Genetic Counselors’ Comfort Level, Attitudes & Experiences Providing Cancer Risk Assessment and Counseling for End-of-Life Patients

Master’s Thesis

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The Faculty of the Graduate School of Arts and Sciences
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Gretchen Schneider, MS, LGC, Advisor

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by
Nicole S. Yang

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Acknowledgements

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ABSTRACT

Genetic Counselors’ Comfort Level, Attitudes & Experiences Providing Cancer Risk Assessment and Counseling for End-of-Life Patients

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Nicole S. Yang

Providing genetic counseling for the end-of-life (EOL) oncology patient population differs from a “traditional” cancer genetic counseling session as it presents numerous, unique challenges. The complexity of counseling EOL patients varies depending on the extent of patients’ visible signs of illness, their level of participation in sessions, the presence of family members and/or the health care proxy, and any underlying psychosocial issues. We explored the experiences and comfort levels of cancer genetic counselors when providing risk assessment and genetic counseling to EOL patients. We utilized an anonymous online survey and received 158 responses. The largest proportion of our participants (45.6%) was between 20-30 years of age. Years of experience ranged from 0.5-32 years, with 85 respondents having 0.5 to 4 years of experience, and 69 participants having more than 5 years of experience. We did not observe a significant relationship between years of experience and comfort level when counseling EOL patients. The vast majority of participants were comfortable discussing topics such as risk assessment and the chances of a patient’s child having the same genetic condition. However,
regardless of years of experience, fewer individuals reported that they were comfortable with discussing psychosocial issues such as support services and exploring the patient’s emotions about their prognosis. Responses to hypothetical scenarios demonstrated that many participants felt discomfort when faced with discordance between a patient’s hopes and physical realities, patient’s fear of dying and disagreement within family members. Participants felt there was a lack of resources, such as case examples, guidelines and educational sessions that could potentially help cancer genetic counselors feel more comfortable when counseling EOL patients. The majority of counselors advised others to approach this “non-traditional” genetic counseling session without expectation, and felt it was important to let the patient guide the session. Additionally, participants felt it was important to give their patients distilled information. Our results provide insight into the experiences and comfort level of cancer genetic counselors when working with EOL patients. Future studies exploring the patient perspective would provide additional insight and, combined with the data from our study, could be used to develop guidelines and resources aimed at increasing genetic counselors’ comfort level when counseling their EOL patients.

**Keywords:** cancer genetic counseling, genetic counselors, end-of-life care, palliative care
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Introduction

Cancer Genetic Counseling & End-of-life Patients

Cancer genetic counselors see a broad range of patients for risk assessment that includes both asymptomatic individuals with a family history of cancer, and affected men and women who are undergoing treatment. At the extreme end of their affected patient population are end-of-life (EOL) patients, for which there may be one last opportunity to provide genetic risk assessment and counseling (Lakhani, Weir Allford, Kai & Barwell, 2013). During genetic counseling, terminally ill patients may learn about hereditary vs. sporadic cancers, risks to family members, and benefits and limitations of genetic testing and/or DNA banking. Patients may choose to pursue genetic testing, or bank blood for future studies. Past research indicates that EOL patients feel that undergoing genetic testing or DNA banking is a positive, altruistic experience that can provide valuable information for their loved ones (Hallowell et al., 2004). Identifying a causative mutation in affected individuals, even at the end of their life, can allow unaffected family members to pursue testing themselves. A number of studies on families with a BRCA1 or BRCA2 mutation have shown that, when EOL patients do not receive cancer risk assessment and counseling, potential carriers go unidentified (Malone et al., 2006; Risch et al., 2006; Thompson, Easton & Consortium, 2002). This in turn, limits the options for individuals who may benefit from discussions regarding risk reduction surgery or chemoprevention.

Palliative care does not traditionally incorporate referrals to a cancer genetic counselor, despite the utility of offering cancer risk assessment and counseling to EOL patients (Lillie, 2011). However, in 2008 Quillin et al. demonstrated the value of including a discussion about
genetics with their palliative care patients. Their study showed that, among the 15 most common admissions diagnoses, a third of patients had “a significant genetic component which is testable, informative and potentially life-saving for the survivors” (Quillin et al., 2008). In a subsequent study, the same group found that 21% (9 out of 43) of their respondents had family histories that indicated a high-risk for a hereditary cancer syndrome (Quillin et al., 2010), which translates to 1 in 5 EOL patients who met criteria for a genetics referral. Fifty-two percent of at-risk individuals, when asked about their awareness regarding genetic testing, reported knowing “almost nothing,” and 67% knew “almost nothing” about DNA banking, regardless of socioeconomic status, ethnic background or educational level (Quillin et al., 2010). Their study suggests that, while it is not uncommon for EOL patients to be considered high risk, many are not referred for risk assessment and genetic counseling.

There are a number of potential reasons why providers do not refer their EOL patients for genetic risk assessment and counseling. Two studies in 2001 and 1992 found that both recurrent cancer patients and their clinicians tended to overestimate the time patients had left to live (Doyle C. et al., 2001 & Buckman R., 1992). Therefore, Von Gruenigen, V. E., & Daly B. J. in 2005 argued the possibility that they also overestimate the window of opportunity for a genetics referral. Another study in 2010 by Meyer et al., found improvement in identifying and referring at-risk ovarian cancer patients at their institution; however, a significant number of individuals did not receive a referral to cancer genetics, and were therefore missed for BRCA1 or BRCA2 mutation testing (Meyer et al., 2010). For many patients, a genetics referral does not always occur until late in disease progression; as physicians are more apt to treat the patient’s illness than refer for genetic risk assessment. However Daniels et al., in 2011, suggested that physicians and other medical professionals might be reluctant to discuss the possibility of hereditary cancer
genetic testing during end of life or palliative care, as patients and families may see it as an additional burden during an increasingly sensitive time. They discussed the importance of assessing comfort levels, as well as the perceived barriers of health care providers in bringing up genetic counseling and testing during EOL patient care.

**Challenges When Providing Genetic Counseling to End-of-Life Patients**

Genetic counseling for EOL patients differs from a “traditional” cancer genetic counseling session and present numerous, unique challenges. The complexity of counseling EOL patients varies depending on the extent of a patient’s visible signs of illness, their level of participation in sessions, the presence of family members and/or the health care proxy and the contribution of psychosocial issues to these difficult conversations. Furthermore, EOL patients may be wrestling with concerns about their poor prognosis or fear of dying, and have psychosocial needs which cancer genetic counselors may feel uncomfortable addressing. To add another layer of complexity, given that the patient’s life expectancy is limited, the determination of mutation status for a hereditary cancer syndrome is time sensitive (Daniels, et al., 2011). Genetic counselors may also need to inform patients and families that testing will not change the course of a patient’s cancer, and test results may only be beneficial to the patient’s relatives. With so many complicating factors involved in counseling sessions with EOL patients, the genetic counselor must prioritize topics of conversation, balance the psychosocial needs of the patient, and relay the appropriate information required for informed consent.

It is important to take the EOL patient and their family’s perspectives into account when providing genetic counseling, as these can be difficult conversations during an emotionally taxing time. Genetic counselors often need to discuss the patient’s and his/her family members’ wishes regarding results disclosure, and who will receive them should the patient pass away.
before they become available; which may be very hard for them to consider (Kirk, 2004). Lastly, family dynamics and/or the need to discuss medical information with the patient’s health care proxy can further complicate the genetic counseling session. Given the sensitive nature of counseling this specific patient population and their families, genetics professionals have to strike a balance between detailing information, while being mindful of the patient’s and their family members’ perspectives, energy levels and emotional resources (Daniels et al., 2011).

In a study exploring experiences with grief and loss within the genetic counseling field, Deeney et al. (unpublished manuscript, 2009) found that while many beginning genetic counselors are comfortable discussing issues involving grief and loss with patients, they were uncomfortable with scenarios involving death and dying. Little data exists however, regarding cancer genetic counselors’ experiences and comfort level counseling terminally ill cancer patients. Therefore, the aims of this study were to: investigate cancer genetic counselors’ experiences with EOL patients, assess factors that affected a genetic counselor’s comfort level when counseling EOL patients, and identify tools and resources that helped cancer genetic counselors feel more comfortable or prepared in counseling this specific population. We hope that this study will provide valuable insight that will guide genetic counselors in counseling their end-of-life cancer patients.
Methods

Study Design

We created a cross-sectional quantitative study using an anonymous online survey generated and implemented through Qualtrics®. The survey is composed of 49 single- and multiple-choice, Likert-scale, and open-ended questions to collect both quantitative and qualitative data. We gathered demographic data such as age, gender, geographic area of practice and number of years the participants have practiced as a cancer genetic counselor. For the purpose of consistency and clarity, we defined “end-of-life” patients at the outset as individuals who are diagnosed with a terminal, late stage cancer who may or may not be in either palliative or hospice care.

The bulk of our survey gathered details about participants’ experiences counseling end-of-life cancer patients including, but not limited to, how many patients they see for cancer risk assessment, and how often and how comfortable participants are counseling end-of-life patients on topics such as benefits and limitations of testing, genetic testing results, DNA banking options, and addressing their patient’s emotional responses. The next section of the survey consisted of scenarios that simulated difficult EOL patient encounters and asked participants to indicate their likelihood of, and comfort level with, discussing different genetic counseling topics. The final section asked participants to reflect on their actual experiences with end-of-life patients and provide advice for others in similar situations. The Brandeis University Institutional Review Board approved this study.

Recruitment
We recruited participants for our study using email blasts through two listserv services: to members of the National Society of Genetic Counselors (NSGC) and members of the Canadian Association of Genetic Counsellors (CAGC). The e-blasts provided a direct link to participate in the survey. In order to be eligible to participate, individuals must be currently working, or have previously worked, as a cancer genetic counselor in the United States or Canada and have counseled at least one EOL cancer patient in person or over the phone. We sent an email recruitment reminder through the NSCG and CAGC listservs approximately 3 weeks after the initial date.

**Data Collection**

Interested individuals could click on the link provided in the e-blasts to go directly to our confidential, anonymous, online survey. We collected our data online to allow for easy access to the survey and to maximize participation. Participation in our study was voluntary and respondents had the option to skip any questions and exit the survey at any time. Additionally, respondents had the option to save their responses and complete the survey at a later time. The survey was open for approximately four weeks (April 19th, 2017 to May 20th, 2017).

At the end of the survey, participants had the option to enter a raffle for one of three $50.00 Amazon.com gift certificates for their time and participation. If participants selected this option, the survey directed them to a separate, confidential, online Qualtrics® survey to enter their name and email address. We randomly selected raffle winners after the survey had closed for data collection.

**Data Analysis**

We analyzed quantitative data using SPSS Statistics Version 23, a statistical software package available through Brandeis University. We analyzed the data using descriptive and frequency
statistics, t-tests and chi-square analyses and other bivariate and multivariate statistics as appropriate to determine relationships between independent and dependent variables. We manually analyzed responses through Microsoft Excel to open-ended questions using an inductive approach to identify key themes.
Results

Survey Participants

We received 167 responses to our survey and excluded nine from data analysis, as they did not meet eligibility criteria. The remaining 158 participants were genetic counselors who have previously worked or are currently working in clinical cancer genetics, either full- or part-time and have counseled at least one EOL patient. Each eligible participant answered the majority of all of the survey questions.

All participants reported the geographic location in which they currently practice genetic counseling (Figure 1). The geographic distribution of respondents by NSGC region throughout the United States and Canada generally reflects that seen in the 2016 Professional Status Survey (NSGC, 2016).

Figure 1. The distribution of 158 respondents as compared to the 2205 genetic counselors who responded in the 2016 NSGC Professional Status Survey. Region 1: CT, MA, ME, NH, RI, VT, CN & Maritime Provinces. Region 2: DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI & Quebec. Region 3: AL, FL, GA, KY, LA, MS, NC, SC & TN. Region 4: AR, IA, IL, IN, KS, MN, MO, ND, NE, OH, OK, SD, Wi &
Ontario. Region 5: AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba & Saskatchewan. Region 6: AK, CA, HI, ID, NV, OR, WA & British Columbia. Other regions: Non-U.S. or Canada in the United States, Canada and other Non-U.S. or Canadian countries as defined by NSGC region. According to the NSGC Professional Status Survey, Salary & Benefits, 2205 genetic counselors participated in their survey. The total number of our survey respondents was N=158.

The largest proportion (45.6%) of our participants were between 20-30 years of age, 37.3% of were 31-40, 9.5% were 41-50 and 6.3% were 51-60. Of the 158 respondents, 150 (96.2%) were female and 6 (3.8%) were male, and 2 did not provide their gender. The average number of years of experience as a genetic counselor was 7.24 years (N=157), in comparison to the average number of years of experience as a clinical cancer genetic counselor, which was 5.98 years (N=155). The majority of the 156 respondents (85.3%) reported that they spend 50% or more of their clinical time as a cancer genetic counselor, with 101 reporting that they spent 100% of their clinical time in this practice area.

We next assessed the rate at which respondents saw patients for an initial visit for risk assessment and genetic counseling. Of the 153 who responded, 47 (30.7%) reported seeing 0-5 patients per week, 77 (50.3%) saw 6-10 patients per week, 20 (13.1%) saw 11-15 patients per week and 8 (5.2%) reported seeing 16-20 patients per week. The vast majority (149 or 98%) of participants reported that, within the initial patients they provided cancer risk assessment and counseling for, they saw 0-2 EOL patients per week (N=152).

The survey then asked participants which medical and allied health professionals referred EOL patients to them. One hundred fifty of 158 participants (94.9%) reported that they received EOL patient referrals from oncologists, 55 (34.8%) reported that patients’ family members referred EOL patients, and 51 (32.2%) reported that patients self-referred. Only 14 individuals (8.9%) reported that members of the palliative care team have referred patients to their clinic. Referrals came less frequently from the patient’s surgeons, primary care physicians/family doctors and specialists, such as obstetrician-gynecologists and gastroenterologists.
Years of Experience as a Clinical Cancer Genetic Counselor & Comfort Level

We divided participants into two roughly equal groups, based on years in clinical cancer practice, to look for differences in experiences and/or comfort level in providing counseling to EOL patients. Eighty-five participants had <5 years of experience (0.5 to 4 years) and 69 participants had ≥5 years (range of 5-32 years) of experience as a cancer genetic counselor. Participants rated how frequently they discussed various topics with their EOL patients, from discussing the patient’s risk of having a hereditary cancer syndrome and discussing benefits and limitations of genetic testing, to psychosocially driven topics such as exploring the patient’s emotional state or feelings about their poor prognosis. Regardless of years of clinical experience, the majority reported that they frequently discussed many of the counseling topics with their EOL patients, with the exception of DNA banking, support services for the patient and/or their family members and the patient’s emotional state/feelings about their prognosis (Table 1). The frequencies of discussing the various counseling topics were not found to be statistically significant when compared between the two groups (P>0.05, Table 1).

<table>
<thead>
<tr>
<th></th>
<th>Years of Experience</th>
<th>Frequency of Responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never/Sometimes</td>
<td>Half/Most/Always</td>
</tr>
<tr>
<td>Chance they have a hereditary cancer N=148</td>
<td>&lt; 5 years</td>
<td>6 (7.4)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td>Risk of their children having the same condition N=148</td>
<td>&lt; 5 years</td>
<td>6 (7.4)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td>DNA banking options N=148</td>
<td>&lt; 5 years</td>
<td>44 (54.3)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>27 (40.3)</td>
</tr>
<tr>
<td>Benefits and limitations of genetic testing N=146</td>
<td>&lt; 5 years</td>
<td>8 (10)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>4 (6.1)</td>
</tr>
<tr>
<td>Genetic testing results N=146</td>
<td>&lt; 5 years</td>
<td>11 (13.8)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>7 (10.6)</td>
</tr>
<tr>
<td>Support services for the patient and/or their family members N=148</td>
<td>&lt; 5 years</td>
<td>41 (50.6)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>34 (50.7)</td>
</tr>
<tr>
<td>Patient’s emotional state/feelings about their poor prognosis N=148</td>
<td>&lt; 5 years</td>
<td>46 (56.8)</td>
</tr>
<tr>
<td></td>
<td>≥ 5 years</td>
<td>38 (56.7)</td>
</tr>
</tbody>
</table>

Table 1. Responses to how likely Cancer Genetic Counselors are to discuss the different genetic counseling topics with their EOL patients by grouped years of experience.
We observed a similar trend regarding participants’ comfort level discussing the same topics when comparing the two groups based on years of experience, with none showing a statistically significant difference. (P>0.05, Table 2).

<table>
<thead>
<tr>
<th>Topic</th>
<th>Frequency of Responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chance they have a hereditary cancer N=148</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Risk of their children having the same condition N=148</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>3 (3.7)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td>DNA banking options N=147</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>12 (14.8)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>4 (7.2)</td>
</tr>
<tr>
<td>Benefits and limitations of genetic testing N=148</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Genetic testing results N=147</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Support services for the patient and/or their family members N=148</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>13 (16)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>11 (16.4)</td>
</tr>
<tr>
<td>Patient’s emotional state/feelings about their poor prognosis N=148</td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>28 (34.6)</td>
</tr>
<tr>
<td>≥ 5 years</td>
<td>16 (23.9)</td>
</tr>
</tbody>
</table>

Table 2. Responses to how comfortable Cancer Genetic Counselors are to discuss the different genetic counseling topics with their EOL patients by years of experience.

When asked to list any additional counseling topics discussed with EOL patients through an open-ended question, the most frequently cited topic by respondents was creating a plan regarding who would receive the genetic testing results should the patient pass away (56.9%, N=58). These discussions, for many counselors, included why that person would be a good choice, and signing appropriate release of information forms. Twelve individuals (20.7%) reported discussing how patients were less likely to benefit directly from genetic testing, and that it would be more beneficial for their relatives. Six individuals reported that they discussed clinical trials, new medications and/or opportunities to participate in research studies. Other less commonly observed themes included: discussion of genetic testing options (e.g. single-gene testing versus panel testing), insurance issues and cost of testing, referrals to other specialists (e.g. palliative care, social work, etc.), and psychosocial issues.
Comfortable & Uncomfortable Factors While Counseling EOL Patients

We asked participants to select, from a specific list of factors, what made them comfortable and uncomfortable in a genetic counseling session with an EOL patient (Table 3). The most frequently reported comfortable factors were: previous professional experience(s) providing genetic counseling for EOL patients (85.1%), opportunities to discuss/process with other genetic counselors (68.9%), and previous personal experience(s) with loss (41.2%). If participants selected “other”, we asked them to describe what additional factors, that were not included on the list, helped them feel more comfortable. Prior work or volunteer experience in a different role that also dealt with end-of-life issues was a general theme that emerged:

“I believe being a prenatal counselor prior to becoming a cancer counselor also helped me feel comfortable talking about end-of-life and poor prognosis. While of course one specialty is talking about the fetus and the other about the person themselves, I dealt with poor prognosis much more frequently in prenatal genetics than I do in cancer genetics. I think it helped the topic be more comfortable overall.”

“Serving on hospital ethics committees for 11 years where most cases were EOL patients”

The most frequently uncomfortable factors participants selected were: increased emotional complexity of counseling EOL patients (61.9%), uncertainty surrounding patient reactions to counseling (57.1%) and difficulty of counseling a patient who is visibly ill (47.6%, Table 3). Similarly, if participants selected “other”, we asked them to disclose the additional factors that added to their discomfort. A handful of participants spoke to their being uncertain about how much the patient knows regarding their prognosis, as demonstrated in the following quote:

“It is often unclear whether or not the patient is aware of their poor prognosis. It is a difficult topic to raise because it is not within our scope of practice to tell a patient their prognosis so you often have to rely on cues from the patient to tell you how much they know/understand.”
A number of participants also expressed feeling as though the genetics consult was not a priority in the patient’s life, or described their counseling sessions as feeling “invasive,” during an especially challenging time.

“Knowing the likelihood that they will pass away before their results [sic], understanding that genetics may not be a priority at such a complex time, considering how to minimize [sic] how invasive we are in the patient’s life and family’s grief [sic]/ coping…”

“There are times when our discussion feels invasive or at the very least not how the patient and their family wish to be spending their time.”

<table>
<thead>
<tr>
<th>Comfortable &amp; Uncomfortable Factors for Clinical Cancer Genetic Counselors</th>
<th>Frequency of Responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Comfortable factors</strong></td>
<td></td>
</tr>
<tr>
<td>Previous professional experience(s) providing genetic counseling for EOL patients</td>
<td>126 (85.1)</td>
</tr>
<tr>
<td>Previous personal experience(s) with loss (e.g. family member who passed away)</td>
<td>61 (41.2)</td>
</tr>
<tr>
<td>Opportunities to discuss/process with other genetic counselors</td>
<td>102 (68.9)</td>
</tr>
<tr>
<td>Opportunities to discuss/process with other medical specialists who are not genetic counselors</td>
<td>59 (39.9)</td>
</tr>
<tr>
<td>Written resources to help process difficult case</td>
<td>27 (18.2)</td>
</tr>
<tr>
<td>Graduate school training specific to counseling EOL patients</td>
<td>40 (27)</td>
</tr>
<tr>
<td>Information gathered from professional meetings e.g. NSCG, CAGC, etc.</td>
<td>28 (18.9)</td>
</tr>
<tr>
<td>Consulting with or attending lectures given by the palliative care team, psychology staff and/or social work team</td>
<td>53 (35.8)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>17 (11.5)</td>
</tr>
<tr>
<td><strong>Uncomfortable factors</strong></td>
<td></td>
</tr>
<tr>
<td>Lack of professional experience(s) providing genetic counseling for EOL patients</td>
<td>50 (34)</td>
</tr>
<tr>
<td>Increased emotional complexity of counseling EOL patients</td>
<td>91 (61.9)</td>
</tr>
<tr>
<td>Lack of training, graduate school or other specific to counseling EOL patients</td>
<td>60 (40.8)</td>
</tr>
<tr>
<td>Effect of emotions from own experiences of loss</td>
<td>25 (17)</td>
</tr>
<tr>
<td>Difficulty of counseling a patient who is visibly ill</td>
<td>70 (47.6)</td>
</tr>
<tr>
<td>Uncertainty surrounding patient reactions to counseling</td>
<td>84 (57.1)</td>
</tr>
<tr>
<td>Concern about family member dynamics</td>
<td>68 (46.3)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>23 (15.6)</td>
</tr>
</tbody>
</table>

**Table 3.** Comfortable and uncomfortable factors for Clinical Cancer Genetic Counselors while counseling EOL patients.
Figure 2. Perceived tools and resources that would help make genetic counselors more comfortable during EOL patient encounters N= 82.

Tools & Resources that Would Help Increase Comfort Level While Counseling EOL Patients

We utilized an open-text response to gather information regarding what additional tools or resources would be helpful for our participants in increasing their comfort level. Forty-three of 82 individuals (52%) who provided input reported that additional professional resources and learning opportunities for genetic counselors, outside of their graduate school training, would be helpful in increasing their comfort level (Figure 2). These resources fell into three main groups:

1. Resources provided by a professional society such as webinars, educational sessions, workshops, written guidelines of what topics to consider during different situations, and case examples.
2. Informational tools or written reports on patient perspectives developed by patients and their families.
3. Opportunities at the workplace for further education such as time to shadow or observe the palliative care team, social workers, psychologists and oncologists.

An additional 18 respondents (22%) reported that training or exposure to EOL patients in graduate school
would help increase their comfort. Another seven respondents reported that having written materials to hand to the patient would be helpful in increasing their comfort level.

**EOL Patient Scenario Questions**

We asked participants to read hypothetical scenarios that involved EOL patients with varying ages, cancer diagnoses, psychosocial needs, and family dynamics to assess what topics genetic counselors would discuss, and how comfortable they would be with different factors in each patient encounter.

Scenario 1 described a 65-year old female EOL patient with pancreatic cancer who attends the appointment with her two daughters. Daughter A is the patient’s designated health care proxy, as her mother is heavily medicated and unable to make medical decisions for herself. The scenario describes the two daughters’ conflicting views on whether or not to pursue genetic testing. Respondents ranked how likely they were to discuss various psychosocially driven topics with the hypothetical patient (Figure 3A). All participants reported that they were likely to discuss the daughter’s “reasons behind wanting/not wanting genetic testing for their mother.” (Figure 3A). Participants responded with similarly high likelihoods regarding other topics with the exception of approximately 48% of participants stating they were likely to discuss “Daughter B being far away from her mother during her illness/decline” (Figure 3A).

Next, participants ranked how comfortable they were discussing the same topics as the previous question (Figure 3B). The responses followed a similar trend observed in the previous question: the majority of participants reported that they were comfortable discussing the topics, with the exception of “Daughter B being far away from her mother during her illness/decline" (Figure 3B) which only 48% of participants said they would feel comfortable discussing.
Overall, the majority of respondents were likely to- and comfortable with- discussing psychosocially driven counseling topics pertaining to this hypothetical EOL patient.

**Figure 3A.** Scenario 1: Proportion of participants who were “likely” to discuss various counseling topics in hypothetical session with complex family dynamics and conflicting views on genetic testing. “Somewhat likely and extremely likely” responses were grouped under “likely.” “Neither likely or unlikely” responses were excluded from our analyses.

**Figure 3B.** Scenario 1: Proportion of participants who were “comfortable” to discussing various counseling topics in hypothetical session with complex family dynamics and conflicting views on genetic testing. “Somewhat comfortable and extremely comfortable” responses were grouped under “comfortable.” “Neither comfortable or uncomfortable” responses were excluded from our analyses.
Scenario 2 described a 45-year old terminally ill, female ovarian cancer patient who is visibly ill, and becomes upset during the session expressing that she is afraid of dying. Ninety-two percent of individuals reported that they were likely to explore the “patient’s thoughts and feelings about not being alive to receive her test results,” while only 79% of individuals reported that they were comfortable discussing it (Figure 4A and 4B). Ninety-five percent responded that they were likely to explore the “patient’s support network” while 89% reported that they were comfortable discussing it (Figure 4A and 4B). Eighty-six percent responded that they were likely to explore the “utility of social services or other resources” with the patient; however only 78% reported they were comfortable talking about it (Figure 4A and 4B). Regarding the last counseling topic, approximately 69% responded that they were likely to explore the “patient’s fears about dying” and an even lower proportion (42%) stated they were comfortable discussing the topic (Figure 4A and 4B).

Figure 4A. Scenario 2: Proportion of participants who were “likely” to discuss various counseling topics in hypothetical session with visibly ill patient who is struggling with her fear of death and dying. “Somewhat likely and extremely likely” responses were grouped under “likely.” “Neither likely or unlikely” responses were excluded from our analyses.
The third scenario described a session with a 35-year-old male terminally ill male, who has Li-Fraumeni syndrome, and his wife. During the session, the patient’s wife expresses her desire to have children. There was more variation in participants’ responses to the third scenario than the previous two (Figure 5A and 5B). Approximately 81% were likely to “explore the couple’s thoughts and feelings about having children,” yet only 73% were comfortable discussing this counseling topic. Only 45% were likely to “explore the couple’s thoughts and feelings about the patient’s infertility” however a slightly higher proportion (50%) of individuals who were comfortable exploring this topic (Figure 5A and 5B). The majority of respondents were unlikely to, and uncomfortable with, “exploring the idea of the patient’s wife parenting alone” (Figure 5A and 5B). Forty percent responded that they were unlikely to “defer to the patient’s oncologist” in contrast to 58% who were comfortable doing so (Figure 5A and 5B).
Figure 5A. Scenario 3: Proportion of participants who were “likely” to discuss various counseling topics surrounding fertility and family planning in session with EOL patient and his wife. “Somewhat likely and extremely likely” responses were grouped under “likely.” “Neither likely or unlikely” responses were excluded from our analyses.

Figure 5B. Scenario 3: Proportion of participants who were “comfortable” to discuss various counseling topics surrounding fertility and family planning in session with EOL patient and his wife. “Somewhat comfortable and extremely comfortable” responses were grouped under “comfortable.” “Neither comfortable or uncomfortable” responses were excluded from our analyses.

At the conclusion of each scenario, we asked participants to delineate further by selecting from a list of potential factors, what would make them uncomfortable in each patient encounter. Table 5 summarizes the responses. In scenario 1, the highest proportion (104 of 125, 83.2%) of
participants reported that the conflict between the patient’s daughters would affect their comfort level. In scenario 2, the uncomfortable factor reported by the highest number of respondents was the patient’s fear of dying (103 out of 123 participants, 83.7%). Lastly, 90 out of 127 (70.9%) individuals reported that the “the possibility of giving false hope to the patient and his wife” was an uncomfortable factor during the third hypothetical scenario.

<table>
<thead>
<tr>
<th>Identified Uncomfortable Factors within Scenario Questions</th>
<th>Frequency of Responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Uncomfortable Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Scenario 1</td>
<td></td>
</tr>
<tr>
<td>The patient is heavily medicated and unable to engage in the session</td>
<td>71 (56.8%)</td>
</tr>
<tr>
<td>There is disagreement between the two sisters regarding performing genetic testing on their mother</td>
<td>104 (83.2%)</td>
</tr>
<tr>
<td>As health care proxy, Daughter A is ultimately the decision-maker</td>
<td>50 (40%)</td>
</tr>
<tr>
<td>Daughter B is hurt by her sister point out that she has not been present during her mother’s illness</td>
<td>52 (41.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (6.4%)</td>
</tr>
<tr>
<td>Scenario 2</td>
<td></td>
</tr>
<tr>
<td>The patient is visibly ill</td>
<td>29 (23.6%)</td>
</tr>
<tr>
<td>Knowledge of her limited time</td>
<td>59 (48%)</td>
</tr>
<tr>
<td>Patient’s concern that she will not be alive to receive her results</td>
<td>41 (33.3%)</td>
</tr>
<tr>
<td>Patient becoming upset</td>
<td>50 (40.7%)</td>
</tr>
<tr>
<td>Patient’s fear of dying</td>
<td>103 (83.7%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (4.1%)</td>
</tr>
<tr>
<td>Scenario 3</td>
<td></td>
</tr>
<tr>
<td>The patient’s infertility and terminally ill status makes it unlikely for future children</td>
<td>84 (66.1%)</td>
</tr>
<tr>
<td>Not enough knowledge regarding the current status of IVF/PGD services available to terminally ill cancer patients to provide for the patient and his wife</td>
<td>45 (35.4%)</td>
</tr>
<tr>
<td>The possibility of giving false hope to the patient and his wife</td>
<td>90 (70.9%)</td>
</tr>
<tr>
<td>Setting realistic expectations for the patient and his wife</td>
<td>78 (61.4%)</td>
</tr>
<tr>
<td>Exploring the couple’s thoughts/feelings about having children, infertility and/or parenting alone, is outside my jurisdiction of practice as a genetic counselor</td>
<td>27 (21.3%)</td>
</tr>
<tr>
<td>The conversation about infertility is outside my scope of practice</td>
<td>30 (23.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (7.1%)</td>
</tr>
</tbody>
</table>

Table 4. Additional factors that caused discomfort among Cancer Genetic Counselors in Scenario 1, N=125, Scenario 2, N=123 and Scenario 3, N=127.

The final portion of our survey solicited advice from participants to genetic counselors that were providing risk assessment and genetic counseling to EOL patients for the first time.
Table 4 summarizes the six commons themes that emerged among our participants’ advice. Twenty-five percent of respondents discussed the importance of letting patients guide the session and prioritizing psychosocial counseling with this specific patient population. A similar proportion addressed the importance of tailoring the genetic counseling session to the patient’s needs. Slightly fewer participants (19.7%) spoke to the type of attitude to take towards the counseling session.

Figure 6. Participants’ advice on counseling EOL patients for the first time, N=152.
Discussion

To our knowledge, our study was the first to explore cancer genetic counselors’ experiences and comfort levels when providing risk assessment and genetic counseling services to EOL patients. We hoped to identify what topics genetic counselors most often discussed with EOL patients, as well as which factors influenced our participants’ comfort level during their counseling sessions. We also aimed to elucidate what tools or resources could potentially help counselors become more comfortable working with EOL patients, and solicited advice for other genetic counselors providing risk assessment and counseling services to EOL patients for the first time. Our hope is that these results will provide insight about genetic counseling for this unique patient population.

The majority of our participants were young (between the ages of 20 to 30) and female, which is consistent with the data from the most recent NSGC Professional Status survey. The average number of years participants have practiced as a genetic counselor in any clinical practice area is 7.24 and as a cancer genetic counselor is 5.98, reflecting a change in practice area for many counselors as is common in the profession. On average, participants spent the majority of their clinical time as a cancer genetic counselor, which is not surprising given that cancer genetic counseling has been the largest growing area of clinical practice for genetic counseling for a number of years.

When participants recalled who referred their EOL patients, the vast majority (94.9%) selected oncologists, which we expected given the extensive care these physicians provide for individuals with cancer, especially ones who are at the end of a long battle. The next two most
commonly reported sources of referrals were patients’ family members (34.8%) followed by the patient themselves (32.2%). This was surprising given the stress and emotions these two groups are likely experiencing at this point in the patient’s illness. This may demonstrate that some patients and family members are aware of the time sensitive nature of pursuing genetic testing. Additionally, family members may also have a desire to seek information and “take care of things” as much as possible, even during the end of the affected individual’s life. This is interesting, in light of Quillin’s study in 2010, which illustrated low awareness in many EOL patients regarding genetic testing and DNA banking services. In our study, since participants reported patients and their family members as referral sources, this would indicate that some had enough awareness to refer themselves or their loved ones for genetic counseling. It is not clear however, whether this is a true reflection of patient and family member referral practices, as the patient themselves were not the ones reporting.

Finally, despite the study by Quillin in 2008 showing the value of integrating genetics into palliative care, fewer than 10% of our respondents reported that palliative care team members referred patients to their practice. This is in keeping with data published subsequent to Quillin’s study, showing very little evidence of palliative care moving to incorporate genetic risk assessment or counseling (Alison, 2011). It is encouraging that at least some participants had referrals from palliative care, as this could suggest that this provider group has begun to have genetic counseling on their radar and are referring more EOL patients who are at higher risk for hereditary cancer syndromes. This could allow for more family members of affected individuals to receive informative and life-saving information about their risk. (Quillin et al., 2008).
Years of Experience and Effect on Participants’ Comfort Level

There was no significant correlation between years of experience and the likelihood of discussing various genetic counseling topics in sessions with EOL patients, based on the data from our study. The majority of counselors in both experience groups reported that they frequently discussed “bread and butter” genetic counseling topics, such as the patient’s risk of having a hereditary cancer syndrome and benefits and limitations of genetic testing with their EOL patients. This is not surprising given that a genetic counselor with any number of years of experience is typically aware of the necessary elements of cancer genetic counseling, and therefore likely to discuss them with patients. Interestingly, fewer respondents in each group reported discussing psychosocially driven topics such as “support services for the patient and/or their family members,” with slightly under half in each saying they “most of the time” or “always” discussed this with their EOL patients. One possible explanation is that our respondents’ patients did not request this information at the time, or that the genetic counselors did not feel a referral to support services was required or necessary. Counselors may also not be aware of local support groups and resources available to this specific patient population. Additionally, only slightly more than 40% in each group reported that they “most of the time” or “always” discussed the “patient’s emotional state/feelings about their poor prognosis”. Again, respondents may not have felt that this discussion was necessary or appropriate based on how the patient, for example, was accepting of, or not upset by, their prognosis at the time of the appointment.

Similarly, we observed no significant correlation between our participants’ years of experience and their comfort level discussing the same topics. This was an unexpected finding, as one would postulate that participants with more years of experience would have a higher
comfort level discussing various genetic counseling topics. One explanation for this observation could be that cancer genetic counselors do not commonly see EOL patients and have not had enough routine practice for counseling to be comfortable. We observed in our data, that 95% of our participants saw 0 to 2 EOL patients per week, data that supports this type of counseling being a rarity. Another explanation could be that, with the expansion of the cancer genetic counseling field, this practice area is getting increased attention during graduate school training and new counselors are coming into the field more prepared to deal with even the most difficult counseling sessions. Therefore, their comfort level may be similar to that of their more experienced colleagues even in their early years in clinical practice.

As expected, the vast majority of participants reported they were comfortable with topics such as risk assessment and the discussion of the patient’s child having the same genetic condition. This is consistent with participants’ high likelihood of discussing these topics, and also reflects genetics counselors’ strengths at being information givers. However, regardless of years of experience, fewer individuals reported that they were comfortable with discussing psychosocial issues such as support services, and exploring the patient’s emotions about their prognosis. This may be due to the inherently uncomfortable nature of exploring psychosocial issues with the patient, and the unpredictability of patient reactions, especially when there is the potential for the themes of death and dying to arise. The other topic that both experience groups said they felt uncomfortable discussing was the logistics of results disclosure with family members once a patient has passed away. Numerous participants mentioned the challenging and sensitive nature of this part of the conversation, and the emotional and logistical complexity it could potentially add to the counseling session. The following quote demonstrates this theme:

“One big one is the logistics of how results will be disclosed -- it is much more common that EOL patients will request that results be disclosed to a spouse or family member instead of directly to themselves... This introduces some additional complexity into the counseling and especially into..."
results disclosure- you can't call and say "Great news, your results were negative" as the patient and their family may have pinned a great deal of hope on finding a mutation that would have opened up this last option for treatment that could have extended their life. While it may be good news for their family members, you could actually be giving very difficult [sic] news by disclosing a negative result. I feel a little uncomfortable addressing this topic for multiple reasons...it is very difficult to discuss EOL issue surrounding facing mortality...”

Factors Contributing to Comfort Level While Counseling EOL Patients

Comfortable Factors

One interesting finding was that a handful of participants reported that experiences gained either working as a genetic counselor in a different area of practice or in a different role or career that dealt with EOL issues added to their comfort level. Our data demonstrated that the average participant is likely to have worked previously, or is currently working simultaneously in practice areas other than cancer genetic counseling. This finding may indicate that broad experiences with critically ill or EOL patients, not just within the cancer genetic counseling setting, and even perhaps outside of genetic counseling altogether, can help increase comfort level when providing counseling to this patient population.

Uncomfortable Factors

Participants selected numerous factors that they felt made them uncomfortable while counseling EOL patients. It was not surprising to learn that the majority of respondents thought that factors which were more difficult to anticipate or control were the most likely to add to their discomfort. These included the increased emotional complexity, the uncertainty of the patients’ reactions to psychosocial counseling and family member dynamics. This suggests the importance of effective contracting and getting a sense of the patient and family’s needs and emotional states, which might also serve to decrease the likelihood of patients or family members introducing unanticipated topics during a counseling session. It was surprising that only half of the participants reported feelings of discomfort while counseling a visibly ill patient. It is
possible that visible illness isn’t as “jarring,” or doesn’t engender feelings of discomfort as much as we anticipated. However, a handful of participants expressed the increased difficulty and the resulting discomfort they felt with the patient’s visible illness as a factor within the session. The following quotes illustrates this viewpoint:

“For patients who are in a lot of pain it is challenging to see them struggle to listen carefully to what is being said.”

“Very often the EOL patient is not lucid, and that is difficult as they are your patient and so is the family member(s) however you are only able to communicate with the family members present.”

“Visible illness” is also a spectrum that includes a wide range of symptoms, so counselors may feel more comfortable counseling patients who are ill but able to participate fully in a session than those who are heavily medicated or in a progressed disease state, and therefore are represented by a healthcare proxy or family members.

**Potential Tools and Resources**

The majority of participants felt that more professional resources and opportunities to learn within their workplace would be helpful in increasing their comfort level when counseling EOL patients. The resources they suggested fell into three major categories: resources provided by a professional society such as webinars, educational sessions, workshops, or written guidelines; informational tools or written reports on patient perspectives developed by patients and their families; opportunities at the workplace for further education such as shadowing the palliative care team, social workers, psychologists and oncologists. Given the uncomfortable factors delineated by participants (increased emotional complexity, uncertainty of patients’ reactions to psychosocial counseling and complicated family dynamics), it seems that resources and guidelines developed to address these issues would be particularly valuable. Respondents also expressed interest in learning more from the patients and family members, although additional research would be required to explore such perspectives.
One-fifth of surveyed counselors felt additional training in graduate school would also be helpful in increasing comfort level. It is unknown how much exposure genetic counseling students have to EOL patient encounters, or how much classroom time is devoted to this specific patient population. Certainly, genetic counseling students see a wide range of patient indications during graduate school, though this might not include providing genetic counseling to EOL oncology patients for every student. One way for training programs to address the need felt among our participants would be by implementing standardized patient encounters through role-play or hired actors and providing feedback. Additionally, as supported by our data, counselors and students can increase their comfort level by encountering EOL patients in different practice areas or works setting, as these experiences with EOL patients, regardless of where they occur, are translatable.

**Hypothetical Scenarios**

The purpose of the first scenario was to assess the participants’ comfort levels with complex family dynamics and conflicting views on genetic testing. We observed that the majority of counselors were likely to- and comfortable with, discussing many of the topics with this EOL patient. There was one exception; that being a slightly higher number of counselors was unlikely to- and less comfortable with, addressing “Daughter B being far away from her mother during her mother’s illness/decline.” It is possible that, compared to other topics such as “reasons for not wanting to do genetic testing,” and addressing “family dynamics”, talking about Daughter B’s physical distance from their mother may seem like a judgment on the part of the counselor. Some genetic counselors may also feel that this is outside their scope of practice. The most pertinent uncomfortable factor in this scenario was the discordance between the two sisters’ opinions regarding genetic testing. In a session like this, there may be relationship factors
influencing the two sisters’ disagreement that go far beyond genetic testing or the session itself that would be difficult and uncomfortable for the counselor to address. However, this is not an uncommon situation; different family members can have different physical and emotional reasons to pursue or not pursue genetic testing. Given that this is a scenario that could easily arise when counseling EOL patients, we suggest that it may be helpful to develop guidelines that offer “things to consider” for this type of patient encounter.

Within the second scenario involving a visibly ill and upset patient, we observed a similar trend as the first scenario; most counselors were generally likely to- and comfortable with, discussing various topics with this hypothetical patient. While sessions with patients at this stage of their illness may be challenging for genetic counselors, most of our participants’ responses indicated they felt prepared to delve into the psychosocial aspects inherent in this situation. Addressing the patient’s fear of dying was the only exception. Although counselors were likely to address her fears, the majority of counselors were uncomfortable doing so. This is consistent with data from the study on grief and loss by Deeney, et.al, (2009) which demonstrated that young genetic counselors had the most difficulty with issues around death and dying. The discomfort level reported by respondents may stem from any number of sources including their own personal experiences and religious beliefs which participants Deeney’s study felt had both a positive and negative effect on their interactions with patients. It is also possible that genetic counselors consider “death and dying” to be a very personal issue and, for that reason, are less comfortable addressing it. Interestingly, despite the discomfort from respondents, many still reported that they were likely to discuss this with the patient.

We saw varied responses from participants regarding the third scenario, which involved a patient and his wife contemplating having children. In fact, more often than not, we observed the
opposite trend than seen in the first two scenarios; the majority of counselors were not likely to discuss half of the topics mentioned. We also saw that a greater number of counselors reported feeling uncomfortable with discussing more topics in this scenario than in the previous two. This suggests that this was the most uncomfortable EOL patient scenario. Setting realistic expectations for the patient and his wife, the decreased likelihood of future children, and the possibility of giving false hope to the patient and his wife were the factors that created discomfort among the highest number of respondents. One possible explanation for these findings is that most counselors have not had this type of discussion during a genetic counseling session and therefore might feel unsure about how they would proceed. The high degree of ambiguity and discordance between the patients’ thoughts and physical reality on having children, and possibly between expectations of the husband and his wife may also add to respondents’ reluctance to discuss many of the issues in this scenario. Being in any situation where one has to shatter a patient or family’s hopes and dreams is difficult for a genetic counselor. In this scenario, given that the patient is likely unable to have children, and his wife may be unaware or in denial of both this and his prognosis, this session would be especially challenging to maneuver, even for an experienced counselor.

Advice for Counseling EOL Patients

Analysis of open response data on advice for other cancer genetic counselors who might have encounters with EOL patients yielded a number of interesting themes.

“Let the patient guide the session”

One salient theme among the advice from many participants was the importance of allowing the patient to guide the session. Respondents discussed the value of coming into a session unassuming and flexible, instead of having set expectations of how the patient will
present. Participants advised that counseling this specific population is not a “traditional cancer
genetic counseling session,” and to be aware that not all EOL cases are identical given the
varying responses to prognosis, disease state and psychosocial factors at play:

“Most important: be very flexible and adapt the consult to each patient's specific needs and
concerns. Don't assume anything by reading the patient's chart beforehand [sic]; else you might
be in for a big surprise!”

“I try to let the patient/family guide me, even more so than with other patients. I need to know
where they are in their "acceptance" of their illness, what they understand, what they are willing
to understand. It helps give me a better basis to frame the conversation.”

Participants also advised that it is best to let what the EOL patient is saying and feeling guide
you and to be especially mindful of a patient’s emotions and physical state.

“...I say to pay extra attention to the patient's fears and worries.”

“...Try to constantly be aware of the patient's current state (whether or not the patient is acting
like they are aware of their poor prognosis). Be aware of family dynamics and have a plan in
place (some type of signed document can be helpful) as to who will receive results if the patient is
deceased prior to results disclosure. Make sure that person is aware of their role and the possible
call in a few weeks to discuss results.”

Tailor the counseling session

Another important theme in the advice participants offered was tailoring the conversation
and counseling for EOL patients. Participants spoke to the necessity of distilling what
information a patient really needs for informed consent. In general, participants expressed that
these counseling sessions were more likely to be psychosocial in nature and less so about
information giving, which is consistent with current literature. The following quotes emphasize
this theme:

“...Accept that this may have less genetic education than other sessions - ensure you give the
patient what they need.”

“Focus on what is important in that moment. It is NOT important to go through inheritance
patterns, the two hit hypothesis or even to take a full pedigree. Patients and families in this stage
have a lot of things to worry about, are speaking to so many different providers and may feel
physically ill or weak. Therefore, it is helpful for the counselor to present only the essential
information that the patient needs to know and focus the discussion on the things that are
important to that patient (whether it is discussing risk for family members, or simply talking about the blanket they are knitting for their grandchild).”

Attitude towards the counseling session

Lastly, many respondents discussed what type of attitude was most beneficial when counseling EOL patients. Participants felt it was crucial to act genuinely, compassionately and respectfully. Some respondents felt it was important to address EOL issues such as a patient’s progressed disease state or their prognosis as they felt this was “the elephant in the room.” Many mentioned however, that EOL patients were often aware of their prognosis and willing to delve into that piece of the conversation depending on their emotional state. This suggests that while genetic counselors may find that discussing prognosis is a challenging and emotionally difficult conversation, addressing the issue in a genuine and compassionate way may lead to a positive experience for both the counselor and the patient in the end. The following quotes support these ideas:

“While it is important to be professional, it is more important to remember to be human. A genuine, compassionate discussion will be much more rewarding for the patient and the GC than a discussion focused on the "science" of the testing…”

“Don't be afraid to address the elephant in the room. It can be scary to come out and say that someone may not be alive when genetic testing results are available, but in most cases, the patient is already thinking the same thing and may more appreciate a direct approach than beating around the bush or avoiding the discussion altogether. You're more prepared than you think, and being genuine and empathic to everything they're going through is the best way you can handle the situation.”

Given the issues that a patient and their loved ones are facing during this time, it is not difficult to imagine that they might see a genetic counseling session as “intrusive,” or “invasive.” However, our participants conveyed a similar idea to Daniels et al., (2011) who reasoned that genetic testing could be “a source for hope for a better outcome for their relatives than what they themselves are experiencing.” Therefore, going into a session with a positive attitude and portraying genetic counseling positively to patients and their families may help to make the
sessions more productive. One respondent advised against rushing, as one needs a respectful amount of time to counsel appropriately:

“Do not feel rushed when speaking with patients or their family members. I often felt that because the patients were dying that I shouldn't take up their time and I often would counsel too quickly when I first started in order to streamline the process…”

Another respondent advised on focusing on the patient:

“I advise focusing on how a genetic assessment may be helpful for the patient - for example, if they want to know why their cancer happened, or what it may mean for their relatives. This helps to cater the session, as well as helps in avoiding feeling like I'm "bothering" the patient, with adding yet another medical appointment.”

Lastly, one respondent echoed the aforementioned idea put forth by Daniels et al. Genetic counselors are there to help provide valuable information for the patient and their family members and their appointment is medically necessary.

“…And remember in the end it's better that they had genetic counseling than not, so just try your best and don't forget to process/debrief with a colleague afterwards.”

**Limitations**

This study had a number of limitations. It was limited by a small sample size (N=158) and therefore, our data may not be generalizable to all clinical cancer genetic counselors. There was also likely sampling bias, as most of our respondents were eager to complete the survey, with the vast majority completing it within a week of the survey opening. These participants may have, for reasons we do not know, been more inclined to share their experiences and give advice than those who did not participate. Additionally, not all respondents completed the open-ended response sections of our survey. Therefore, the themes that emerged may not be generalizable to our participant population or to cancer genetic counselors as a whole. A final limitation was recall bias, as our study did not observe or survey cancer genetic counselors who had recently
counseled an EOL patient in real-time. Rather, we asked our participants to reflect back on prior experiences, which may have been anywhere from 1-32 years in the past.

**Future Directions**

The future directions of this research are two-fold. The first are the aims of this researcher. Our study gathered additional data on cancer genetic counselors’ experiences with DNA banking and the patients’ health care proxies that we did not cover in this paper. Additionally, we requested that our participants describe an experience in which they provided cancer risk assessment and genetic counseling for an EOL patient. We received many anecdotes that were beyond the capacity of this work to include. This researcher aims to analyze further, the valuable stories and experiences shared with us by our participants.

Further studies in the future involving a larger sample size would aim to determine whether the results of this study are truly reflective and consistent with the experiences of a larger body of cancer genetic counselors. Additionally, since counseling EOL patients is not limited to cancer genetics, but occurs in all areas of the genetic counseling practice, it would be interesting to compare and contrast what themes emerge from separate studies surveying prenatal and pediatric genetic counselors. Studies looking at the experiences of families and EOL patients during counseling sessions would also be extremely valuable in rounding out our knowledge base. Finally, the information presented in this study can serve as a basis for developing formal guidelines for cancer genetic counselors when counseling their EOL patients.
**Conclusion**

To our knowledge, our study was the first to elucidate cancer genetic counselors’ experiences and comfort levels with providing risk assessment and genetic counseling services to EOL oncology patients. Our data demonstrated that cancer genetic counselors provide services for EOL patients although it is not a common occurrence for most practices. We did not observe a significant correlation between our participants’ years of experience and their comfort level discussing a number of counseling topics. However, we discovered that the most salient contributors to feelings of discomfort were factors that were more difficult to anticipate or control, such as the uncertainty of the patients’ reactions to psychosocial counseling. We also found, in the hypothetical scenarios, that discordance was more likely to cause discomfort in the majority of counselors; whether that be discordance between family members about whether to pursue genetic testing or discordance between patient’s desires and the reality of their situation. Counselors perceived a lack of professional resources and opportunities to learn more about EOL patient care and they had many suggestions on how to educate them and improve their comfort level when counseling these patients. Participants did say that they increased their comfort level by encountering EOL patients in different practice areas or jobs, and that this experience was translatable. The majority of counselors advised others, since this was not a traditional genetic counseling session, to approach these patients without expectations. They felt it was important to take cues from the patient and let that guide the session, to distill the information you give to the patient as much as possible and to recognize that it might be more pertinent to discuss psychosocial EOL issues. Lastly, respondents emphasized that, while genetic counseling for
these patients may feel intrusive, it is important to recognize the value it has in potentially uncovering life-saving information for unaffected family members.
References


perceived awareness of DNA testing and banking. *J Genet Couns, 19*(5), 497-525. doi:10.1007/s10897-010-9308-y


Subject: Genetic Counselors’ Comfort Level, Attitudes and Experiences Providing Cancer Risk Assessment and Counseling for End-of-life Patients

Seeking Current or Previous Cancer Genetic Counselors to Participate in a Research Study

You are invited to participate in an online research study to investigate cancer genetic counselors’ comfort levels, attitudes, and conversations with end-of-life, palliative care cancer patients. As part of my Master’s thesis at Brandeis University, I am seeking to:

1. Investigate clinical cancer genetic counselors’ experiences and comfort levels with counseling patients who are visibly ill and have a poor prognosis, on issues including family planning, risks to offspring and genetic testing or DNA banking
2. Investigate the experiences and comfort levels of clinical cancer genetic counselors when discussing providing risk assessment and counseling to their patients’ health care proxy.

This study is open to clinical genetic counselors who currently work, or have worked, in the cancer genetic counseling setting and have counseled “end-of-life,” cancer patients either in person or over the phone.

This anonymous survey will take an average of 20 minutes of your time. All participants who complete the survey are eligible to enter a drawing for one of three $50 Amazon.com gift cards. If you choose to enter the drawing, you will be directed to a separate survey to provide your email address. This is to ensure that your survey responses will not be connected to your email address.

This study was reviewed and approved by the Brandeis University Institutional Review Board. If you have any questions or concerns, please do not hesitate to contact me (nsyang4@brandeis.edu) or the Principal Investigator Gretchen Schneider MS, CGC (gretchen@brandeis.edu) by email.

If you wish to participate in the study, please click on the link provided below. Thank you in advance for your time and participation.

Please click here to take the survey. https://brandeis.qualtrics.com/jfe/form/SV_4IrPolOKtnCmXY1

Sincerely,

Nicole Yang
Master’s Degree Candidate, Class of 2017
Genetic Counseling Program
Brandeis University

Gretchen Schneider, MS, CGC
Licensed Genetic Counselor
Genetic Counseling Program
Brandeis University
Reminder e-blast

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Licensed Genetic Counselor
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Appendix B: Study Instrument

Section 1 - Inclusion criteria, demographic information & About the GC

Welcome! You are invited to participate in this study because you have worked, or are currently working as a clinical cancer genetic counselor and have counseled “end-of-life,” cancer patients either in person or over the phone. The purpose of this study is to investigate cancer genetic counselors’ comfort levels, attitudes, and conversations with end-of-life, palliative care cancer patients. As part of my Master’s thesis at Brandeis University, I am seeking to: 1. Investigate clinical cancer genetic counselors’ experiences and comfort levels in counseling patients, who are visibly ill and have poor prognoses on issues including family planning, risks to offspring and genetic testing or DNA banking 2. Investigate the experiences and comfort levels of clinical cancer genetic counselors when discussing providing risk assessment and counseling to their patients’ health care proxy. Your responses to this online survey will be anonymous and will take an average of 20 minutes of your time. Participation in this survey is voluntary. You may skip any question you do not feel comfortable answering, or you may exit the survey at any time. Please only take this survey once. Participants may benefit from our study by feeling that they are contributing to the genetic counseling and scientific literature. The risks to our participants are minimal, however, potential risks could include feeling distressed when answering questions about various terminally ill, "end-of-life" patient encounters. All participants who complete the survey are eligible to enter a draw for one of three $50 Amazon.com gift cards. If you enter the drawing, you will be directed to a separate survey to provide your email address. This is to ensure that your survey responses will not be connected to your email address. The Brandeis University Institutional Review Board reviewed and approved this study. If you have any questions or concerns, please do not hesitate to contact me (nsyang4@brandeis.edu) or the Principal Investigator Gretchen Schneider MS, CGC (gretchen@brandeis.edu) by email.

By clicking "Yes, I consent!" you acknowledge that you have read the information above and you consent to participate in this survey.

☐ Yes, I consent! (1)

☐ No, thank you. (2)

Q1 Do you currently work, or have previously worked, as a cancer genetic counselor? (Full-time or part-time)

☐ Yes (1)

☐ No (2)
Q2 Our study defines an end-of-life or, "EOL" patient as: *A cancer patient who is diagnosed with a terminal, late stage cancer.*

Q3 As a cancer genetic counselor, have you seen/counseled an EOL patient?

- Yes (1)
- No (2)

Q4 In which geographical area do you currently practice genetic counseling?

- Region 1: CT, MA, ME, NH, RI, CT, CN, Maritime Provinces (1)
- Region 2: DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec (2)
- Region 3: AL, FL, GA, KY, LA, MS, NC, SC, TN (3)
- Region 4: AR, IA, IL, KS, MI, MN, MO, ND, NE, OH, OK, SD, Wi, Ontario (4)
- Region 5: AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan (5)
- Region 6: AK, CA, HI, ID, NV, OR, WA, British Columbia (6)
- Non- U.S. or Canada (7)
Q5 Please tell us your age.

- 20-30 (1)
- 31-40 (2)
- 41-50 (3)
- 51-60 (4)
- 61-70 (5)
- 71+ (6)

Q6 Please tell us your gender.

- Male (1)
- Female (2)
- Prefer not to answer (3)

Q7 How many years have you been practicing as a genetic counselor?

Q8 How many years have you been practicing as a CLINICAL CANCER genetic counselor?
Q9 What proportion of patients do you see in the following practice areas? Your values must total 100%. Example: If you spend 100% of your time in clinical cancer, slide the bar beside cancer to 100%.

- Cancer (1)
- Prenatal (2)
- Preconception (3)
- Pediatrics (4)
- General Genetics (5)
- Adult (including complex diseases) (6)
- Cardiology (7)
- Research (8)
- Other: (9)

The rest of the survey will pertain to your work, and the patients you see, within the clinical cancer genetic counseling setting.

Q10 Approximately how many INITIAL patients do you see for cancer risk assessment and genetic counseling per week?

- 0-5 patients/week (1)
- 6-10 patients/week (2)
- 11-15 patients/week (3)
- 16-20 patients/week (4)
- 21-25 patients/week (5)
- 26+ patients/week (6)
Q11 Of the INITIAL patients you provide cancer risk assessment and genetic counseling for, approximately how many EOL patients do you see per week?

- 0-2 patients/week (1)
- 3-4 patients/week (2)
- 5-6 patients/week (3)
- 7-8 patients/week (4)
- 9-10 patients/week (5)
- 11+ patients/week (6)

End of Block

Section 2 - Talking with EOL patients

Q12 Which of the following individuals refer the EOL patients that you counsel? Please select all that apply.

- Oncologists (1)
- Palliative care team (2)
- Self-referred (3)
- Patient's family member (4)
- Other: (5) ____________________________
Q13 Which of the following individuals most often refer the EOL patients that you counsel? Please click and move to rank from 1= most often to 5= least often.

____ Oncologists (1)
____ Palliative care team (2)
____ Self-referred (3)
____ Patient's family member (4)
____ Other: (5)

Q14 In which of the following locations do you counsel your EOL patients? Please select all that apply.

☐ Clinic (1)
☐ Inpatient ward (2)
☐ Long-term care facility (3)
☐ Patient's home (4)
☐ Other: (5) ___________________

Q15 In which of the following locations do you most often counsel your EOL patients? Please click and move to rank from 1=most often to 5= least often.

____ Clinic (1)
____ Inpatient ward (2)
____ Long-term care facility (3)
____ Patient's home (4)
____ Other: (5)
Q16 How frequently do you discuss each of the following topics with the EOL patients you counsel?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Never (1)</th>
<th>Sometimes (2)</th>
<th>About half the time (3)</th>
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<td>Benefits and limitations of genetic testing (4)</td>
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<td>Genetic testing results (5)</td>
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<td>Support services for the patient and/or their family members (6)</td>
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<td>Patient's emotional state/feelings about their poor prognosis (7)</td>
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</table>
Q17 What is your COMFORT LEVEL when speaking to EOL patients about the following topics?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Extremely uncomfortable (1)</th>
<th>Somewhat uncomfortable (2)</th>
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Q18 Please list any additional topics not captured in the previous two questions that you have discussed with your EOL patients, and whether or not you were comfortable addressing those topics.
Q19 Which of the following have helped you be more comfortable as a cancer genetic counselor when counseling EOL patients? Please select all that apply.

☐ Previous professional experience(s) providing genetic counseling for EOL patients (1)

☐ Previous personal experience(s) with loss (i.e. family member who passed away) (2)

☐ Opportunities to discuss/process with other genetic counselors (3)

☐ Opportunities to discuss/process with other medical specialists who are not genetic counselors (4)

☐ Written resources to help process difficult cases (5)

☐ Graduate school training specific to counseling EOL patients (6)

☐ Information gathered from professional meetings e.g. NSGC, CAGC, etc (7)

☐ Consulting with or attending lectures given by the palliative care team, psychology staff and/or social work team (8)

☐ Other: (9) ________________________________________________
Q20 Of your chosen responses, which of the following have been the most helpful when counseling EOL patients? Please click and move to rank, 1 = most helpful.

______ Previous professional experience(s) providing genetic counseling for EOL patients (1)
______ Previous personal experience(s) with loss (i.e. family member who passed away) (2)
______ Opportunities to discuss/process with other genetic counselors (3)
______ Opportunities to discuss/process with other medical specialists who are not genetic counselors (4)
______ Written resources to help process difficult cases (5)
______ Graduate school training specific to counseling EOL patients (6)
______ Information gathered from professional meetings e.g. NSGC, CAGC, etc (7)
______ Consulting with or attending lectures given by the palliative care team, psychology staff and/or social work team (8)
______ Other: (9)

Q21 Which of the following factors make you uncomfortable when counseling EOL patients? Please select all that apply.

☐ Lack of professional experience(s) providing genetic counseling for EOL patients (1)
☐ Increased emotional complexity of counseling EOL patients (2)
☐ Lack of training, graduate school or other specific to counseling EOL patients (3)
☐ Effect of emotions from own experiences of loss (4)
☐ Difficulty of counseling a patient who is visibly very ill (5)
☐ Uncertainty surrounding patient reactions to counseling (6)
☐ Concern about family member dynamics (7)
☐ Other: (8) ________________________________________________
Q22 Please rank your chosen responses from MOST comfortable to LEAST comfortable. Please click and move to rank, 1 = most comfortable

_____ Lack of professional experience(s) providing genetic counseling for EOL patients (1)
_____ Increased emotional complexity of counseling EOL patients (2)
_____ Lack of training, graduate school or other specific to counseling EOL patients (3)
_____ Effect of emotions from own experiences of loss (4)
_____ Difficulty of counseling a patient who is visibly very ill (5)
_____ Uncertainty surrounding patient reactions to counseling (6)
_____ Concern about family member dynamics (7)
_____ Other: (8)

Q23 What additional resources and tools would be helpful in increasing your comfort level when counseling EOL patients?
Q24 What mechanisms do you use to process after providing risk assessment and genetic counseling to EOL patients? Please select all that apply.

☐ Informal discussion/processing of cases with other genetic counselors (1)

☐ Informal discussion/processing of cases with other medical specialists who are not genetic counselors (2)

☐ Discussion/processing cases at interdisciplinary team meetings (3)

☐ Discussion/processing in formal peer process groups (4)

☐ Discussion/processing with a partner, friend or family member (5)

☐ Self-care activities that reduce stress (e.g. exercise, journaling) (6)

☐ Other: (7) ________________________________________________

The next section will explore EOL patients and their experiences with genetic testing and/or DNA banking.

Q25 When you discuss genetic testing with EOL patients, how often do they opt for testing?

☐ Never (1)

☐ Sometimes (2)

☐ About half the time (3)

☐ Most of the time (4)

☐ Always (5)
Q26 For EOL patients who chose genetic testing, please rank the reasons they cited from the most to least common. Please click and move to rank, from 1= most common to 6= least common.

_____ Would be valuable information for their children (1)
_____ Would be valuable information for other family members (2)
_____ Important for patient to know their own mutation status (3)
_____ Prefer DNA testing to DNA banking (4)
_____ Pressure from family members (5)
_____ Other: (6)

Q27 For those patients who declined genetic testing, please rank the reasons they cited from the most to least common. Please click and move to rank from 1= most common to 6= least common.

_____ Did not think that it would be valuable information for them (1)
_____ Did not think it would be valuable for their family members (2)
_____ Felt too overwhelmed or emotion to make decisions at that time (3)
_____ Preferred DNA banking to genetic testing (4)
_____ Discovered testing was not covered by insurance/too expensive (5)
_____ Other: (6)

Q28 How often do your EOL patients opt for DNA banking?

- Never (1)
- Sometimes (2)
- About half the time (3)
- Most of the time (4)
- Always (5)
Q29 You selected that you do not offer DNA banking services to your EOL patients. Please tell us why.

☐ Regulation set by our institution (1)

☐ Limited resources or time to offer DNA banking services (2)

☐ Other: (3) ________________________________________________

Q30 For EOL patients who chose DNA banking, please rank the reasons they cited from the most common to the least common. Please click and move to rank from 1 = most common to 6 = least common.

_____ Felt DNA could be used for future testing and provide valuable information for family members (1)

_____ Preferred DNA banking to genetic testing (2)

_____ Discovered DNA testing was not covered by insurance/too expensive (3)

_____ Was not sure whether they would live long enough to receive the results (4)

_____ Had sample collected after previous testing was negative or uninformative (5)

_____ Other: (6)

Q31 For EOL patients who declined DNA banking, please rank the reasons they cited from the most common to the least common. Please click and move to rank from 1 = most common to 5 = least common.

_____ Preferred genetic testing to DNA banking (1)

_____ Did not think that DNA banking will provide valuable information to family members in the future (2)

_____ Felt too overwhelmed or too emotional to make a decision (3)

_____ Thought DNA banking was too expensive/don't wish to pay out-of-pocket (4)

_____ Other: (5)
Q32 How often do your counseling sessions with EOL patients include their:

<table>
<thead>
<tr>
<th></th>
<th>Never (1)</th>
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<tr>
<td>Partner (1)</td>
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<td>Children (2)</td>
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<td>Siblings (3)</td>
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<td>Parents (4)</td>
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<td>Health care proxy (5)</td>
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<td>Palliative care team members (6)</td>
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<td>Other: (7)</td>
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</table>
### Q33 When you are speaking with your EOL patient's health care proxy, how often you do discuss the following topics?

<table>
<thead>
<tr>
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<tr>
<td>Benefits and limitations of genetic testing (4)</td>
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<tr>
<td>Results of previously ordered genetic testing (if any) (5)</td>
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<tr>
<td>DNA banking options (6)</td>
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</table>
Q34 What is your comfort level with speaking to the patient's health care proxy about the following topics?

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<thead>
<tr>
<th></th>
<th>Extremely uncomfortable (1)</th>
<th>Somewhat uncomfortable (2)</th>
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Q35 What are some of the difficulties you face while speaking to the patient's health care proxy?
Section 4 - Scenario Intro and Scenario 1 block

The following section involves scenarios providing genetic counseling for EOL patients. Please read each scenario and answer the questions to the best of your ability.

Q36 1. A 35-year old male has been referred to your clinic. His clinical symptoms are consistent with Li-Fraumeni syndrome and he is terminally ill. He has been referred for TP53 testing. He and his wife attend the counseling session. During the session, the patient's wife raises the topic of future children. They do not have any children together or from any prior relationships. She states: "if it's possible, we're hoping to have children."
Q37 How likely would you be to include the following in your counseling of this patient and his wife?

<table>
<thead>
<tr>
<th></th>
<th>Extremely unlikely (1)</th>
<th>Somewhat unlikely (2)</th>
<th>Neither likely nor unlikely (3)</th>
<th>Somewhat likely (4)</th>
<th>Extremely likely (5)</th>
</tr>
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<tbody>
<tr>
<td>Exploring the couple's thoughts and feelings about having children (1)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Exploring the couple's thoughts and feelings about the patient's infertility (2)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Exploring the idea of wife parenting alone (3)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Deferring to the patient's oncologist (4)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Speaking with them about IVF/PGD services (5)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Referring them to a fertility specialist (6)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Other: (7)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Q38 How COMFORTABLE would you be including each of the following in your counseling of the patient and his wife?

<table>
<thead>
<tr>
<th></th>
<th>Extremely uncomfortable (1)</th>
<th>Somewhat uncomfortable (2)</th>
<th>Neither comfortable nor uncomfortable (3)</th>
<th>Somewhat comfortable (4)</th>
<th>Extremely comfortable (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploring the couple's thoughts and feelings about having children (1)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Exploring the couple's thoughts and feelings about the patient's infertility (2)</td>
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<td>○</td>
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<td>○</td>
</tr>
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<td>Deferring to the patient's oncologist (4)</td>
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<td>○</td>
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</tr>
<tr>
<td>Other: (7)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q39 What factor(s), if any, make you uncomfortable about this session with the patient and his wife? Please select all that apply.

☐ The patient's infertility and termially ill status makes it unlikely for future children (1)

☐ Not enough knowledge regarding the current status of IVF/PGD services available to terminally ill cancer patients to provide for the patient and his wife (2)

☐ The possibility of giving false hope to the patient and his wife (3)

☐ Setting realistic expectations for the patient and his wife (4)

☐ Exploring the couple's thoughts/feelings about having children, infertility and/or parenting alone, is outside my jurisdiction of practice as a genetic counselor (5)

☐ The conversation about infertility is outside the scope of practice (6)

☐ Other: (7) ________________________________________________

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Block 7 - Scenario 2

Q40 An 65-year old female has been referred to your clinic. She is a terminally ill, pancreatic cancer patient. She is unable to make her own decisions due to her disease progression. Her two daughters are with her during her appointment. Daughter A currently lives with the mother, provides all of her care and is the mother's health care proxy. Daughter B lives on the other side of the country. Daughter A says she wants genetic testing done on their mother, but Daughter B disagrees. Daughter A argues that she is the health care proxy, and has provided all of their mother's care during her decline, a comment which Daughter B says is hurtful.
Q41 How likely are you to explore each of the following during your counselling session with this family?

<table>
<thead>
<tr>
<th></th>
<th>Extremely unlikely (1)</th>
<th>Somewhat unlikely (2)</th>
<th>Neither likely nor unlikely (3)</th>
<th>Somewhat likely (4)</th>
<th>Extremely likely (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasons behind wanting/not wanting genetic testing for their mother (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoughts/feelings about their mother's declining health (2)</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Stress of Daughter A providing care for their mother and her role as health care proxy (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Family dynamics (4)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Daughter B being far away from her mother during her illness/decline (5)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usefulness of social services or other resources (6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: (7)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q42 How COMFORTABLE would you be exploring the following in your counseling session with this family?

<table>
<thead>
<tr>
<th>Reasons behind wanting/not wanting genetic testing for their other (1)</th>
<th>Extremely uncomfortable (1)</th>
<th>Somewhat uncomfortable (2)</th>
<th>Neither comfortable nor uncomfortable (3)</th>
<th>Somewhat comfortable (4)</th>
<th>Extremely comfortable (5)</th>
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<tr>
<td>Other: (7)</td>
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</tbody>
</table>
Q43 What factor(s), if any, make you uncomfortable about this patient, her daughters and/or this session? Please select all that apply.

☐ The patient is heavily medicated and unable to engage in the session (1)

☐ There is disagreement between the two sisters regarding performing genetic testing on their mother (2)

☐ As health care proxy, Daughter A is ultimately the decision-maker (3)

☐ Daughter B is hurt by her sister pointing out that she has not been present during her mother's illness (4)

☐ Other: (5) ________________________________________________

End of Block

Block 8 - Scenario 3

Q44 A 45-year old female has been referred to your clinic. She is a terminally ill, ovarian cancer patient. You go to meet with her at the in-patient wing. Immediately, you notice that she is visibly ill and has a wheelchair in the corner of her room. You have been told by the nurses that she does not have many weeks to live. During the session, you explain the purpose of your visit and discuss the details of genetic testing/DNA banking. The patient states that she is happy to undergo testing for the sake of her children. However, she raises the concern that she will not be alive to receive her results. Your patient starts to become upset and says, "I am afraid of dying."
Q45 How likely would you be to explore the following during your session with this patient?

<table>
<thead>
<tr>
<th></th>
<th>Extremely unlikely (1)</th>
<th>Somewhat unlikely (2)</th>
<th>Neither likely nor unlikely (3)</th>
<th>Somewhat likely (4)</th>
<th>Extremely likely (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient's thoughts and feelings about not being alive to receive her test results (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient's fears about dying (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient's support network—partner, children, other family, friends, etc. (3)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utility of referral to social services or other resources (4)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: (5)</td>
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<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Q46 How COMFORTABLE would you be exploring the following in your counselling of this patient?

<table>
<thead>
<tr>
<th></th>
<th>Extremely uncomfortable (1)</th>
<th>Somewhat uncomfortable (2)</th>
<th>Neither comfortable nor uncomfortable (3)</th>
<th>Somewhat comfortable (4)</th>
<th>Extremely comfortable (5)</th>
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<td>○</td>
<td>○</td>
</tr>
<tr>
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<td>○</td>
<td>○</td>
<td>○</td>
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</tr>
<tr>
<td>Patient's support network - partner, children, other family, friends, etc. (3)</td>
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<td>○</td>
<td>○</td>
<td>○</td>
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</tr>
<tr>
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<td>○</td>
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<td>○</td>
</tr>
<tr>
<td>Other: (5)</td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tr>
</tbody>
</table>
Q47 What factors (if any) make you feel uncomfortable about this patient and this session? Please select all that apply.

☐ Patient is visibly ill (1)

☐ Knowledge of her limited time (2)

☐ Patient's concern that she will not be alive to receive her results (3)

☐ Patient becoming upset (4)

☐ Patient's fear of dying (5)

☐ Other: (6) ________________________________________________

End of Block

Block 9 - Wrap up scenario question

Q48 Please describe an experience in which you provided cancer risk assessment and counselling for an EOL patient. What factors made the session comfortable or uncomfortable for you? Do you wish that you had said/done anything differently? If so, what?

_________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

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_________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

Q49 What advice would you give to genetic counselors who are providing risk assessment and genetic counseling to EOL patients for the first time?
Section 4 - Survey completion

Thank you for completing this survey! If you would like to be entered for a chance to win a $50 Amazon gift card, select "yes," and you will be directed to another survey to fill out the appropriate information. The information that you provided in this survey will not be linked to the draw.

☐ Yes, please! (1)

☐ No, thank you. (2)