I, Katherine B. Armstrong, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:
The Genetic Counseling Experience in a Multidisciplinary Childhood Cancer Survivor Center

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This work and its defense approved by:

Committee chair: Rajaram Nagarajan, MD
Committee member: Debra Kent, MSN
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The Genetic Counseling Experience in a Multidisciplinary Childhood Cancer Survivor Center

A thesis submitted to the Graduate School of the University of Cincinnati in partial fulfillment of the requirements for the degree of Master of Science

In the Department of Pediatrics of the College of Medicine

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by

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Abstract

Background. The majority of children who are diagnosed with cancer are surviving into adulthood, which has led to the development of a specialized area of multidisciplinary healthcare specific to cancer survivorship and focuses on detection, provision of care, and counseling for the survivor regarding the late effects of therapy. In 2007, the Cincinnati Children’s Hospital Medical Center (CCHMC) Cancer Survivor Center (CSC) added a certified genetic counselor to provide genetic risk assessment for hereditary cancer syndromes and genetic counseling to pediatric cancer survivors and their families. Methods. Survivors in the CSC who were at least eighteen years old (N=75) and the parent/caregiver of survivors under the age of eighteen (N=39) were asked about their genetic counseling experience through a paper or online questionnaire. In addition, 148 survivors and parents/caregivers who had not received genetic counseling were surveyed. All participants were also asked their opinion of the most appropriate time for childhood cancer survivors to receive genetic counseling. Results. Most participants expressed satisfaction with the genetic counseling service (82% of survivors and 89% of parents/caregivers), and 78% of survivors and 74% of parents/caregivers found the information useful. Overall, about 40% of patients and parents/caregivers indicated that they would have preferred genetic counseling 1-5 years after the completion of cancer treatment, but the remaining participants were split in determining the most appropriate time to receive genetic counseling in relation to the time of diagnosis and during cancer treatment. Conclusions. This study reveals that genetic counseling in a pediatric cancer survivor clinic is a desired and valuable service. Discussion of the impact of a family history of cancer and the presence of hereditary cancer syndromes should begin around the time of the childhood cancer diagnosis and should be revisited throughout and after the child’s cancer treatment.
Keywords: childhood cancer survivor, multidisciplinary care, genetic counseling, patient satisfaction
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Background

Pediatric Cancer Survivorship

Approximately 12,400 children and adolescents are diagnosed with cancer each year in the United States, and fortunately nearly 80% are cured as a result of improved treatments, including chemotherapy, surgery, and radiation therapy, and advances in supportive care and radiology [1-3]. This growing number of survivors has generated a new concern related to secondary effects of the survivors’ cancer treatments [4-7]. Therefore, childhood and adolescent cancer survivors require comprehensive follow-up care in order to detect and manage late-onset effects and specialized long term care and to assure effective health management [8].

Some survivors are also at risk for second malignancies due to underlying hereditary cancer syndromes, which account for up to 10% of childhood cancers [9-10]. Of note, a recent study of pediatric cancer survivors in a large cancer survivor center revealed that 29% of patients qualified for a genetics follow-up evaluation based largely on features of family history, the patient’s medical history, as well as specific tumor types [11]. Children with hereditary cancer syndromes should have access to specialized care so that they receive appropriate surveillance, along with management of syndrome-related risks and complications, for themselves and for their family members [12].

Assessment of patients’ perspectives of genetic counseling

Genetic counseling has become more important in the care of cancer survivors and their families as the knowledge of hereditary cancer syndromes and the access to genetic testing has become more widely available. Braithwaite, et al., proposed that “for genetic counseling to be considered effective, there needs to be evidence that it improves the accuracy of an individual’s
perceived likelihood of developing the disease and his or her knowledge of the disease genetics with no adverse emotional impact” such as increased worry [13].

Research has assessed patient perspective and satisfaction with many types of genetic counseling, including cancer genetic counseling [14-17]. One such study, led by DeMarco, et al., developed the Genetic Counseling Satisfaction Scale (GCSS) to assess a sample of 61 women undergoing counseling and genetic testing for hereditary breast and ovarian cancer. Results showed that patients were highly satisfied in each of the areas assessed including feeling equipped to make decisions, feeling understood by the genetic counselor, and feeling better about their health [17]. In another study by Li, et al., after parents of children with hearing loss received education from a genetic counselor, they expressed increased motivation to follow through with genetic testing because of their strong belief in the benefits of genetic testing and were more likely to attribute hearing loss to genetic causes [18].

Research has also shown that genetic counseling can result in a decreased perceived risk and level of anxiety/worry for women with a personal or family history of breast cancer [16,19-20]. One study reported no change in overall distress before and after seeing a genetic counselor, but reported a significant reduction in the perceived likelihood of being a carrier of the cancer-causing genetic mutation [19]. Bjorvatn, et al., found that patients significantly overestimated their own risk of developing cancer before their genetic counseling session when compared to after the session. Additionally, a statistically significant difference was observed and revealed a decreased level of worry before and after the session [16]. Another study described only a slight decrease in anxiety level but showed that the women’s perceived risk of developing cancer shifted to be more accurate after they received genetic counseling [20].
The goals of this study were to: 1) assess the perspectives of childhood cancer survivors and their parents/caregivers on the value and usefulness of the genetic counseling they received and 2) compare the perceived risk and associated level of worry related to cancer development in the cancer survivor and in other family members between those who had and had not received genetic counseling.

Methods

Study Population

This study was conducted at CCHMC between September 2011-May 2012 with approval from the Institutional Review Boards at CCHMC and the University of Cincinnati. Inclusion criteria included childhood cancer survivors who were at least five years past the date of their diagnosis and two years post cancer treatment being followed in the CCHMC CSC (presenting at least once to the CSC since January 2001). The participants were the survivors who were at least 18 years old or the parents/caregivers of survivors younger than 18 years old. Patients with a known diagnosis of a genetic disorder or who reported to have had a genetics appointment previous to their meeting with the genetic counselor in the CSC were excluded from this study. Other exclusion criteria included not being able to read English and being unable to complete the questionnaire.

Some potential participants spoke with a certified genetic counselor during an annual appointment in the CSC since March 2007. Therefore, we evaluated four study groups within the target population: those under and over 18 years of age who had and had not received genetic counseling. Of the patients who were at least 18 years old, 329 had not received genetic counseling, and 210 had received genetic counseling. Patients under the age of 18 were not able to participate, so their parents/caregivers were asked to complete the questionnaire. In this group,
142 had not received genetic counseling, and 112 had received genetic counseling. Actual responses are shown in Table I. The patients’ ages were calculated at the time the questionnaires were mailed out in September 2011. Parents/caregivers of patients over the age of 18 were not surveyed in this study.

In addition, the participants who received genetic counseling were stratified into two groups: those who were at an increased risk to have a hereditary cancer syndrome and were given follow-up recommendations and those who were at a lower risk for a hereditary cancer syndrome and did not require further follow-up at that time. The genetic counselor determined which category to place participants into based on the personal and family histories of cancer and published literature. Participants who had not received genetic counseling could not be categorized due to insufficient information.

**Procedures**

The participants were mailed a questionnaire which was designed by the study staff for each of the four groups (see Supplemental Appendices I-IV). Versions of the questionnaire included questions designed by the study staff as well as previously validated questions from published studies. Questions from Lerman’s Cancer Worry Scale (CWS) were used to measure the level of worry related to cancer development [21]. As the CWS is specific to breast cancer, the questions were modified to include all forms of cancer. Questions to measure perceived risk of cancer development were based on those found in a study that measured perceived risk of breast cancer development in daughters of mothers with a personal history of breast cancer [22]. Perceived risk was assessed by asking responders their beliefs about the likelihood that the childhood cancer survivor or other family members would develop a subsequent cancer. For those participants who received genetic counseling, several questions based off of Shiloh’s
validated Satisfaction with Genetic Counseling Scale were used to assess patients’ and their parent/caregiver’s satisfaction with the genetic counseling session and the usefulness of the information that was received [15].

The study staff designed additional questions for the patients who had not received genetic counseling in the CSC to measure their desire to receive genetic counseling. If participants who had received genetic counseling did not recall this encounter, they were instructed to skip the questions regarding their genetic counseling experience. Demographic questions included the age and gender of the parent/caregiver (for the parent/caregiver questionnaires), level of education, and marital status.

The questionnaires were pre-tested by cancer survivors in the CSC. They responded to the surveys and reported no recommendations for changes. These survivors were no longer eligible to participate in the actual study. Paper copies of the questionnaires and a letter of invitation were then mailed to eligible participants. The letter contained all of the necessary elements of consent, which waived the documentation of consent. Completing and returning the surveys was accepted as the participant’s consent to participate. Identification codes were used to link the responder to his/her demographic information extracted from the databases noted below.

The initial mailing was followed four weeks later with a reminder postcard to nonresponders, inviting participation by either answering the paper questionnaire, or via an identical online version of the questionnaire that was created using Research Electronic Database Capture (REDCap™). REDCap™ is a secure, web-based database that includes an interface for data entry and online surveys, audit trails that will track changes made to the data, export procedures to common statistical software, and importation capabilities. Data collected from the
completed paper and online questionnaires was recorded and stored in REDCap™ hosted at CCHMC.

In addition to the responses collected by questionnaire, the primary investigator (PI) accessed the CSC database to obtain information on participants which included gender, address, ethnicity, type of childhood cancer, patient’s age at diagnosis of the childhood cancer, patient’s date of birth, medical record number, and any notes mentioned in the “Genetic Comments” section of the database. Some patients had recurrent cancers in childhood and/or adulthood while others have been diagnosed with one single childhood cancer. Therefore, the number of years since the patient’s cancer diagnosis was measured using the patient’s age at the most recent cancer diagnosis. Additionally, the PI accessed a clinical database that was started in March 2007 by the genetic counselor who provided genetic counseling services to patients in the CSC. The database included a list of the patients who had received genetic counseling and the date of their visit, important information gathered during the session, and any recommendations that were given to the patients.

*Statistical Methods*

Data were summarized using mean, standard deviation, and range for continuous variables and percentage and frequency for categorical variables. Where appropriate, the proportions were compared with various statistical methods including Pearson’s chi-square and Fisher’s exact tests (both two-tailed). $P<0.05$ was considered to be significant. Statistical analysis was performed using R statistical software (http://cran.r-project.org).

*Results*

*Demographics*
Parents/caregivers who participated were primarily female (92%) and Caucasian (95%) ranging from age 30 to 67 (Table II). Childhood cancer survivors (patients) who participated were primarily Caucasian (95%) with 57% females ranging from age 18 to 58. The mean number of years since the patient’s most recent cancer diagnosis was 14.4±7.3 years. The most commonly diagnosed cancers were acute lymphoblastic leukemia (ALL), neuroblastoma, and Hodgkins disease.

**Genetic Counseling Outcome**

Of participants who recalled their genetic counseling session, 41 (82%) patients and 24 (89%) parents were very or somewhat satisfied with the genetic counseling (Table III). Fifty-one (76%) patients and 29 (76%) parents did not express specific interest in or need for an additional consultation with the genetic counselor. Moreover, 39 (78%) patients and 20 (74%) parents found genetic counseling to be very or somewhat useful. Of the participants who had not received genetic counseling, 36 (37%) patients and 21 (47%) parents expressed an interest in receiving genetic counseling. When asked their opinion of the best time for childhood cancer survivors and/or their families to speak with a genetic counselor, 21 (26%) parents felt that it would be at the time of their child’s cancer diagnosis. Thirty-two (40%) parents felt that they would have preferred genetic counseling 1-5 years after the completion of the child’s cancer treatment while 24 (30%) would have preferred it sometime during the child’s cancer treatment. Patients diagnosed with cancer at or after fourteen years of age responded similarly with 15 (33%) at the time of diagnosis, 19 (41%) indicating they would have preferred genetic counseling 1-5 years after their cancer treatment, and 9 (20%) during treatment. As shown in Table III, the majority of participants stated that they were not aware of the possibility of hereditary childhood cancer syndromes at the time of the childhood cancer diagnosis.
Perceived Risk

Study participants were asked how likely they thought the childhood cancer survivor was to develop a subsequent cancer at some point in their lives. As shown in Table IV, of the patient participants, 55 (56%) of those who had not received genetic counseling and 35 (47%) who had received genetic counseling believed that they were very likely or likely to develop another cancer. Of the parents, 23 (50%) of those who had not received genetic counseling and 23 (61%) of those who had received genetic counseling suspected that their child was very likely or likely to develop a subsequent cancer. When asked about their perceived risk of developing another cancer in comparison to the occurrence of cancer in the survivor’s peers, 104 (60%) patients and 63 (73%) parents perceived the survivor’s risk to be a lot higher or higher (Table V). None of the reported comparisons were statistically significant.

The participants who received genetic counseling were then stratified into two groups based on the likelihood of having a hereditary cancer syndrome. Of patients, 8 (53%) in the increased risk category and 27 (46%) in the low risk category reported that they thought they were very likely or likely to develop another cancer in their lifetime (Table VI). Eleven (73%) patients in the increased risk category and 31 (52%) in the low risk category thought that their chance to get an additional cancer was a lot higher or higher than their peers. Also, 7 (78%) parents with children who were placed in the increased risk category and 16 (55%) in the low risk category considered their children to be very likely or likely to develop an additional cancer. When asked about their children’s compared risk, 8 (89%) parents with children at increased risk and 21 (70%) of the low risk group thought their child had a lot higher or higher risk to develop a subsequent cancer.

Level of Worry
Participants were asked about the level of worry that they experienced regarding subsequent cancer development. Table IV shows thirty-six (36%) patients who had not received genetic counseling and 18 (24%) who had received genetic counseling worried all the time or often. Of parents, 18 (39%) of those who had not received genetic counseling and 13 (33%) who had received genetic counseling worried all the time or often about their child developing another cancer. In regards to their own children developing cancer, 20 (27%) patients who had not received genetic counseling and 14 (26%) who had received genetic counseling worried all the time or often. Eight (19%) parents who had not received genetic counseling and 3 (9%) who had expressed that they worried all the time or often about their other children developing cancer at some point in their lives. Overall, 34 (27%) patients and 11 (14%) parents worried all the time or often that their children or other children would develop cancer (p-value = 0.036) (Table V).

Discussion

The results of this study support the inclusion of genetic counseling in the care of childhood cancer survivors and their families. A previous study showed that close to one-third of pediatric cancer survivors were eligible for a follow-up genetics evaluation based on their family histories of cancer or other conditions, cancer types, and/or the survivors’ medical histories [11]. Therefore, the need for genetic counseling in this population was established, but it was unclear if patients and their parents/caregivers desired this additional service or found it beneficial. This study assessed the clinic population’s perspectives and showed a vast majority of patients and their parents/caregivers finding the information that they received in their genetic counseling sessions to be useful. Moreover, the majority of participants expressed their satisfaction with the genetic counseling. This is especially impressive given that the genetic counseling was, in most cases, unsolicited by the patient or family. In addition, many participants who had not yet spoken
with a genetic counselor disclosed their desire to receive genetic counseling. Parents/caregivers were more interested in obtaining genetic counseling than patients themselves, but over one-third of both groups indicated interest. Additionally, it is important to note that the majority of participants were unaware of the existence of hereditary childhood cancer syndromes. Hence, there is a need to educate patients and their families on these conditions, which can be provided by a genetic counselor.

A particular question of interest that still remains for healthcare providers is the appropriate time to provide genetic services in the setting of childhood cancer. In this study population, it was clear that patients and their parents/caregivers thought that the genetic counseling should be provided no later than five years after the completion of their cancer treatment. Patients and parents were split, though, in determining the most appropriate time for genetic counseling in relation to the time of the cancer diagnosis, during cancer treatment, or after treatment. These results raise some interesting considerations. The healthcare providers and genetic counselors who serve this population should discuss the impact of family history and the presence of hereditary cancer syndromes with patients and their families from the time of diagnosis and continue this discussion well beyond their treatment. From a clinical perspective, receiving genetic services at the time of diagnosis may aid in the establishment of an appropriate surveillance program in the patient and their family members that may allow for early detection of cancers. However, if genetic services are only received at the time of diagnosis, multiple potential limitations exist including difficulty with retention of information due to the likely overwhelmed and fragile state that many of these families find themselves in at the time of a childhood cancer diagnosis. In addition, a single genetic risk assessment at the time of diagnosis could be limited if future cancers in family members have not yet developed. Continuing to
update family and medical histories and adjusting genetic risk assessment accordingly may be the most effective approach.

Even though few statistically significant results were found, differences could be appreciated between study groups. For example, participants who received genetic counseling generally worried less about subsequent cancer development than those who had not received genetic counseling. A goal of genetic counseling is to establish an accurate genetic risk assessment while making no contribution to a negative emotional toll [13]. The data suggest achievement of this goal because participants who received genetic counseling did not report increased levels of worry.

Differences regarding perceived risk were not as clear between those who had and had not received genetic counseling. In some cases, genetic counseling may have changed risk perception; however, the differences may have been masked by the challenge in comparing the cancer survivors at an increased risk versus those at a low risk for developing subsequent cancers. Therefore, following data collection, responses from participants who received genetic counseling were stratified into risk categories and compared based off of their assessed risk for a hereditary component to cancer development. Even though this comparison was limited by sample size, for both questions regarding perceived risk, more patients and parents/caregivers in the low risk group perceived their risk for subsequent cancer development to be lower than the participants in the increased risk group. Therefore, the data suggests that communication of a genetic risk assessment in a genetic counseling session results in more accurate perceived risk. Overall, parents/caregivers expressed higher levels of worry and perceived risk regarding subsequent cancer development than the patients themselves. Of note, results from this study
revealed somewhat lower levels of worry in parents of pediatric cancer survivors than other reports in the literature [23-24].

Moreover, for all participants, perceived risk did not correlate with levels of worry about the cancer occurrence. For example, participants who reported increased perceived risk did not directly experience an elevated level of worry about the cancer development. As a result, one cannot conclude that individuals in this population experience a balanced burden of perceived risk and worry. Even further, both patients’ and parents/caregivers’ perception of an increased likelihood of developing another cancer did not seem to be rooted in a belief that the cause of cancer was hereditary. They found it much less likely to develop cancer as a result of a hereditary component, even though they felt an increased risk to develop cancer at some point in their lifetimes.

As stated above, parents/caregivers tended to express higher levels of worry compared to patients except when asked about cancer development in other children. There was a statistically significant difference in patients who worried more about cancers developing in their children compared to parents/caregivers who worried less often about their other children developing cancer. This was not a direct comparison since the questions slightly differed between the patient and parent/caregiver questionnaires and because the parent/caregiver’s answers may have been influenced by the ages of their other children. The comparison is still interesting to note, though, and may infer that childhood cancer survivors perceived an increased probability of passing on a genetic predisposition to cancer to their children when compared to parents/caregivers of cancer survivors.

In this study, the desired sample size for all four study groups was not reached, which may have resulted in a reduction of power. Another limitation of the study was that some
patients over the age of 18 at the time of the survey were younger than 18 years old when they received genetic counseling in the CSC. Since the genetic counselor saw patients in the CSC starting in 2007, the study group that could have fallen into this category was the 18 to 23 year old patients who received genetic counseling. Since these participants were asked specific questions about the genetic counseling session, recall for some may not have been the most accurate since they could have been as young as fourteen years old when they received the genetic counseling. Similarly, several questions asked patients their thoughts regarding factors at the time of their diagnosis. Responses to these questions from patients who were diagnosed with cancer younger than fourteen years old were excluded.

Future research in a multicenter study can ensure a larger sample size and increased power to allow more comparisons. In addition, future study in this area would be enhanced by a prospective design to reduce the impact of recall bias and other factors inherent in a retrospective study.

In conclusion, genetic counseling provided to pediatric cancer survivors is a desired and is perceived to be a beneficial service. Discussion of the impact of a family history of cancer and the presence of hereditary cancer syndromes should begin around the time of the childhood cancer diagnosis and should be revisited throughout and after the child’s cancer treatment. Lastly, receiving genetic counseling results in a slight decrease in overall worry related to subsequent cancer development for the cancer survivor and for their parent/caregiver, and this service appears to aid in a more accurate risk perception.

Acknowledgments
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REFERENCES

### TABLE I. Survey Response

<table>
<thead>
<tr>
<th></th>
<th>Patients &lt;18 years old (filled out by parent/caregiver)</th>
<th>Patients ≥18 years old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had not received genetic counseling in the CSC</td>
<td>52 completed questionnaires 4 excluded N=48 (37% response)</td>
<td>102 completed questionnaires 2 excluded N=100 (31% response)</td>
</tr>
<tr>
<td>Received genetic counseling in the CSC</td>
<td>39 completed questionnaires None excluded N=39 (35% response)</td>
<td>76 completed questionnaires 1 excluded N=75 (36% response)</td>
</tr>
<tr>
<td></td>
<td>Overall</td>
<td>Parent + GC</td>
</tr>
<tr>
<td>---------------</td>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>n</td>
<td>262</td>
<td>39</td>
</tr>
<tr>
<td><strong>Current age of parent (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean±SD</td>
<td>43.5±6.4</td>
<td>43.2±5.3</td>
</tr>
<tr>
<td>Range</td>
<td>30-67</td>
<td>33-56</td>
</tr>
<tr>
<td><strong>Current age of patient (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean±SD</td>
<td>22.8±9.7</td>
<td>13.3±3.0</td>
</tr>
<tr>
<td>Range</td>
<td>6-58</td>
<td>6-17</td>
</tr>
<tr>
<td><strong>Years since most recent cancer diagnosis</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean±SD</td>
<td>14.4±7.3</td>
<td>10.9±2.8</td>
</tr>
<tr>
<td>Range</td>
<td>1-38</td>
<td>6-16</td>
</tr>
<tr>
<td><strong>Gender of parent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>80(92%)</td>
<td>36(92%)</td>
</tr>
<tr>
<td><strong>Gender of patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>142(54%)</td>
<td>19(49%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>250(95%)</td>
<td>38(97%)</td>
</tr>
<tr>
<td>Black</td>
<td>6(2%)</td>
<td>1(3%)</td>
</tr>
<tr>
<td>Other</td>
<td>6(2%)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Cancer diagnoses</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ALL</td>
<td>(25%)</td>
<td>(33%)</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>(9%)</td>
<td>Neuroblastoma (18%)</td>
</tr>
<tr>
<td>Other</td>
<td>(66%)</td>
<td>(49%)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Cancer diagnosed in the childhood cancer survivor

<sup>b</sup>Some cancer survivors were diagnosed with more than one type of cancer
TABLE III. Genetic Counseling Outcome

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Parents/Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recall of the genetic counseling session</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>43(58%)</td>
<td>27(69%)</td>
</tr>
<tr>
<td>No/Unsure</td>
<td>31(42%)</td>
<td>12(31%)</td>
</tr>
<tr>
<td><strong>Participant satisfaction</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very satisfied/Somewhat satisfied</td>
<td>41(82%)</td>
<td>24(89%)</td>
</tr>
<tr>
<td>Somewhat unsatisfied/Very unsatisfied</td>
<td>9(18%)</td>
<td>3(11%)</td>
</tr>
<tr>
<td><strong>Usefulness of the genetic counseling</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very useful/Somewhat useful</td>
<td>39(78%)</td>
<td>20(74%)</td>
</tr>
<tr>
<td>Somewhat useless/Very useless</td>
<td>11(22%)</td>
<td>7(26%)</td>
</tr>
<tr>
<td><strong>Interest in genetic counseling</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36(37%)</td>
<td>21(47%)</td>
</tr>
<tr>
<td>No/Don’t Care</td>
<td>61(63%)</td>
<td>24(53%)</td>
</tr>
<tr>
<td><strong>Most appropriate time to speak with a GC</strong>&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At childhood cancer diagnosis</td>
<td>15(33%)</td>
<td>21(26%)</td>
</tr>
<tr>
<td>During cancer treatment</td>
<td>9(20%)</td>
<td>24(30%)</td>
</tr>
<tr>
<td>1-5 years after treatment</td>
<td>19(41%)</td>
<td>32(40%)</td>
</tr>
<tr>
<td>≥6 years after treatment</td>
<td>3(7%)</td>
<td>3(4%)</td>
</tr>
<tr>
<td><strong>Aware of hereditary cancer syndromes at diagnosis</strong>&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16(33%)</td>
<td>38(44%)</td>
</tr>
<tr>
<td>No/Unsure/Too young to know</td>
<td>33(67%)</td>
<td>49(57%)</td>
</tr>
<tr>
<td><strong>Likelihood that cancer had a hereditary cause</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very likely/Likely</td>
<td>25(26%)</td>
<td>12(25%)</td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>71(74%)</td>
<td>35(75%)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Participants received genetic counseling.

<sup>b</sup>Participants had not received genetic counseling.

<sup>c</sup>Patients were diagnosed with a pediatric cancer at ≥14 years of age. The remaining patients were excluded from this question.
TABLE IV. Comparisons Between Participants Who Had and Had Not Received Genetic Counseling

<table>
<thead>
<tr>
<th></th>
<th>No Genetic Counseling</th>
<th>Received Genetic Counseling</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Perceived risk of a subsequent cancer reported by patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Likely/Likely</td>
<td>55 (56%)</td>
<td>35 (47%)</td>
<td></td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>44 (44%)</td>
<td>39 (53%)</td>
<td>0.282</td>
</tr>
<tr>
<td><strong>Perceived risk of a subsequent cancer reported by parents/caregivers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Likely/Likely</td>
<td>23 (50%)</td>
<td>23 (61%)</td>
<td></td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>23 (50%)</td>
<td>15 (40%)</td>
<td>0.335</td>
</tr>
<tr>
<td><strong>Level of worry about a subsequent cancer reported by patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All the time/Often</td>
<td>36 (36%)</td>
<td>18 (24%)</td>
<td></td>
</tr>
<tr>
<td>Sometimes/Rarely or never</td>
<td>63 (64%)</td>
<td>57 (76%)</td>
<td>0.081</td>
</tr>
<tr>
<td><strong>Level of worry about a subsequent cancer reported by parents/caregivers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All the time/Often</td>
<td>18 (39%)</td>
<td>13 (33%)</td>
<td></td>
</tr>
<tr>
<td>Sometimes/Rarely or never</td>
<td>28 (61%)</td>
<td>26 (67%)</td>
<td>0.580</td>
</tr>
<tr>
<td><strong>Level of worry about cancer development in children reported by patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All the time/Often</td>
<td>20 (27%)</td>
<td>14 (26%)</td>
<td></td>
</tr>
<tr>
<td>Sometimes/Rarely or never</td>
<td>54 (73%)</td>
<td>40 (74%)</td>
<td>0.889</td>
</tr>
<tr>
<td><strong>Level of worry about cancer development in survivor’s siblings reported by parents/caregivers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All the time/Often</td>
<td>8 (19%)</td>
<td>3 (9%)</td>
<td></td>
</tr>
<tr>
<td>Sometimes/Rarely or never</td>
<td>35 (81%)</td>
<td>32 (91%)</td>
<td>0.328</td>
</tr>
</tbody>
</table>
TABLE V. Overall Comparisons Between Patients and Parents/Caregivers

<table>
<thead>
<tr>
<th>Perceived risk of a subsequent cancer compared to peers</th>
<th>Patients</th>
<th>Parents/Caregivers</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>A lot higher/Higher</td>
<td>104(60%)</td>
<td>63(73%)</td>
<td></td>
</tr>
<tr>
<td>Same</td>
<td>57(33%)</td>
<td>18(21%)</td>
<td></td>
</tr>
<tr>
<td>Lower/A lot lower</td>
<td>12(7%)</td>
<td>5(6%)</td>
<td>0.105</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of worry about a subsequent cancer</th>
<th>Patients</th>
<th>Parents/Caregivers</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>All the time/Often</td>
<td>54(31%)</td>
<td>31(36%)</td>
<td></td>
</tr>
<tr>
<td>Sometimes/Rarely or never</td>
<td>120(69%)</td>
<td>54(64%)</td>
<td>0.382</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of worry about cancer development in children</th>
<th>Patients</th>
<th>Parents/Caregivers</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>All the time/Often</td>
<td>34(27%)</td>
<td>11(14%)</td>
<td></td>
</tr>
<tr>
<td>Sometimes/Rarely or never</td>
<td>94(73%)</td>
<td>67(86%)</td>
<td>0.036</td>
</tr>
</tbody>
</table>
TABLE VI. Perception of Subsequent Risk Stratified by Likelihood of Hereditary Cancer Syndrome

<table>
<thead>
<tr>
<th>Perceived risk of a subsequent cancer reported by patients</th>
<th>Increased Risk(^a)</th>
<th>Low Risk(^a)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Likely/Likely</td>
<td>8(53%)</td>
<td>27(46%)</td>
<td></td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>7(47%)</td>
<td>32(54%)</td>
<td>0.600</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived risk of a subsequent cancer reported by parents/caregivers</th>
<th>Increased Risk(^a)</th>
<th>Low Risk(^a)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Likely/Likely</td>
<td>7(78%)</td>
<td>16(55%)</td>
<td></td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>2(22%)</td>
<td>13(45%)</td>
<td>0.273</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived risk of a subsequent cancer compared to peers reported by patients</th>
<th>Increased Risk(^a)</th>
<th>Low Risk(^a)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>A lot higher/Higher</td>
<td>11(73%)</td>
<td>31(52%)</td>
<td></td>
</tr>
<tr>
<td>Same</td>
<td>3(20%)</td>
<td>23(38%)</td>
<td></td>
</tr>
<tr>
<td>Lower/A lot lower</td>
<td>1(7%)</td>
<td>6(10%)</td>
<td>0.392</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived risk of a subsequent cancer compared to peers reported by parents/caregivers</th>
<th>Increased Risk(^a)</th>
<th>Low Risk(^a)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>A lot higher/Higher</td>
<td>8(89%)</td>
<td>21(70%)</td>
<td></td>
</tr>
<tr>
<td>Same</td>
<td>1(11%)</td>
<td>6(20%)</td>
<td></td>
</tr>
<tr>
<td>Lower/A lot lower</td>
<td>0</td>
<td>3(10%)</td>
<td>0.691</td>
</tr>
</tbody>
</table>

\(^a\)Participants received genetic counseling.
SUPPLEMENTAL APPENDIX I. Questionnaire for parent/caregiver who has not received genetic counseling in the CSC

Are you the parent/caregiver of a cancer survivor?

[ ] Yes
[ ] No

If yes, please continue with the questionnaire. If no, please do not fill out this questionnaire.

1. Have you or your child had a previous genetics evaluation prior to being seen in the long-term follow up Cancer Survivor Center?

[ ] Yes
[ ] No
[ ] Unsure

If yes, why?
______________________________________________________________

2. When you found out that your child had cancer, were you aware that some childhood cancers can be hereditary? (Hereditary cancers are caused by changes in the genetic makeup of a person and may be passed down from a parent to their child, or in some cases, the genetic change can be new in the individual.)

[ ] Yes
[ ] No
[ ] Unsure

3. Check the factor, if any, that you believe had the biggest impact on your child’s risk to get cancer.

[ ] Environmental factors (such as air pollution; harmful chemicals; exposures before he/she was born)

[ ] Medical factors (such as being born early; medications)

[ ] Family history (such as having a close family member with cancer; having a known risk that can be hereditary)

[ ] Lifestyle (such as diet; stress; smoking)

[ ] None

[ ] Other: _______________________________________________________________

4. How likely do you think your child’s cancer is/was due to a hereditary cause?

[ ] Very likely

[ ] Likely

[ ] Unlikely

[ ] Very unlikely

5. How frequently do you worry that your child will get an additional cancer?

[ ] All the time

[ ] Often

[ ] Sometimes

[ ] Rarely or never
6. How likely do you think your child is to get another cancer sometime in his/her lifetime?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

7. Compared to your child’s friends, what do you think are his/her chances of getting an additional cancer in his/her lifetime?
   [ ] A lot higher
   [ ] Higher
   [ ] Same
   [ ] Lower
   [ ] A lot lower

8. How frequently do you worry that your family members (siblings, parents, aunts, uncles, nieces, and nephews) will get cancer sometime in their lifetime?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never

9. How likely do you think it is that your family members could develop cancer due to a hereditary cause?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

10. Do you have any children other than your cancer survivor?
    [ ] Yes (answer question 10a)
    [ ] No (skip to question 11)

10a. If yes, how frequently do you worry that your other child(ren) will get cancer sometime in their lifetime?
    [ ] All the time
    [ ] Often
    [ ] Sometimes
    [ ] Rarely or never

11. Our records show that you have not met with a genetic counselor at your child’s visit to the long-term follow up Cancer Survivor Center. Would you like to speak with a genetic counselor?
    [ ] Yes  *Please call the CCHMC Hereditary Cancer Program at [phone number] to schedule an appointment or to speak with a genetic counselor.
    [ ] No
    [ ] Don’t care
12. In your opinion, when do you think would be the best time to talk to a genetic counselor?
[ ] At the time my child was diagnosed with cancer
[ ] During my child’s cancer treatment
[ ] 1-5 years after my child ended cancer treatment
[ ] More than 6 years after my child ended cancer treatment
SUPPLEMENTAL APPENDIX II. Questionnaire for childhood cancer survivor who has not received genetic counseling in the CSC

Are you a cancer survivor?
[ ] Yes
[ ] No

If yes, please continue with the questionnaire. If no, please do not fill out this questionnaire.

1. Have you had a previous genetics evaluation prior to being seen in the long-term follow up Cancer Survivor Center?
[ ] Yes
[ ] No
[ ] Unsure

If yes, why?______________________________________________________________

2. When you found out that you had cancer, were you aware that some childhood cancers can be hereditary?  (Hereditary cancers are caused by changes in the genetic makeup of a person and may be passed down from a parent to their child, or in some cases, the genetic change can be new in the individual.)
[ ] Yes
[ ] No
[ ] Unsure
[ ] I was too young to know

3. Check the factor, if any, that you believe had the biggest impact on your risk to get cancer.
[ ] Environmental factors (such as air pollution; harmful chemicals; exposures before you were born)
[ ] Medical factors (such as being born early; medications)
[ ] Family history (such as having a close family member with cancer; having a known risk that can be hereditary)
[ ] Lifestyle (such as diet; stress; smoking)
[ ] None
[ ] Other: __________________________________________

4. How likely do you think your cancer is/was due to a hereditary cause?
[ ] Very likely
[ ] Likely
[ ] Unlikely
[ ] Very unlikely

5. How frequently do you worry about getting an additional cancer?
[ ] All the time
[ ] Often
[ ] Sometimes
[ ] Rarely or never
6. How likely do you think you are to get another cancer sometime in your lifetime?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

7. Compared to your friends, what do you think are your chances of getting an additional cancer in your lifetime?
   [ ] A lot higher
   [ ] Higher
   [ ] Same
   [ ] Lower
   [ ] A lot lower

8. How frequently do you worry that your family members (siblings, parents, aunts, uncles, nieces, and nephews) will get cancer sometime in their lifetime?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never

9. How likely do you think it is that your family members could develop cancer due to a hereditary cause?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

10. Do you have children or plan on having children?
    [ ] Yes (answer question 10a)
    [ ] No (skip to question 11)
    [ ] Unsure (skip to question 11)

   10a. If yes, how frequently do you worry that your children will get cancer sometime in their lifetime?
       [ ] All the time
       [ ] Often
       [ ] Sometimes
       [ ] Rarely or never

11. Our records show that you have not met with a genetic counselor in the long-term follow up Cancer Survivor Center. Would you like to speak with a genetic counselor?
    [ ] Yes  *Please call the CCHMC Hereditary Cancer Program at [phone number] to schedule an appointment or to speak with a genetic counselor.
    [ ] No
    [ ] Don’t care
12. In your opinion, when do you think would be the best time to talk to a genetic counselor?

[ ] At the time I was diagnosed with cancer
[ ] During my cancer treatment
[ ] 1-5 years after ending my cancer treatment
[ ] More than 6 years after ending my cancer treatment
SUPPLEMENTAL APPENDIX III. Questionnaire for parent/caregiver who received genetic counseling in the CSC

Are you the parent/caregiver of a cancer survivor?
   [ ] Yes
   [ ] No
If yes, please continue with the questionnaire. If no, please do not fill out this questionnaire.

1. When you found out that your child had cancer, were you aware that some childhood cancers can be hereditary? (Hereditary cancers are caused by changes in the genetic makeup of a person and may be passed down from a parent to their child, or in some cases, the genetic change can be new in the individual.)
   [ ] Yes
   [ ] No
   [ ] Unsure

2. Check the factor, if any, that you believe had the biggest impact on your child’s risk to get cancer.
   [ ] Environmental factors (such as air pollution; harmful chemicals; exposures before he/she was born)
   [ ] Medical factors (such as being born early; medications)
   [ ] Family history (such as having a close family member with cancer; having a known risk that can be hereditary)
   [ ] Lifestyle (such as diet; stress; smoking)
   [ ] None
   [ ] Other: ____________________________________________________________

3. Our records show that your child has met with a genetic counselor in the long-term follow up Cancer Survivor Center. Were you present when he/she saw the genetic counselor?
   [ ] Yes (go to question 4)
   [ ] No (skip to question 11)
   [ ] Unsure (Please attempt questions 4-10 even if you do not recall this meeting.)

   4. **Before** seeing a genetic counselor, how likely did you **think** your child’s cancer is/was due to a hereditary cause?
      [ ] Very likely
      [ ] Likely
      [ ] Unlikely
      [ ] Very unlikely

   5. **After** seeing a genetic counselor, how likely did you **think** your child’s cancer is/was due to a hereditary cause?
      [ ] Very likely
      [ ] Likely
      [ ] Unlikely
      [ ] Very unlikely
6. Which of the following did the genetic counselor recommend? (check all that apply)
   [ ] Gather more information about our family history of cancer.
   [ ] Consider genetic testing.
   [ ] Discuss the option of a genetics evaluation for one of my relatives.
   [ ] Return for a follow up appointment in the genetics division.
   [ ] No follow up recommendations were given to us.
   [ ] I do not recall.

7. If follow up was recommended, did you complete the suggested follow up? (check all that apply)
   [ ] Yes, I gathered more information about our family history of cancer.
   [ ] Yes, I considered genetic testing.
   [ ] Yes, I discussed with my relative the option for them to receive a genetics evaluation.
   [ ] Yes, I returned for a follow up appointment in the genetics division.
   [ ] No, we did not follow up.
   [ ] I do not recall.

8. Did the genetic counselor talk to you about a genetic syndrome(s) that could have caused your child’s cancer or other cancers in your family members?
   [ ] Yes
   [ ] No
   [ ] Unsure

9. How useful did you find the information you received in genetic counseling?
   [ ] Very useful
   [ ] Somewhat useful
   [ ] Somewhat useless
   [ ] Very useless

10. How would you rate your overall satisfaction with the genetic counseling?
    [ ] Very satisfied
    [ ] Somewhat satisfied
    [ ] Somewhat unsatisfied
    [ ] Very unsatisfied

11. In your opinion, when do you think would be the best time to talk to a genetic counselor?
    [ ] At the time my child was diagnosed with cancer
    [ ] During my child’s cancer treatment
    [ ] 1-5 years after my child ended cancer treatment
    [ ] More than 6 years after my child ended cancer treatment
12. How frequently do you worry that your child will get an additional cancer?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never

13. How likely do you think your child is to get another cancer sometime in his/her lifetime?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

14. Compared to your child’s friends, what do you think are his/her chances of getting an additional cancer in his/her lifetime?
   [ ] A lot higher
   [ ] Higher
   [ ] Same
   [ ] Lower
   [ ] A lot lower

15. How frequently do you worry that your family members (siblings, parents, aunts, uncles, nieces, and nephews) will get cancer sometime in their lifetime?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never

16. How likely do you think it is that your family members could develop cancer due to a hereditary cause?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

17. Do you have any children other than your cancer survivor?
   [ ] Yes  (answer question 17a)
   [ ] No  (skip to question 18)

17a. If yes, how frequently do you worry that your other child(ren) will get cancer sometime in their lifetime?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never
18. Would you like to speak with a genetic counselor again?
   [ ] Yes  *Please call the CCHMC Hereditary Cancer Program at [phone number] to schedule an appointment or to speak with a genetic counselor.
   [ ] No
SUPPLEMENTAL APPENDIX IV. Questionnaire for childhood cancer survivor who received genetic counseling in the CSC

Are you a cancer survivor?
[ ] Yes
[ ] No
If yes, please continue with the questionnaire. If no, please do not fill out this questionnaire.

1. When you found out that you had cancer, were you aware that some childhood cancers can be hereditary? (Hereditary cancers are caused by changes in the genetic makeup of a person and may be passed down from a parent to their child, or in some cases, the genetic change can be new in the individual.)
[ ] Yes
[ ] No
[ ] Unsure
[ ] I was too young to know

2. Check the factor, if any, that you believe had the biggest impact on your risk to get cancer.
[ ] Environmental factors (such as air pollution; harmful chemicals; exposures before you were born)
[ ] Medical factors (such as being born early; medications)
[ ] Family history (such as having a close family member with cancer; having a known risk that can be hereditary)
[ ] Lifestyle (such as diet; stress; smoking)
[ ] None
[ ] Other: _______________________________________________________________

3. Our records show that you have met with a genetic counselor in the long-term follow up Cancer Survivor Center. Do you recall talking to the genetic counselor?
[ ] Yes (go to question 4)
[ ] No (skip to question 11)
[ ] Unsure (Please attempt questions 4-10 even if you do not recall this meeting.)

4. Before seeing a genetic counselor, how likely did you think your cancer is/was due to a hereditary cause?
[ ] Very likely
[ ] Likely
[ ] Unlikely
[ ] Very unlikely

5. After seeing a genetic counselor, how likely did you think your cancer is/was due to a hereditary cause?
[ ] Very likely
[ ] Likely
[ ] Unlikely
[ ] Very unlikely
6. Which of the following did the genetic counselor recommend? (check all that apply)
   [ ] Gather more information about my family history of cancer.
   [ ] Consider genetic testing.
   [ ] Discuss the option of a genetics evaluation for one of my relatives.
   [ ] Return for a follow up appointment in the genetics division.
   [ ] No follow up recommendations were given to me.
   [ ] I do not recall.

7. If follow up was recommended, did you complete the suggested follow up? (check all that apply)
   [ ] Yes, I gathered more information about my family history of cancer.
   [ ] Yes, I considered genetic testing.
   [ ] Yes, I discussed with my relative the option for them to receive a genetics evaluation.
   [ ] Yes, I returned for a follow up appointment in the genetics division.
   [ ] No, I did not follow up.
   [ ] I do not recall.

8. Did the genetic counselor talk to you about a genetic syndrome(s) that could have caused your cancer or cancers in your family members?
   [ ] Yes
   [ ] No
   [ ] Unsure

9. How useful did you find the information you received in genetic counseling?
   [ ] Very useful
   [ ] Somewhat useful
   [ ] Somewhat useless
   [ ] Very useless

10. How would you rate your overall satisfaction with the genetic counseling?
    [ ] Very satisfied
    [ ] Somewhat satisfied
    [ ] Somewhat unsatisfied
    [ ] Very unsatisfied

11. In your opinion, when do you think would be the best time to talk to a genetic counselor?
    [ ] At the time I was diagnosed with cancer
    [ ] During my cancer treatment
    [ ] 1-5 years after ending my cancer treatment
    [ ] More than 6 years after ending my cancer treatment
12. How frequently do you worry about getting an additional cancer?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never

13. How likely do you think you are to get another cancer sometime in your lifetime?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

14. Compared to your friends, what do you think are your chances of getting an additional cancer in your lifetime?
   [ ] A lot higher
   [ ] Higher
   [ ] Same
   [ ] Lower
   [ ] A lot lower

15. How frequently do you worry that your family members (siblings, parents, aunts, uncles, nieces, and nephews) will get cancer sometime in their lifetime?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never

16. How likely do you think it is that your family members could develop cancer due to a hereditary cause?
   [ ] Very likely
   [ ] Likely
   [ ] Unlikely
   [ ] Very unlikely

17. Do you have children or plan on having children?
   [ ] Yes (answer question 17a)
   [ ] No (skip to question 18)
   [ ] Unsure (skip to question 18)

   17a. If yes, how frequently do you worry that your children will get cancer sometime in their lifetime?
   [ ] All the time
   [ ] Often
   [ ] Sometimes
   [ ] Rarely or never
18. Would you like to speak with a genetic counselor again?
   [ ] Yes  *Please call the CCHMC Hereditary Cancer Program at [phone number] to schedule an appointment or to speak with a genetic counselor.
   [ ] No
SUPPLEMENTAL DATA TABLE I. Likelihood of Hereditary Cause of Cancer Before and After Receiving Genetic Counseling

**Parent/Caregiver**

<table>
<thead>
<tr>
<th></th>
<th>Before GC</th>
<th>After GC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Likely/Likely</td>
<td>20 (36.4%)</td>
<td>16 (30.2%)</td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>35 (63.6%)</td>
<td>37 (69.8%)</td>
</tr>
<tr>
<td>Missing</td>
<td>20</td>
<td>22</td>
</tr>
<tr>
<td>Total (n)</td>
<td>55</td>
<td>53</td>
</tr>
</tbody>
</table>

Wilcoxon signed rank test: p=0.51

**Patient**

<table>
<thead>
<tr>
<th></th>
<th>Before GC</th>
<th>After GC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Likely/Likely</td>
<td>10 (29%)</td>
<td>8 (27%)</td>
</tr>
<tr>
<td>Unlikely/Very unlikely</td>
<td>24 (71%)</td>
<td>22 (73%)</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Total (n)</td>
<td>34</td>
<td>30</td>
</tr>
</tbody>
</table>

Wilcoxon signed rank test: p=1
SUPPLEMENTAL DATA TABLE II. Follow-up Recommendations Given by the Genetic Counselor Compared to Participant Recall

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Parent/Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correctly Recalled Follow up recs</td>
<td>26 (47%)</td>
<td>20 (63%)</td>
</tr>
<tr>
<td>Incorrectly Recalled Follow up recs</td>
<td>29 (53%)</td>
<td>12 (38%)</td>
</tr>
<tr>
<td>Of the ones with follow up recs, did they follow up?</td>
<td>Yes: 6</td>
<td>Yes: 2</td>
</tr>
<tr>
<td></td>
<td>No: 4</td>
<td>No: 3</td>
</tr>
<tr>
<td>Missing</td>
<td>20</td>
<td>7</td>
</tr>
<tr>
<td>Total (n)</td>
<td>55</td>
<td>32</td>
</tr>
</tbody>
</table>

Chi square: p-value = 0.1378
SUPPLEMENTAL DATA TABLE III. Level of Worry Regarding Cancer Development in Other Family Members

**Parent/Caregiver**

<table>
<thead>
<tr>
<th></th>
<th>Had not received GC</th>
<th>Received GC</th>
</tr>
</thead>
<tbody>
<tr>
<td>All the time/Often</td>
<td>13 (27.7%)</td>
<td>13 (33.3%)</td>
</tr>
<tr>
<td>Sometimes/Rarely or Never</td>
<td>34 (72.3%)</td>
<td>26 (66.7%)</td>
</tr>
<tr>
<td>Total (n)</td>
<td>47</td>
<td>39</td>
</tr>
</tbody>
</table>

Chi-squared test: p-value = 0.568

**Patient**

<table>
<thead>
<tr>
<th></th>
<th>Had not received GC</th>
<th>Received GC</th>
</tr>
</thead>
<tbody>
<tr>
<td>All the time/Often</td>
<td>27 (27.3%)</td>
<td>18 (24%)</td>
</tr>
<tr>
<td>Sometimes/Rarely or Never</td>
<td>72 (72.7%)</td>
<td>57 (76%)</td>
</tr>
<tr>
<td>Total (n)</td>
<td>99</td>
<td>75</td>
</tr>
</tbody>
</table>

Chi-squared test: p-value = 0.625