cancer, pancreatic cancer, prostate cancer, endometrial cancer, and melanoma skin cancers (Network, 2021). Screening for LFS includes frequent colonoscopy, mammogram, breast MRI, dermatologic examinations, full body MRI and brain MRI. Also due to the occurrence of rare cancers and second malignancies frequent physical and neurological examinations are recommended.

colonoscopy. Other screenings could include; endometrial biopsy for the risk of endometrial cancer, pancreatic screening at a specialized, high volume center, urinalysis for the risk of urothelial cancer and upper endoscopy for the risk of gastric cancer. Risk reduction could include abdominal hysterectomy and bilateral salpingo-oophorectomy to address the uterine and ovarian cancer risks on an individualized basis.

Most cancer genes have well established lifetime cancer risks, however, as research continue to grow, we learn that there can be exceptions to the rule. Historically, patients were only tested for certain cancer syndromes if their personal and /or family history met the clinical criteria for that condition. This may have selected for higher penetrant mutations. Now due to widespread genetic testing using large gene panels we have discovered mutations in genes where the personal and family history of cancer does not meet the definition of that syndrome. This may mean that the lifetime risk cancer estimates quoted to patients may be based on high-penetrant families and may overestimate risk for other families. For example, research suggests that there are individuals with pathogenic CDH1 mutations who have no family history of gastric cancer but a history of lobular breast cancer (Jakubowska et al., 2010). This phenomenon is not restricted to CDH1 and could be a cause for concern when GCs counsel a patient on the cancers associated with their pathogenic variants.

As discussed, there are multiple screening and risk reduction strategies for cancers related to mutations in BRCA1/2, CDH1, TP53, and the Lynch syndrome genes. While increased surveillance can aid in early detection and prophylactic procedures have been shown to reduce the risk of certain cancers, the procedures do not come without physical and psychological risks. The screening options occur frequently, begin at young ages, can
be invasive, and can lead to an increase in anxiety (Meiser, 2005). The risk-reducing strategies are permanent can alter the person’s body, and/or can negatively impact the patient’s quality of life (Hallowell et al., 2017). For example, women with a pathogenic mutation in *BRCA1/2* who undergo prophylactic mastectomy and/or bilateral salpingooophorectomy can deal with physical symptoms including pain post-surgery and premature menopause. Additionally, it has been documented that some women can feel a profound loss of femininity as a result of the loss of their breasts and a loss of their ability to bear a child (Meadows, Padamsee, & Paskett, 2018). It has also been documented that the strain of surgery mixed with this perceived defeminization can also lead to struggles in romantic relationships (Sherman, Woon, French, & Elder, 2017).

Individuals who carry a pathogenic mutation in *CDH1* who have undergone a prophylactic gastrectomy have a greatly reduced risk for the development of gastric cancer, however, their lives are permanently altered. Post gastrectomy patients are prone to experience postprandial fullness, dumping syndrome, hypoglycemia and vitamin deficiencies (Hallowell et al., 2017; Network, 2020a). Individuals who carry a pathogenic mutation in *TP53* (LFS) are counseled on their near 100% risk to develop a cancer over the course of their lifetime. This knowledge coupled with the frequent and invasive screening recommendations can provoke both anxiety and sadness (Werner-Lin et al., 2020).

Finally, individuals who carry a pathogenic mutation in any of the Lynch Syndrome (LS) genes are recommended to undergo frequent colonoscopies starting at a young age. Colonoscopies are an effective diagnostic test, however, the preparation for a colonoscopy is laborious and at times uncomfortable. While an individual with average
colon cancer risk will undergo this process once every 10 years starting at the age of 45, individuals with LS start screening in their twenties and repeat the process every 2-5 years. The frequent screenings and high cancer risks associated with LS can lead to increased levels of anxiety and depression (Galiatsatos, Rothenmund, Aubin, & Foulkes, 2015).

Patients who test positive for a pathogenic mutation in \textit{BRCA1/2}, \textit{CDH1}, \textit{TP53}, and/or Lynch Syndrome genes have a wide array of management options available to them, however, these management options can sometimes lead to long term psychological distress. This impact is well characterized for \textit{BRCA1/2}, \textit{CDH1}. \textit{TP53} and Lynch Syndrome patients in current literature (Hallowell et al., 2017) (Eliezer, Hadley, & Koehly, 2014; Schwartz et al., 2004; Werner-Lin et al., 2020). While the patient’s short and long term distress as a result of testing positive has been explored i, the effect on the health professionals who deliver this information is not.

An unavoidable aspect of the genetic counseling profession is the delivery of positive genetic testing results. When a GC provides a positive test result there are multiple ways this information can be received and multiple ways that a counselor can respond to the patient to address their needs. Invariably a GC will act with compassion and empathy when reviewing a positive test result with a patient. Current studies on GCs and burnout focus on characterizing and identifying burnout as a result of compassion fatigue, job dissatisfaction, and poor work/life balance (Johnstone et al., 2016). These studies focus on the typical measures of burnout that are common in most professions and currently there has been very little research into the effects of repeated positive
disclosures in other GC settings, including; hereditary cancer, prenatal, pediatrics, neurology and/ or cardiac genetics.

This study aims to characterize and quantify the levels of anxious feelings, sadness, indignation and penetrance concerns a GC may experience prior to disclosing a pathogenic variant in BRCA1/2, CDH1, TP53 and Lynch syndrome. Additionally, we aim to see if time in practice curtails the targeted emotions, if there is a relationship between certain genes and higher levels of the target emotions and identify if GCs have access to the resources, they need to cope with the target emotions should they arise.

We believe that we will see an increase in the target emotions in counselors prior to counseling patients on these results. We believe that this increase will be greater when associated with CDH1 and TP53 mutations as compared to BRCA1/2 and Lynch syndrome mutations. We anticipate a greater degree of targeted emotions as it relates to CDH1 and TP53 due to their associated cancer risks, medical management recommendations, rarity in clinic and uncertainty surrounding the penetrance of pathogenic variants in these genes. We hope that this data will help to identify if GCs are struggling with the emotions of interest and if so, characterize this effect and lead to a better understanding of what can be done to lessen the effect.
Materials and Methods

Survey:

A 35-question quantitative and qualitative survey was distributed via email to all GCs within the National Society of Genetic Counselors (NSGC) listserv. The survey aimed to recruit responses from GCs in the cancer setting. The survey was created utilizing Qualtrics and included multiple-choice and open-ended questions. These questions attempted to assess the respondent’s demographics (both personal and practice), their baseline emotional state, their emotional response prior to counseling patients on pathogenic mutations in the target genes and what can be done to mitigate any negative effects. All surveys were filled out anonymously and no identifying information was collected. An email was sent out to all GCs within the listserv with an anonymous link to the Qualtrics survey. The survey was available for one month after the initial email. A secondary reminder email was sent out two weeks later. All survey respondents would self-identify as having experience in the cancer setting. GCs who did not complete the survey or did not indicate experience in the cancer setting were removed from the analysis.

Data Analysis:

Survey responses were tabulated and basic statistics (mean, median, mode, percentages) were calculated utilizing Microsoft Excel. Mann Whitney U analysis was utilized to identify statistically different patterns of emotional response in relation to the genes of interest. Mann-Whitney U analysis is a non-parametric analysis compatible with Likert scales.
Results

Respondent Demographics:

Our study population was made up of 63 GC respondents. Standard demographic information was collected including age, gender identity and ethnicity. The majority of the respondents were white females between the ages of 23-35 years.

Table 1: Standard demographics of respondents (N=63)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>62</td>
<td>98.40%</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>1.60%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>60</td>
<td>95.20%</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>1.60%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>1.60%</td>
</tr>
<tr>
<td>African American</td>
<td>1</td>
<td>1.60%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>24-35</td>
<td>54</td>
<td>85.70%</td>
</tr>
<tr>
<td>36-45</td>
<td>7</td>
<td>11.10%</td>
</tr>
<tr>
<td>46-50</td>
<td>2</td>
<td>3.20%</td>
</tr>
</tbody>
</table>

Practice Demographics:

Practice demographics of the respondents were collected including: years in practice, years in the cancer setting and percentage of time in the cancer setting.

Table 2: Practice Demographics of Respondents (N=63)

<table>
<thead>
<tr>
<th>Years in Practice</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4</td>
<td>39</td>
<td>62.00%</td>
</tr>
<tr>
<td>5-9</td>
<td>14</td>
<td>22.20%</td>
</tr>
<tr>
<td>10-19</td>
<td>8</td>
<td>12.70%</td>
</tr>
<tr>
<td>20-29</td>
<td>1</td>
<td>1.55%</td>
</tr>
<tr>
<td>Abstained</td>
<td>1</td>
<td>1.55%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years in Cancer Setting</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>46</td>
<td>73.02%</td>
</tr>
<tr>
<td>6-10</td>
<td>14</td>
<td>22.22%</td>
</tr>
</tbody>
</table>
Clinic demographics were collected from each respondent, including the number of patients, as well as the number of positive *BRCA1/2, CDH1, TP53* and Lynch Syndrome test results disclosed and counseled in the clinic each month. Overall a majority of the respondents reported seeing approximately 26-50 patients in their clinic each month and disclosing and counseling < 10 patients/month on positive *BRCA1/2, CDH1, TP53* and/or Lynch syndrome.

Table 3: Clinic Demographics (N=63)

<table>
<thead>
<tr>
<th>Percent of time in Cancer Setting</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>76-100</td>
<td>51</td>
<td>80.95%</td>
</tr>
<tr>
<td>51-75</td>
<td>5</td>
<td>7.94%</td>
</tr>
<tr>
<td>26-50</td>
<td>6</td>
<td>9.56%</td>
</tr>
<tr>
<td>&lt;20</td>
<td>1</td>
<td>1.55%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Patients Seen for Hereditary Cancer Consultation</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 10</td>
<td>2</td>
<td>3.21%</td>
</tr>
<tr>
<td>10-25</td>
<td>4</td>
<td>6.35%</td>
</tr>
<tr>
<td>26-50</td>
<td>26</td>
<td>41.27%</td>
</tr>
<tr>
<td>51-75</td>
<td>10</td>
<td>15.87%</td>
</tr>
<tr>
<td>76-100+</td>
<td>20</td>
<td>31.75%</td>
</tr>
<tr>
<td>Abstain</td>
<td>1</td>
<td>1.55%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of Positive Results in Genes of Interest</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 10</td>
<td>57</td>
<td>90.48%</td>
</tr>
<tr>
<td>10-25</td>
<td>6</td>
<td>9.52%</td>
</tr>
</tbody>
</table>

Baseline Anxious Feelings and Sadness Measurements:

The respondents rated their current levels of anxious feelings and sadness utilizing a Likert scale. The Likert scale ranged from 0-5, with 0 meaning the respondent was not currently experiencing anxious feelings and/or sadness and 5 meaning the respondent was experiencing a high level of anxious feelings and/or sadness. Of our
respondents 44% reported experiencing a moderate level of anxiety when taking the survey and 22% reported experiencing a moderate level of sadness while taking the survey. Of the respondents, 11% reported experiencing concomitant moderate levels of anxious feeling and sadness at the time of survey.

Table 4: Baseline Anxious Feelings and Sadness (N=63)

<table>
<thead>
<tr>
<th>Experiencing Anxious Feeling at Time of Survey</th>
<th>Number</th>
<th>Percentage</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>28</td>
<td>44.44%</td>
<td>2.86</td>
</tr>
<tr>
<td>No</td>
<td>35</td>
<td>55.56%</td>
<td>0.86</td>
</tr>
<tr>
<td>Overall</td>
<td>63</td>
<td>100%</td>
<td>1.75</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Experiencing Sadness at Time of Survey</th>
<th>Number</th>
<th>Percentage</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>22.22%</td>
<td>2.43</td>
</tr>
<tr>
<td>No</td>
<td>49</td>
<td>77.78%</td>
<td>0.2</td>
</tr>
<tr>
<td>Overall</td>
<td>63</td>
<td>100%</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Emotional Impact Prior to Counseling Patients on Pathogenic Variants:

Utilizing a 0-5 Likert scale, with 0 being no effect and 5 being a large effect, respondents were asked to rank their level of anxious feelings, sadness, and penetrance concerns in relation to counseling patients with pathogenic variants in BRCA1/2, CDH1, TP53 and Lynch syndrome (Figure 1). Additionally, respondents were asked if they have ever experienced indignation for their patients who have tested positive. The raw data shows us that GCs are experiencing levels of anxious feelings and sadness above baseline.
Figure 1: Pre-Counseling Emotions Experienced

Figure 1: Average levels of Anxious feelings, Sadness and Penetrance concerns experienced by GCs prior to counseling patients with pathogenic variants in \textit{BRCA1/2}, \textit{CDH1}, \textit{TP53} and Lynch syndrome as compared to baseline.
Figure 2: Indignation Experienced by Gene Family

<table>
<thead>
<tr>
<th>Gene Family</th>
<th>CDH1 Indignation</th>
<th>BRCA1/2 Indignation</th>
<th>TP53 Indignation</th>
<th>Lynch Syndrome Indignation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDH1 YES</td>
<td>41%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDH1 NO</td>
<td>59%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 YES</td>
<td></td>
<td>43%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 NO</td>
<td>57%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TP53 YES</td>
<td>44%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TP53 NO</td>
<td>56%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LS YES</td>
<td></td>
<td></td>
<td>31%</td>
<td></td>
</tr>
<tr>
<td>LS NO</td>
<td>69%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 2: Indignation experienced by GCs associated with the genes of interest. a. CDH1 indignation, b. BRCA1/2 indignation, c. TP53 indignation d. LS indignation.

Raw Data Controlling for Time in the Cancer Setting and Positive Disclosures Per Month:

Our raw data was controlled for taking into account the time respondents have spent in the cancer setting and the number of positive results disclosed each month in the
genes of interest. With time in practice, we separated our respondents into those who have spent between 1-5 years in the cancer setting (n=46) and those who have spent more than 5 years in the cancer setting (n=17). Of those 46 who have spent between 1-5 years in the cancer setting, 42 of them are GCs with 1-4 years of experience. For those who spent between 1-5 years in the cancer setting their baseline levels of anxious feelings was 1.9 and their baseline sadness was 0.8. For those who spent more than 5 years in the cancer setting their baseline anxiety was 1.3 and their baseline sadness was 0.4. When reviewing we found that while the levels of baseline and pre counseling emotions were lower in the respondents who spent more than 5 years in the cancer setting, their pre counseling emotions were still above their baseline. (Figures 3 and 4)

Figure 3: Pre-Counseling Emotions Experienced by GCs with 1-5 Years’ Experience

![Figure 3](image)

**Figure 3:** Average levels of the emotions of interest experienced by genetic counselors who have spent between 1-5 years in the cancer setting.
Figure 4: Pre-Counseling Emotions Experienced by GCs with 5+ Years’ Experience

With the number of positive disclosures in the genes of interest per month, we controlled the data by separating our respondents into those who disclose less than 10 positive results per month (n=57) and those who disclose between 10-25 positive results per month (n=6). For those who disclose less than 10 positive results per month their baseline levels of anxious feelings was 1.9 and their baseline sadness was 0.7. For those who disclose between 10-25 positive results per month their baseline anxiety was 0.5 and their baseline sadness was 0.5. We found that while the levels of baseline and pre counseling emotions were lower in the respondents who disclose between 10-25 positive results per month, their pre counseling emotions were still above their baseline. (Figures 5 and 6)
Figure 5: Pre-Counseling Emotions Experienced by GCs who disclose <10 Positive Results Per Month in the Genes of Interest

![Bar chart showing average emotion levels for different genes of interest.]

Figure 5: Average levels of the emotions of interest experienced by GCs who disclose less than 10 positive results in the genes of interest per month.
Figure 6: Pre-Counseling Emotions Experienced by GCs who disclose Between 10-25 Positive Results Per Month in the Genes of Interest

Statistical analysis of difference between $BRCA1/2$, $CDH1$, $TP53$ and Lynch syndrome psychological impact:

A cursory review of the survey respondents pointed to a significant difference in the levels of anxious feelings, sadness and/or penetrance concerns experienced by GCs prior to counseling patients with pathogenic mutations in $CDH1$ and $TP53$ vs. $BRCA1/2$ and Lynch syndrome. To investigate this correlation a Mann-Whitney U (MWU) test was used utilizing a p value of < 0.5 to determine significance. This analysis confirms the hypothesis that GCs would experience a significant increase in anxious feelings, sadness and penetrance concerns when counseling patients with pathogenic variants in $CDH1$ and $TP53$ versus $BRCA1/2$ and LS. One outlier to our hypothesis is the significantly increased amount of sadness respondents experience when counseling patients on $TP53$ vs. $CDH1$. 
Table 5: Mann-Whitney U Results

<table>
<thead>
<tr>
<th>Genes Compared</th>
<th>U</th>
<th>Z score</th>
<th>P Value (p&lt;.05)</th>
<th>Significant Difference?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anxious Feelings</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 v. CDH1</td>
<td>974</td>
<td>-4.09</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. TP53</td>
<td>833.5</td>
<td>-4.85</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. Lynch Syndrome</td>
<td>1916</td>
<td>0.18</td>
<td>0.86</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. TP53</td>
<td>1357</td>
<td>-0.93</td>
<td>0.35</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. Lynch syndrome</td>
<td>888</td>
<td>-4.46</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>TP53 v. Lynch syndrome</td>
<td>747</td>
<td>-5.23</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Sadness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 v. CDH1</td>
<td>1248.5</td>
<td>-2.61</td>
<td>0.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. TP53</td>
<td>822</td>
<td>-4.91</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. Lynch Syndrome</td>
<td>1873.5</td>
<td>0.39</td>
<td>0.70</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. TP53</td>
<td>1082.5</td>
<td>-2.57</td>
<td>0.01</td>
<td>Yes</td>
</tr>
<tr>
<td>CDH1 v. Lynch syndrome</td>
<td>1154</td>
<td>-3.01</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>TP53 v. Lynch syndrome</td>
<td>733.5</td>
<td>-5.3</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Penetrance Concerns</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 v. CDH1</td>
<td>1049.5</td>
<td>-3.86</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. TP53</td>
<td>1015</td>
<td>-3.74</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. Lynch Syndrome</td>
<td>1724</td>
<td>1.12</td>
<td>0.26</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. TP53</td>
<td>1425</td>
<td>-0.36</td>
<td>0.72</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. Lynch syndrome</td>
<td>876</td>
<td>-4.52</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>TP53 v. Lynch syndrome</td>
<td>886</td>
<td>-4.36</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Correction for Outliers:

To correct for outliers, any respondent who reported a moderate to high level of baseline anxious feelings and sadness was removed from the analysis. Of the 63 respondents, six reported experiencing elevated levels (3-5 on the likert scale) in baseline anxiety and depression. When removed from analysis the same patterns of significance
were observed, however, this did result in a slight increase in p-values. Despite the increase in p-value, the differences remained significant (p-value < 0.5).

Table 6: Outlier Corrected Mann Whitney U Analysis

<table>
<thead>
<tr>
<th>Genes Compared</th>
<th>U</th>
<th>Z score</th>
<th>P Value (p&lt;.05)</th>
<th>Significant Difference?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anxious Feelings</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 v. CDH1</td>
<td>745</td>
<td>-4.25</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. TP53</td>
<td>633</td>
<td>-4.95</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. Lynch Syndrome</td>
<td>1594</td>
<td>-0.17</td>
<td>0.87</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. TP53</td>
<td>1120</td>
<td>-0.89</td>
<td>0.37</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. Lynch syndrome</td>
<td>743</td>
<td>-4.26</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>TP53 v. Lynch syndrome</td>
<td>629</td>
<td>-4.97</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Sadness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 v. CDH1</td>
<td>994</td>
<td>-2.68</td>
<td>0.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. TP53</td>
<td>647</td>
<td>-4.86</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. Lynch Syndrome</td>
<td>1589</td>
<td>0.201</td>
<td>0.84</td>
<td>No</td>
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<tr>
<td>CDH1 v. TP53</td>
<td>897</td>
<td>-2.43</td>
<td>0.02</td>
<td>Yes</td>
</tr>
<tr>
<td>CDH1 v. Lynch syndrome</td>
<td>962</td>
<td>-2.89</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>TP53 v. Lynch syndrome</td>
<td>615</td>
<td>-5.05</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Penetrance Concerns</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA1/2 v. CDH1</td>
<td>902</td>
<td>-3.23</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. TP53</td>
<td>832</td>
<td>-3.57</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>BRCA1/2 v. Lynch Syndrome</td>
<td>1408</td>
<td>1.23</td>
<td>0.22</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. TP53</td>
<td>1148</td>
<td>-0.54</td>
<td>0.59</td>
<td>No</td>
</tr>
<tr>
<td>CDH1 v. Lynch syndrome</td>
<td>742</td>
<td>-4.26</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
<tr>
<td>TP53 v. Lynch syndrome</td>
<td>713</td>
<td>-4.33</td>
<td>&lt;.01</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Alteration of Practice Protocols and Changes in Genetic Counseling Specialty

When asked if experiencing the target emotions lead to a change in the way the GC practiced, five respondents described changes made in their practice due to
experiencing the targeted emotions. The common themes seen in these responses were a push for in-person meetings to counsel on positive results and reserving specific appointment times for positive results, before lunch or at the end of the day to allow for extra time with the patients if needed and to allow the counselor time to relax before or after the appointment.

When asked if experiencing the target emotions lead to the GC wishing to change specialties, five of the 63 respondents reported they have switched specialties due to experiencing the targeted emotions. Of these five, two described leaving prenatal positions to work in cancer due to experiencing the targeted emotions in the prenatal setting. The remaining three described wanting to leave the clinical setting to pursue a career in a laboratory or industry setting.

Mitigation of Psychological Impact Through Time in Practice

Respondents were asked if they felt that time in the field mitigated their pre-counseling anxiety, sadness and penetrance concerns and how long into their careers did they notice a change in their pre-counseling emotional response. Out of the 63 respondents, 84.1% reported that they felt that time in practice mitigated the emotional effects pre-positive result counseling while 15.9% responded that they felt it didn’t. Out of the 63 respondents, 30 offered clarifying remarks quantifying how long into their practice they felt this emotional response began to lessen.

Table 7: Years in Practice Leading to Emotional Response Mitigation

<table>
<thead>
<tr>
<th>Years in Practice</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>15</td>
<td>50%</td>
</tr>
<tr>
<td>2-3</td>
<td>13</td>
<td>43%</td>
</tr>
<tr>
<td>4-5</td>
<td>1</td>
<td>3.5%</td>
</tr>
<tr>
<td>5+</td>
<td>1</td>
<td>3.5%</td>
</tr>
</tbody>
</table>
Half of this sub population reported that this change was noticed within the first year of practice. The remaining 50% of this sub population reported noticing this effect at a minimum of two years into practice.

**Resource Availability:**

In addition to time in practice, resource availability was solicited from the respondents. Out of our respondents 81% of reported that they felt they had access to resources to help them manage any emotional fallout they may experience counseling patients on pathogenic mutations in \textit{BRCA1/2, CDH1, TP53} and LS. In contrast 19% reported that they felt they did not have access to the resources they would need should experience alone not mitigate the emotional impact. Out of the 63 respondents, 92% felt that their fellow GCs and other coworkers were a great source of support when dealing with tough emotions in relation to counseling patients with pathogenic variants in \textit{BRCA1/2, CDH1, TP53} and LS. Meditation, mindfulness, self-care and job sponsored short term counseling services were other resources mentioned by respondents.

**How do GCs Characterize the Impact of Repeat Exposure to \textit{BRCA1/2, CDH1, TP53} and LS Positive Counseling?:**

Table 8: Description of the Impact

<table>
<thead>
<tr>
<th>Psychological Impact</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Lingering Effects</td>
<td>24</td>
<td>54.50%</td>
</tr>
<tr>
<td>Lingering Effects</td>
<td>20</td>
<td>45.50%</td>
</tr>
</tbody>
</table>

Respondents were asked to describe the impact they felt with repeat disclosure of positive results had on their mental health. Of our 63 respondents 44 answered this question while 19 did not. Of those who responded 54.5% reported that they felt there
was no lingering effects and qualified this with statements such as “It’s part of the job” and “It benefits the patient”. Additionally, 45.5% reported that they felt there were lingering effects. They qualified this with statements such as; “The effect is short lived” and “The effect is situational”. In reference to the effect being situation four respondents talk about CDH1 and TP53. Common reasons included; “CDH1 and TP53 have uncertain penetrance”, “CDH1 is tough due to gastrectomy and life impact” and “No CDH1 or TP53 cases yet”.

What do GCs Feel Can be Done to Minimize the Impact?

Respondents were asked their opinion on what they felt could be done to minimize the impact of repeat exposure to counseling patients on positive test results in BRCA1/2, CDH1, TP53 and LS. Out of the 63 respondents 37 provided their input on this question and 23 did not. The overall themes that emerged from the GCs responses included: seeking support from other GCs, more focused training in GC programs, mindfulness, firm work/home boundary, and finally, a change in perspective. Of these 37 respondents, five stated that taking the time to reframe a positive result from an adverse life event to a positive one can help to mitigate the effect. These respondents pointed out that while these results may be unpleasant, ultimately, they are for the benefit of the patient and their extended family.

Outside Circumstances and the COVID effect:

Survey respondents were asked to describe any outside factors not addressed in the survey that could cause an increase in the targeted feelings that were unrelated to counseling on pathogenic mutations. Of our 63 respondents 30 outlined other instances where the targeted emotions were elevated due to circumstances unrelated to counseling
patients on a positive result. Of these 30 respondents 30% reported that receiving an unexpected result caused an elevation of the targeted emotions. Two other commonly reported events included counseling and testing multiple family members for a familial variant and receiving results with discordant classification in Clinvar. When we look at the respondents who talk about familial variants, 25% of them clarified that this increase in difficult emotions was due to multiple positive results associated with familial variant testing. Respondents were asked if they felt the pandemic has increased their levels of anxious feelings and/or sadness in relation to their job and, if so, how? Of our 63 respondents 49.2% of them reported that they feel the pandemic has increased their levels of anxious feeling and/or sadness in relation to their job. Of these respondents 25 offered responses as to why they felt there was an increase in anxiety and/or depression. Three typical responses made up most of these responses, including lack of the ability to build rapport with patients over telemedicine, concerns for COVID transmission between GC and patient (for those in clinic), and finally, diminishment of colleague support due to working from home.
Discussion

The Psychological Impact of Counseling Patients with BRCA1/2, CDH1, TP53 and Lynch Syndrome Pathogenic Variants:

GCs in the cancer setting repeatedly deliver the news that an individual has tested positive for a pathogenic variant in BRCA1/2, CDH1, TP53 and/or LS. What does this repeated exposure do to the psyche of a GC? Statistically, we can identify that the GCs who took part in this study experienced anxious feelings, sadness, and penetrance concerns when counseling patients with pathogenic variants in the genes of interest. These emotions rose above our baseline measurements for anxious feelings (1.75) and sadness (0.7). Factors such as counseling on multiple positive results per month and having more time in practice resulted in lower baseline anxious feelings, lower baseline sadness and lower levels of pre counseling emotions of interest. While these factors lowered these emotional levels overall, we still saw an increase in pre counseling emotions over baseline.

Additionally, consistent with our hypothesis, a significant increase in the amount of anxious feelings, sadness and penetrance concerns GCs experience when counseling on CDH1 and TP53 vs. BRCA1/2 and LS was recognized. While we have created a foundation for quantifying and characterizing this impact, it’s also essential to see how GCs perceive this impact. While we can see an elevation in the targeted emotions before counseling, most survey respondents reported that this impact is short-lived and does not lead to long-term psychological effects. This tells us that the coping strategies available to GCs may be working to mitigate the emotions of interest which could help to minimize the risk of compassion fatigue.
Management of the Effect:

We explored several factors which may influence how or why this effect is mitigated. The first variable investigated was time in practice. In general, we know that the longer an individual is in a job the more natural that job becomes to them. The majority of survey respondents believed that around 0-3 years in practice lead to decreased anxious feelings, sadness, and penetrance concerns that come with counseling patients on positive results in *BRCA1/2, CDH1, TP53* and LS. This range was consistent in the overall data, in those that have spent between 1-5 years in the cancer setting and those who have been in the cancer setting for more than 5 years.

While time in practice is a mitigating factor, resource availability seems to be an essential factor in managing these challenging emotions—the first being access to other GCs. Genetic counseling is still a niche career, and other GCs can be a great resource to talk about tough cases with as they would understand its intricacies like no other. The vast majority (92%) of our survey respondents agreed that having access to other GCs is an excellent resource for mitigating challenging emotions. In addition to time in practice and colleague support, access to work-sponsored counseling programs was also found to be a comfort to the respondents. Finally, a few other coping strategies were commonly suggested by the respondents. The first being a shift in mindset about positive genetic testing results. While the natural response to a positive genetic test result is that it is “bad news,” realizing that this information gives patients a true assessment of their cancer risk and access to management to reduce their risk can help assuage an increase in the targeted emotions. The final coping strategy was self-care; several respondents talked
about setting a firm work/home life boundary and practicing mindfulness exercises such as meditation and yoga.

Coping strategies appear to be a suitable method for the prevention of long-term psychological impacts; however, when we look at the data, we can see in the short-term counselors, despite these strategies, still experience some level of increases anxious feelings, sadness and/or penetrance concerns before counseling patients with a pathogenic mutation in *BRCA1/2, CDH1, TP53* and LS. The question remains, what can be done to help lessen the short-term effects? The answer may be to do nothing as these short-term effects may, in fact, be a sign of professional health. Compassion fatigue is a common sign of burnout in the genetic counseling field; repeated exposure to challenging emotions can lessen their impact on a GC and impact their ability to counsel (Lee, Veach, MacFarlane, & LeRoy, 2015). Feeling these challenging emotions can be healthy when they are situational and can help a GC empathize with their patients, increase rapport and lead to an overall better experience for the counselor and patient.

Outliers and Their Effects on the Psychological Impact:

This survey focused on the psychological impact that counseling patients with pathogenic mutations in *BRCA1/2, CDH1, TP53*, and LS has on a GC. However, other situations impact this effect outside of just receiving and counseling patients on these results. A large subset of survey respondents indicated that receiving unexpected positive results and/or counseling multiple family members on a familial variant can increase the levels of anxious feelings, sadness, and or penetrance concerns that a GC could experience. Unexpected results can be difficult for the patient and the GC, as they both may be surprised by the results putting them in the position to adapt to new information.
With familial variant testing a GC could be exposed to repeat positive results in a short amount of time and they could be more emotionally invested in this family due to meeting with them several times and building a relationship. As with counseling patients on positive results in the genes of interest, we see the emergence of a situational increase in the emotions of interest. As we discussed above, this may be a sign of professional health; however, respondents offered insight into how GCs could be given an advantage when it comes to facing these scenarios. Survey respondents discussed in their comments that more exposure to these scenarios in their GC training programs could help them be more prepared for these situations when they arise in clinic.

The final outlier discussed that could increase the emotions of interest is the current COVID19 pandemic. The pandemic has not only altered the way we live our day-to-day lives, but it has also changed the way medical practices operate. This rapid and unexpected change in daily operations has left many GCs quickly adapting to a new COVID-19 environment. Approximately half of the survey respondents indicated that they felt that the pandemic has significantly altered their normal practice operations. Of note, respondents reported that telemedicine counseling reduced their perceived rapport with their patients. Additionally, they felt that the loss or reduction of in-person counseling opportunities negatively impacted the disclosure of positive results. Some felt that their patients were not getting the emotional support that they would in an in-person setting.
Professional Applications:

As suggested by this study, GCs are experiencing transient increases in anxious feelings, sadness, and penetrance concerns when counseling patients with pathogenic mutations in *BRCA1/2, CDH1, TP53*, and LS. These effects appear to be mitigated by GC program training, access to other GCs, self-care, and perspective on the positive aspects of a positive genetic testing result. An area of improvement to be investigated is whether GC training programs should offer more time preparing counselors to deal with unexpected results and the cascade of positive results that could result from a familial variant. While students rotate through the cancer setting, coming across either of these scenarios is all based on chance. In classroom roleplay, these scenarios can be included or increased to help students and future GCs be a little more prepared for these challenging scenarios.

In addition to these recommendations, utilizing this type of survey may help us understand how and where GCs may be struggling emotionally. The template we employed to assess burnout in the genetic counseling field is based on other professions, including medicine and psychology. At this juncture this profession has many of its own intricacies which may not be fully explored using current templates. Focusing our research into the professional health of GCs may be more informative when we adapt traditional methodologies to incorporate all aspects of this field.

Study Limitations:

This study attempted to characterize the psychological impact on GCs who repeatedly counsel patients on positive genetic testing results in *BRCA1/2, CDH1, TP53*, and LS. Areas that are limited within this study include the respondent population, the
small number of genes assessed, and the COVID-19 pandemic. This study was able to draw its conclusions due to a robust number of survey respondents. Where this study population lacked was in the amount of time the respondents have spent in practice. Of our respondents 67% are new to the profession spending only 1-4 years as a practicing GC. With the limited time these GCs have spent in practice it is hard to draw conclusions about the long-term effects that repeat exposure to disclosing positive results in the genes of interest may have on a GCs mental health. Additionally, as we saw when we reanalyzed our data related to time in practice, GCs who have spent between 1-5 years in the cancer setting, on average, have higher levels of baseline anxious feelings, higher levels of baseline sadness and higher levels of the target emotions prior to counseling. Considering that the majority of our respondents fall into this group, it is conceivable that this could impact our results and skew them towards significance. The lack of diversity in the respondent’s time of practice also raises the concern of ascertainment bias. More GCs with less experience in the field could have elected to participate in this survey because they recently graduated from a training program and wanted to help a student, or because as our data shows newer GCs are prone to higher levels of baseline anxiety. Additionally, with the lack of research into this topic in the cancer or other GC settings, it is hard to differentiate if the study population is typical or under the influence of ascertainment bias.

Another limitation is the small number of genes studied. BRCA1/2, CDH1, TP53, and LS are well-studied and established genes with aggressive management recommendations. While they serve as a good template for this type of research, the cancer setting has become much more nuanced with the advent of panel testing. There are
many more clinically relevant genes in the cancer setting with preliminary evidence that offer patients a more ambiguous picture of their cancer risks and management options. These genes are becoming more common and could act as a source of the target emotions in the cancer setting. This study was focused on genes that are well studied and have aggressive management criteria, which may limit the ability to apply these findings to cancer genetic counseling as a whole. The final limitation of this study is the COVID-19 pandemic. The rapid evolution of the pandemic and the resulting anxiety and sadness could act as a confounding factor when it comes to the responses of this survey. This unprecedented event cannot be controlled for and could skew this studies data.

Future Directions:

This study serves as a novel template for assessing the psychological impact of counseling patients in the cancer setting. Moving forward, this template could be used to study the emotional response GCs experience in relation to other genes in the cancer setting. Another option for future study could be to repeat this study in a group of GCs suffering from burnout to see if there is a significant difference in the levels of their pre-counseling anxious feelings, sadness and penetrance concerns compared to individuals who are not experiencing burnout. Additionally, GCs in other settings could be surveyed to see if they face a similar increase in the target emotions prior to counseling. Finally, it could be compelling to see how counselors rank their pre-counseling levels of the emotions of interest when presented with unexpected results and familial variants in the clinic.
Conclusion:

GCs in the cancer setting who counsel patients on pathogenic results in *BRCA1/2*, *CDH1*, *TP53*, and LS are experiencing increased levels of anxious feelings, sadness, and concerns about penetrance before counseling patients on these results. There is a significant difference in these short-term emotions related to counseling patients on *CDH1* and *TP53* pathogenic mutations as compared to *BRCA1/2* and LS. This effect appears to arise from the aggressiveness of the management recommendations associated with *CDH1* and *TP53* mutations, their rarity in clinic, the complexity of the counseling, the variable penetrance estimated for gastric cancers associated with *CDH1* mutations and the limited management options available for certain *TP53* associated cancers.

Overall, this increase in the emotions of interest appears to be self-limiting and may not lead to long term effects. The limited scope of these effects could be a sign of professional health and could indicate that most cancer GCs who experience these emotions on a narrow scale are currently not at risk of compassion fatigue and burnout. Our survey respondents reported that between 0-3 years in practice can lead to a reduction in the emotions of interest prior to counseling. While we see a reduction in the levels of the emotions of interest prior to counseling on the targeted genes in more experienced GCs we also see a reduction in their baseline levels of anxious feelings and sadness. These experienced GCs still experience higher than baseline levels of the emotions of interest prior to counseling which points to comfort in the job rather than compassion fatigue. Additional factors that help mitigate long-term effects and temper short-term effects include support from colleagues, access to counseling services, an awareness of the benefits of positive genetic testing, and well-established self-care
regimes. The genetic counseling profession will at times put counselors in a position that may increase their levels of anxious feelings, sadness or penetrance concerns, but through utilization of coping strategies and further research into this topic was can continue to discover where GCs are struggling and what can be done to fix it.
References


Appendix: Qualtrics Survey Questions

Demographic Questions

Please choose the response that best fits your scenario

1) What is your age?
   - 24-35
   - 36-45
   - 46-50
   - 51+
2) What is your gender?
   - Male
   - Female
   - Transgender
   - Nonbinary
3) What is your Ethnic Background?
   - White, Non-Hispanic
   - Black or African American
   - Hispanic
   - Asian
   - American Indian or Alaskan Native
   - Native Hawaiian or Another Pacific Islander
   - Other Race
4) How many years have you been in practice?
   - 1-4
   - 5-9
   - 10-19
   - 20-29
   - 30+

5) How many of those years have been in a cancer setting?
   - 1-5
   - 6-10
   - 11-20
   - 21-30
   - 30+

6) What percentage of your time do you spend counseling on cancer?
   - Less than 10%
   - 10%-25%
   - 26%-50%
   - 51%-75%
   - 76%-100%

7) What is the approximate volume of cancer genetic patients in your clinic each month?
   - Less than 10
   - 10-25
   - 26-50
   - 51-75
8) Approximately how many positive results in *BRCA 1/2, CDH1, TP53* and/or Lynch syndrome genes do you counsel patients on each month?

- 1-2
- 3-4
- 5-6
- 7-8
- 9+

9) Are you currently experiencing anxiety? (Y/N)

10) Are you currently experiencing depression? (Y/N)

11) Please rate your current levels of anxiety and/or depression

   Anxiety: 0 1 2 3 4 5
   Depression: 0 1 2 3 4 5

**Emotional Response Questions**

**Indignation** - anger or annoyance provoked by what is perceived as unfair treatment

Please rank your feelings from 0-5 (with 0 being not at all and 5 being a great amount)

**BRCA1/2**

1) Please rate your level of anxious feelings prior to counseling a patient with a *BRCA1/2* positive test result
2) Please rate your level of sadness prior to counseling a patient with a \textit{BRCA1/2} positive test result

3) Please rate your level of concern about the penetrance of \textit{BRCA1/2} pathogenic variants

4) Have you ever experienced indignation in relation to your patients \textit{BRCA1/2} positive test result? (Y/N)

\textit{CDH1}

1) Please rate your level of anxious feelings prior to counseling a patient with a \textit{CDH1} positive test result

2) Please rate your level of sadness prior to counseling a patient with a \textit{CDH1} positive test result

3) Please rate your level of concern about the penetrance of \textit{CDH1} pathogenic variants

4) Have you ever experienced indignation in relation to your patients \textit{CDH1} positive test result? (Y/N)

\textit{TP53}

1) Please rate your level of anxious feelings prior to counseling a patient with a \textit{TP53} positive test result

2) Please rate your level of sadness prior to counseling a patient with a \textit{TP53} positive test result

3) Please rate your level of concern about the penetrance of \textit{TP53} pathogenic variants

4) Have you ever experienced indignation in relation to your patients \textit{TP53} positive test result? (Y/N)

\textbf{Lynch Syndrome}
1) Please rate your level of anxious feelings prior to counseling a patient with a Lynch syndrome positive test result

2) Please rate your level of sadness prior to counseling a patient with a Lynch syndrome positive test result

3) Please rate your level of concern about the penetrance of Lynch syndrome pathogenic variants

4) Have you ever experienced indignation in relation to your patients Lynch syndrome positive test result? (Y/N)

**Counseling Questions**

Please choose the response that best fits your scenario

1) How are positive results disclosed in your clinic?
   - Only in-person
   - Only by phone
   - By video meeting (Doxy.me, Zoom etc)
   - By video meeting and/or phone
   - By phone/video with a follow-up in-person visit
   - Other, explain:

2) How are positive results counseled in your clinic?
   - Only in-person
   - Only by phone
   - By video meeting (Doxy.me, Zoom etc)
   - By video meeting and/or phone
   - By phone/video with a follow-up in-person visit
• Other, explain:

3) Have you ever altered the way your practice operates due to anxious feelings, sadness and/or indignation you may have experienced on the job? (Yes/No)

4) If Yes, how so?

5) Have you ever considered changing specialties or jobs due to anxious feelings, sadness and/or indignation you have experienced as a result of your job? (Yes/No)

6) Do you feel your co-workers and other genetic counselors are a good resource to talk to if you experience tough emotions surrounding your job? (Yes/No)

7) If Yes, How so?

8) Do you feel that experience in the field helps to mitigate these tough emotions through repeated exposure? (Yes/No)

9) If Yes, how long did it take you for you to realize a change?

10) Do you feel that you have access to resources to manage any anxious feelings, sadness and/or indignation you may have experienced? (Yes/No)

11) If Yes, what are some of these resources?

12) In your own words, please describe the impact of counseling patients on pathogenic mutations in BRCA1, BRCA2, TP53, CDH1 and/or Lynch syndrome genes has had on your mental health.

13) What do you think can be done to minimize the psychological effect counseling patients with positive BRCA1/2, CDH1, TP53 and/or Lynch syndrome testing has on genetic counselors?

14) Do you feel that the COVID19 pandemic has increased the anxious feelings, sadness and/or indignation associated with your job? (Yes/No)
15) How so?

16) In your own words, please explain circumstances related to counseling patients on

*BRCA1/2, CDH1, TP53* and/or Lynch syndrome pathogenic mutations not talked about in this survey that may have had an effect on your anxiety, depression and/or indignation levels. (For example, getting an unexpected result or counseling a patient with a lot on their plate).