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Professional Issues

A Survey of Patients' Experiences with the Cancer Genetic Counseling Process: Recommendations for Cancer Genetics Programs

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In order to promote ongoing quality improvement of not only the Penn State Cancer Genetics Program, but also other cancer risk assessment programs throughout the country, we developed, piloted and conducted a survey to explore patient expectations, experiences, and satisfaction with the cancer genetic counseling process. The comprehensive survey was mailed to 340 eligible patients, 156 (45.9%) of whom returned the completed survey within the allotted time. Responses to closed-ended questions were tallied and open-ended questions were content analyzed. Major findings show that: (1) Patients were seeking cancer-related information and support throughout the cancer risk assessment process and were interested in participating in available research studies; (2) The setting in which patients are seen for cancer risk assessment may pose potential emotional ramifications; (3) Misperceptions regarding insurance discrimination and lack of insurance coverage persist; (4) Patients view the genetic counselor as responsible for updating them about new discoveries. Specific recommendations for cancer genetics programs are included.

KEY WORDS: cancer genetic counseling; cancer risk assessment; quality improvement; patient satisfaction; hereditary cancer.

INTRODUCTION

Over the past 15 years, cancer genetics programs have been developed to accommodate the increasing demand for cancer risk assessment and predisposition testing. Currently in the United States, there are more than 450 genetic counseling professionals who specialize in cancer genetics in over 300 programs (NSGC Familial Cancer Risk Counseling Special Interest Group Directory, 2003; NCI Cancer Genetics Services Directory). Many of these programs were developed with guidance from colleagues already practicing in the field of cancer genetics and from information contained in the Cancer Genetic Counseling Starter Packet, a document founded by members of the NSGC Familial Cancer Risk Counseling Special Interest Group. In 1998, the Penn State Cancer Genetics Program was established to provide patients in central Pennsylvania with a personal and/or family history of cancer access to information and guidelines related to the prevention and early detection of cancer.

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Most previous studies of cancer genetic counseling have found that patients reported consultations to be informative and positive (Bonadona *et al*., 2002; Julian-Reynier *et al*., 1998; Stacey *et al.*, 2002). For example, several studies reported that patients found written summaries of genetic consultations to aid communication and that patients wanted more written information on topics such as prevention and lifestyle options (Collins *et al*., 2000; Hallowell and Murton, 1998; Stacey *et al.*, 2002). There have been concerns also, about potential negative consequences of genetic counseling and testing (Kash *et al*., 2000). For example, risk assessment may cause patient anxiety, distress, frustration, and dissatisfaction, and patients may continue to display high levels of worry, to overestimate their risk of cancer, and experience difficulty in conveying their results to others despite genetic counseling (Bonadona *et al*., 2002; Freyer *et al*, 1999; Watson *et al*., 1999).

Consequently, the primary goal of the current study was to improve the quality of the genetic counseling process and follow-up within the Penn State Cancer Genetics Program. Specifically, the objectives of the study were to (1) assess the referral process, the genetic counseling experience, personal outcomes, follow-up and overall impressions of the Cancer Genetics Program and (2) identify areas for improvement within the Penn State Cancer Genetics Program.

METHODS

Study Design and Instrument

The study design was a mailed, self-administered survey with open and closed-ended questions that were developed by the authors. Several questions were specifically requested by members of the NSGC Cancer Genetics Special Interest Group. The survey instrument assessed sources of patient referrals, patient satisfaction and expectations, changes in risk perception, dissemination of information to friends and relatives and decision-making based on knowledge gained from the cancer risk assessment. A pilot survey of three respondents resulted in minor modifications to the draft instrument. The final instrument consisted of 80 questions on 15 pages (Appendix). The study was approved by the Institutional Review Board of the Penn State Hershey Medical Center.

Study Population

The study population consisted of patients who received genetic counseling from a cancer genetics professional of the Penn State Cancer Institute (hereto referred to as the Cancer Genetics Program) at either the Penn State Hershey Medical Center (Hershey, PA), Lehigh Valley Hospital and Health Network (Allentown, PA), or Mount Nittany Medical Center (formerly Centre Community Hospital) (State College, PA) between October 1998 and December 2004. These three sites are all full members of the Penn State Cancer Institute with both Allentown and State College being approximately 100 miles from the Penn State Hershey Medical Center campus. Patients were excluded from the study if they were less than 18 years of age at their first visit or if they were currently residing outside of the United States. Also, patients were excluded if the Penn State Tumor Registry reported that they were deceased prior to survey administration.

Survey Administration

The instrument, along with a cover letter explaining the purpose of the survey, was mailed to 340 patients. Participants were requested to return the completed instrument within 2 to 4 weeks in an enclosed stamped, addressed envelope. A follow-up reminder and thank you letter was sent one month after the survey was initially mailed. All completed instruments returned within 4 weeks of mailing the follow-up reminder and thank you letter were included in the analyses.

Data Analysis

In the current report, we present frequencies of responses. Questions with an invalid or missing response from an individual were excluded from analysis. Consequently, the total number of responders for each question may not equal 156, the total number of responders. To examine the representativeness of the respondents, we used a chi-squared test to compare the gender, history of cancer and clinical site distribution of the responders with the distribution of eligible participants. Each of the three tests was not statistically significant, suggesting that the responding sample was similar to that of the eligible participants.

RESULTS

Demographics

Of the 340 eligible participants, 156 (45.9%) returned the completed survey within the allotted time frame; 14 instruments were returned after the deadline but were not included in the current analysis. Correspondence for 13 (3.8%) eligible participants was returned by the U.S. Post Office for invalid addresses. The distribution sample consisted of 142 (91.0%) females, 13 (8.3%) males and 1 responder who did not specify gender (Table I). Participants were predominantly female, White, Non-Hispanic and married. Approximately 50% of respondents had an income of at least $75,000 per year. While almost 60% had a college degree, almost 25% had not attended any college.

Table I. Participant Demographics ($N = 156$)[a]

Variable	N	%	Mean
Gender			
Female	142	91.0	
Male	13	8.3	
Age in years	153		50.6
Previous cancer diagnosis	153		
Yes	85	55.6	
No	68	44.4	
Marital status	156		
Married	127	81.4	
Single with partner	11	7.1	
No current partner	10	6.4	
Divorced	5	3.2	
Widowed	2	1.3	
Separated	1	0.6	
Educational level		155	
Graduate or professional school	35	22.6	
Some graduate or professional school	17	11.0	
College	39	25.2	
Some college or technical school	28	18.1	
High school	34	21.9	
Less than high school	2	1.3	
Ethnicity[b]	153		
Not Hispanic or Latino	151	98.7	
Hispanic or Latino	3	2.0	
Race	155		
Caucasian	153	98.7	
African-American	1	0.6	
American Indian/Alaska Native	1	0.6	
Total annual household income	144		
>$75,000	69	47.9	
$50,001–75,000	34	23.6	
$35,001–50,000	26	18.1	
$20,001–35,000	12	8.3	
<$20,000	3	2.1	

[a]Total N may not always equal 156 because some patients chose not to respond to the question.
[b]One patient identified membership in both ethnic categories.

Referral Process

Physicians or nurses referred the majority of patients, as indicated by 126 out of 155 responders (81.3%). Eighteen (11.6%) learned about the program from a family member or friend, 6 (3.9%) through a website or newspaper article, and 14 (9.0%) through other avenues, such as attending professional lectures and programs, working as a hospital employee, participating in a research study coordinated by a genetic counselor and by searching the phone book.

Ninety-six (66.7%) out of 144 responders indicated the physician or nurse initially suggested they consider cancer genetic counseling, whereas 32 (22.2%) responders indicated the discussion about cancer genetic counseling was initiated by the patient. An additional 16 responders (11.1%) indicated the discussion was initiated by a genetic counselor or family member.

Prior to receiving cancer genetic counseling, 133/153 respondents reported their sources of cancer information as physicians and other health professionals (86.9%), 86 reported family members (56.2%), 82 used internet websites (53.6%), 65 used magazines (42.5%), 63 reported organizations or advocacy groups (41.2%), 45 reported friends (29.4%), 40 referenced television (26.1%), 37 used newspapers (24.2%) and 9 mentioned support groups (5.9%). An additional 9.2% (14/153) used other sources, such as books, scientific journals, professional seminars and other cancer patients. Of note, the majority of patients, 122 out of 154 responders (79.2%) found the appointment letter and information packet about the cancer risk assessment process, mailed prior to their visit, useful.

Genetic Counseling Experience

Prior to their first appointment, 145 out of 156 patients (93.0%) indicated they had informed family members that they were pursuing cancer genetic counseling and/or testing. Of those, 107 (73.8%)

indicated their family members were supportive or very supportive of this decision. However, 38 patients (26.2%) reported their family members as being only somewhat supportive, unsupportive or very unsupportive. Of those patients who did not inform family members, reasons included the private nature of the information, wanting to protect their family from worry, not feeling support from family, wanting to wait until test results were available and not having any close relatives remaining. Prior to their first appointment, 122 out of 155 patients (78.7%) indicated they had informed friends that they were pursuing cancer genetic counseling and/or testing. Of those, 95 (77.2%) indicated their friends were supportive or very supportive of this decision. Of 33 patients (21.3%) who did not inform friends, reasons included that the information was considered personal or that they did not have friends close enough with whom to share the information. One patient stated, "...if I tested positive for a greater cancer risk, I wanted to be careful with that information." Out of 156 patients who completed the survey, 83 (53.2%) brought a family member or friend to the genetic counseling visit(s). Reasons given for bringing a family member or friend included having another person present to hear the information and ask additional questions, answering questions about family history as well as providing emotional support and/or objectivity. Reasons for not bringing a support person to the genetic counseling visit(s) included a desire to filter the information, lack of child care, family living at a distance, ease of visit in comparison to cancer treatment and possessing an independent nature.

Of 93 patients who pursued genetic testing following counseling, 89 (95.7%) indicated they were glad with their decision. Reasons stated included peace of mind, the need to know for children and other family members and that the information enabled family members to make important decisions about their future care. While waiting for test results, 67 of 93 responders (72.0%) felt pleased that they had pursued testing and 47 (50.5%) felt empowered in that they were taking charge of their health care. Forty-two patients (45.2%) felt anxious while waiting for their results, 19 (20.4%) expressed fear for themselves and their family, and 7 (7.5%) felt a lack of control over their results. Of importance, no patients expressed feeling depressed. Of 32 patients found to carry a genetic mutation, 27 (84.4%) were pleased that they had pursued testing and 17 (53.1%) felt that they were taking charge of their health care. Six patients (18.8%) expressed fear for themselves and their family, 3 (9.4%) felt anxious about their results and 3 (9.4%) felt a lack of control over their results. Two patients (6.3%) expressed feeling depressed.

Of 55 responders who decided not to pursue genetic testing, 35 (63.7%) did so because the insurance company would not cover the testing and/or they felt the out-of-pocket costs were too high. Approximately 38% (21/55) felt the risk for a mutation was not high enough, whereas 20% (11/55) equally expressed concerns about insurance/employment discrimination and that the results would not influence medical decisions. Of importance, combined percentages are greater than 100% because responders were permitted to check more than one reason for not pursuing genetic testing. Only 3 patients (5.5%) decided not to have genetic testing because they were anxious about possible results. Other reasons given (15/55 or 27.3%) for not pursuing genetic testing included important life events such as pregnancy and adoption, and not being identified as the key person to pursue testing.

With regards to the visit itself, 140 out of 156 patients (89.7%) thought the length of the appointment (approximately 90 min) was ideal. However, when asked what amount of time was sufficient to review their family history, provide education about various risk factors for cancer and review their individualized cancer risk assessment, the majority (86/153 or 56.2%) thought that 30–60 min was adequate whereas 48 (31.4%) felt 61–90 min was adequate.

Most patients (137/156 or 87.8%) were satisfied, very satisfied, or extremely satisfied with the physical location at which their appointment was held. Of those patients who were seen in a cancer center setting, some did express difficulty with the waiting room environment. Reasons expressed for not being extremely satisfied with the physical location included the waiting room being too crowded (17/73 or 23.3%), the meeting room being uncomfortable (11/73 or 15.1%), parking being too far from the clinic (10/73 or 13.7%) and not enough to do while in the waiting room (6/73 or 8.2%). One patient stated he/she was "uncomfortable sitting in a waiting room with those waiting for their cancer treatment. Made me very anxious—like looking at your own possible future." Another patient stated, "I found this to be very depressing and reminded me of my previous experience as a cancer patient 'reporting' for treatment. I did not want to be identified as a cancer patient because I had been cancer free for over 17 years..." Several patients expressed displeasure with regards to the meeting room, including one person

who stated it was "very small—felt claustrophobic, no windows," and another who stated, "I think the décor of the room could have been more cheerful rather than clinical." Suggestions for improvement included one patient who stated, "I think an area designed for genetic counseling would be appreciated rather than being in the same crowded area as the many patients coming for chemo and testing."

During their first visit, additional services that the patients would have liked to receive included nutritional information (44/74 or 59.5%), education about herbal or complementary medicine/supplements (43/74 or 58.1%), cancer screening tests such as CA125, clinical breast exams and mammograms (25/74 or 33.8%), and education about performing breast self exams (7/74 or 9.5%).

Personal Outcomes

Contrary to popular perception, only 5 patients (3.2%) felt they experienced some form of insurance discrimination. No responders reported experiencing employment discrimination.

Nearly all patients (98.7%) shared information from their cancer risk assessment or genetic testing with family members. Means of communication with family members included 86.9% in person and 69.3% by telephone. Less frequently used means included email (16.3%) and by letter (9.2%). The majority of patients shared general information learned (76.0%), as well as their specific genetic test results (63.6%). The family tree was shared by 39.0%, and 33.1% shared the summary letter. Approximately, 15% of responders reported experiencing difficulties or challenges with sharing information with family members. Examples of such challenges included approaching disapproving relatives and the inability to answer questions or to gauge how much information relatives desired. Some reasons given for not sharing information with family members were not wanting to increase anxiety and transferring the responsibility of communication to a closer relative.

Follow-Up

Medical documents provided following the cancer risk assessment were deemed useful by most patients. Specifically, 140 out of 143 responders (97.9%) found the summary letter to be useful, 93.8% (122/130) found the family tree useful, and 99.0% (97/98) found the genetic test results to be useful. The information contained in the summary letter, the family tree and the genetic test results was considered beneficial because it helped the patient remember information presented during the visit (111/145 or 76.6%), it helped explain risks for relatives (103/145 or 71.0%), it made information presented during the visit easier to understand (100/145 or 69.0%), it confirmed correct understanding of information presented (77/145 or 53.1%) and it provided information to the physician upon which to make medical decisions (63/145 or 43.4%). One particular comment regarding the usefulness of the information was that the patient has "taken the above information and created two files—one for each of my children with all my health history for their future knowledge and benefit. . ." The overwhelming majority of patients (131/136 or 96.3%) thought that the summary letter contained the correct amount of information (the summary letters were typically three pages in length depending on the complexity of the family history and whether or not a hereditary predisposition was found). Only 2.9% (4/136) felt there was too little information and 0.7% (1/136) thought there was too much information. Similarly, 134 out of 135 patients (99.3%) liked the format of the summary letter. Suggestions to improve the format of the summary letter included putting risks from the various models in chart form, putting cancer risk management strategies in bullet form rather than paragraph form, and identifying relatives on the family tree so that it is easier for patients to read and understand. Of 107 responders who were seen for more than one visit, 56 (52.3%) said that they preferred one letter at the end of each visit while 51 (47.7%) said that they preferred one letter after the final visit.

Other resources that patients reported being useful to complement the cancer risk assessment included written information in the form of pamphlets, brochures, etc. (84/117 or 71.8%), website addresses (81/117 or 69.2%), a referral network of one family to another with similar circumstances (34/117 or 29.1%) and support group information (17/117 or 14.5%). One patient expressed interest in remaining on a distribution or email list for ongoing receipt of updated articles. When patients were asked who would be responsible for contacting them if a new gene were discovered several years after their cancer risk assessment that could possibly explain their personal and/or family history, 86 of 139 (61.9%) responded that it would be the genetic counselor's responsibility. An additional 25.9% (36/139) said it would be

the patient's responsibility, and 12.2% (17/139) said it would be the referring physician's responsibility. If a cancer gene were identified in their family, 137 out of 147 patients (93.2%) said that the patient would be responsible for telling their relatives. Only 5.4% (8/147) and 1.4% (2/147) responded that it would be the genetic counselor's and the referring physician's responsibility, respectively.

Of 93 responders who pursued genetic testing, 65 (70%) indicated their insurance was billed whereas 20 (21.5%) indicated that their insurance was not billed. Approximately 63% (46/73) of those patients whose insurance was billed for genetic testing indicated that 76–100% of the cost was reimbursed. Reasons for not submitting a claim to insurance for genetic testing given by 32 responders included 9 who said that the insurance would not cover the genetic testing (28.1%), privacy issues (7/32 or 21.9%) and no insurance coverage (4/32 or 12.5%). Other reasons given by 7 responders (21.9%) included that the genetic testing was provided at no cost as part of a research study, contractual arrangements between the insurance company and the hospital, and hospital billing error.

To evaluate the importance of outreach clinics, patients were asked if they would have been willing to travel 1.5 to 3.5 h for cancer genetic counseling if a program had not been available locally. Of the 148 responders, 59 (39.9%) indicated yes, 61 (41.2%) indicated maybe, and 17 (11.5%) stated no.

Overall Impressions

Overall, 124 out of 136 patients (91.2%) indicated that most or all of their expectations were met, whereas 10 out of 136 patients (7.4%) indicated that only some of their expectations were met. When patients were asked in what ways the Cancer Genetics Program could meet their expectations better, responses included more frequent visits to outreach clinics, more convenient parking, facilitation of specimen collection and coordination of cancer risk assessment with other appointments the same day. One patient stated, "If interested in trials, as I am, keep me abreast of ongoing trials and qualifications." Overall, 149 out of 155 patients (96.1%) were satisfied, very satisfied, or extremely satisfied with the Cancer Genetics Program whereas 2.6% (4/155) reported being only somewhat satisfied. A number of patients indicated that the genetic counselor was one of the most positive aspects of the Cancer Genetics Program. One patient stated that the counselor was "very knowledgeable and explained new and complex things in a very understandable way. She also didn't push the testing; she definitely made me know that was up to me." Another patient stated the counselor was "great—extremely professional, thorough and compassionate." The counselor was found to be "caring, calm, reassuring, sympathetic" and "very concerned for my emotional well being during the process. . ." Another positive aspect of the program was the convenience of having appointments available locally at outreach clinics. Some suggestions made for improving the Cancer Genetics Program included making patient records available in an electronic format, such as secure email or a CD, providing follow-up contact if new genes are identified, making better accommodations within the hospital regarding the waiting and meeting rooms, and making more frequent visits to the outreach clinics. Overall, 93.5% of patients (145/155) would encourage friends or relatives to pursue cancer genetic counseling through the Cancer Genetics Program.

DISCUSSION

Previous research has demonstrated a need for national guidelines on practice and quality improvement, as well as for limiting barriers among patients referred for genetic counseling (Geer *et al.*, 2001; Lea, 1996). Our survey found that patients were largely satisfied with the Penn State Cancer Genetics Program, including the referral process, the genetic counseling experience, personal outcomes, follow-up and overall impressions of the Cancer Genetics Program. The survey further identified areas of improvement within the Penn State Cancer Genetics Program, which may have relevance for other cancer risk assessment programs in the United States (Table II).

Referral Process

Most referrals were initiated by the patient's physician/nurse, especially the oncologists and obstetricians/gynecologists. This observation emphasizes the importance of keeping referral sources abreast of new developments in the field of cancer genetics. Methods might include giving professional lectures at medical conferences, providing a quarterly or annual newsletter and referring medical professionals to the Cancer Genetics Program website for up-to-date

Table II. Recommendations for Cancer Genetics Programs

Identified need	Mechanisms to address need
Educate referral sources about new developments in cancer genetics	Develop quarterly/annual newsletter Provide professional lectures/in-services Advertise enhanced website URL
Educate members of the community	Participate in community health fairs Host public forum on reducing cancer in the community
Educate the media	Embrace media interviews
Enhance patient information packet	Provide brochures, information sheets, videotapes Provide URLs of reputable websites
Provide support to patients during the cancer genetic counseling process	Provide access to online support groups, peer support helpline, etc. Develop a hereditary cancer support group
Address genetic discrimination concerns	Provide brochure or fact sheet discussing concerns regarding genetic discrimination Provide access to legislative news about genetic discrimination so patients have up-to-date information.
Address gaps in insurance coverage for genetic counseling and testing	Apply for grant funding Hold fundraisers Seek out charitable contributions
Improve cancer genetic counseling setting	See patients in a prevention/wellness clinic or other location separate from the oncology clinic
Provide guidance on dissemination of information to relatives	Discuss recommendations during counseling visit Develop brochure or information sheet
Address disparity between patients and counselors regarding duty to recontact	Develop a "What's New in Cancer Genetics" page on enhanced website Inform past patients via mass mailing about enhanced website and "What's New" page as a means to keep updated on new discoveries and enhancements to technology Include website URL in summary letter of prospective patients and encourage use of "What's New" page to keep updated

information. More informal methods, such as in-services to specific medical specialty offices, could also be employed. Additionally, educational efforts should be focused towards the general public since approximately 25% of patients self-refer. Methods might include attending community health fairs, holding a public forum on reducing cancer in the community and developing a program website that is user-friendly and contains tools to help identify high-risk families, as well as the latest information regarding "What's New in Cancer Genetics."

Sources of cancer information used by patients include physicians and other health professionals, family members, magazines, the internet, and various organizations/advocacy groups. Our data indicates that over 50% of patients have access to the internet, thus highlighting this mode of communication as one means to recontact patients should new information become available. The responses also reveal that the media influences patient knowledge, and therefore, genetics professionals should embrace opportunities to be interviewed for television, radio, newspaper and magazine articles, websites, etc.

The majority of patients found the cancer genetics packet mailed prior to their visit to be helpful. The packet contains background information about the cancer risk assessment process, a family history and personal history questionnaire, and current fees. An introductory letter and map provides details about each patient's appointment time and location. Patients indicated that additional information would be helpful prior to their appointment in the form of videotapes, as well as referencing reputable websites on the internet; therefore, including these elements in the packet should be considered.

Genetic Counseling Experience

Patients experienced increased anxiety and fear, while waiting for their test results. As such, patients may benefit from additional support during this time period and they should be made aware of available resources that may serve this important role. The FORCE website (Facing Our Risk of Cancer Empowered, www.facingourrisk.org) is one such resource which was developed to provide information and support to women who are at increased risk for breast and/or ovarian cancer and their families. A peer-support helpline represents another possible resource, such as one initially developed by the University of Pennsylvania, Abramson Cancer Center in

collaboration with FORCE and supported by a research grant through the US Department of Defense Breast Center Research Program (1-866-824-RISK). By making these resources available, patients can receive additional support, not only during a time of uncertainty while waiting for test results, but also afterwards as they adjust to and utilize the information for medical management decisions in consultation with their physicians. Additionally, these resources can provide support to patients as they face new challenges in transmitting complex information to family members who may not always be receptive. Of importance, most patients who were identified to carry a mutation were pleased that they had pursued testing. However, 6 out of 32 patients (18.8%) found to carry a mutation still expressed feelings of fear for family and self, similar to those waiting for test results. To address this need, some programs have developed support groups specifically for patients with a hereditary predisposition to cancer. Although there are inherent challenges in sustaining the membership of such a specialized support group, it is an area which, if fostered, could substantially improve the overall experience of patients undergoing genetic testing, adjusting to results which identify a hereditary predisposition to cancer and embarking on the task of sharing this information with relatives at risk.

Insufficient coverage of testing by the insurance company and potential for insurance/employment discrimination were two reasons given by responders for not pursuing genetic testing. Over the course of this study, as both patients and medical professionals have become more comfortable with cancer predisposition testing, concerns about insurance and employment discrimination have somewhat lessened. Although the Health Insurance Portability and Accountability Act (HIPAA) and the Americans with Disabilities Act (ADA) provide some protection on a federal level and a number of states have enacted legislation to provide protection to its constituents (National Conference of State Legislatures), our findings show that patients remain concerned. To address this fear upfront, especially since it may hinder some patients from following through with their scheduled appointment, the issue of genetic discrimination should be addressed in the introductory packet by way of a pamphlet or fact sheet with websites provided so patients may seek out additional information. Hopefully, in the future, these concerns will further diminish if the Genetic Information Non-Discrimination Act is passed (National Human Genome Research Institute, NIH). In the meantime, genetic counselors should seek out their representatives and take advantage of every opportunity to support legislation that will eradicate the fear of discrimination. With regards to insufficient coverage of testing mentioned by patients who decided not to pursue genetic testing, an increasing number of insurance companies, over the course of this study, are recognizing the value of and reimbursing for genetic testing when appropriate. When, however, there are gaps in coverage, it behooves the genetic counselor to seek out other sources of potential funding such as the financial hardship programs offered by some genetic testing laboratories or various fundraisers or charitable donations. For example, the Four Diamonds Fund at the Penn State Hershey Medical Center recently covered genetic testing of the APC gene for a pediatric patient who was diagnosed with hepatoblastoma and who had a family history of colorectal cancer and polyposis when the insurance company denied coverage citing the requested test was considered investigational/experimental. For some patients, the financial roadblock may be getting coverage for the genetic counseling visit(s). To this end, the Penn State Hershey Medical Center has recently received a grant from the Pennsylvania Department of Health to provide genetic counseling services to patients with Medical Assistance.

Several questions in our study addressed satisfaction with appointment length, the counselor, and the physical location in which patients were seen. Although the majority of patients thought that the first session, which typically lasts 90 min, was the right amount of time, 56.2% felt that 30–60 min was sufficient time to cover the necessary information. One potential way to increase the efficiency of cancer genetic counseling services would be to mail supplementary materials with the appointment packet, such as pamphlets, videotapes, CDs, etc. that address key information prior to the first appointment (Green, 1998–2000, Green *et al.*, 2004, 2005). One study, for example, showed that use of an interactive computer program on breast cancer risk and genetic testing by patients could shorten the length of counseling sessions and allows counselors to focus more on patients' individual risks and specific psychological concerns (Green *et al.*, 2005). This would also address specific requests by patients for informational videotapes. In addition, patients could be referred to an enhanced program website, with links provided to a wide variety of cancer genetics-related information. Based on findings from this survey, the Penn State Cancer Genetics Program plans to initiate

improvements to its website which can be accessed at www.hmc.psu.edu/cancer/services/genetics.htm.

With regards to counselor satisfaction, the overwhelming majority of patients were very satisfied with the genetic counselor's knowledge and skills, caring attitude, ability to explain concepts in an understandable manner and overall performance. These observations further underscore the high level of competency of genetic counselors as appropriately trained health professionals to provide these services. Further, genetic counselors, in general, do not have the same time constraints imposed on the majority of referring physicians/nurse specialists.

Although the overwhelming majority of patients said that they were very or extremely satisfied with the physical location in which their appointment was held, comments obtained from those less satisfied provided insight into potential areas for improvement. This information could prove useful, especially for those centers that may be in the process of designing a new building housing all cancer-related services. A popular comment concerned the anxiety experienced while waiting in the reception area along with cancer patients in various stages of treatment. Unfortunately, due to space limitations at a number of centers, this may not be feasibly possible. Patients also expressed discomfort with the meeting room, which was described as being too small, cold, and without windows. Thus, it would best serve patients to have a designated reception area and meeting room, separate from the oncology clinic that addresses these sensitive issues.

Personal Outcomes

In our study, an overwhelming majority of patients (153 of 156 surveyed) indicated that they shared information from their cancer risk assessment and/or genetic testing with family members and, as expected, patients shared more information with those more closely related than with more distant relatives. Most patients disclosed this information in person (133/153 or 86.9%) and over the telephone (106/153 or 69.3%). Of the documents provided by the Cancer Genetics Program, 98 out of 154 responders (63.6%) used the genetic test results to communicate information to relatives, 39.0% (60/154) shared the family tree, and 33.1% (51/154) shared the summary letter. These findings emphasize the importance of these documents as a means for patients to communicate complex information to relatives and contrasts greatly with other health care settings where such documentation is typically not provided to patients for the purpose of facilitating communication between patients and family members. Of those who did share information, 23 out of 151 responders (15.2%) experienced difficulties or challenges. Although this represents a minority, possible interventions could include providing suggestions on how to approach relatives during the last visit or mailing an informative brochure along with the summary letter to address ways to approach relatives in a non-threatening manner and to anticipate various reactions in an effort to facilitate the communication process. Alternatively, patients could access this information on the enhanced program website.

Approximately 5 out of 156 patients (3%) perceived, whether real or not, some form of insurance discrimination, and none experienced employment discrimination. Some patients perceived that if insurance did not pay (for example, for blood tests) that this was a form of insurance discrimination when most likely it reflected a specific exclusion of that policy. Thus, it is important for studies analyzing cases of insurance discrimination to document the specific circumstances to confirm that the experience is consistent with actual discrimination.

Follow-Up

Summary letters serve a dual purpose, not only as medical-legal documents to clarify the content of a patient encounter but also to serve as an educational format for the patient to reinforce what was learned during the counseling session(s). Baker *et al.* (2002) recognizing the importance of these written documents, developed patient letter-writing guidelines to serve as a teaching tool for students learning this important skill and as a resource for practicing genetic counselors. In addition, Rosenthal presented a contributed paper at the 24th Annual Education Conference of the National Society of Genetic Counselors on patient attitudes towards follow-up letters in the cancer genetics clinic and hopes to use the data in the design of a clinical trial comparing different formats for providing follow-up information to genetic counseling patients (Rosenthal, 2005 AEC presentation). Based on our survey findings, most patients thought the summary letter contained the correct amount of information, and they liked the format. However, approximately half of the patients would prefer one letter at the end of each visit. As such, patients now

receive documentation at the end of each visit, which not only serves to keep the patient informed but also helps provide insight regarding the labor-intensive nature of the cancer genetic counseling process.

Approximately 72% of patients (84/117) expressed interest in receiving more written information to complement the family tree and summary letter. Further, 69% (81/117) expressed interest in relevant website addresses. These requests could easily be addressed by including a list of cancer-specific websites in the summary letter or referring patients to the enhanced program website.

While 14.5% (17/117) expressed interest in having a hereditary cancer support group, this endeavor presents a number of challenges, including difficulty in maintaining a large, active membership, since the number of patients found to have an inherited predisposition is small and there is a limited timeframe during which patients find support groups most relevant to their needs. Although a local, on-site support group would be ideal, an online support group, such as FORCE, evolved, in part, as a result of these challenges, and may actually represent a more appealing alternative for some patients who do not feel comfortable with the personal interaction that occurs within the traditional support group setting.

Interestingly, the majority of patients said that it is the genetic counselor's responsibility to recontact the patient with new information. This patient expectation represents a daunting task for genetic counselors and other medical professionals, so much so that the Social, Ethical and Legal Issues Committee of the American College of Medical Genetics developed a policy statement to address this concern (Hirschhorn, 1999). Currently, the Cancer Genetics Program summary letter mailed to each patient explicitly states that they should contact the genetic counselor if they would like to be updated on new discoveries that may apply to their family. To further address this patient expectation, the program website will be enhanced to include a "What's New in Cancer Genetics" page, which will be referenced in the summary letter so that patients are encouraged to access information about new cancer genetic discoveries. In this manner, the disparity between patients and genetic counselors with regards to who has primary responsibility for recontacting with new information could be minimized.

The insurance companies that were billed for genetic testing are indeed covering the majority of cost involved with approximately 63% of patients (46/73) indicating that 76–100% of the total cost was reimbursed. For those patients who did not submit a claim to insurance, reasons included concerns about the potential for discrimination, concerns about the extent of insurance coverage and enrollment in research studies where genetic testing was provided free of charge. These concerns reveal potential barriers to pursuing genetic testing and may influence whether patients feel comfortable in scheduling and keeping appointments for cancer risk assessment. Such concerns should be addressed preferably at the time of referral and reinforced during the appointment so that they do not present a barrier to pursuing cancer genetic counseling and the option of cancer genetic testing if appropriate. Additionally, new patients could be referred to the enhanced program website, containing both facts and myths about insurance and employment discrimination to address this misperception prior to an appointment.

Overall Impressions

Although the overwhelming majority of patients had all or most of their expectations met and were extremely satisfied, very satisfied, or satisfied with the Cancer Genetics Program, several areas of improvement were identified. One suggestion included more frequent visits to outreach clinics. To accommodate this request, marketing efforts on the part of the genetic counselor and/or institution would be required to enhance the number of appropriate referrals to help justify the additional time and expense incurred by traveling to outreach sites. These marketing efforts could include presenting lectures at various hospital forums and within the surrounding community, as well as hosting in-services for local referring physicians' offices. Another suggestion for improvement was more convenient parking. The importance of this issue warrants additional emphasis, especially with the population of patients being seen at the Cancer Genetics Program, a number of whom are undergoing treatment for their diagnosis of cancer. Another suggestion was to coordinate the cancer risk assessment with other appointments on the same day. While this request can be accommodated, it presents financial repercussions to the institution, which typically cannot receive payment for two visits on the same day with identical diagnosis codes. One patient expressed interest in being kept up to date regarding ongoing trials and their qualifications. This suggestion could be addressed by making a list of relevant websites that contain information regarding

available clinical trials both within the institution and across the country. Additionally, links could be added to the enhanced program website where patients can access information about available research studies. Patients could also be given the option of receiving an eblast notice when new information is posted on the program website and may become a more appealing method of reaching large numbers of patients with new information as more patients access the internet for their own personal use.

Limitations

There are several limitations to this study. One inherent limitation is the retrospective nature in which the study was conducted, with some patients being seen anywhere from 6 months to approximately 7 years prior to completing the survey, thus generating varying degrees of recall bias. In the future, patients could be surveyed in a prospective manner as they are going through the cancer genetic counseling process to address this limitation. In addition, quality of life questionnaires could be utilized prospectively to provide a useful comparison. Another limitation was imposed by the number of qualitative questions in the study, which precluded quantitative analysis. Lastly, the study population was drawn from a network of hospitals from a mostly rural area of Pennsylvania, and as such, the patient demographics may be quite different from other programs where there are multiple centers providing genetic counseling services within a small area.

Implications for Future Research

Future research, such as multivariable analyses which were raised by other questions in this study but not reported here, are needed to explore various aspects of the cancer risk assessment process. For example, it would be helpful to explore the experiences and motivations of those with a previous diagnosis of cancer versus those who have no personal history of cancer. In fact, certain patient types have been found to be more associated with certain motivations; for example, cancer patients tend to seek genetic counseling for the sake of their children, while healthy clients tend to seek counseling for their own sake (Julian-Reynier *et al.*, 1998). By understanding the motivations of patients seeking cancer risk assessment, cancer genetics programs can be tailored to better meet their expectations.

CONCLUSION

This study identified several areas amenable to improvement within the Cancer Genetics Program. Patients are seeking as much cancer-related information and support as possible, not only prior to and during but also after their visit(s) to the Cancer Genetics Program. Patients suggested information in the form of videotapes, websites, etc., and expressed topics of interest included nutrition, alternative medicine, etc. Patients also requested documentation of their visits in alternative forms such as a CD. Further, cancer genetics programs should be cognizant of the setting in which patients are seen for cancer risk assessment due to the potential emotional repercussions as demonstrated by a number of answers to some of the qualitative questions in our survey. Patients pursuing cancer risk assessment are eager to further research knowledge. As a result, cancer genetics programs should actively make various studies available. For example, the Penn State Cancer Genetics Program has recently begun offering participation in a tissue bank for those patients identified to carry a hereditary predisposition to cancer.

As a result of this survey, our program intends to make a number of enhancements to the cancer genetic counseling process at our institution, including adding materials to the information packet and supplementing the website with links to ongoing trials, new information about genetic discoveries that have clinical relevance, chat rooms, etc. In addition, patients will now be provided with documentation after each visit, and hopefully plans to break ground for a new building in 2006, housing all cancer services, will address patients' comments about the setting in which they were seen.

Despite clinical cancer genetics services being available for the past 10–15 years, misperceptions persist regarding insurance discrimination and lack of insurance coverage. In addition there are widely differing expectations between patients and genetic counselors with regards to whose responsibility it is to update about future discoveries. Additional surveys on a regular basis would promote further enhancement of cancer genetics programs and improve the experiences of both patients and their families.

APPENDIX

PENN STATE CANCER INSTITUTE

CANCER GENETICS PROGRAM SURVEY

1998 – 2004

To better understand the needs of individuals and families who seek cancer genetic counseling, we would appreciate your input on as many of the following questions as possible. If any of the questions make you feel uncomfortable, please leave them blank. For each question, check only one answer unless otherwise specified.

This survey is confidential.

Please do not put your name on any page.

By completing this survey, you are giving us your consent to participate in this study.

REFERRAL PROCESS

1. How did you hear about the Penn State Cancer Genetics Program? Please check all that apply.

❒ Physician / nurse ❒ Family member / friend ❒ Support group

❒ Newspaper article ❒ Website

❒ Other (please specify)_____

2. Who suggested you pursue cancer genetic counseling or did you self-refer?

❒ Physician / nurse ❒ Self-refer ❒ Other (please specify)_____

3. If you were referred by your physician / nurse, in what specialty does he / she practice? If you were not referred by your physician / nurse, please skip to the next question.

❒ Family physician / General practitioner ❒ Internal Medicine

❒ OB / GYN ❒ Oncologist

❒ Other (please specify) _____

❒ Don't know

4. Have you *ever* been diagnosed with cancer? ❒ Yes ❒ No

5. Why did you pursue cancer genetic counseling? Please check all that apply.

❒ To understand my personal risk of cancer

❒ To understand my children's risk of cancer

❒ To relieve anxiety

❒ I was encouraged by a family member

❒ I was encouraged by a physician or other health professional

❒ Other (please specify) _____

6. What previous sources of cancer information have you used? Please check all that apply.

❒ Physician / Other health professional ❒ Family

❒ Friends ❒ Support group

❒ Television ❒ Newspaper

❒ Magazines ❒ Internet websites

❒ Organization / Advocacy group (such as the American Cancer Society)

❒ Other (please specify) _____

7. a. Did the Cancer Genetics Packet and appointment letter mailed prior to your visit provide useful information regarding the cancer risk assessment process?

❒ Yes ❒ No ❒ Don't remember

b. If not, what additional information would have been helpful prior to your appointment? Please be specific.

_____

_____

_____

_____

8. At which location were you seen for your cancer risk assessment?

❒ Milton S. Hershey Medical Center

❒ Lehigh Valley Hospital

❒ Centre Community Hospital / Mount Nittany Medical Center

9. If you were seen at either the Lehigh Valley Hospital or Centre Community Hospital / Mount Nittany Medical Center, would you have been willing to travel to the Milton S. Hershey Medical Center if the cancer genetic counseling services were not available locally?

❒ Yes ❒ No ❒ Not sure

GENETIC COUNSELING EXPERIENCE

10. Prior to your appointment, did you inform *family members* that you were pursuing cancer genetic counseling and / or testing? ❒ Yes ❒ No

11. If you did inform *any of your family members* about pursuing cancer genetic counseling and / or testing, how supportive were they?

❒ Very unsupportive

❒ Unsupportive

❒ Somewhat supportive

❒ Supportive

❒ Very supportive

12. If you *did not* inform *family members* about pursuing cancer genetic counseling and / or testing, why not?

_____

_____

_____

13. Prior to your appointment, did you inform *any of your friends* that you were pursuing cancer genetic counseling and / or testing? ❒ Yes ❒ No

14. If you did inform *friends* about pursuing cancer genetic counseling and / or testing, how supportive were they?

❒ Very unsupportive

❒ Unsupportive

❒ Somewhat supportive

❒ Supportive

❒ Very supportive

15. If you did not inform *friends* about pursuing cancer genetic counseling and / or testing, why not?

16. Did you bring a family member or friend to your genetic counseling visit(s)?

❒ Yes ❒ No ❒ Sometimes

17. If you *did* bring someone to one or more visits, in what ways did you find their presence helpful or not helpful?

18. If you *did not* bring a support person to one or more of your visits, was there a specific reason?

19. If you were not diagnosed with cancer before your visit, did the cancer risk assessment suggest your personal risk for cancer was higher, lower or similar to what you expected?

❒ Higher ❒ Lower ❒ Similar ❒ Don't remember

20. Did the cancer risk assessment suggest your risk for a genetic mutation was higher, lower, or similar to what you expected?

❒ Higher ❒ Lower ❒ Similar ❒ Don't remember

21. a. Did the cancer risk assessment indicate that it was appropriate to consider the option of genetic testing? ❒ Yes ❒ No ❒ Don't remember

b. If yes, did you obtain genetic testing? ❒ Yes ❒ No ❒ Not yet

22. If you did pursue genetic testing, please rank in order from 1 thru 5 (**1 = least important**, **5 = most important**) the factors that influenced you the most. If you did not pursue genetic testing, please skip to question 26.

	Least Important		↔		**Most Important**
Recommended by physician	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
Personal need to know / make medical decisions	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
Personal need to make family planning decisions	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
For the benefit of children and future generations	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
For the benefit of other family members	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5

23. a. If you had genetic testing, are you glad you did? ❒ Yes ❒ No ❒ Undecided

b. Please specify why or why not?

_____
_____
_____

24. If you had genetic testing, how did you feel while waiting for the test results? Please check all that apply.

❒ Anxious ❒ Depressed ❒ Lack of control over results

❒ Fear for family and self ❒ Pleased that I pursued testing

❒ Taking charge of my healthcare ❒ Other (please specify) _____

_____
_____
_____

25. If you had genetic testing and were identified to carry a genetic change or mutation, how have you adjusted to the information over time? Please check all that apply.

❒ Anxious ❒ Depressed ❒ Lack of control over results

❒ Fear for family and self ❒ Pleased that I pursued testing

❒ Taking charge of my healthcare ❒ Other (please specify) _____

_____
_____
_____

26. If you decided *not* to have genetic testing, why not? Please check all that apply.

❒ Risk for mutation not high enough

❒ Insurance company would not cover the testing

❒ Out-of-pocket costs were too high

❒ Concern about insurance / employment discrimination

❒ Anxious about possible results

❒ Results would not influence medical decisions

❒ Other (please specify) _____

27. How many appointments did you have for cancer genetic counseling?

❒ 1 ❒ 2 ❒ 3 ❒ >3

28. During your first visit to the Cancer Genetics Program, was the appointment…

❒ Too long ❒ Too short ❒ Just right

29. At your first appointment, what amount of time do you feel is enough to review your family history, provide education about the genetic and other risk factors for the cancers in your family, and review your individualized cancer risk assessment?

❒ < 30 minutes

❒ 30–60 minutes

❒ 61-90 minutes

❒ 91–120 minutes

❒ > 120 minutes

30. Regarding your visit(s) to the Cancer Genetics Program, how satisfied were you with your counselor? **1 = very dissatisfied** 2 = dissatisfied 3 = somewhat satisfied 4 = satisfied **5 = very satisfied**

	Very Dissatisfied		↔		**Very Satisfied**
her knowledge and skills	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
her caring attitude	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
ability to explain concepts in understandable manner	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5
overall performance	❒ 1	❒ 2	❒ 3	❒ 4	❒ 5

31. Regarding your visit(s), how satisfied were you with the physical location in which your appointment was held?

❒ Not at all satisfied

❒ Somewhat satisfied

❒ Satisfied

❒ Very satisfied

❒ Extremely satisfied

32. If you were not extremely satisfied with the physical location in which your appointment was held, please indicate what aspect(s) you found unsatisfactory.

❒ Parking too far from clinic ❒ Waiting room too crowded

❒ Not enough to do while in waiting room ❒ Meeting room not comfortable

❒ Other (please specify) _____

_____

_____

_____

33. If you were not extremely satisfied with the physical location in which your appointment was held, please offer suggestions for improvement.

_____

_____

_____

34. What other services would you have liked to receive during your first visit? Please check any that apply.

❒ Education about performing breast self exams

❒ Cancer screening tests (clinical breast exam, mammogram, CA125, etc.)

If yes, please specify. _____

❒ Nutritional information

❒ Education about herbal or complementary medicine / supplements

❒ Other (please specify) _____

PERSONAL OUTCOMES

35. How did your cancer risk assessment and / or genetic testing change your feelings of:

Anxiety, fear, stress	❒ Increased	❒ Decreased	❒ No change
Control, empowerment	❒ Increased	❒ Decreased	❒ No change
Guilt	❒ Increased	❒ Decreased	❒ No change
Self-esteem	❒ Increased	❒ Decreased	❒ No change
Depression	❒ Increased	❒ Decreased	❒ No change

36. Did you share any information from your cancer risk assessment and / or genetic testing with your family members? ❒ Yes If yes, answer questions 37 – 40.

❒ No If no, skip to question 41.

37. If you *did* share information with your family members, please specify who you shared with. Check all that apply.

❒ Spouse/Partner ❒ Mother ❒ Father

❒Sister(s) ❒ Brother(s) ❒ Son(s)

❒ Daughter(s) ❒ Aunt(s) ❒ Uncle(s)

❒Niece(s) ❒ Nephew(s) ❒ Cousins(s)

❒ Other (please specify) _____

38. If you *did* share information with family members, how did you share it? Please check all that apply. ❒ Telephone ❒ In person ❒ Letter ❒ Email

39. If you *did* share information with family members, what specifically did you share? Please check all that apply.

❒ Summary letter ❒ Family tree

❒ Genetic test results ❒ General information learned

40. If you *did* share information with family members, did you experience any difficulties or challenges? ❒ Yes ❒ No If yes, please provide specific details.

_____
_____
_____
_____

41. If you *did not* share information from your cancer risk assessment and / or genetic testing with your family members, why not?

_____
_____
_____
_____

42. Did the information from your cancer risk assessment and / or genetic testing help you in making medical decisions and / or did you make changes in your health behaviors (diet, exercise, smoking/drinking habits, etc)?

Surveillance (mammograms, colonoscopy, breast self exam, etc.)

❒ Yes ❒ No If yes, please specify.

_____
_____
_____

Health behaviors (diet, exercise, etc) ❒ Yes ❒ No If yes, please specify.

_____
_____
_____
_____

Chemoprevention (Ex: Tamoxifen) ❒Yes ❒No If yes, please specify.

_____
_____
_____
_____

Prophylactic surgery (removal of healthy tissue, such as breast, ovaries, etc.)

❒ Yes ❒ No If yes, please specify.

_____

_____

_____

_____

43. As a result of your cancer risk assessment and / or genetic testing, did you use any of the following health services within the hospital? If yes, check each service you used.

❒ Education about performing breast self exams

❒ Cancer screening tests (mammogram, ultrasound, colonoscopy, CA125, etc.)
If yes, please specify. _____

❒ Physician consultation (OB / GYN, surgeon, oncologist, etc.)
If yes, please specify. _____

❒ Other health services (nutritionist, mental health specialist, etc.)
If yes, please specify. _____

❒ Preventive surgery (mastectomy, oophorectomy, colectomy, etc.)
If yes, please specify. _____

❒ Clinical trial participation (STAR, SELECT, etc.)
If yes, please specify. _____

❒ Other services
If yes, please specify. _____

44. As a result of your cancer risk assessment and / or genetic testing, did you use any health services elsewhere? If yes, check each service you used.

❒ Education about performing breast self exams

❒ Cancer screening tests (mammogram, ultrasound, colonoscopy, CA125, etc.)

❒ Physician consultation (OB / GYN, surgeon, oncologist, etc.)

❒ Other health services (nutritionist, mental health specialist, etc.)

❒ Clinical trial participation (STAR, SELECT, etc.)

❒ Other services (please specify) _____

45. Following your cancer risk assessment and / or genetic testing, did you experience employment discrimination and / or insurance discrimination? Check any that apply.

❒ Insurance discrimination ❒ Employment discrimination

46. If you did experience discrimination, please provide details.

_____

_____

_____

_____

FOLLOW-UP

47. What was the most important piece of information you learned from your cancer risk assessment?

_____

_____

_____

_____

48. Please describe anything that you learned that was surprising or contrary to what you thought.

_____

_____

_____

_____

49. Following your cancer genetic counseling visit(s), did you find the information below useful?

Summary letter ❒ Yes ❒ No

Family tree ❒ Yes ❒ No

Genetic test results ❒ Yes ❒ No ❒ Not applicable

50. If you found the summary letter, family tree, and / or genetic test results useful, how was the information beneficial? Please check any that apply and feel free to elaborate further in the space below.

❒ Helped remember information presented during visit

❒ Made information presented during the visit easier to understand

❒ Provided information to physician upon which to make medical decisions

❒ Confirmed correct understanding of information presented

❒ Helped explain risks for relatives

❒ Other

_____

_____

_____

_____

51. If you did not find the summary letter, family tree, and / or genetic test results useful, why not?

_____

_____

_____

_____

52. Please answer the following regarding the information provided in the summary letter.

❒ Too much information ❒ Too little information

❒ Correct amount of information

53. a. Did you like the format of the summary letter?

❒ Yes ❒ Mostly Yes ❒ Mostly No ❒ No

b. What suggestions, if any, do you have for improving the summary letter?

_____

_____

_____

_____

54. If you were seen for more than one visit, would you prefer:

❒ One letter at the end of each visit ❒ One letter after the final visit

55. What other resources would you find useful to complement the cancer risk assessment? Check any that apply.

❒ Written information (pamphlets, brochures, etc.)

❒ Website addresses

❒ Referral network (one-on-one referral to other families with similar concerns)

❒ Support group

❒ Other (please specify) _____

56. If a new cancer gene was discovered several years after your cancer risk assessment that may explain your personal and / or family history of cancer, who do you think is responsible for contacting you with this information? **Please check only one answer.**

❒ Your responsibility to recontact the cancer risk assessment program

❒ The genetic counselor's responsibility to recontact the family

❒ The referring physician's responsibility to recontact the family

57. a. If a cancer gene were identified in your family, who is responsible for informing your relatives? ❒ Your genetic counselor ❒ Your referring physician ❒ You

b. If you checked genetic counselor and / or referring physician above, do you think the counselor or physician needs your permission to inform your relatives?

❒ Yes ❒ No ❒ Don't know

58 a. Was your insurance company billed for the genetic counseling visit(s)?

❒ Yes ❒ No ❒ Don't know

b. If so, what percentage did the insurance company reimburse?

❒ 0% ❒ 1% - 25% ❒ 26% - 50%

❒ 51% - 75% ❒ 76% - 100% ❒ Don't know

59. If a claim was not submitted to your insurance company, why not?

❒ Insurance would not cover visit(s).

❒ No insurance coverage.

❒ Privacy issues (concern about the potential for insurance discrimination).

❒ Don't know

❒ Other (please specify) _____

60. What was your total out-of-pocket expense for the cancer genetic counseling visit(s), not including any genetic testing?

❒ $0 - $50

❒ $51 - $100

❒ $101 - $200

❒ > $200

❒ Don't know

61. If insurance had not covered the genetic counseling visit(s) in full, what amount would you have been willing to pay out-of-pocket for the cancer risk assessment?

❒ $0 - $50

❒ $51 - $100

❒ $101 – 200

❒ > $200

❒ Don't know

62. a. If you pursued genetic testing, was your insurance company billed?

❒ Yes ❒ No ❒ Don't know

b. If so, what percentage did the insurance company reimburse?

❒ 0% - 25%

❒ 26% - 50%

❒ 51% - 75%

❒ 76% - 100%

❒ Don't know

63. If a claim was not submitted to your insurance company for the genetic testing, why not?

❒ Insurance would not cover genetic testing.

❒ No insurance coverage.

❒ Privacy issues (concern about the potential for insurance discrimination).

❒ Other (please specify) _____

❒ Don't know

64. If you pursued genetic testing, what was your total out-of-pocket expense?

❒ $0 - $250

❒ $251 - $500

❒ $501 - $750

❒ $751 - $1,000

❒ > $1,000

❒ Don't know

65. If insurance had not covered the genetic testing in full, what amount would you have been willing to pay out-of-pocket?

❒ $0 - $250

❒ $251 - $500

❒ $501 – $750

❒ $751 - $1,000

❒ > $1,000

❒ Don't know

66. If the Penn State Cancer Genetics Program had not been available at the hospital where you were seen, would you have traveled to an established program in Philadelphia, Pittsburgh or Baltimore to receive the services? ❒Yes ❒ No ❒ Maybe ❒ Don't know

OVERALL IMPRESSIONS

67. To what extent did the Penn State Cancer Genetics Program meet your expectations?

❒ None of my expectations were met

❒ Some of my expectations were met

❒ Most of my expectations were met

❒ All of my expectations were met

68. In what ways could the Penn State Cancer Genetics Program meet your expectations better? Please be specific.

_____
_____
_____

69. Please provide your overall assessment of the Penn State Cancer Genetics Program.

❒ Not at all satisfied

❒ Somewhat satisfied

❒ Satisfied

❒ Very satisfied

❒ Extremely satisfied

70. What were some of the positive aspects of undergoing the cancer risk assessment in the Penn State Cancer Genetics Program? Please be specific.

_____
_____
_____

71. In what ways can we improve the services provided by the Penn State Cancer Genetics Program? Please be specific.

_____
_____
_____
_____

72. Would you encourage friends or relatives to pursue cancer genetic counseling through the Penn State Cancer Genetics Program if appropriate?

❒ Yes ❒ No ❒ Not sure

DEMOGRAPHIC INFORMATION

73. What is your gender? ❒ Male ❒ Female

74. What is your year of birth? 19_____

75. What is your marital status?

❒ Married ❒ Single with partner ❒ No current partner

❒ Widowed ❒ Divorced ❒ Separated

76. What county (Dauphin, Lehigh, Centre, etc.) do you live in?_____

77. What is the highest level of school you have completed? Please check only one answer.

❒ Less than high school

❒ High school

❒ Some college or technical school

❒ College

❒ Some graduate or professional school

❒ Graduate or professional school

78. Please check the appropriate box designating your ethnicity.

❒ Hispanic or Latino ❒ Not Hispanic or Latino

79. Please check the appropriate box designating your race.

❒ American Indian / Alaska Native ❒ Asian

❒ Native Hawaiian / Pacific Islander ❒ Black or African American

❒ White

80. Please provide an estimate of your total annual household income.

❒ Less than $20,000

❒ $20,001 - $35,000

❒ $35,001 - $50,000

❒ $50,001 - $75,000

❒ > $75,000

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REFERENCES

Baker, D. L., Eash, T., Schuette, J. L., & Uhlmann, W. R. (2002). Guidelines for writing letters to patients. *J Genet Couns*, *11*(5), 399–418.

Bonadona, V., Saltel, P., Desseigne, F., Mignotte, H., Saurin, J.-C., Wang, Q., *et al.* (2002). Cancer patients who experienced diagnostic genetic testing for cancer susceptibility: Reactions and behavior after the disclosure of a positive test result. *Cancer Epidemiol Biomarkers & Prev*, *11,* 97–104.

Collins, V., Halliday, J., Warren, R., & Williamson, R. (2000). Assessment of education and counseling offered by a familial colorectal cancer clinic. *Clin Genet*, *57,* 48–55.

Freyer, G., Dazord, A., Schlumberger, M., Conte-Devolx, B., Ligneau, B., Trillet-Lenoir, V., *et al.* (1999). Psychosocial impact of genetic testing in familial medullary-thyroid carcinoma: A multicentric pilot-evaluation. *Ann Oncol*, *10*(1), 87–95.

Geer, K. P., Ropka, M. E., Cohn, W. F., Jones, S. M., & Miesfeldt, A. (2001). Factors influencing patients' decisions to decline cancer genetic counseling services. *J Genet Counsel*, *10*(1), 25–40.

Green, M. J., Peterson, S. K., Wagner Baker, M., Friedman, L. C., Harper, G. R., Rubinstein, W. S., *et al.* (2005). Use of an educational computer program before genetic counseling for breast cancer susceptibility: Effects on duration and content of counseling sessions. *Genet Med*, *7*(4), 221–229.

Green, M. J., Peterson, S. K., Wagner Baker, M., Friedman, L. C., Harper, G. R., Rubinstein, W. S., *et al.* (2004). Effect of a computer-based decision aid on knowledge, perceptions and intentions about genetic testing for breast cancer susceptibility: A randomized trial. *JAMA*, *292*(4), 442–452.

Green, M. J. (1998–2000). Breast Cancer Risk and Genetic Testing, Version 2.0. CD-ROM. Wisconsin Alumni Research Foundation.

Hallowell, N., & Murton, F. (1998). The value of written summaries of genetic consultations. *Patient Educ Couns*, *35*(1), 27–34.

Hirschhorn, K., *et al.* (1999). Duty to re-contact. *Genet Med*, *1*(4), 171–172.

Julian-Reynier, C., Eisinger, F., Chabal, F., Aurran, Y., Bignon, Y. –J., Nogues, C., *et al.* (1998). Cancer genetic clinics: Why do women who already have cancer attend? *Eur J Cancer*, *34*(10), 1549–1553.

Kash, K. M., Ortega-Verdejo, K., Dabney, M. K., Holland, J. C., Miller, D. G., & Osborne, M. P. (2000). Psychosocial aspects of cancer genetics: Women at high risk for breast and ovarian cancer. *Semin Surg Oncol*, *18,* 333–338.

Lea, D. H. (1996). Emerging quality improvement measures in genetic counseling. *J Genet Counsel*, *5*(3), 123–137.

National Conference of State Legislatures, www.ncsl.org/programs/health/genetics/ndishlth.htm.

National Human Genome Research Institute, NIH, www.genome.gov/10002077.

NCI Cancer Genetics Services Directory, www.cancer.gov/search/geneticsservices/.

NSGC Familial Cancer Risk Counseling Special Interest Group Directory (2003).

Rosenthal, E. (2005). Patient attitudes towards follow-up letters in the cancer genetics clinic. 24th Annual Education Conference, Los Angeles, CA.

Stacey, D., DeGrasse, C., & Johnston, L. (2002). Addressing the support needs of women at high risk for breast cancer: Evidence-based care by advanced practice nurses. *Oncol Nurs Forum*, *29*(6), E77–E84.

Watson, M., Lloyd, S., Davidson, J., Meyer, L., Eeles, R., Ebbs, S., *et al.* (1999). The impact of genetic counseling on risk perception and mental health in women with a family history of breast cancer. *Br J Cancer*, *79*(5–6), 868–874.