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Exploring Hereditary Cancer Among Dying Cancer Patients—A Cross-Sectional Study of Hereditary Risk and Perceived Awareness of DNA Testing and Banking

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Abstract

Hereditary cancer assessment at the end of life is a relatively unexplored area, but it could be critical for surviving family members. This study explored the prevalence of hereditary cancer among dying cancer patients and assessed patients' perceived awareness of DNA testing and/or banking in a public access hospital. Palliative care patients with cancer from a single institution (or their medical-decision-making surrogates for patients unable to answer for themselves) completed structured interviews. Information was collected through medical records review and structured interviews for 43 dying cancer patients. Information for 9 patients was collected from surrogates. Nine patients (21%, 95% CI=8.8% to 33.1%) had strong genetic risk. Currently available genetic tests could have addressed this risk for several patients. None had previous genetic counseling, testing or DNA banking. Among strong-risk patients, about half of patients/surrogates had heard/read "almost nothing" about genetic testing (44%) and DNA banking (67%). Perceived genetic awareness was not associated with genetic risk, and neither were sociodemographic characteristics. The proportion of hereditary cancer may be at least as high in the palliative care population as in other clinical settings, but awareness and uptake among patients are low. These conditions are not being recognized upstream and families are losing valuable information.

Keywords

Hereditary; Neoplasm; Cancer; Genetic screening; DNA banking; End of life; Genetic testing; Genetic counseling

Introduction

Identifying patients' risks and providing personalized prevention recommendations are key goals of cancer genetic counseling and testing (Berliner and Fay 2007). Yet, for dying cancer patients these outcomes are not medically indicated. Instead, it is the *familial* nature of genetics assessment that may be of value to this population. This attention to genetic legacy is an understudied phenomenon that might be of medical significance to surviving family members, and of personal psychological benefit to dying cancer patients (Lillie 2006; Quillin et al. 2008a; Skirton et al. 2006).

About 5% to 10% of cancers arise in individuals with autosomal dominant cancer susceptibility (Offit 1998; Garber and Offit 2005). Unfortunately, many of these families will not have identifiable genetic markers for their risks by currently available tests. For example, at most, half of families with hereditary breast cancer will test positive for a clinically useful mutation (Wooster and Weber 2003). Thus, without a known mutation in the family, a healthy woman with a strong family history of breast cancer cannot be fully reassured by negative genetic test results, and DNA banking could be more valuable.

Professional guidelines, such as those of the National Comprehensive Cancer Network (2008), can be helpful for identifying newly diagnosed patients for genetics risk assessment. While time of diagnosis represents an important opportunity for this triage, this does not always happen (Fowler et al. 2005; Grover et al. 2004; Shannon et al. 2002). The prevalence of unidentified hereditary cancer among dying cancer patients is unknown. Furthermore, whether these patients are aware of genetic testing for cancer risk or storing a blood sample for future family use (i.e., DNA banking), is unknown. This study aimed to fill these gaps.

The objectives of this study were to: 1) among end-of-life hospitalized oncology patients, estimate the proportion of patients with hereditary cancer risk appropriate for genetic services, and 2) assess perceived awareness of genetic testing and DNA banking among patients likely to have hereditary risk. We hypothesized the proportion of hereditary cancer risk in our sample would be similar to the proportion of hereditary cancer overall in the population (i.e., about 5% to 10%). While it is unlikely that the prevalence of hereditary cancer risk differs in this population, these data are not documented elsewhere in the literature. Identifying the prevalence of hereditary cancer risk in this population, particularly if patients have not had prior genetics evaluation, is a critical step in light of the proposed need for genetic services in this population (e.g., Lillie 2006; Quillin et al. 2008a). Relatedly, we anticipated awareness would be low regarding genetic testing and especially regarding DNA banking. We also wanted to explore any differences in awareness by sociodemographic characteristics.

Methods

We conducted a cross-sectional exploratory study of hereditary cancer among advanced cancer patients, utilizing in-person structured interviews and medical records reviews.

Sample Population and Recruitment

Participant recruitment occurred for about seven months in the spring and summer of 2008 at Virginia Commonwealth University Health System (VCUHS) in downtown Richmond, Virginia. The VCUHS is an academic public-access health system and provides a significant proportion of indigent care for the state. The patient population reflects the Richmond metropolitan area, and about half of the patients are African-American. Eligible participants were adult, English-speaking patients at VCUHS in the palliative care and oncology units with advanced cancer diagnoses. For patients not able to answer questions themselves, their adult medical decision-making surrogates were eligible to participate.

Patient identification, consent, administration of structured interviews, and medical records reviews were conducted by a research assistant. The research assistant had a masters degree in clinical psychology and had previous research experience. Training specific to this project included hospital records review, patient confidentiality, and administration training required at our institution to gain access to hospital electronic medical records. She was further trained through review of a study manual about conducting valid structured research interviews. Concepts were reinforced in training sessions with the Principal Investigator along with interview practice sessions.

Following successful training, the research assistant reviewed hospital admission notes for the palliative care and oncology units daily and selected patients who were either on the palliative care unit because of advanced disease, or because they had been admitted to the oncology service with terminal cancer. The research assistant obtained informed consent from all participants, and the study was approved by the Virginia Commonwealth University Institutional Review Board. If patients were not able, or preferred not, to answer questions for themselves due to their medical condition, their medical decision-making surrogate was invited to participate. Although patients and surrogates likely differ in terms of family history knowledge and attitudes toward genetic testing, for the purposes of this study surrogates' responses were considered critical, since they are the ones reporting family history and deciding about genetic testing for the patient.

Instrumentation

Medical Records—Patient medical records were reviewed by the research assistant using a study-specific data abstraction form (Appendix) to confirm cancer diagnoses and to assess for any previous interaction with genetics services.

Structured Interviews—The research assistant verbally administered structured interviews to patients or to the patients' medical decision-making surrogates. The interview schedules are included in the Appendix. Interviews were anticipated to take 15 to 30 min to complete.

Variables

To estimate the proportion of cancers that appear to have a hereditary component, the primary data were cancer diagnoses (types and ages of onset) for patients and their first- and second-degree relatives, as reported by the participant. Based on this information, patients

were classified as having “strong,” or “moderate/average” genetic risk by the principal investigator who is a genetic counselor, certified by the American Board of Genetic Counseling. Consensus clinical criteria for referral for hereditary cancer syndromes were used whenever available. For patients with breast, ovarian, endometrial, colon, or prostate cancer, the risk classification scheme developed by Scheuner et al. (1997) was used. Patients with family histories of breast and/or ovarian cancer were assessed to see if they met criteria for *BRCA1* and *BRCA2* genetic testing referral, according to relevant guidelines of the National Comprehensive Cancer Network (NCCN) (2008) and the United States Preventive Services Task Force (USPSTF) (2005). If family history was unknown or data were otherwise missing, family history was assumed to be negative for cancer.

Perceived awareness of genetic testing and DNA banking was assessed with the question, “How much have you heard or read about genetic testing [DNA banking] for cancer risk?” (Durfy et al. 1999; Quillin et al. 2008b) Participants responded on a 4-point scale with answers ranging from “Almost nothing” to “A lot.” Race/ethnicity, educational background, and household annual income of participants (patients or surrogates) were also elicited through the interviews. Ages of patients were calculated from dates of birth abstracted from medical records. We did not collect data about ages of medical decision-making surrogates.

Sample Size

The initial target enrollment for this study was 150 participants. This sample size was originally chosen based on expectations of perceived genetic awareness among participants. Based on a previous study, about 10% of research participants were expected to have high awareness (i.e., to report having heard or read “a lot” about genetic testing (Quillin et al. 2008b)). A sample size of 150 would have allowed us to estimate this proportion with a 95% confidence interval that is +/−5%. The recruitment rate was lower than expected, and the recruitment period was not extended due to limited funding.

Data Analyses

All analyses were conducted using SAS v.9.1.3. Reported family histories and data from medical records were reviewed by a genetic counselor who was certified by the American Board of Genetic Counseling. The proportion of families meeting hereditary cancer criteria or having “strong” genetic risk was assessed, and a 95% confidence interval for the proportion was obtained, using the BINOMIAL option in SAS. The proportion of participants having various levels of awareness was also estimated for genetic testing and DNA banking. Chi-square analyses were conducted to look for differences in awareness of genetic testing and DNA banking by genetic risk. We also looked for differences in the prevalence of hereditary cancer risk by sociodemographic characteristics (race, income, and educational background) with Chi-square analyses. For association analyses involving small proportions, Fisher’s exact test was used. Alpha levels of $p<.05$ were considered statistically significant.

Although the participant pool included a mix of patients answering for themselves ($n=34$) and medical decision-making surrogates ($n=9$), for data analyses we did not distinguish these types of participants. In clinical practice, when a patient cannot communicate with her

or his care providers, communicating family health history and deciding about genetic testing are responsibilities of a decision-making surrogate when one is available. Thus, for the goal of identifying hereditary cancer in clinical palliative care practice, this exploratory study utilized relevant clinical information just as it would come to a provider—either from the patient or from a medical decision-making surrogate.

Results

From January to July, 2008, 88 patients were screened eligible, and we recruited 43 for a recruitment rate of 49%. Fifty-eight of the 88 patients were actually approached and invited to the study, so the acceptance rate was 74%. Thirty-four participants were patients answering for themselves, and nine participants were medical decision-making surrogates. Attempts to recruit many patients failed because it was an inconvenient time (e.g., patient sleeping, had visitors, patient getting a procedure). This occurred for at least 36% of patients who were not recruited. Other reasons for patients declining study participation included imminent death (i.e., death expected within 24 h) or discharge from the hospital, the patient or others conveying to the research assistant that it was not a good time for discussion (e.g., family visiting), lack of availability of a surrogate decision maker, participants feeling overwhelmed because of concurrent involvement in another research study, and general lack of interest in participating in research. No one who declined expressed discomfort with the study topic. Some data were missing for five participants because they were not able to complete the interview in the hospital and were lost to follow up, despite several attempts to reach them by phone.

About half of the participants (20/39) reporting race were African-American. Mean age of patients in the study was 55 years (Median 54, Range: 19 to 87). About 20% of study participants had a college education or more, and the annual income for 27% of participants was less than $15,000.

Overall, nine (21%, 95% CI=8.8% to 33.1%) of the 43 patients had family histories suggestive of hereditary risk (Table 1). This included eight families that met criteria by Scheuner et al. (1997), five that met NCCN (2008) criteria for breast/ovarian cancer, and two that met USPSTF (2005) criteria for breast/ovarian cancer. One family met criteria for familial lung cancer (Bailey-Wilson et al. 2004).

Among all participants, more than half reported they had heard or read “almost nothing” about genetic testing (52%) and DNA banking (67%). The proportion of participants with this low perceived awareness of genetic services was similar between those with and without hereditary cancer by family history ($p>.05$). Similarly, presence of hereditary cancer risk was not associated with educational background, income, race, or age (Table 2).

Discussion

The aims of this study were to assess the proportion of hereditary cancer among dying cancer patients, their awareness of genetic testing and DNA banking, and to look for associations of hereditary risk with genetic awareness and sociodemograpic variables. In this sample, about one in five patients met criteria for genetics referral. This was higher than

anticipated, though the 95% confidence interval of this proportion overlapped with the typical estimated 5% to 10% of cancer patients expected to have hereditary risk. It would be unrealistic to expect any one set of criteria to have both perfect sensitivity and specificity, and, for purposes of genetics referral, it is likely appropriate to have higher sensitivity at the cost of some specificity (i.e., higher toleration for false screen positives). For example, the USPSTF (2005) estimated 2% of the general population (having no personal history of cancer) would meet their criteria for *BRCA1* and *BRCA2* referral, compared to a population *BRCA1* and *BRCA2* carrier rate of much lower than 1%. A subsequent study (Palomaki et al. 2006) found an actual screen positive rate of 7.5%. Using a checklist approach, Bellcross et al. (2009) found a similar proportion (6.2%) of women in a mammography clinic had at least a 10% chance of having a *BRCA1* or *BRCA2* mutation, and thus might be appropriate for referral. Subsequent studies showed a positive screen rate closer to 2% when multiple criteria agree (McClain et al. 2008). Among women with breast or ovarian cancer, one study found 20.6% screened positive using a 10% mutation probability threshold by the Myriad model (Dominguez et al. 2005), whereas a study among Japanese patients found 7.5% screened positive using the same criterion (Komata et al. 2009). Hampel et al. (2004) tested a comprehensive set of criteria for use among healthy individuals and cancer patients and found that 14.9% were considered to be high risk. The findings from the current study are within the range found in the literature.

While the purpose of this study was not to test various methods for identification of hereditary risk, it is notable that the criteria used [Scheuner et al. (1997) classification, NCCN (2008), USPSTF (2005), and expert genetic counseling review] did not identify, on face value, any inappropriate referrals. Genetic testing was not a part of the study, so it is unknown what proportion of patients had identifiable mutations. However, given the limited clinical sensitivity of currently available genetic tests, the missed opportunities for hereditary risk counseling and DNA banking in these families is notable.

Relatedly, about half of all patients, including those with hereditary risk had heard/read almost nothing about genetic testing and DNA banking. This low awareness is similar to levels found in other studies (Durfy et al. 1999; Quillin et al. 2008a, b). These findings reinforce that providers cannot assume that patients with family histories will know about the availability of genetic services. None of the patients was seen by our institution's genetics clinic, and none reported having previous clinical genetic testing for cancer risk or banking DNA (data not shown). Risk for genetic disease cut across all levels of sociodemographic characteristics, suggesting the implications of our findings may apply broadly, at least for the characteristics identified in this study (e.g., race, income).

Study Limitations

This study has limitations. First, we recruited fewer participants than we had planned. Funding and time limitations contributed to this lower sample size. Still, the participant characteristics, in terms of cancer diagnoses and sociodemographics, were typical of patients at our institution. There is no obvious bias in our sample that would suggest results are not generalizable to other clinical settings such as the one in our study. Still, a larger sample size would help support the applicability of our findings to the larger patient population. The

study was also limited by patient report of family history. We also note that awareness was assessed through a single-item measure that only captured perceived, self-reported exposure to genetic information. Although this measure has literature precedence, the use of a single measure could compromise precision, and we note that it may not capture actual knowledge of genetics effectively. Finally, although we were able to confirm patients' diagnoses, we did not attempt to confirm reported family history. These limitations notwithstanding, in clinical practice patient report will likely be the main source of family history data.

Practice Implications

If confirmed, the implications of this study are important for the practice of genetic counseling. Prevalence of unidentified hereditary cancer is likely at least as high among dying cancer patients in this study as the hypothesized 5% to 10%. Yet, at least at one institution that has expert and readily available genetic consultation services, and likely elsewhere, it does not appear that this risk is being addressed. The opportunities for involvement of genetic counselors may be lost when the patient dies, often within hours or days of the belated recognition of genetic risk. Surviving relatives may be losing opportunities to know if their family has detectable genetic markers for cancer risk, with lost opportunities for genetic counseling, prevention, screening, and early treatment.

Research Recommendations

Though exploratory, findings from this study support a related research agenda. First, given the small sample size, confirmatory studies at other institutions would be helpful. If the underutilization of genetic services is confirmed, future studies would be warranted to identify patient, surrogate, and provider facilitators and barriers relevant for genetic services. Ultimately, intervention research to test models for genetic services delivery at the end of life could help to address this unmet need. The high prevalence of low awareness suggests that stage-of-change interventions, such as the Precaution Adoption Process Model (Weinstein 1988) and the Transtheoretical Model (Prochaska and DiClemente 2005) might be particularly effective. Once awareness is raised, additional studies could investigate barriers and facilitators of genetic testing and banking relevant for decision-making and counseling. Although testing and banking intentions were investigated in our study, the low prevalence of genetic awareness limit the usefulness of those data, even among the small proportion of patients suspected of having hereditary cancer. It should also be noted that end-of-life research should continue in tandem with efforts to identify hereditary cancer upstream—sooner after diagnosis or, ideally, before diagnosis based on family health history.

In addition, further work is needed to address the potential practical and ethical challenges and alternatives for integrating genetic testing and DNA banking in palliative care. DNA banking is typically not covered by insurance and can cost hundreds of dollars. While this is certainly less than the cost of most clinical genetic tests, this financial barrier could be significant for many patients. Furthermore, future genetic testing of the banked sample might not be covered by insurance. Insurance coverage for clinical genetic testing is often based on "medical necessity", typically referring to the necessity for the patient herself, rather than the patient's family. Thus, while a patient might meet family history criteria for

testing, it might be difficult for ordering providers to justify medical necessity for dying cancer patients.

Alternatively, identification of hereditary cancer may still be of benefit to patients' families even without DNA banking or testing. The family history interview might identify other living affected relatives who are appropriate for testing. Or, the death of a patient from cancer could serve as a "teachable moment" for surviving family members that could prompt them to adopt cancer prevention or screening practices (Humpel et al. 2007). Future research studies are needed to address these potentially impactful questions.

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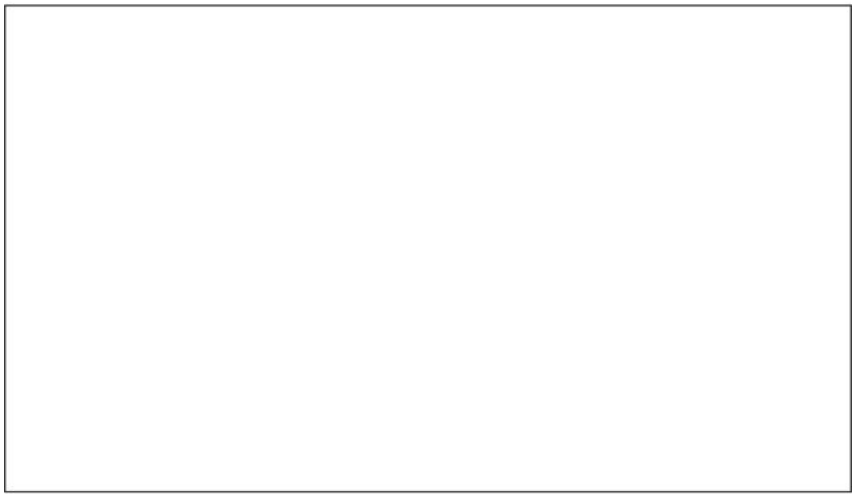
Appendix

Medical Record Data Abstraction From

Study ID#_____

1. Date of chart review: __ __ - __ __ - 20__ __
2. Patient Name:_____
3. Patient Medical Record Number:_____
4. Date of birth: __ __ - __ __ - 19__ __
5. Gender:
   - □1 Female
   - □2 Male
6. Patient's cancer diagnosis:_____
7. How is family cancer history documented in the chart (check all that apply)?
   - □1 No documentation of family cancer history
   - □2 Checkboxes / table on intake form
   - □3 Palliative care provider notes. What type(s) of provider?_____
   - □4 Noted in other medical records (i.e., not VCUHS PCU)
   - □5 Other documentation_____
8. In the space below, indicate what family history of cancer can be gleaned from the chart:



9. Is there documentation of a request for genetics consult?
   - □1 Yes
   - □2 No

10. Is there documentation of discussion about genetic testing?
    - □1 Yes
    - □2 No

11. Is there documentation of discussion about DNA banking?
    - □1 Yes
    - □2 No

Genetics Assessment (To Be Completed by Genetics Researcher)

Based on the family history information from the medical record by Scheuner et al. criteria (1997) what is the genetic contribution to cancer in this family?
- □1 Average
- □2 Moderate
- □3 Strong

Does the family history meet USPSTF criteria for BRCA referral?
- □1 Yes
- □2 No

Does the family history meet NCCN criteria for genetics referral for breast cancer?
- □1 Yes
- □2 No

Does the family history meet current clinical criteria for a cancer genetic syndrome?
- □1 Yes_____
- □2 No

Patient Interview about Cancer Genetic Screening at the End of Life

[For Patients Answering for Themselves]

Study ID#_____ Today's Date_____

Patient Name_____

Patient Medical Record Number_____

Thank you for taking time to answer some questions about genetic screening for cancer. This interview should take about 30 minutes. Do you have any questions before we start?

First I would like to ask you some questions about what you might already understand concerning genetic testing for cancer.

1. Please tell me in your own words what you think "genetic testing" is?

_____

_____

For the rest of this interview, "genetic testing" refers to a blood test that looks for a marker of cancer risk that can be passed on in families like other traits.

2. How much have you heard or read about genetic testing for cancer risk?
   - □1 Almost nothing
   - □2 Relatively little
   - □3 A fair amount
   - □4 A lot

3. Has anyone in your family, related by blood, ever had genetic testing for inherited cancer risk?
   - □1 Yes
     a) How is that person related to you _____
     b) What type of testing was it?_____
     c) What did the results show?_____
   - □2 No
   - □9 Not sure

4. Have you ever had genetic testing for inherited cancer risk?
   - □1 Yes
     a) For what gene(s) were you tested?_____
     b) What did the results show?_____
     c) What are some reasons you chose to have testing?

     _____

     _____

     d) What do you understand about the meaning of this test result for you?

     _____

     _____

     e) What do you understand about the meaning of this test result for your family?

     _____

     _____

f) Did you share your test results with other family members?
□1 Yes
□2 No
Skip to #13

□2 No
□9 Not sure

5. At the present time, which of the following statements describes your thoughts about having genetic testing for family susceptibility to cancer?
□1 I definitely will not get tested
□2 I probably will not get tested
□3 I probably will get tested
□4 I definitely will get tested

6. What are some reasons you might choose to have genetic testing if it was offered to you?
_____
_____
_____

7. What are some reasons you might choose *not* to have genetic testing if it was offered to you?
_____
_____
_____

8. What information would be important for you to have when making a decision about genetic testing?
_____
_____
_____

9. If you had genetic testing, how concerned would you be about the privacy of your test results?
□1 Not at all concerned
□2 Somewhat concerned
□3 Quite concerned
□4 Extremely concerned

10. If you had genetic testing, how concerned would you be about emotional distress from test results?
□1 Not at all concerned
□2 Somewhat concerned
□3 Quite concerned
□4 Extremely concerned

11. If you had genetic testing, how concerned would you be about your relationship with other family members?
□1 Not at all concerned
□2 Somewhat concerned
□3 Quite concerned
□4 Extremely concerned

12. If you had genetic testing, how likely would you be to share results with your other family members?
    - □1 Not at all likely
    - □2 Somewhat likely
    - □3 Quite likely
    - □4 Extremely likely

13. How would you prefer to receive information about genetic testing? (check all that apply)
    - □1 Written materials, like brochures
    - □2 A conversation with my doctor or nurse
    - □3 An appointment with a genetics specialist
    - □4 A friend who is knowledgeable
    - □5 A family member
    - □6 An educational video
    - □7 The Internet or World Wide Web
    - □8 Another resource_____
    - □9 I am not interested in receiving genetic testing information.

14. How would you share your genetic test results with your family? (Check all that apply)
    - □1 I would want my healthcare professional to talk to them
    - □2 A letter from my healthcare professional
    - □3 An educational video
    - □4 A brochure or other written materials
    - □5 A website
    - □6 Other_____
    - □7 I would not want to use any resources
    - □8 I would not want to share my results with family members

Now I am going to ask you some questions about DNA banking.

15. Please tell me in your own words what you think "DNA banking" is?

    _____

    _____

For the rest of this interview "DNA banking" refers to collecting and storing your genetic material (usually a blood sample) that could be used by family members in the future for clinical genetic testing or research.

16. How much have you heard or read about DNA banking?
    - □1 Almost nothing
    - □2 Relatively little
    - □3 A fair amount
    - □4 A lot

17. Has anyone in your family ever banked DNA?
    - □1 Yes a) How is that person related to you? _____
      b) Why did they bank DNA?_____
    - □2 No
    - □9 Not sure

18. Have you ever banked your DNA?
- □1 Yes a) Why?_____
  Skip to #23
- □2 No
- □9 Not sure

19. At the present time, which of the following statements describes your thoughts about banking DNA for family susceptibility to cancer?
- □1 I definitely will not bank my DNA
- □2 I probably will not bank my DNA
- □3 I probably will bank my DNA
- □4 I definitely will bank my DNA

20. What are some reasons you might choose to bank DNA if it was offered to you?

_____
_____
_____

21. What are some reasons you might choose *not* to bank DNA if it was offered to you?

_____

22. If you banked your DNA, how concerned would you be about who might access your genetic information in the future?
- □1 Not at all concerned
- □2 Somewhat concerned
- □3 Quite concerned
- □4 Extremely concerned

23. How would you prefer to receive information about DNA banking? (check all that apply)
- □1 Written materials, like brochures
- □2 A conversation with my doctor or nurse
- □3 An appointment with a genetics specialist
- □4 A friend who is knowledgeable
- □5 A family member
- □6 An educational video
- □7 The Internet or World Wide Web
- □8 Another resource_____
- □9 I am not interested in receiving information about DNA banking.

Now I am going to ask you some questions about your personal and family histories of cancer.

24. What kind of cancer do you have?_____

25. How old were you when you were diagnosed?_____

26. What do you think is the likely cause of your cancer?

_____

27. How likely do you think it is that there is a genetic or inherited component to your cancer?
- □1 Extremely unlikely
- □2 Somewhat unlikely
- □3 Neither likely nor unlikely
- □4 Somewhat likely
- □5 Extremely likely

For this part of the survey I will ask you about your family, including those who have and have not had cancer. Please think about just family members who are related by blood (not in-laws)

28. How many brothers and sisters do you have, including those who have died?_____

29. Did any of your brothers and sisters have cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Brother or Sister	*Type of Cancer*	*Age at Diagnosis*

30. How many children, including those who have died?_____

31. Did any of your children have cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Son or Daughter	*Type of Cancer*	*Age at Diagnosis*

32. How many nieces and nephews, related by blood, including those who have died?_____

33. Have any of your nieces or nephews had cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Niece or Nephew	*Type of Cancer*	*Age at Diagnosis*

34. Did your mother have cancer?
    - □1 Yes a) What type of cancer?_____
      b) How old was she when she was diagnosed?_____
    - □2 No
    - □9 Not sure

35. How many brothers and sisters did your *mother* have (your aunts and uncles)?_____

36. Did any of your *mother's* brothers and sisters have cancer?
    - □1 Yes (complete table below)
    - □2 No
    - □9 Not sure

Maternal Aunt or Uncle	*Type of Cancer*	*Age at Diagnosis*

37. Did your mother's mother (your maternal grandmother) have cancer?
    - □1 Yes a) What type of cancer?_____
      b) How old was she when she was diagnosed?_____
    - □2 No
    - □9 Not sure

38. Did your mother's father (maternal grandfather) have cancer?
    - □1 Yes a) What type of cancer?_____
      b) How old was he when he was diagnosed?_____
    - □2 No
    - □9 Not sure

39. Did your father have cancer?
    - □1 Yes a) What type of cancer?_____
      b) How old was he when he was diagnosed?_____
    - □2 No
    - □9 Not sure

40. How many brothers and sisters did your *father* have (your aunts and uncles)?_____

41. Did any of your *father's* brothers and sisters have cancer?
    - □1 Yes (complete table below)
    - □2 No
    - □9 Not sure

Paternal Aunt or Uncle	*Type of Cancer*	*Age at Diagnosis*

42. Did your father's mother (your paternal grandmother) have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was she when she was diagnosed?_____
- □2 No
- □9 Not sure

43. Did your father's father (paternal grandfather) have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was he when he was diagnosed?_____
- □2 No
- □9 Not sure

Finally, I would like to ask you a few questions about payment for genetic testing and DNA banking, and your background.

44. How much money would you be willing to pay to have genetic testing for yourself?

	Yes	No
Up to $99	□1	□2
Up to $499	□1	□2
Up to $999	□1	□2
Up to $2,499	□1	□2
More than $2,500	□1	□2
I wouldn't be willing to pay any money	□1	□2
IDK	□9	
No Response	□99	

45. How much money would you be willing to pay to bank your DNA?

	Yes	No
Up to $99	□1	□2
Up to $499	□1	□2
Up to $999	□1	□2
Up to $2,499	□1	□2
More than $2,500	□1	□2
I wouldn't be willing to pay any money	□1	□2
IDK	□9	
No Response	□99	

46. Regarding your ethnic background, do you consider yourself to be Hispanic or Latino?
- □1 Hispanic or Latino
- □2 Not Hispanic or Latino

47. Which of the following do you consider yourself to be? (check all that apply)
    - □1 American Indian or Alaska Native
    - □2 Asian
    - □3 Black or African American
    - □4 Native Hawaiian or other Pacific Islander
    - □5 White
    - □6 Other _____

48. Do you have any Jewish Eastern European (Ashkenazi) ancestry?
    - □1 Yes
    - □2 No
    - □9 Not sure

49. What was your highest level of formal education completed?
    - □1 Less than high school
    - □2 Some high school
    - □3 H.S. diploma/GED
    - □4 Some college
    - □5 Completed college
    - □6 Some post-grad
    - □7 Completed post-grad

50. What was your total household income in the last calendar year?
    - □1 Less than $15,000
    - □2 $15-34,999
    - □3 $35-74,999
    - □4 $75,000 +

51. What is your religion?
    - □1 Protestant
    - □2 Jewish
    - □3 Roman Catholic
    - □4 Other_____
    - □5 None
    - □9 Don't know

52. Do you consider religion to be an important part of your life, or not?
    - □1 Yes
    - □2 No
    - □9 I don't know

53. How important would you say your religious beliefs are for providing guidance in your day-to-day living?
    - □1 Not important
    - □2 Somewhat important
    - □3 Important
    - □4 Very important
    - □9 I don't know

54. On a scale of 1 – 10 how comfortable were you answering these survey questions? 1 being extremely uncomfortable, 10 being extremely comfortable with 2 – 9 in between.

1 Extremely Uncomfortable ---------- *10 Extremely Comfortable*

1	2	3	4	5	6	7	8	9	10

(If score is 9 or 10 skip to question 53.)

54a. What about this survey made you UNcomfortable?

_____

_____

_____

55. Are there any other thoughts you have about this survey?

_____

_____

_____

STUDY ID # _____

MRN _____

Genetics Assessment (Completed by Genetics Researcher)

56. Based on the reported family history information by Scheuner et al. criteria (1997) what is the genetic contribution to cancer in this family?
- □1 Average
- □2 Moderate
- □3 Strong

57. Does the family history meet USPSTF criteria for BRCA referral?
- □1 Yes
- □2 No

58. Does the family history meet NCCN criteria for genetics referral for breast cancer?
- □1 Yes
- □2 No

59. Does the family history meet current clinical criteria for a cancer genetic syndrome?
- □1 Yes_____
- □2 No

Surrogate Interview about Cancer Genetic Screening at the End of Life

[For Medical Decision-Making Surrogates Answering for Patients]

Study ID#_____ Today's Date_____

Patient Name_____

Relationship of surrogate to patient_____

Patient Medical Record Number_____

Thank you for taking time to answer some questions about genetic screening for cancer. This interview should take about 30 minutes. For some of the questions I will ask you to try to answer the question as if you were answering on behalf of the patient (e.g., type of cancer), while other questions, such as your awareness and understanding of genetic tests, will reflect your own beliefs and understanding. Do you have any questions before we start?

First I would like to ask you some questions about what you might already understand concerning genetic testing for cancer.

1. Please tell me in your own words what you think "genetic testing" is?

   _____

   _____

For the rest of this interview, "genetic testing" refers to a blood test that looks for a marker of cancer risk that can be passed on in families like other traits.

2. How much have you heard or read about genetic testing for cancer risk?
   - □1 Almost nothing
   - □2 Relatively little
   - □3 A fair amount
   - □4 A lot

3. Has anyone in <u>your</u> family, related by blood, ever had genetic testing for inherited cancer risk?
   - □1 Yes
     a) How is that person related to you _____
     b) What type of testing was it?_____
     c) What did the results show?_____
   - □2 No
   - □9 Not sure

4. Have <u>you</u> ever had genetic testing for inherited cancer risk?
   - □1 Yes
     a) For what gene(s) were you tested?_____
     b) What did the results show?_____
     c) What are some reasons you chose to have testing?

     _____

     _____

d) What do you understand about the meaning of this test result for you?

_____

_____

e) What do you understand about the meaning of this test result for your family?

_____

_____

g) Did you share your test results with other family members?

□1 Yes

□2 No

Skip to #13

□2 No

□9 Not sure

5. At the present time, which of the following statements describes your thoughts about having genetic testing for family susceptibility to cancer?
   - □1 I definitely will not get tested
   - □2 I probably will not get tested
   - □3 I probably will get tested
   - □4 I definitely will get tested

6. What are some reasons you might choose to have genetic testing if it was offered to you?

   _____

   _____

   _____

7. What are some reasons you might choose *not* to have genetic testing if it was offered to you?

   _____

   _____

   _____

8. What information would be important for you to have when making a decision about genetic testing?

   _____

   _____

   _____

9. If you had genetic testing, how concerned would you be about the privacy of your test results?
   - □1 Not at all concerned
   - □2 Somewhat concerned
   - □3 Quite concerned
   - □4 Extremely concerned

10. If you had genetic testing, how concerned would you be about emotional distress from test results?
    - □1 Not at all concerned
    - □2 Somewhat concerned
    - □3 Quite concerned
    - □4 Extremely concerned

11. If you had genetic testing, how concerned would you be about your relationship with other family members?
    - □1 Not at all concerned
    - □2 Somewhat concerned
    - □3 Quite concerned
    - □4 Extremely concerned

12. If you had genetic testing, how likely would you be to share results with your other family members?
    - □1 Not at all likely
    - □2 Somewhat likely
    - □3 Quite likely
    - □4 Extremely likely

13. Has anyone in the patient's family, related by blood, ever had genetic testing for inherited cancer risk?
    - □1 Yes
        a) How is that person related to the patient? _____
        b) What type of testing was it?_____
        c) What did the results show?_____
    - □2 No
    - □9 Not sure

14. Has the patient ever had genetic testing for inherited cancer risk?
    - □1 Yes
        a) For what gene(s) was s/he tested?_____
        b) What did the results show?_____
        c) What do you understand about the meaning of this test result for the patient?
        _____
        _____
        e) What do you understand about the meaning of this test result for the patient's family?
        _____
        _____
        Skip to #19
    - □2 No
    - □9 Not sure

15. At the present time, which of the following statements describes your thoughts about the patient having genetic testing for family susceptibility to cancer?
    - □1 S/he definitely will not get tested
    - □2 S/he probably wil lnot get tested
    - □3 S/he probably will get tested
    - □4 S/he definitely will get tested

16. What are some reasons you might choose to have genetic testing for the patient if it was offered?
    _____
    _____
    _____

17. What are some reasons you might choose *not* to have genetic testing for the patient?

_____
_____
_____

18. What information would be important for you to have when making a decision about genetic testing for the patient?

_____
_____
_____

19. How would you prefer to receive information about genetic testing? (check all that apply)

□1 Written materials, like brochures
□2 A conversation with my doctor or nurse
□3 An appointment with a genetics specialist
□4 A friend who is knowledgeable
□5 A family member
□6 An educational video
□7 The Internet or World Wide Web
□8 Another resource_____
□9 I am not interested in receiving genetic testing.

20. How would you share your genetic test results with your family? (Check all that apply)

□1 I would want my healthcare professional to talk to them
□2 A letter from my healthcare professional
□3 An educational video
□4 A brochure or other written materials
□5 A website
□6 Other_____
□7 I would not want to use any resources
□8 I would not want to share my results with family members

Now I am going to ask you some questions about DNA banking.

21. Please tell me in your own words what you think "DNA banking" is?

_____
_____

For the rest of this interview "DNA banking" refers to collecting and storing your genetic material (usually a blood sample) that could be used by family members in the future for clinical genetic testing or research.

22. How much have you heard or read about DNA banking?

□1 Almost nothing
□2 Relatively little
□3 A fair amount
□4 A lot

23. Has anyone in your family ever banked DNA?

□1 Yes a) How is that person related to you? _____
b) Why did they bank DNA?_____

□2 No

□9 Not sure

24. Have you ever banked your DNA?

□1 Yes a) Why?_____
Skip to 28??

□2 No

□9 Not sure

25. At the present time, which of the following statements describes your thoughts about banking DNA for family susceptibility to cancer?

□1 I definitely will not bank my DNA

□2 I probably will not bank my DNA

□3 I probably will bank my DNA

□4 I definitely will bank my DNA

26. What are some reasons you might choose to bank DNA if it was offered to you?

_____
_____
_____

27. What are some reasons you might choose *not* to bank DNA if it was offered to you?

_____
_____
_____

28. Has anyone in the patient's family ever banked DNA?

□1 Yes a) How is that person related to the patient? _____
b) Why did they bank DNA?_____

□2 No

□9 Not sure

29. Has the patient ever banked DNA?

□1 Yes a) Why?_____
Skip to #33

□2 No

□9 Not sure

30. At the present time, which of the following statements describes your thoughts about banking the patient's DNA for family susceptibility to cancer?

□1 I definitely will not bank my DNA

□2 I probably will not bank my DNA

□3 I probably will bank my DNA

□4 I definitely will bank my DNA

31. What are some reasons you might choose to bank the patient's DNA if it was offered?

_____
_____
_____

32. What are some reasons you might choose *not* to bank the patient's DNA if it was offered?

_____
_____
_____

33. If you banked your DNA, how concerned would you be about who might access your genetic information in the future?
    - □1 Not at all concerned
    - □2 Somewhat concerned
    - □3 Quite concerned
    - □4 Extremely concerned

34. How would you prefer to receive information about DNA banking? (check all that apply)
    - □1 Written materials, like brochures
    - □2 A conversation with my doctor or nurse
    - □3 An appointment with a genetics specialist
    - □4 A friend who is knowledgeable
    - □5 A family member
    - □6 An educational video
    - □7 The Internet or World Wide Web
    - □8 Another resource_____
    - □9 I am not interested in receiving information about DNA banking.

Now I am going to ask you some questions about the patient's personal and family histories of cancer.

35. What kind of cancer does s/he have?_____

36. How old was s/he when s/he were diagnosed?_____

37. What do you think is the likely cause of her/his cancer?

_____

38. How likely do you think it is that there is a genetic or inherited component to her/his cancer?
    - □1 Extremely unlikely
    - □2 Somewhat unlikely
    - □3 Neither likely nor unlikely
    - □4 Somewhat likely
    - □5 Extremely likely

For this part of the survey I will ask you about the patient's family, including those who have and have not had cancer. Please think about just family members who are related by blood (not in-laws)

39. How many brothers and sisters does s/he have, including those who have died?_____

40. Did any of her/his brothers and sisters have cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Brother or Sister	*Type of Cancer*	*Age at Diagnosis*

41. How many children, including those who have died?_____

42. Did any children have cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Son or Daughter	*Type of Cancer*	*Age at Diagnosis*

43. How many nieces and nephews, related by blood, including those who have died?_____

44. Have any nieces or nephews had cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Niece or Nephew	*Type of Cancer*	*Age at Diagnosis*

45. Did the patient's mother have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was she when she was diagnosed?_____
- □2 No
- □9 Not sure

46. How many brothers and sisters did the patient's *mother* have (aunts and uncles)?_____

47. Did any of the patient's *mother's* brothers and sisters have cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Maternal Aunt or Uncle	*Type of Cancer*	*Age at Diagnosis*

48. Did the patient's mother's mother (maternal grandmother) have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was she when she was diagnosed?_____
- □2 No
- □9 Not sure

49. Did the patient's mother's father (maternal grandfather) have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was he when he was diagnosed?_____
- □2 No
- □9 Not sure

50. Did the patient's father have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was he when he was diagnosed?_____
- □2 No
- □9 Not sure

51. How many brothers and sisters did the patient's *father* have (aunts and uncles)?_____

52. Did any of the patient's *father's* brothers and sisters have cancer?
- □1 Yes (complete table below)
- □2 No
- □9 Not sure

Paternal Aunt or Uncle	*Type of Cancer*	*Age at Diagnosis*

53. Did the patient's father's mother (paternal grandmother) have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was she when she was diagnosed?_____
- □2 No
- □9 Not sure

54. Did the patient's father's father (paternal grandfather) have cancer?
- □1 Yes a) What type of cancer?_____
  b) How old was he when he was diagnosed?_____
- □2 No
- □9 Not sure

55. Does the patient have any Jewish Eastern European (Ashkenazi) ancestry?
- □1 Yes
- □2 No
- □9 Not sure

56. How much money would you be willing to pay to have genetic testing for the patient?

	Yes	No
Up to $99	□1	□2
Up to $499	□1	□2
Up to $999	□1	□2
Up to $2,499	□1	□2
More than $2,500	□1	□2
I wouldn't be willing to pay any money	□1	□2
IDK	□9	
No Response	□99	

57. How much money would you be willing to pay to bank the patient's DNA?

	Yes	No
Up to $99	□1	□2
Up to $499	□1	□2
Up to $999	□1	□2
Up to $2,499	□1	□2
More than $2,500	□1	□2
I wouldn't be willing to pay any money	□1	□2
IDK	□9	
No Response	□99	

Finally, I would like to ask you a few questions about your background.

58. Regarding your ethnic background, do you consider yourself to be Hispanic or Latino?
- □1 Hispanic or Latino
- □2 Not Hispanic or Latino

59. Which of the following do you consider yourself to be? (check all that apply)
- □1 American Indian or Alaska Native
- □2 Asian
- □3 Black or African American
- □4 Native Hawaiian or other Pacific Islander
- □5 White
- □6 Other _____

60. What was your highest level of formal education completed?
- □1 Less than high school
- □2 Some high school
- □3 H.S. diploma/GED
- □4 Some college
- □5 Completed college
- □6 Some post-grad
- □7 Completed post-grad

61. What was your total household income in the last calendar year?
- □1 Less than $15,000
- □2 $15-34,999
- □3 $35-74,999
- □4 $75,000 +

62. What is your religion?
- □1 Protestant
- □2 Jewish
- □3 Roman Catholic
- □4 Other_____
- □5 None
- □9 Don't know

63. Do you consider religion to be an important part of your life, or not?
- □1 Yes
- □2 No
- □9 I don't know

64. How important would you say your religious beliefs are for providing guidance in your day-to-day living?
- □1 Not important
- □2 Somewhat important
- □3 Important
- □4 Very important
- □9 I don't know

65. On a scale of 1 – 10 how comfortable were you answering these survey questions? 1 being extremely uncomfortable, 10 being extremely comfortable with 2 – 9 in between.

1 Extremely Uncomfortable ---------- *10 Extremely Comfortable*

1	2	3	4	5	6	7	8	9	10

(If score is 9 or 10 skip to question 63.)

65a. What about this survey made you UNcomfortable?

_____
_____
_____

66. Are there any other thoughts you have about this survey?

_____
_____
_____

Study ID#_____
MRN # _____

Genetics Assessment (Completed by Genetics Researcher)

67. Based on the reported family history information by Scheuner et al. criteria (1997) what is the genetic contribution to cancer in this family?
□1 Average
□2 Moderate
□3 Strong

68. Does the family history meet USPSTF criteria for BRCA referral?
□1 Yes
□2 No

69. Does the family history meet NCCN criteria for genetics referral for breast cancer?
□1 Yes
□2 No

70. Does the family history meet current clinical criteria for a cancer genetic syndrome?
□1 Yes_____
□2 No

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Table 1

Family Characteristics for Those with Strong Genetic Risk for Cancer

Patient Diagnosis(es)	Reported Family History of Cancer	Criteria Met[a]
Squamous cell anal cancer, 44 years old, not HIV-related	Maternal aunt with breast cancer at age 40 years Maternal grandmother with bone cancer at age 64 years	Scheuner et al. (1997) NCCN
Colorectal cancer, 50 years old	None	Scheuner et al. (1997)
Leukemia, 27 years old	Maternal aunt/uncle with colorectal cancer, 28 years old Paternal aunt/uncle with breast cancer, 43 years old Paternal aunt/uncle with throat or lung cancer, 58 years old Paternal grandmother with breast cancer, age unknown	Scheuner et al. (1997) NCCN
Colorectal cancer, 49 years old	Maternal aunt/uncle with breast cancer, 40 years old Maternal aunt/uncle with colorectal cancer, 85 years old Maternal aunt/uncle with colorectal cancer, 75 years old Maternal aunt/uncle with lung cancer, 75 years old Maternal grandmother with ovarian cancer, 75 years old Paternal aunt with breast cancer, 68 years old Paternal aunt with breast cancer, 68 years old Paternal grandmother with ovarian cancer, 75 years old	Scheuner et al. (1997) NCCN USPSTF
Colorectal cancer, 47 years old	Maternal aunt/uncle with lung cancer, 58 years old Father with cancer of unknown type, 40 years old	Scheuner et al. (1997)
Lung cancer, 78 years old	Child with colorectal cancer, 49 years old Son with prostate cancer, 55 years old Father with cancer of unknown type, unknown age	Scheuner et al. (1997)
Breast cancer, 60 years old	Sister with breast cancer, 65 years old Mother with ovarian cancer and leukemia, 70 years old Father with bladder cancer, 82 years old Paternal uncle with esophageal cancer, 77 years old	Scheuner et al. (1997) NCCN USPSTF
Colorectal cancer, 43 years old	Mother with breast cancer, 39 years old Paternal aunt/uncle with colon cancer, unknown age Paternal grandparent with breast cancer, unknown age	Scheuner et al. (1997) NCCN
Pancreatic cancer, 54 years old	Three sisters with lung cancer at a young age, one at 36 and the other two diagnosed at unknown ages, but likely early-onset (before menopause)	Bailey-Wilson et al. (2004)

[a] *NCCN*, National Comprehensive Cancer Network (2008); *USPSTF* United States Preventive Services Task Force (2005)

Table 2

Association Between Patient Characteristics and Hereditary Cancer Risk

Category	n[a]	Average/Moderate Genetic Risk (n=34) (%)	Strong Genetic Risk (n=9) (%)	*p*-Value[b]
Awareness of Genetic Testing				
Almost nothing	22	54.6	44.4	0.714
At least some	20	45.4	55.6	
Awareness of DNA Banking				
Almost nothing	26	66.7	66.7	1.000
At least some	13	33.3	33.3	
Educational Background				
Up to college	30	60.0	66.7	1.000
At least college	9	40.0	33.3	
Annual Income				
<$15,000	10	21.4	44.4	0.127
$15,000–$34,999	10	35.7	0.00	
$35,000–$74,999	11	25.0	44.4	
$75,000+	6	17.9	11.1	
Race/Ethnicity[c]				
African American	20	48.3	66.7	0.454
Caucasian	18	51.7	33.3	
Patient Age (mean)	54.6 years	55.1 years	52.9 years	0.717[d]

[a] Total within categories may be less than 43 because of missing data

[b] Fisher's exact test

[c] One participant who reported "Other" race was excluded from this analysis

[d] T-test