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TITLE: Next Generation Education for Prevention: Defining Educational Needs,
Attitudes, Concerns, Life Plans of 18 to 24 Year Old Daughters of *BRCA1/2*
Mutations Carriers

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14. ABSTRACT The goals of this study were to 1) describe in-depth the knowledge, attitudes, health behaviors, and life plans of a cohort of 40 daughters, ages 18-24 years, of mothers who are <i>BRCA1/2</i> mutation carriers, and 2) define specific health educational, psychological, insurance and medical needs of this population. We found significant genetics knowledge gaps, high cancer-related distress, worries about the impact of <i>BRCA1/2</i> risk and risk reduction options on marriage and childbearing and high levels of interest in a targeted, web-based resource about <i>BRCA1/2</i> for young, high-risk women. The major data source for this project were the 40 in-depth, qualitative (semi-structured) telephone interviews with 18-24 year old daughters of <i>BRCA1/2</i> mutation carriers. Additional quantitative data included demographic and family history questionnaires, the Brief Symptom Inventory-18, Impact of Event Scale and the Breast Cancer Genetic Testing Knowledge Scale. Subjects were selected from among the age-eligible daughters of mutation-positive women tested at the DFCI, Mass General Hospital (MGH), and Beth Israel Deaconess Medical Center (BIDMC) between 2000-2009. Having this data has enabled us to proceed towards development of a psycho-educational health and support intervention targeted to the identified needs of 18-24-year-old daughters of <i>BRCA1/2</i> mutation carriers which could ultimately reduce mortality and morbidity. We believe that an educational intervention to help inform young women as they come to an age at which they can make independent decisions about genetic testing and breast cancer screening would be valuable and potentially life-saving in its impact. This intervention will, we hope, encourage high-risk, young women to consider earlier the choices they face with regard to hereditary cancer risk and will empower them through provision of more accurate genetic information.					
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INTRODUCTION:

Data from this study has the potential to answer an important question about *BRCA1/2* genetic testing, i.e. what do those who are told by a relative, especially those informed as children, understand about hereditary breast cancer and what are the gaps or misperceptions in their knowledge? Are the gaps sufficient to cause us to challenge the present mode of spreading family information about hereditary risk by word of mouth through relatives? Are there ethical, more flexible models professionals might adopt? We know that not all relatives are informed and that while much telling occurs soon after genetic testing, in some cases, it is delayed many years. We know that parents who are mutation carriers worry most about impact on their children, yet we know little or nothing about what those children understand. We believe that an educational intervention to help inform young women as they come to an age at which they can make independent decisions about genetic counseling and testing and breast cancer screening initiation at age 25 would be valuable and potentially life-saving in its impact. This intervention would, hopefully, encourage high-risk, young women to consider earlier the choices they face with regard to their hereditary cancer risk and would empower them through provision of more accurate genetic information.

The goals of this study were to 1) describe in-depth the knowledge, attitudes, health behaviors, and life plans of a cohort of 40 daughters, ages 18-24 years, of mothers who are *BRCA1/2* mutation carriers, and 2) define specific health educational, psychological, insurance and medical needs of this population. Having this data has enabled us to proceed towards development of a psycho-educational intervention targeted to the identified health and support needs of 18-24-year-old daughters of *BRCA1/2* mutation carriers, which could ultimately reduce mortality and morbidity. The major data source for this project were the 40 in-depth, qualitative (semi-structured) telephone interviews with 18-24 year old daughters of *BRCA1/2* mutation carriers. Additional quantitative data has been gathered from subjects including demographic and family history questionnaires, the Brief Symptom Inventory-18, Impact of Event Scale and the Breast Cancer Genetic Testing Knowledge Scale. Subjects were selected from among the age-eligible daughters of the approximately 1000 *BRCA1/2*-positive women who have been tested at the DFCI, the Mass General Hospital (MGH), and the Beth Israel Deaconess Medical Center (BIDMC) between years 2000-2009.

BODY:

During Phase I of the project, we completed the recruitment and enrollment of 40 daughters of *BRCA1/2* mutation carriers, ages 18-24. These 40 participants completed both the quantitative assessment and qualitative interview components of our study. This represented major progress in Year 2, after an initial year in which progress had been limited due to IRB and access issues. It should be noted that the accessing and enrolling these 40 daughters of *BRCA1/2*-positive mothers required a good deal of effort; young adults are a challenging group to reach and to schedule for interviews. 101 mothers with one or more age-eligible daughters who had received genetic counseling and testing at one of three Harvard teaching hospitals were approached. Our pool was reduced to 80 mothers with potentially eligible daughters, since 21 mothers were either found to be ineligible, were not able to be reached, or had died. A total of 22 mothers declined to provide their daughter's contact information and an additional 5 mothers were unresponsive to multiple attempts to contact and were considered passive decliners. 53 mothers (66%) provided contact information for their daughters. We invited 58 daughters to participate in our study (more than one daughter was recruited in five families when daughter #1 was either unresponsive to multiple attempts to contact (n=3) or had served as a pilot subject (n=2)). One daughter became ineligible when her mother died before the daughter completed participation. Two

daughters actively declined and nine were not responsive to multiple contacts and were assumed to be passive decliners. Forty-five daughters agreed to participate (5 pilot and 40 research subjects) and completed both the quantitative and qualitative portions of the study for a participation rate of 78%. One additional daughter was consented and completed the quantitative assessment for our study but became unresponsive to attempts to contact for the purpose of scheduling her qualitative interview. This daughter's quantitative data was not used in the data analysis phase of the study. The development of the coding book for the study was completed by the end of Month 28. All of the qualitative interviews were transcribed and coded. Reliability over 80% was achieved among three trained coders.

Data from our study show that daughters of mutation carriers actively remember learning that their mother is a *BRCA1/2* mutation carrier and also remember advice from the disclosing parent about how they should utilize this information. However, gaps in knowledge about *BRCA1/2* and breast cancer risks were common as were misconceptions about when and how genetic testing could be achieved. Importantly, one third of daughters of mutation carriers incorrectly thought it was false that breast cancer occurs at earlier ages among *BRCA1/2* mutation carriers than among women in the general population. Without knowing this, the rationale is lost for why experts recommend that mutation carriers or women at very high risk initiate breast screening several decades before women at normal risk. In our cohort, knowledge of the mother's mutation status was not associated with higher-than-average general distress (as measured by the BSI-18), which may encourage parental disclosure in the future. Daughters did report considerable cancer-related distress (as measured by the IES and self-report). About a quarter of the daughters had scores on the IES above the level of the clinical cutoff and more than a third reported ratings of "very high" or "to an extreme" on a 5-point Likert scale of cancer related distress. Some of the anxiety was linked to inadequate knowledge or misconceptions about *BRCA1/2* and about risk-reducing surgery. Daughters also had considerable misconceptions in their thinking about hereditary cancer risk and genetic testing. Many daughters reported high anxiety about the potential impact of their hereditary cancer risk and desire to undergo risk-reducing surgery on their marriage and childbearing plans. A quarter of the daughters worried "a great deal" or "to an extreme" (4 or 5 on a 5-point Likert scale) about the cancer risks of their largely unborn children. While most plan to undertake genetic testing (and 7 of the 40 had already had testing), some ambivalence or hesitancy about the timing of testing was evidenced, with daughters citing a wide range of possible future times when they might seek testing. Some feared that identification as a mutation carrier could have adverse emotional effects, while others cited beliefs about the inevitability of their getting cancer to explain why they were not worried about the outcome of genetic testing. Various trajectories of cancer worry were reported, with diminishing anxiety cited by some daughters over time as they adjusted to knowing their mother's mutation status. Others reported increasing cancer-related anxiety as they got older and closer to the time when they should begin testing or screening or when cancer might be more likely to occur.

With the data from Phase I of the project, we worked closely with the renowned Health Communications Core (HCC) of the Dana-Farber Cancer Institute, health communication experts and graphic designers, to create 4 pilot web intervention pages. This included 2 pilot versions of the Home Page and a section landing page on "Genetic Counseling" and an interior section page on "Dating and Hereditary Cancer". These were designed to appeal in both content and format to the concerns and preferences of young adult women. The HCC were particularly skilled at this, as they have designed other materials for young adult women with early breast cancer in recent years.

During Phase II of the project, we recruited and interviewed nine daughters for pilot evaluation of the intervention. Recruitment was stopped after 9 interviews (rather than 10) as the findings were generally positive and saturation seemed to have been achieved. In addition, recruiting a tenth subject might have had to involve training an additional interviewer (as the interviewer had to leave to begin medical school). Recruitment took somewhat longer than anticipated. All interviews were transcribed by the RA and entered into Atlas-ti qualitative analysis software. A coding manual was developed and the 9 interviews were coded and analyzed. Interviews with the 9 young women who reviewed the intervention pilot pages allowed us to gather important format and content feedback from daughters of mutation carriers. Daughters valued the easy availability of accurate factual material about *BRCA1/2*. They also particularly valued the range of “voices”, both professional and peer voices, conveying the information. They sanctioned inclusion of basic medical/genetic terms, stories from peers about the decisions they had reached and the dilemmas encountered along the way. They wanted links to genetic resources and information about how to locate and utilize genetic services and appropriate medical providers. They wanted clarification of myths and misconceptions regarding *BRCA1/2*. They valued the clarity of the information provided and approved the general format and amount of page information. They suggested a change of program name, finding “25 and Staying Alive” both non-specific and a bit frightening. They valued the inclusion of a personal timetable for each young woman to complete about when she thought she would access genetic counseling, testing, screening and other medical contacts she needed related to *BRCA1/2*. They recommended small wording changes and told us they found it easy to access desired information. They valued the trustworthy, reliable nature of the way information was conveyed. They suggested we utilize Facebook and other social media to reach young women at high risk. In general, they were highly appreciative of the targeting of this important genetic information to their needs and concerns.

Data from our study provide a firm basis for development of a web-based, psycho-educational intervention for 18-24 year old daughters of *BRCA1/2* mutation carriers. We hope to be able to find funding to develop the intervention and to conduct a multi-site, randomized clinical trial to test the utility and efficacy of the intervention in improving genetic knowledge, reducing cancer-related distress and improving readiness for breast cancer screening beginning at age 25 in this high-risk cohort. We are currently applying for funding to enable us to pursue these important goals.

Completed Tasks:

Develop interviews: Months 0 to 4 – An extensive interview schedule with probe questions to guide the interviews with the 40 study subjects was developed. This involved clarifying the many goals we had for the qualitative interview and translating these goals into questions appropriate for the age and anticipated genetic awareness of the subjects. This involved iterative attempts to word and re-word questions to avoid repetition, insure that the questions were phrased in ways which were impartial and age-appropriate and encourage open-ended, full responses. The interview outline was submitted to the Dana-Farber/Harvard Cancer Center Institutional Review Board on August 3, 2009. The interview contained sections on General Information and Current Status, Cancer Experience in the Family, Finding Out about Mother’s Result, Talking with Others about Hereditary Cancer, Thinking about Counseling and Testing, Health Behaviors, Heredity in the News, Future Resources, and Response to Interview Participation.

Develop questionnaire: Months 0 to 4 – We developed the questionnaire which was completed by the 40 research subjects prior to their participation in the telephone interview. This involved adapting some questions to the young adult age population being investigated in this project (for

example, realizing that identification of SES was complicated by the frequent, but inconsistent financial dependence of many (but not all) in this age group, requiring changes in certain items. The questionnaire included questions about the subject's demographics (education, employment, family income), marital status, living circumstances, parenting status, cancer family history, personal medical history, insurance status, concerns about cancer and heredity, experience with genetic counseling and/or testing. It also incorporated the 2 standard measures which were part of this study, the BSI-18 and the Erlich Breast Cancer Genetic Testing Knowledge Scale and the Impact of Event Scale, a measure commonly used in cancer genetics research. Our questionnaire was formatted for subject ease in use and pre-tested with several non-subjects. The completed questionnaire was also submitted to the Dana-Farber/Harvard Cancer Center Institutional Review Board on August 3, 2009.

Consult with and review materials with consultants: Months 1-7 – We had several consultations with our consultants. They were all involved in reviewing the interview and questionnaire items. We also consulted with the physician consultants about a plan to access eligible subjects from their Progeny databases. We conferred on eligibility criteria and methods of using the database to access specific information about age-eligible children. Unfortunately, in December 2009, the person who had directed the DFCI Cancer Risk and Prevention Clinic registry abruptly left the clinic after 5 years and much experience with the Progeny database. Her replacement needed several months of training after being hired. After she had been trained, we had extensive eligibility data on nearly 200 mothers at the 3 participating hospitals who had undergone *BRCA1/2* genetic testing and had consented to further contact for research purposes. Many of these mothers had multiple age-eligible daughters. This reassured us that we would have no trouble accruing the needed 40 subjects for our research.

Get approval from DFCI/HCC and USAMRMC Institutional Review Boards: Months 2-8 While we experienced some initial delays in both endeavors, we received approval for our study from both the Dana-Farber/Harvard Cancer Center and the USAMRMC Institutional Review Board and were able to obtain a Certificate of Confidentiality from the National Institutes of Health. We were delayed for more than 2 months in getting the Certificate of Confidentiality from the National Institutes of Health. While this usually has a pretty quick turnaround time, in our case this was not so, as the person assigned to review applications and grant certificates for proposals which fell under the jurisdiction of the National Human Genome Research Institute, Dr. Elizabeth Thomson, was out for surgery for several months, our application was misplaced for a while and our permission was delayed until Dr. Thomson was sufficiently recuperated to be able to read our application and grant our request for a Certificate.

After developing our questionnaires and interview schedule in the second quarter of the project as anticipated, we submitted these research materials to both IRBs. On November 27, 2009, we were granted permission by the USAMRMC Institutional Review Board to begin our subject enrollment for this project. On December 3, 2009, we submitted an amendment to the DF/HCC IRB to make what we had thought would be minor changes to our protocol and patient materials to indicate that we had received our Certificate of Confidentiality, to clarify that all mothers approached would have previously given permission for research re-contact, to request permission to call mothers who had not indicated unwillingness to provide their daughter(s)' contact information 2 weeks after the sending of the letter and information form to them to insure they had received the materials and to answer any questions about the study they might have, and that we wished to add an optional space on our information form for mothers who declined to give us their daughter(s)' contact information to tell us why they were declining. We had anticipated this would be a quick process, likely an expedited process. However, this amendment was sent to the whole IRB and resulted in several written communications with the IRB. We

further clarified for them that the mothers were not subjects, just informants and successfully answered all of the IRB's concerns except their request (unrelated to our amendment requests) that we add to the mother's letter a statement that the mother "has carefully considered the risks of their daughters participating in the study, including the possibility of distress and a breach of confidentiality". While we stated that we would gladly answer any questions the mother may have about this research, we were not formally asking the mother to make a decision about the risks and benefits of the research for their adult daughters. We made clear that we would fully discuss with the invited daughters, the potential participants in our study, prior to their signing (or not signing) of the consent forms, all potential risks, including those of distress and breach of confidentiality. We stated that we encouraged mothers to tell their daughters that they had given us their contact information and that we made clear to the daughters that it was their mothers who had given us information to allow us to invite their participation. We had added a statement to the information form that the mothers signed stating that they understood that this information – their participation in genetic testing at a participating clinic – would be mentioned to their daughters in the explanation of why they were invited to participate. However, we did not think it advisable or accurate to ask the mothers to state they have considered the risks and benefits of the research for their adult daughters. However, the IRB did not agree with our counter-argument. While we were offered an opportunity to bring our argument to the entire IRB 3 weeks later, we instead withdrew the amendment so that we could begin our piloting of our questionnaire and interview as soon as possible using permission granted previously by both our IRBs. This was acceptable to the DF/HCC IRB. However, this delayed until mid-January our ability to send out requests to mother of eligible subjects.

Pilot interviews and questionnaire: Months 13-14 – We piloted the basic study questionnaires and procedures with 5 pilot subjects, all daughters of *BRCA1/2* mutation carriers. When complete, we invited participation of initial subjects.

Contact mothers for permission to contact their daughters, accrue and consent patients: Months 12-20 – We contacted 101 mothers who are *BRCA1/2* mutation positive and whom we believed had daughters 18-24 years of age requesting contact information for their daughters. Our pool was reduced to 80 mothers with potentially eligible daughters since 21 mothers were either found to be ineligible, were not able to be reached, or had died. Twenty-two mothers declined to give us permission. Five mothers were considered to be passive decliners after many unsuccessful attempts to reach them over an extended period of time. We received permission from 53 mothers to contact one or more of their daughters, which amounted to a mother participation rate of 66%. Our final participation rate for daughters was 78%.

Train research associate for interviewing: Months 14-15 – We trained a total of four graduate student research interviewers. Three were originally trained, but one had to drop out after doing four interviews because of the burden of her graduate studies. A second interviewer also had serious medical problems which interfered with her being able to complete the last several interviews assigned to her. All interviewers had prior academic coursework on qualitative interviewing and had conducted research using qualitative methods. Each interviewer read the study protocol and discussed the project aims with Dr. Patenaude. Questions were answered regarding the nature of the study population, *BRCA1/2* genetic testing and screening and surveillance recommendations for mutation carriers, the extent of probing demanded by the interview schedule, respect for autonomy of subjects and their rights to not answer or to discontinue the interview. Interviewers were trained in persistence and call strategies necessary to reach and schedule the interviewees and were provided with information about preferred times for contact for each subject. They were also extensively trained in the handling of any subject distress which might arise and had 24-hour contact information for the PI and project RA (both

mental health professionals), both of whom were informed of when interviews were being conducted.

Monitor interview quality and consistency: Months 16-22 – All interviewers read two transcripts of Dr. Patenaude, the PI, conducting project pilot interviews. The first three interviewers conducted a pilot interview which was listened to with the PI at length for suggestions about improvements in the approach to questions and handling of follow-up questions. By the time the last interviewer joined the project, all pilot interviews had been conducted, so she could not do a pilot interview. She was a highly experienced interviewer, however, and she listened to the tape of Dr. Patenaude conducting a project pilot interview and went over it in detail with Dr. Patenaude before conducting her own first interview on this project. All first interviews were listened to together by Dr. Patenaude and the interviewer for suggestions about improvement. As needed, additional interviews were listened to with Dr. Patenaude until it was felt that interviewer quality was established.

Conduct interviews: Months 16-26 – Forty subject interviews which averaged 56 minutes in length were conducted via telephone. These interviews required an average of five phone calls each to schedule with this highly mobile, busy group of young adults. The interviews were all conducted in one session. One subject reported minor distress, but, when followed up with a phone call from the PI, the subject said she was fine and no further distress was noted by the PI. Many subjects said they found the interview helpful and/or interesting. All subjects who initiated an interview completed the interview and no topics were omitted.

Developed database and entered quantitative data: Months 12-26 – Quantitative responses of all 40 subjects who completed participation in the project were entered into the project database. Statistical analyses were conducted by the project biostatistician, Dr. Julie Aldridge, of the Dana-Farber Department of Biostatistics. Analyses on data related to the daughters' genetics knowledge, cancer-related distress and interest in web-based intervention are complete and have been included in our forthcoming article in *Psycho-Oncology*.

Transcribe interviews: Months 16-27 – Interviews were transcribed by Cambridge Transcriptions, an experienced transcription company which does local court recordings and transcribes for other major research universities in the Boston area. In addition, they provided us with digital records of the interviews. The project RA listened to the digital recording to insert or correct any missing or incorrectly transcribed material. This guaranteed that the transcription was a highly accurate record of the conversation which took place during the telephone interview.

Develop coding manual: Months 24-28 – Using Atlas-ti, a coding manual was developed. The PI coded a number of pilot and project interviews, creating and editing the code book as she proceeded. These codes were discussed with the research team to ensure that they allowed us to answer all of the questions we proposed to answer with this research. We then honed down the final Code Book which was used to train the other coders. The project interviews, which were used to develop the Code Book, were recoded along with the remaining interviews.

Hire and train coders: Months 25-29 – We utilized currently employed graduate level staff to code the interviews. Training involved reviewing of the codes with Dr. Patenaude to make sure there was a shared understanding of their meaning and limits. Coders then coded 1-2 training interviews from the group of pilot interviews. These were reviewed and discussed with the interviewers. Coding of the first several project interviews were also discussed with Dr. Patenaude to ensure the reliability and consistency of the application of codes.

Work with consultants to develop the psycho-educational intervention: Months 25-32 – We discussed our study findings and plans for the development of the educational intervention with Drs. Tung, Ryan, Garber, Partridge and Tercyak. We enlisted their suggestions for the nature and format of the intervention that we developed. We completed our work with Catherine Coleman and the Dana-Farber/Harvard Health Communications Core, graphic designers and cancer communication experts, to design the pilot pages of the intervention which we presented to 9 subjects for feedback to help in design of the ultimate intervention. We completed discussion of the overall outline of the intervention. The home page of the intervention and a section landing page (“Genetic Counseling”) and an inner page of another section on “Dating and Hereditary Cancer” were completed. The graphics for these sections were also completed and are included in page 84-87 of the appendices. We were very pleased with the graphic design for the web pages and with the presentation of content on these pages. Two graphic versions of the home page were completed and compared in the pilot test with daughters of mutation carriers. We also completed formulation of the questions to be asked of participants in the piloting (pages 79-83 of the appendices). These materials were submitted to the DFCI IRB and we received approval on 11/23/2011. On 12/2/2011 we submitted an amendment for the pilot intervention to the USAMRMC IRB. We received approval on 3/7/2012 and recruited eligible daughters for pilot testing of the intervention materials. The 9 intervention pilot subjects, all daughters of mutation carriers, provided detailed feedback about the pilot pages which will be invaluable in the actual development of the intervention.

Coding of interviews: Months 27-31 – The coding was completed for all 40 subjects. Reliability of over 80% was established between coders.

Analyze coded data: Revised Schedule: Months 27-48 (previously Months 17-26) – We completed analysis of all of the extensive qualitative narratives. Narratives helped to inform the “voice” and content of the intervention pages which have been developed. Narrative material also helped prioritize the format and presentation style of the web pages which have been designed to date. There is a great deal of coded material of great interest. We have utilized it in writing qualitative reports for journal articles and in presentations to increase the effectiveness of our message.

Integrate qualitative and quantitative data: Revised Schedule: Months 27-48 (previously Months 24-28) – As shown in the *Psycho-Oncology* publication of our data which is in press, we have usefully combined quantitative outcomes with clarifying qualitative narratives for optimal effect. This combination is highly effective, illustrating more than quantitative data alone how genuinely engaged and interested in learning more about *BRCA1/2* subjects are and conveying the nature and complexity of the daughters’ distress, fears, misconceptions and needs. Integration of qualitative and quantitative data will continue as we continue to publish findings from this study.

Pilot educational intervention: Months 37-41 – For Phase II of the project, the piloting of our mini-intervention pages, we again assembled names and addresses of mothers we needed to ask for daughters’ contact information to invite the daughters’ participation in our interview. We reviewed the status of the mothers whose daughters we contacted to insure that there had been no maternal deaths in the interim. A staff research assistant was trained to conduct the telephone interviews for the pilot intervention. She worked extensively over several months on her interviewing skills under the direction of Dr. Patenaude. She also conducted and recorded several practice telephone interviews on volunteers. Dr. Patenaude reviewed these recordings and felt the RA was well prepared to conduct the study interviews for the pilot testing of the intervention materials. Recruitment and interviewing was completed for the pilot educational intervention. A

total of nine daughters of *BRCA1/2* mutation carriers were interviewed for pilot evaluation of the intervention. Recruitment was stopped after 9 interviews (rather than 10) as the findings were generally positive and saturation seemed to have been achieved. In addition, recruiting a tenth subject might have had to involve training an additional interviewer (as the interviewer had to leave to begin medical school). Recruitment took somewhat longer than anticipated. All interviews were transcribed by the RA and entered into Atlas-ti qualitative analysis software. A coding manual was developed and the 9 interviews were coded and analyzed. We discussed at length the recommendations and preferences expressed by the 9 daughters of mutation carriers with the Harvard Dana-Farber Cancer Communications Core staff who helped us to develop the intervention pilot pages and, when we have future funding, we will work with them to integrate daughters' preferences and suggestions into the final web intervention to be tested in a future clinical trial.

Write journal articles, research reports, parent brochure or web content: Months 25-48 –

The first manuscript from this project entitled, “*Young Adult Daughters of BRCA1/2 Positive Mothers: What Do They Know about Hereditary Cancer and How Much Do They Worry?*”, is in press in *Psycho-Oncology*, a major research journal. The paper reports on the daughters' memories of parental disclosure and advice regarding hereditary cancer risk, their knowledge and misconceptions about *BRCA1/2* inheritance, and the nature and extent of their cancer-related distress and future plans for genetic counseling and testing. It is a mixed methods report. The next paper, which is in progress, will focus on daughters' expressed interest in *BRCA1/2* education, knowledge of and plans for breast cancer screening and risk reduction, as well as specific information preferences and content and format recommendations for website intervention received from both the 40 daughters of *BRCA1/2* mutation carriers who participated in Phase I interviews and the 9 daughters of *BRCA1/2* mutation carriers who were intervention (Phase II) subjects responding to pilot web pages developed by the Dana-Farber/Harvard Health Information Core. A complete list of additional presentations that have resulted from this research is outlined in the Reportable Outcomes section below.

Plan further research: Months 34-48 – An application was submitted a DOD Expansion grant for full development of our psycho-educational, web-based intervention for 18-24 year old daughters of *BRCA1/2* mutation carriers and pilot testing to establish health outcomes associated with access to the intervention for young adult daughters of women who carry *BRCA1/2* mutations. We hope in future research to also include daughters of mutation carriers whose fathers were the mutation carrier and daughters of mothers who were mutation carriers but the mother is now deceased from her breast or ovarian cancer, as we believe these groups of daughters will likely have even greater informational and support needs related to their *BRCA1/2* risks.

KEY RESEARCH ACCOMPLISHMENTS:

- Established the feasibility of accessing young adult daughters of living *BRCA1/2* mutation carriers using our method of contacting them by accessing their contact information from their mothers. Compliance rate for mothers: 66%
- Conducted 40 interviews with 18-24 year old daughters of mothers who are *BRCA1/2* mutation carriers. Established the feasibility of reaching and enrolling young adult daughters of *BRCA1/2* mutation carriers in psychosocial research. Compliance rate for daughters: 78%
- Completed assessment of breast cancer genetics knowledge, emotional distress and cancer-related distress among 40 daughters of *BRCA1/2* mutation carriers.

- Scored and entered research data on quantitative assessments for 40 daughters of mutation carriers.
- Transcribed and coded all 40 interviews.
- Designed the pilot pages of the intervention and received DFCI IRB approval and USAMRMC approval for Phase II of the project.
- Completed recruitment and interviewing for the pilot educational intervention.
- Transcribed and coded all 9 interviews of Phase II of the project.
- Produced a manuscript from the project entitled, “*Young Adult Daughters of BRCA1/2 Positive Mothers: What Do They Know about Hereditary Cancer and How Much Do They Worry?*”, which is in press in *Psycho-Oncology*, a major research journal.
- Reported outcomes of this study to national and international professional meetings of genetic counselors, cancer geneticists, and psychosocial researchers in cancer genetics.

REPORTABLE OUTCOMES:

1. Patenaude, A.F. (October, 2009). *Next Generation Prevention: Genetics Knowledge and Educational Needs of Young Adult Daughters of BRCA1/2 Mutation Carriers*. Presented at the 59th Annual Meeting of the American Society of Human Genetics (ASHG), Honolulu, Hawaii
2. Patenaude, A.F., Tung, N.M., Ryan, P.D., Hewitt, L., Garber, J.E. (April, 2011). *What Do Young Adult Daughters of BRCA1/2+ Mothers Know about Hereditary Risk? How Much Do They Worry?* Presented at the 12th International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC), Amsterdam, The Netherlands
3. Patenaude, A.F., Tung, N.M., Ryan, P.D., Hewitt, L., Garber, J.E. (August, 2011). *What Do Young Adult Daughters of BRCA1/2 Mutation Carriers Know about Hereditary Risk? How Much Do They Worry?* Presented at The Department of Defense (DOD) Breast Cancer Research Program 6th Era of Hope Conference, Orlando, Florida
4. Henderson, A., Patenaude, A.F. (July, 2012). *Targeting 18-24 Year Old Daughters of BRCA1/2 Mutation Carriers: How Do We Reach and Support Young Women at High Risk for Breast and Ovarian Cancer?* Presented at the Leadership Alliance National Symposium, Hartford, Connecticut
5. Patenaude, A.F. (October, 2012). *Young Adult Women at Risk of Hereditary Breast/Ovarian Cancer: Impact on Dating and Childbearing*. Presented at the National Society of Genetic Counselors (NSGC) 31st Annual Education Conference, Boston, Massachusetts
6. Patenaude, A.F., Tung, N.M., Ellisen, L.W., Hewitt, L., Aldridge, J., Garber, J.E. (November, 2012). *Next Generation Prevention of Hereditary Breast/Ovarian Cancer: What Daughters of Mutation Carriers Know and Feel and What They Want to Know*. Presented at the International Psycho-Oncology Society Meeting, Brisbane, Australia
7. Patenaude, A.F., Tung, N.M., Ryan, P.D., Ellisen, L.W., Hewitt, L., Schneider, K.A., Shannon, K., Tercyak, K.P., Aldridge, J., Garber, J.E. (March, 2013). *Next Generation Education: Daughters of BRCA1/2 Mutation Carriers: Cancer-Related Distress, Genetics Knowledge and Interest in Future Psycho-Educational Intervention*. Invited presentation to the Familial Cancer Clinic, North Shore Hospital, Sydney, Australia.

8. Patenaude, A.F., Tung, N.M., Ryan, P.D., Ellisen, L.W., Hewitt, L., Schneider, K.A., Shannon, K., Tercyak, K.P., Aldridge, J., Garber, J.E. (March, 2013). *Next Generation Education: Daughters of BRCA1/2 Mutation Carriers Report Preferences for Receipt of Genetic Information and Support*. Presented at the 13th International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC), Sydney, Australia
9. Patenaude, A.F., Tung, N.M., Ryan, P.D., Hewitt, L., Aldridge, J., Garber, J.E. (in press). What Do Young Adult Daughters of *BRCA1/2* Positive Mothers Know about Hereditary Risk? How Much Do They Worry? *Psycho-Oncology*.
10. Applied for the Department of Defense Breast Cancer Idea Expansion Award Federal Grant, December 2012

PROJECT PERSONNEL:

- Andrea Patenaude, Ph.D.
- Judy Garber, M.D., M.P.H.
- Ann Partridge, M.D., M.P.H.
- Julie Aldridge, M.S.
- Larissa Hewitt, M.S.W., L.I.C.S.W.
- Margery Rosenblatt, M.A.
- Carly Grant, M.S., C.G.C.
- Caitlin Young, M.A.
- Lara Birk, M.A.
- Elizabeth Tov, M.A.
- Melanie Gaiser, M.P.H., M.A.
- Julia Koretski, B.A.

CONCLUSION:

We have established the feasibility of reaching out to mothers who are in the *BRCA1/2* cancer registries at three Harvard teaching hospitals and, through contact information they provided, of accessing and enrolling young adult daughters of *BRCA1/2* mutation carriers for psychosocial studies in hereditary cancer. This study has yielded quantitative and qualitative measures of the young women's knowledge of breast cancer genetic testing and of their own hereditary cancer risks, their attitudes towards information acquisition about hereditary breast cancer and *BRCA1/2* genetic testing, and their knowledge of and plans to utilize (or not utilize) recommended screening strategies and risk-reduction options. Preliminary analyses suggest that there are significant gaps in essential breast cancer genetics knowledge among this cohort. Data also show that there is high cancer-related distress among 18-24 year old daughters of mutation carriers, especially related to their mother's and their own cancer risks and childbearing plans.

So What?

Our data strongly suggests that young adult daughters of mutation carriers are a population of high-risk women who have, to date, been neglected in terms of outreach for provision of genetic services. Psycho-educational interventions aimed at this population should be developed to improve genetic knowledge and reduce cancer-related distress. We hope to be able to show that access to the targeted, psycho-educational intervention we plan to develop based on our IDEA grant findings will not only empower daughters of *BRCA1/2* mutation carriers, but will also

result in their seeking genetic testing and breast cancer screening earlier than do daughters of mutation carriers without intervention access. We are hopeful that getting a DOD Expansion grant would enable us to complete the desired and needed intervention, and that having it would allow us to prepare young women better for the demands of living with *BRCA1/2* in ways which reduce their risk of developing breast and ovarian cancer.

This research is the first to document the educational needs and high cancer-related distress of this critical group of high-risk women, 18-24 year old daughters of *BRCA1/2* mutation carriers. Presentations of this work to professional audiences from the U.S. to Australia have drawn attention to this professionally underserved group and have offered specific suggestions for effective targeting of educational materials and support options to the needs of these young women. We believe our work will help our field to recognize the necessity for more active professional outreach to daughters of *BRCA1/2* mutation carriers.

Having deeply invested as a nation in the discovery of the *BRCA1/2* genes which cause most hereditary breast/ovarian cancer, it seems imperative to also develop interventions to help young women at 50% risk of carrying their parent's *BRCA1/2* mutation find their way at the recommended age of 25 to the cancer screening and medical services they require to reduce their extraordinary cancer risks. It is also important to provide support for the considerable cancer-related distress they experience as they reach adulthood and plan for their futures. Screening and consideration of risk-reduction surgical options will color the lives of these young, high-risk women for at least the next 30-40 years. How and when they approach screening may influence whether they develop and die from early or repeated cancers, as did previous generations in their families, or whether they reap the benefits of genetic discoveries to find cancers at early, more treatable stages or prevent the cancers entirely, empowered by awareness of their hereditary risks and confidence in their abilities to take life-saving action.

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APPENDICES:

Session Proposal for the 2009 American Society of Human Genetics Meeting

“Frontiers in Cancer Genetic Testing: Addressing the Needs of Children, Adolescents, and Young Adults”

Speaker:

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Title: Next Generation Prevention: Genetics Knowledge and Educational Needs of Young Adult Daughters of *BRCA1/2* Mutation Carriers

Presentation Content: Young adult daughters (18-24 years) of *BRCA1/2* mutation carriers are at 50% risk of carrying mutations predisposing to high risks for breast and ovarian cancer. The youngest age group typically accepted for *BRCA1/2* testing, they are recommended to begin targeted screening at age 25. Few have undergone genetic counseling. We discuss approaches to educate this population about their risks, insurance needs (often neglected) and the implications of screening and risk-reduction recommendations for their life plans. Genetics and primary care providers also need guidance about care of this population, the first of the next generation of high risk cancer genetics patients.

Session Description: An overview of 1) The growing provision of genetic testing services in pediatric oncology clinics, 2) family communication to children, adolescents, and young adults about hereditary cancer risk, 3) particular ethical considerations in care of children for hereditary cancer susceptibility and genetic testing and 4) preparation for service provision to the next generation of cancer genetics patients. Speakers include David Malkin M.D., leading pediatric cancer genetics researcher and clinician, Katherine Schneider M.P.H., a founder of the field of cancer genetic counseling, Dr. Ken Tercyak, premier researcher on family communication of *BRCA1/2* results to minor children, Dr. Andrea Farkas Patenaude, Harvard Medical School researcher on psychological aspects of cancer genetics, and Dr. Ben Wilfond, expert in pediatric bioethics. Dr. Alan Guttmacher, Acting Director of the National Human Genome Research Institute and a pediatric geneticist by training, will discuss session presentations in the context of future areas of genome research and applications.

David Malkin M.D., a leading cancer genetics researcher and clinician will describe recent dilemmas experienced in the interface of genetics research results and clinical genetic testing services for pediatric oncology patients.

Katherine Schneider M.P.H., one of the founders of the field of cancer genetic counseling, will describe the role of a genetic counselor in a pediatric oncology genetics clinic. This session will offer an understanding of unique challenges for the pediatric cancer genetics counselor, a topic not part of the typical genetic counseling curriculum.

Dr. Ken Tercyak, the premier researcher on family communication of *BRCA1/2* results to minor children, will present his surprising data on the extent of sharing to even quite young children about parental test results and factors predicting or hindering communication. He will also discuss ongoing research to provide parents with learning aids to help in communication of genetic information to children. Dr. Andrea Farkas Patenaude, psychologist researcher at Harvard Medical School, will discuss the educational needs of young adult (18-24 year old) daughters of *BRCA1/2* mutation carriers, the youngest members of the next generation to seek cancer genetics services, to try to reduce the morbidity and morbidity of hereditary breast and ovarian cancer. Consideration of what genetics knowledge these women have received from their parents and what their attitudes are towards genetic counseling and testing can inform planning for future genetics services. Dr. Ben Wilfond, a senior ethicist and expert in pediatric bioethics, will discuss how the approach to responding to requests by parents for clinical genetic test results about cancer susceptibility has evolved, as well how considerations about which research results to provide have developed. Dr. Alan Guttmacher, Acting Director of the National Human Genome Research Institute, will be the Discussant for our session. A pediatric geneticist by training, Dr. Guttmacher will discuss the session presentations in the context of future areas of genome research and applications.

Session Rationale: Cancer genetic testing will increasingly include children, adolescents and young adults as 1) inherited genetic factors underlying many pediatric cancers and related conditions are better understood and 2) as the children of recently tested adult mutation carriers become the next generation of cancer genetics patients. Knowledge of how genetic counseling is undertaken for pediatric cancer populations and of the challenges of integrating genetics research results in clinical pediatric oncology settings will be discussed. We will also provide an overview of data on how young children are being informed by their parents about the parents' genetic test results and how young adults make decisions about utilization of genetic services, uptake of their own genetic testing and adherence to recommendations for screening and prevention options. Twenty-first century genetics providers and professionals in associated fields who understand the medical, psychological and ethical considerations relevant to the participation of children, adolescents, and young adults in genetic services and as members of high-risk cancer families will enhance provision of appropriate services to this important population.

Learning Objectives and How the Attendees Will Benefit: Attendees will be provided with an overview of the importance of pediatric cancer genetics and of inherent dilemmas translating pediatric research results into clinical genetics practice. They will learn about the practice of genetic counseling in the pediatric oncology setting and about ethical issues which arise in this context. They will also gain an understanding of how parents convey genetic information about cancer susceptibility to their offspring and about interventions which may help parents with decision-making about talking to children about familial hereditary disease. Attendees will also gain an appreciation of the needs for genetic services and education of young adults who are the daughters of *BRCA1/2* mutation status as they come of age.

Objectives:

1. To understand the growing importance of training for working with pediatric cancer genetics patients and to learn how pediatric cancer genetics counseling and testing differs from more standard cancer genetics practice,

2. To understand parents' decision-making about the sharing of personal genetic information with children, adolescents, and young adults and about the educational and clinical genetic practice needs of young adults as they attempt to integrate knowledge of familial hereditary cancer risk and of their personal risks into plans for genetic counseling, testing, and, if carriers, for future targeted screening and consideration of risk-reduction measures.
3. To learn about the ethical issues particular to minor children's involvement in pediatric genetics practice, research and family communication,

Target Audience: This session will have learning targets for both pediatric and adult geneticists and oncologists and for genetic counselors, especially cancer genetic counselors. Pediatric geneticists will have much to gain from this session since relatively few centers have to date provided pediatric cancer genetics services. Genetic counselors will be especially interested since provision of counseling to pediatric cancer genetics clinics is a new and growing field and one not typically taught in the standard genetic counseling curriculum. Even cancer genetic counselors may not yet have done pediatric counseling. Adult geneticists and oncologists will also typically have had little or no direct contact with the minor children of their tested patients, even though $\frac{1}{2}$ - $\frac{1}{3}$ of their patients have minor children. Attendance at this session can also provide education about family communication which could enhance the ability of cancer genetics professionals to provide much-desired guidance to their patients in talking to their children about hereditary risk. All genetics professionals and primary care providers can utilize information about the development of genetics services for the next generation of child, adolescent, and young adult cancer genetics patients.

Abstract for the 2011 International Meeting on Psychosocial Aspects of Hereditary Cancer

Presented at the 12th International Meeting on Psychosocial Aspects of Hereditary Cancer, Amsterdam, The Netherlands (April, 2011)

What Do Young Adult Daughters of *BRCA1/2*+ Mothers Know about Hereditary Risk; How Much Do They Worry?

Authors: **Andrea Farkas Patenaude Ph.D.^{1*}**, Nadine Tung M.D.², Paula Ryan M.D.³, Larissa Hewitt M.S.W.¹, and Judy E. Garber M.D., M.P.H.¹

Affiliations: 1: Dana-Farber Cancer Institute, Boston, MA; 2: Beth Israel-Deaconess Medical Center, Boston, MA; 3: Massachusetts General Hospital, Boston, MA

Introduction: Daughters of *BRCA1/2* mutation carriers have 50% chance of inheriting cancer risks up to 85% for breast cancer (often early onset) and 60% for ovarian cancer. We lack data on what young at-risk women know about their risks and recommended screening/risk-reduction measures and data on their anxiety about hereditary cancer. Data are needed for development of targeted educational materials to improve timely screening initiation and risk-reducing interventions which could reduce morbidity and, ultimately, mortality in this high-risk group.

Methods: Thirty-four daughters (aged 18-24 years) of living *BRCA1/2* -positive mothers (mothers previously tested at one of 3 Harvard hospitals) completed written questionnaires and qualitative telephone interviews about their knowledge of hereditary breast/ovarian cancer risk and screening and risk-reduction surgery, worry about hereditary cancer and the impact of their mother's genetic status on their plans for counseling/testing.

Results: Utilizing an established measure (Erblich et al., 2005), knowledge of daughters about hereditary breast cancer was significantly below that of women who had undergone genetic counseling, as shown by the absence of overlap in 95% confidence intervals of the groups. Narratives confirm knowledge is limited about screening and risk-reduction options and recommended screening initiation age. Worry about hereditary breast/ovarian cancer was high among daughters; 15% scored above the clinical cut-off of the Brief Symptom Inventory-18 (BSI-18) and nearly half say they worried a great deal or to an extreme about hereditary cancer.

Conclusion: Targeted interventions are needed to educate young, high-risk women about screening and to reduce anxiety about hereditary cancer.

*Presenting author

Abstract for the 2011 Era of Hope Meeting

Presented at The Department of Defense (DOD) Breast Cancer Research Program 6th Era of Hope Conference, Orlando, Florida (August, 2011)

What Do Young Adult Daughters of *BRCA1/2* Mutation Carriers Know about Hereditary Risk and How Much Do They Worry

Authors: **Andrea Farkas Patenaude Ph.D.^{1*}**, Nadine Tung M.D.², Paula Ryan M.D.³, Larissa Hewitt M.S.W.¹, and Judy E. Garber M.D., M.P.H.¹

Affiliations: 1: Dana-Farber Cancer Institute, Boston, MA; 2: Beth Israel-Deaconess Medical Center, Boston, MA; 3: Massachusetts General Hospital, Boston, MA

Background and Objectives: Daughters of *BRCA1/2* mutation carriers have a 50% chance of inheriting cancer risks up to 85% for breast cancer (often early onset) and 60% for ovarian cancer. Genetic testing and uptake of enhanced screening remains sub-optimal, especially for 25-40 year old mutation carriers (Botkin, 2003; Claes 2005). Accurate knowledge is a prerequisite to informed decision making and adherence to health recommendations. We lack data on what young, at-risk women know about their risks and recommended screening/risk-reduction measures and about their anxiety related to hereditary cancer. These data are needed for development of targeted educational materials to improve timely screening initiation and risk-reducing interventions which could reduce morbidity and, ultimately, mortality in this high-risk group. A health educational intervention which provides high-risk women who are 18-24 years old with the knowledge and skills they need to adopt active coping and health-affirming screening methods at the earliest appropriate age could ultimately save lives.

The objectives of our project are to 1) Describe in-depth the genetic knowledge, attitudes, health behaviors, and life plans of 40 daughters, ages 18-24 years, of mothers who are *BRCA1/2* mutation carriers, and 2) Define specific health educational, psychological, insurance and medical needs of this population.

Methodology: Thirty-four daughters (aged 18-24 years) of living *BRCA1/2*-positive mothers (mothers previously tested at one of 3 Harvard hospitals) completed written questionnaires including the Brief Symptom Inventory-18 (BSI-18), Impact of Event Scale (hereditary cancer as the event), and Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ) and qualitative telephone interviews about their knowledge of hereditary breast/ovarian cancer risk and screening and risk-reduction surgeries, worry about hereditary cancer and the impact of their mother's genetic status on their future planning, including plans for genetic testing.

Results to Date: 38 daughters have enrolled to date and 34 have completed participation. Participation rate is 70%. Participants were an average of 21 years of age; the majority were either college students or college graduates. 88% were single. Six had mothers with no cancer history, 5 mothers had ovarian cancer, 22 had breast cancer, and one mother had had breast and ovarian cancer. Phone interviews averaged 56 minutes in length.

Knowledge of daughters about hereditary breast/ovarian cancer genetics was significantly below that of women who had undergone genetic counseling, as shown by the absence of overlap in the 95% confidence intervals of the groups' responses to a standardized instrument. Narratives confirm knowledge is limited about screening and risk-reduction options, including age at which cancer screening should be initiated. Worry about hereditary breast/ovarian cancer was high among daughters; 15% scored above the clinical cut-off of the BSI-18 and nearly half said they worried a great deal or to an extreme about hereditary cancer.

Conclusion: Young, high-risk women have little knowledge about the probabilities and options for managing the cancers for which their risks are remarkably increased. Educational interventions may reduce their anxiety about hereditary breast/ovarian cancer, and ultimately

improve their participation in effective screening and risk reducing interventions that improve survival and quality of life.

*Presenting author

Targeting 18-24 Year Old Daughters of BRCA1/2 Mutation Carriers: How Do We Reach and Support Young Women at High Risk for Breast and Ovarian Cancer?

Authors: Alesha Henderson and Andrea Farkas Patenaude, PhD.
Dana-Farber Cancer Institute, Boston, MA and Harvard University, Cambridge, MA



Background

In the mid-1990s, the *BRCA1* and *BRCA2* genes were found that cause hereditary breast and/or ovarian cancer. These genes are located on chromosomes 17 and 13 in the United States (National Cancer Institute, 2009). Recommendations have been developed for early detection of cancers in *BRCA1/2* mutation carriers. Risk-reducing surgery (prophylactic mastectomy and oophorectomy) have also been shown to significantly reduce risks in this population. Genetic testing for *BRCA1/2* typically is not considered until age 18 for those at high risk and female mutation carriers are recommended to begin screening at age 25. Many women are not well informed about their hereditary cancer risks and many do not begin screening at the recommended age. Disclosure is hindered by the complexity of the information itself, by difficulties in parent-child communication about this emotionally sensitive topic and by parental uncertainty about how to communicate this information (Susan Clarke, 2007). *BRCA1/2* carriers become they feel a sense of responsibility for their children's health (Treyak, 2001). Some mothers do not disclose their status because they fear their children will worry or become anxious. Reports from parents who have spoken with their children about genetic testing suggest that parents feel their children often did not fully understand the meaning of the information conveyed (Bradbury, 2007).

A study at the Dana-Farber Cancer Institute, which is the parent study of the current study, involved the interviews of 40 daughters whose mothers were known carriers of the *BRCA1/2* mutation. The Dana-Farber Cancer Institute, both Dana-Farber Cancer Institute and Dana-Farber Cancer Hospital, provided contact information to allow researchers to recruit their daughters to participate in the study. Consented and enrolled daughters completed a family history questionnaire and measures of general and cancer-related distress, and participated in a qualitative interview. The interview focused on the daughters' perception of learning about *BRCA1/2* mutations, health behaviors, understanding of risk, life decisions, and emotional responses. Findings of the study were that daughters' distress was high, daughters had significant *BRCA1/2* knowledge gaps, and they were eager for high quality information about *BRCA1/2*. The conclusion was that a comprehensive educational intervention about *BRCA1/2* and associated cancer risks was needed for this age group. Pilot pages were developed based on narratives from 40 daughters. Our current project involves nine telephone interviews with daughters of mutation carriers which were conducted to determine the acceptability of the content and format of the pilot pages, which suggestions for other aspects of the intervention presentation.

The website would provide information for young adult *BRCA1/2* mutation carriers about:

- Education about genetic counseling
- Life as a *BRCA1/2* mutation carrier
- Dating Concerns
- Recommended screening
- Future steps
- Support

Methods

A four page pilot for a possible web-based intervention for 18-24 year old daughters was developed based on the narratives of the first study. This was done in conjunction with health communication associates at DF/HCC Health Communications Core. It was hoped that the web intervention would increase knowledge about *BRCA1/2* testing and the daughters' readiness to undergo genetic testing and, if appropriate, screening. The webpage was designed with younger women in mind. The language, format, and content of the page were designed to appeal to young women. Subjects added their preferences of receiving information from genetic counselors, physicians, and peers.

Nine telephone interviews with 18-24 year old daughters of *BRCA1/2* mutation carriers were conducted to assess the acceptability of the web-based intervention pilot pages and daughters' preferences for format and content. Participants were recruited similarly to the initial study which recruited daughters by contacting the mutation-positive mothers who were patients at the Dana-Farber Cancer Institute. Both first and second daughters of mutation-positive mothers were interviewed. Interviews were transcribed and coded. Coding for the telephone interviews was derived by creating a coding manual which was developed in Atlas-ti by thematic analysis relevant to the content of the web-based intervention. The codes focused not only on content and genetic knowledge but also format, colors, preferences, and the daughters' attitudes towards potentially living with a *BRCA1/2* hereditary cancer predisposition.

Results

Things We Have Learned about Preferred Formats (Presentation)

Photographs:
-The daughters preferred photos of young women over drawings of women and preferred photos of themselves with their mothers in the photos.
-The daughters valued the diverse background represented in the photos because they felt it implied that *BRCA1/2* mutations could affect people of many different ethnic backgrounds.

Ease of Understanding:

-The daughters generally found the content understandable.
-Because the language is understandable to me, I'm not a doctor so it's nice language that I can relate to. -Subject 1
-While some of the daughters appreciated that the information was provided in simple terms, others preferred that the information be provided in medical terms.

Dating Section

-The majority of the daughters found the dating section helpful and interesting.
-Some of the daughters had thought about this potential impact the *BRCA1/2* mutations would have on dating, while others had not.

Social Media

-Some daughters suggested a Facebook page about *BRCA1/2* mutations. -Concerns were expressed about possible privacy issues.
-When talking about Facebook page I'm interested in hearing from other girls my age who have tested positive for *BRCA1/2*, how did that make you feel? -Subject 6

Results Continued

Genetic Counseling Section:

-Many of the daughters were interested in the content and of the genetic counseling and testing section.
-Some of the daughters said that the information was a bit overwhelming and others described the section as "boring," but they all thought it was important.
-Most daughters thought they would at some point want to speak with a genetic counselor.
-What was your emotional response to the "Genetic Counseling" page? I guess reassuring because it gave clear steps that you can take to go forward and what you can do, and when you can start screenings. -Subject 8

Things We Have Learned About the Target Population

Support Needs:
-The majority of the daughters expressed wanting not to feel alone dealing with the *BRCA1/2* mutation.
-The daughters suggested that a discussion board be incorporated into the website.
-The resources on the website provided them with places to turn and made them feel more empowered with regard to *BRCA1/2* mutations.
Narratives:
-The experiences of other daughters who were mutation carriers as reflected in the quotes on the pilot pages validated the feelings that the young women experienced.
-The daughters wanted to know the paths that other women have taken with regard to *BRCA1/2*.
-Hearing about the experiences of others provided a sense of support.
-Because the only people I know that have to deal with this are my cousins and I don't know anyone else that has to deal with this so it would be kinda nice to read other stories. -Subject 1

Credibility:
-The women wanted a website that they could trust to provide accurate information about the mutation.
-The daughters felt as if the fact that the website was developed at the Dana-Farber Cancer Institute provided them with a sense of security because it is a well-known U.S. cancer center.

Justification of Emotions:

-Many of the women expressed a range of sentiments evoked by the pilot pages about the hereditary breast and ovarian cancer predisposition (Sadness, Worry, Encouragement, Hope).
-The range of feelings reflected in their family experiences and their current concerns about cancer.
-The full range of those emotions should be reflected in a future web intervention.
-It did feel a bit sad to me but, it's not a happy topic so that's probably why, but it feels hopeful as well. -Subject 8

Important Knowledge about Participants:

-The majority of the women wanted to know how to stay healthy in light of their *BRCA1/2*-associated risks.
-They also wanted to know what future steps they should plan on taking with regard to genetic counseling and testing and recommended screening.
-What do you think the "My Plan For Me" section should be? An area for you to think of what you can do in the future to keep yourself healthy and lower your risks. -Subject 3

Conclusions

-The young women were very interested in learning more about the *BRCA1/2* mutations and hereditary cancer risk and what effect their possible hereditary predisposition might have on their lives.
-Generally, the women felt the website was appropriately geared to their age group, 18-24 years old, and level of interest.
-The majority of the women felt as if they could believe the information that was provided because it came from a well-known U.S. cancer center.



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**YOUNG ADULT
WOMEN AT HIGH RISK
OF HEREDITARY
BREAST/OVARIAN
CANCER: IMPACT ON
DATING &
CHILDBEARING**

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- ◉ Paula Ryan M.D.
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- ◉ Sara Orozco Psy.D.

**CANCER RISKS OF DAUGHTERS OF
MUTATION CARRIERS**

- ◉ 50% risk of carrying maternal *BRCA1* or *BRCA2* mutation
- ◉ If carrier, 56-85% lifetime breast cancer risk
- ◉ If carrier, 20-60% lifetime ovarian cancer risk
- ◉ Breast cancer risk starts much earlier than for women in the general population
- ◉ Women 20-29 years have **17-19x** the breast cancer risk of women that age in the general population (Antoniou et al, 2003).

**Off the Radar-
Women ages 18-24 are:**



- ◉ Old enough to have *BRCA1/2* genetic testing
- ◉ but too young to begin screening for breast or ovarian cancer.
- ◉ Unlikely to have had Cancer Genetic Counseling
- ◉ Dependent upon parental transmission of information about familial risk; likely to be incomplete, inaccurate, and/or out of date
- ◉ Parents may not be listened to re: health

**DFCI Cancer Risk & Prevention Clinic
Population**

- ◉ **<1% of patients tested for *BRCA1/2* are under age 25**
- ◉ **3.5% are ages 25-30.**

What We Don't Know:

- ◉ What they understand from what parents told them when minors.
- ◉ How they think about or make decisions about counseling, testing, screening, risk-reducing surgery.
- ◉ Best time, methods to approach young adults who are children of mutation carriers.

Study of 18-24 year old Daughters of *BRCA1/2* Mutation Carriers (n=40)

- Family Hx and Demographic Questionnaire
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- Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ-27) (Erblich, 2005)
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Funded by U.S. Department of Defense Breast Cancer Program, Grant #BC084061:W81XWH-09-1-0217

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 - For the mean scores: calculated from n, mean, and standard deviation
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- Distress
- Interest in genetic counseling/testing
- Educational intervention preferences

Approach through Living Mothers

- Letter to mothers inviting them to give us contact information on daughters 18-24 years old
- Have to have told daughter about their *BRCA1/2* mutation test result

- Mothers eager to talk



- 66% Provided daughter contact information
- 78% Participation Rate for Invited Daughters

Eligibility Criteria

- Daughter of mother who is *BRCA1/2*+(mother may have had ca)
- 18-24 years old
- Mother must have disclosed her result
- Daughter has never had cancer
- Must speak English
- Willingness to participate in interview and complete questionnaire

DEMOGRAPHICS (N=40)		
Age	Mean	21.2 years
Race	White	100 %
Education	High school graduate	7.5%
	Some college	57.5%
	College graduate	35.0%
	Full-time student	32.5%
Work Status	Employed	42.5%
	Unemployed and looking for work	2.5%
	Unemployed and not looking for work	5.0%
	Both student and employed	17.5%
Marital Status	Single	90.0%
	Married	5.0%
	Living as married	5.0%
Has Children?	Yes	7.5%
	No	92.5%

GENETIC COUNSELING and TESTING		n	%
Participant had genetic counseling	YES	8	20
	NO	32	80
Participant had genetic testing	YES	7	17.5
	NO	33	82.5
Participant's genetic test result	Positive	1	2.5
	True Negative	6	15
	Not Tested	33	82.5

What They Do Know

More than 75% know:

- Fathers can pass down breast cancer gene mutation.
- *BRCA1/2* mutation carriers are at increased risk for ovarian cancer as well.
- Not all *BRCA1/2* mutation carriers develop cancer.
- A mutation carrier who has had breast cancer has a higher risk of collateral breast cancer.

What They Don't Know

50% or more do not know:

- The risk for breast cancer in the general population is about 12%.
A woman with a sister with a *BRCA1/2* mutation has a 50% risk of carrying a mutation.
- A woman who has her ovaries out still has some residual risk of developing ovarian cancer.

What They Don't Know

33% or more think the following statement is false:

- Breast cancer occurs at younger ages in women who carry *BRCA1/2* mutations.

Misconceptions

- Genetic testing not possible until age 24.
- Genetic testing only for people with cancer.
- Mutation can skip generation.
- Separate genes control breast, ovarian risk.
- Cervical cancer related to *BRCA1/2*.
- Have to have my ovaries out by age 30.

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Results of BGKQ-27, by group

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*Suggests that knowledge level of daughters is less than that of women initiating counseling.

Cancer Worries : % scoring
4= a great deal or 5=to an extreme

How much do you worry about:

- Cancer risk being inherited in your family?

40 %

- Getting cancer in the future? **37.5%**

- Whether your child/children (present or future) will develop cancer in the future?

23 %

What Triggers Cancer Worry?

- Doing BSE
- Mom's MD visits
- Smoking
- Memories of Mom's cancer
- Seeing breast cancer on TV
- Talking about kids
- Health classes
- Mother talking to me about sunscreen

**DATING WORRIES
OF
DAUGHTERS OF MUTATION
CARRIERS**

- When do I bring up my cancer risk?
- What do I say?
- Will it change our relationship?
- Will it scare him/her off?
- Will he/she think I can't have children?
- Can I have children and stay healthy?
- Will he/she be supportive?
- Will he/she want me to be tested now?

**My mom mentioned that to
future boyfriends..**

I shouldn't mention it ever..Until we're like married-it's a much too cynical viewpoint than mine...Like my current boyfriend, I've been w/ for 4 months and ...I haven't been very clear with him, but he understands that my mother and my MGM have a genetic mutation ..I figure if he's smart enough to draw the appropriate conclusion, I don't plan on spelling it out for him for a little while..D011

Since I'm new here...

I haven't been too comfortable talking about it yet..No, I haven't talked about it with him (BF). B042

**How do the conversations go (with
boyfriends)?**

Well, they never go bad, it's just kind of this problem and thinking about it...It's not like it goes horrible, but it's not a serious serious conversation about it I guess. D049

“Well, he’s very supportive..

He’s sort of like, if it happens, he would be there and all that.” B46

“He was possibly scared, but

anyone would be, but very supportive. I think that in any relationship, if love is strong enough it’s not going to -those types of things aren’t going to push someone away.” B36

“My boyfriend was fine...

I can’t recall what he said, to be honest.” B45

“I talk to my husband a little bit about it...

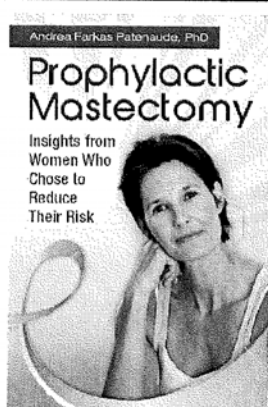
My husband wants me to find out if I have the gene, like as soon as possible, but I’m not really in a hurry. I’m not even 24 yet, so I know you can’t really do anything about it till you’re 25. I’m not in the big of a hurry...like, he doesn’t get it. He doesn’t get that nothing can be done about it yet, so, like he doesn’t understand and it gets annoying for me to explain it to him. I’m glad he’s interested and he’s just trying to tell me what he thinks is best, but I just don’t think he knows what’s best for me when it comes to that.”M25

I have a long-term boyfriend who I talk to about that...

And he was very supportive...but I mean there’s really nothing he could do for me at this point because I don’t have cancer...And he was very ill...He’s going through liver failure now and he’s waiting for a list for transplant now.”D52

Daughter of living mutation carrier, age 22

..And who knows, maybe I won’t ...Like I think that once I’m done having my children, I’ll probably just get my ovaries out. I don’t need them. And then I guess, something they say you can get, like a mastectomy before you even know you have cancer to prevent it from happening. I don’t know how I feel about that, but definitely not until, after I’m like, married so someone will, like, love me.



Prophylactic Mastectomy and the Single Girl

- Many fears
- Depends a lot on how he is told
- Making it a test usually not helpful
- Relationship-dependent
- "Not a breast man"
- More often it is the woman who feels less attractive; men seem to adjust in good relationships.
- In bad relationships, may tip the balance.

What Women Undergoing PM Want from Partners

- Listening
- Some want them to take part in decision; others want freedom to decide themselves.
- Support for decision
- Go to MD visits
- Expect temporary as well as permanent change
- Willing to talk
- OK to acknowledge losses
- Caretaking during recovery

Experiencing Prophylactic Mastectomy

- Can strengthen relationship
- Can trigger breakup, but only if prior deterioration.
- Woman more likely to be self-critical
- Partner can help her realize it is her self-image, not relationship issue.

Conclusions

- We need to develop appropriate models for genetic counseling, screening and presentation of risk-reduction options in formats which will engage people of varying ages.
- Taking care of families with hereditary cancer predisposition involves counseling over the lifetime.

Future Work: The Next Generation

- Study impact of having a mother die from breast or ovarian cancer on attitudes, actions of 18-24 year old daughters of mutation carriers
- Longitudinal studies
- Development of interventions and studies of efficacy and impact of intervention
 - ✦ to assist in information sharing and
 - ✦ encourage early screening

Abstract for the 2012 International Psycho-Oncology Society Meeting

Presented at the International Psycho-Oncology Society Meeting, Brisbane, Australia (November, 2012)

Next generation prevention of hereditary breast/ovarian cancer: What daughters of mutation carriers know and feel and what they want to know

Authors: **Andrea Farkas Patenaude**^{1*}, Nadine M. Tung², Leif W. Ellisen³, Larissa Hewitt¹, Julie Aldridge¹, Judy E. Garber¹

Affiliations: 1: Dana-Farber Cancer Institute, Boston, MA; 2: Beth-Israel Deaconess Medical Center, Boston, MA; 3: Massachusetts General Hospital, Boston, MA

Aims: Educating the next generation of high-risk (50% risk of carrying *BRCA1/2* mutation) women about their cancer risks, genetic counseling and testing, targeted screening and risk-reduction options is an important translational responsibility of genetic professionals. To effectively reach this group of women, old enough for *BRCA1/2* genetic testing but below the age of screening initiation (age 25), data are needed assessing their cancer-related distress and psychological support and psychoeducational needs.

Methods: A mixed methods study highlighted 40 qualitative telephone interviews with 18-24 year old daughters of *BRCA1/2* –positive mothers from 3 Boston teaching hospitals about their understanding of their individual and family cancer risks, their reactions to knowing about hereditary cancer, family communication experience, impact on life planning and interpersonal relationships, and interest in further education and support about hereditary cancer. Coding utilized Atlas-ti software; Analysis was according to Weiss(1994)¹. Questionnaires assessed family cancer history, demographics, breast cancer genetic knowledge(BGKQ-27)², general(BSI-18)³ and cancer-related(IES)⁴ distress. Descriptive statistics, including 95% CIs, were reported and examined against previously reported data for overlapping qualities.

Results: Hereditary cancer-related distress for 18-24 year old daughters (IES mean=16.9, 95%CI 12.92- 20.88) was as high as that of women reporting for genetic testing⁵ (IES mean=15.1, 95%CI 13.11-17.09) and tested mutation carriers⁶ (IES mean=16.1, 95%CI 9.57-22.63). A third of our sample reported very high cancer-related distress (IES $\geq$ 20). Daughters' breast cancer genetic knowledge was lower (BGKQ mean=16.7, 95%CI 15.52-17.93) than that for older women initiating testing² (BGKQ mean=20.7, 95%CI 18.3- 23.1). There was no difference between distress scores of young women whose mothers had had cancer versus those who had not. Narratives illustrate cancer-related concerns of these high-risk women, especially about dating and childbearing and their desire for web-based, targeted information.

Conclusions: Daughters of *BRCA1/2* mutation carriers need and want web-available information and support regarding hereditary cancer risks.

*Presenting author

Presentation Slides for the Familial Cancer Clinic at the North Shore Hospital, Sydney, Australia

Next Generation Prevention of Hereditary
Breast/Ovarian cancer: What Daughters of Mutation
Carriers Know and Feel and What they Want to Know

AF PATENAUE^{1,2,3}, NM TUNG^{2,3,4}, LW ELLISEN^{2,3,4},
L HEWITT¹, J ALDRIDGE¹, JE GARBER^{1,2,4}
¹DANA-FARBER CANCER INSTITUTE, ²BETH
ISRAEL-DEACONNESS MEDICAL CENTER,
³MASSACHUSETTS GENERAL HOSPITAL,
⁴HARVARD MEDICAL SCHOOL, BOSTON MA USA

Cancer Risks of Daughters of Mutation Carriers

- 50% risk of carrying maternal *BRCA1* or *BRCA2* mutation
- If carrier, 56-85% lifetime breast cancer risk
- If carrier, 20-60% lifetime ovarian cancer risk
- Breast cancer risk starts much earlier than for women in the general population
- Women 20-29 years have 17-19x the breast cancer risk of women that age in the general population (Antoniou et al, 2003).

Off the Radar- Women ages 18-24 are:



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- But too young to begin screening for breast or ovarian cancer.
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- Parents may not be listened to re: health

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- **<1% of patients tested for *BRCA1/2* are under age 25**
- **3.5% are ages 25-30.**

What We Don't Know:

- What they understand from what parents told them when minors.
- How they think about or make decisions about counseling, testing, screening, risk-reducing surgery.
- Best time, methods to approach young adults who are children of mutation carriers.

Study of 18-24 year old Daughters of *BRCA1/2* Mutation Carriers (n=40)

- Family Hx and Demographic Questionnaire
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- Qualitative Interviews

Funded by U.S. Department of Defense Breast Cancer Program, Grant #BC084061:W81XWH-09-1-0217

Interviews focus on:

- Learning about maternal *BRCA1/2* result
- Impact of family cancer experience
- Understanding personal risk and implications of risk
- Current health behaviors
- Attitudes towards screening, risk reduction options
- Impact of knowing on life plans
- Insurance
- Distress
- Interest in genetic counseling/testing
- Educational intervention preferences

Findings will be used to:

1. Plan content, format of educational intervention to better communicate with young adult group of daughters of *BRCA1/2* mutation carriers.
2. Plan study of efficacy of educational intervention in raising screening uptake at age 25

Statistical Methods

- Normality assumptions were checked
- Two-sided, 95% confidence intervals (CIs)
 - For the mean scores: calculated from n, mean, and standard deviation
 - For proportion of high scores: calculated using exact binomial
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Approach through Living Mothers

- Letter to mothers inviting them to give us contact information on daughters 18-24 years old
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- Daughter of *BRCA1/2*+ mother (mother may have had ca)
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- Daughter has never had cancer
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	Employed	42.5%
	Unemployed and looking for work	2.5%
	Unemployed and not looking for work	5.0%
	Both student and employed	17.5%
Marital Status	Single	90.0%
	Married	5.0%
	Living as married	5.0%
Has Children?	Yes	7.5%
	No	92.5%

CANCER HISTORY		n	%
Personal Cancer History	Type of cancer(s)		
Personal Cancer History	No cancer	40	100
	No cancer	9	22.5
	Breast Cancer	21	52.5
	Ovarian Cancer	7	17.5
	Both Breast and Ovarian	1	2.5
Maternal Cancer History	Both Breast and Ovarian	1	2.5
	Thyroid	1	2.5
	Both Breast and Lung	1	2.5
	Unknown	1	2.5
Paternal Cancer History	No Cancer	33	82.5
	Breast Cancer	0	0
	Prostate Cancer	1	2.5
	Pancreatic Cancer	0	0
	Other	5	12.5
Sisters with Cancer	Unknown	1	2.5
	No Cancer	40	100
Brothers with Cancer	No Cancer	38	95
	Retinoblastoma	1	2.5
	Skin Cancer	1	2.5

GENETIC COUNSELING and TESTING		n	%
Participant had genetic counseling	YES	8	20
	NO	32	80
Participant had genetic testing	YES	7	17.5
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What They Do Know

More than 75% know:

- Fathers can pass down breast cancer gene mutation.
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Cancer Worries : % scoring 4= a great deal or 5=to an extreme

How much do you worry about:

- Cancer risk being inherited in your family?
40 %
- Getting cancer in the future? **37.5%**
- Whether your child/children (present or future) will develop cancer in the future?
23 %

NARRATIVES:How much do you worry about getting cancer yourself?

"A lot!" D050 20 year old

"I mean I definitely do worry about it. My take on ..everything that's happened to my family is either you're going to get it or you're not. There is no in between. Do I think I am going to get it? Yeah, I do." M027 24 year old

"Um, not so much. Maybe because I am only 22, ..and I'm painfully anal and vigilant about going to the doctor ..I'm pretty pushy with the doctor...Cuz I don't really wanna have a preventative mastectomy..I like my boobs! Right! D011 22 year old

What Triggers Cancer Worry?

- Doing BSE
- Mom's MD visits
- Smoking
- Memories of Mom's cancer
- Seeing breast cancer on TV
- Talking about kids
- Health classes
- Mother talking to me about sunscreen

Brief Symptom Inventory -18
Global Score : GSI

Only 10% (n=4) score over clinical cut-off score (63)

Impact of Event Scale: Comparison of Total Means

IES Total Mean Score	n	Confidence Interval
DFCI : 18-24 year old daughters of BRCA1/2 mutation carriers	40	(12.92, 20.88)
Quebec: women, BRCA1/2 carriers, 1-month post-disclosure (Dorval et al., 2006)	45	(5.89, 13.71)
Australia: women seeking genetic counseling (Meiser et al., 2001)	218	(13.11, 17.09)
Australia: women BRCA1/2 carriers; 12 mos. Post-disclosure (Meiser et al., 2002)	20	(9.57, 22.63)
Belgium : women BRCA1/2 carriers; 12 mos. Post-disclosure. (Claes et al., 2005)	34	(6.12, 14.68)
London : women seeking genetic counseling with family hx of breast cancer (Watson et al., 1999)	267	(15.63, 19.41)
Norway : men & women, seeking counseling, with family hx of breast cancer or CRC (Bjorvatn et al., 2009)	212	(11.09, 13.61)
Netherlands (women, post-counseling, pre-disclosure for BRCA1/2) (van Oostrom et al., 2007)	175	(21.60, 27.00)*

High Distress on IES from DMC

Similar to women:

- Seeking genetic counseling
- Women who are mutations carriers – 1 month post-disclosure
- Women who are mutation carriers- 12 months post-disclosure

Dating Worries of Daughters of Mutation carriers

- When do I bring up my cancer risk?
- What do I say?
- Will it change our relationship?
- Will it scare him/her off?
- Will he/she think I can't have children?
- Can I have children and stay healthy?
- Will he/she be supportive?
- Will he/she want me to be tested now?

My mom mentioned that to future boyfriends..

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How do the conversations go (with boyfriends)?

Well, they never go bad, it's just kind of this problem and thinking about it...It's not like it goes horrible, but it's not a serious serious conversation about it I guess. Do49

"Well, he's very supportive..

He's sort of like, if it happens, he would be there and all that." B46

"My boyfriend was fine...

I can't recall what he said, to be honest." B45

"I talk to my husband a little bit about it..."

My husband wants me to find out if I have the gene, like as soon as possible, but I'm not really in a hurry. I'm not even 24 yet, so I know you can't really do anything about it till you're 25. I'm not in that big of a hurry...like, he doesn't get it. He doesn't get that nothing can be done about it yet, so, like he doesn't understand and it gets annoying for me to explain it to him. I'm glad he's interested and he's just trying to tell me what he thinks is best, but I just don't think he knows what's best for me when it comes to that."M25

Daughter of living mutation carrier, age 22

...And who knows, maybe I won't ...Like I think that once I'm done having my children, I'll probably just get my ovaries out. I don't need them. And then I guess, something they say you can get, like a mastectomy before you even know you have cancer to prevent it from happening. I don't know how I feel about that, but definitely not until, after I'm like, married so someone will, like, love me.

Psycho-Oncology, in press, Report of DMC's cancer-related distress and *BRCA1/2*-knowledge gaps

• Young adult daughters of *BRCA1/2* positive mothers: What do they know about hereditary cancer and how much do they worry?

Andrea F. Patenaude*, Nadine Tung, Paula D. Ryan, Leif W. Ellisen, Larissa Hewitt, Katherine A. Schneider, Kenneth P. Tercyak, Julie Aldridge and Judy E. Garber.

- Common, important misconceptions re: *BRCA1/2*
- A third have high levels of cancer-related distress
- Much concern about dating, childbearing
- Desire for more, better, accurate information

What Daughters of *BRCA1/2* Mutation Carriers (DMC) Want to Know:

- "The risks, all the options that you have, what age to start getting the testing done" B38
- "Pros and cons of testing, what it means for your future, how it can be prevented, changing your health or whatever." B39
- "...links to receive help, like lots of facts about it and maybe links where you can go to a genetic counselor, how testing works, next steps after testing.." B41
- "Frequently asked questions" B38



What Want to Know-2

- "How to take care of yourself, how to do something about it." B42
- "Stories ...to help them make their decisions of how other people approached it, how they felt afterwards." D8
- "What a mutated gene is, how it's passed on, what sort of effect it has, like how it works would be cool." D11
- "What *BRCA1* is, and what you can do" D28
- Accuracy: "Maybe it's hosted by a hospital or a cancer center...who has a name behind it so people know the information is accurate." D13



A Personal Timeline

"A page on some things I could do in my life ..would refer to from time to time to make sure I was on the right track as far as eating healthy, exercising, not smoking, staying out of the sun, whatever advice it gives me...Also a timeline of what sort of tests I need to get, what those tests are - b/c I've never been through a mammogram... making it less abstract and more real and, thus, less scary." D11



Preferences for Delivery



- Vast majority prefer online
- Some want pamphlet or brochure
- Some want video
- Few say want only 1:1 conversation with medical provider or parent

Why the Web?

"We all use the Internet and I know a lot of times I putter around online and so if I can learn something while I'm puttering around online, that would be great.. also for people who are shy and don't necessarily feel comfortable discussing it, but who need something more in depth than a small brochure could provide." D11

"Easy to access and you can get as much information as you want." D13

"People can get to the areas they're really interested in." D53

"Private, it's anonymous" M18

Can update

"You can always lose a pamphlet, but on the Internet, it's always going to be in the same place." D52

Want a Website:

- Website + open phone line
- Website + brochure ("like to read pamphlets when I'm waiting for things." B33
- "Online-Technology is such a part of our lives." B36
- "Internet: I don't mind talking to people, but sometimes I'd rather not." B38
- Website+ Discussion Forum for daughters when mothers are sick.
- Web: "Some people just want to be able to research it privately, without even talking to anyone, reading what other people have to say about it...like online journals." B41
- Website + Frequently Asked Questions (FAQs)

Preferred Web Formats

- Quick Bullet Point Facts
- Pictures
- A Dateline (TV news magazine) special on the Internet
- Stay pretty neutral about testing, unbiased, cold facts
- Online preferred for people who are shy
- "Need something more in depth than a small brochure could provide" D11
- "More useful if it's tailored towards women prior to starting the screening, a young age when they're not that concerned b/c of the age." D53
- Chat room – talk to kids who have the same problem

Prefer to Hear About Online From:

- Doctors – most common answer;
 - Doctor=Expert
 - Doctors who perform mastectomies or the test you mentioned
 - Panel of geneticists, surgeons, Ob/Gyns
- Genetic Counselor
- Researcher
- Peers who have had genetic testing- Also very common
- Teenagers: "Hearing it from an adolescent, yk, decreases the age difference, makes it a little more peer closer in perspective."
- Group of Kids with parents w/cancer
- Therapist who's dealt with people my age.. "[who] can understand the emotional needs as well as the informational needs." D11



When might you utilize this resource?

- "If one of my children was really concerned about genetic testing." B32
- "If I ever want to get tested." B33
- "I think I know pretty much...so, I really wouldn't use it." B38.
- "Once I'm tested"
- "If I were thinking of getting tested like at this point in my life and I wasn't sure if it would be beneficial or if I was like confused." B39

When would use:

- "I could just easily go on and read people's experiences and then read about the procedures.. People are going to do it rather than making phone calls." B41
- To teach a class about wellness B45
- For school projects or research projects D55
- When my mom was telling me..would have been nice to look at something I could read for myself." D8
- "If I was talking to my cousins, looking it over before I went so I knew more what I was talking about." D10

When might use it:

- "If I wanted to take it upon myself to look up information and get a different perspective other than my mother." D14
- After I got tested. M25
- Like when I found out my grandmother or somebody got cancer M44

Ever Wanted to Hear Less about Hereditary Cancer, Genetic Testing? NO

- "I think it's a tool we have and we might as well use it...it that's gonna help someone prevent something or catch it early, that's really important." M22
- "I've always been used to it being talked about a lot." D50
- "No, I haven't heard enough of it." D51
- "It's not a fun subject, but I haven't felt uncomfortable." M44
- "No, cuz the people I talk to are people I reach out to talk to, like my primary care or the genetic counselors." D20.



Ever Wanted to Hear Less about Hereditary Cancer, Genetic Testing?-YES

- A few; "I'm just not sure that now is the right time for me." D49
- Before, but not now opposed: "When my mom first told me, I didn't want to know about the test..didn't want to hear about it..but now as I've gotten a little bit older and learned more about it, the subject doesn't make me uncomfortable any more." M18
- Own way: "She thinks I'm 5 b/c she thinks it hasn't gone thru my head b/c I handle it so calmly. I don't react the same way she does" D11

Ever Wanted to Hear Less about Hereditary Cancer, Genetic Testing?-YES- Too Much

- Too much focus: "I went home and spent time with my parents and it's pretty much all I heard from my mom-every night, it was lecture after lecture. By the end of the week, I had definitely heard enough about testing". D14
- Too long: "We kind of butt heads on it...anytime she talks about genetics or breast cancer or heredity and genes...anytime it's longer than 5 minutes, I can't stand it." M15.



Fears

- Graphic pictures of breast reconstruction at seminar for mutation carriers was scary.
- "I don't think all possible negative aspects need to be put up on the internet b/c you can't ask questions." B36
- "Should be informational, without the intent to scare kids into getting tested or scare them about, if they get tested, this could happen." B39
- "They could be aware, but not frightened." B42
- "You don't want to completely scare like a 12 yr. old." D8



Fears – 2

- “Not: ‘Have a mastectomy!’ D29
- “Say lots of options if someone is +, can mean different things for different people. D50.
- “I know I get really emotional and sometimes it’s really scary to talk about it or even think of going to talk to like a genetic counselor...can be really daunting...[if online] you could just go and wouldn’t be any pressure, you wouldn’t have to schedule an appointment, it would be easier.” D58
- [Don’t include] “The amount of people who don’t survive it.” M15

How Much Statistics to Provide?

Pro

- [should include?] “I think statistics”. B41
- “I think statistics are important, that’s like the one thing that like catches everyone.” D29
- “People don’t get it ..until they see a statistic” M25



Con

- “Not statistics b/c I think that kind of loses its appeal to this audience...I wouldn’t want anybody telling me you have a set chance of developing cancer” D6
- “..have to be careful about statistics...statistics can be misleading, can also change, depending on what research study you believe...so, if you’re going to put statistics, don’t put every little thing, put the most important things and things you know to be valid.” D52

DMC Suggest Advertising in:

- Women’s magazines
- Facebook
- Commercials



- I feel like knowledge is like, yk, power...You can know things before something goes wrong and that ‘s what my mother wanted when she wanted me to get tested b/c she wanted me to be aware of everything and not be blindsided by it like she was.” M27



“I think this study is important ‘cause it’s something that’s growing and people need to be aware of it. [We need] more information...Doctors need to be forced to talk about it more with kids that they know it runs in their family.” B36



Limitations

- Only daughters of living mothers: Cancer worry may be greater among daughters whose mothers have died of breast cancer.
- Sample lacks socio-economic and cultural diversity; High education level
- Only daughters whose mothers disclosed and who were willing to let us contact daughters.

Conclusions:

- Largely, daughters want accurate *BRCA1/2* information.
- **Implications for Parents Talking to Daughters:**
 - Listen to daughter's tolerances: Short discussions, not lectures more effective
 - Talk when you can contain your own emotions
- **Implications for Professional Outreach to Daughters**
 - We need to find ways to reach daughters earlier, before age 25.

Conclusions

- **Cancer-related Worry among 18-24 year old daughters suggests considerable concern about hereditary cancer.**
- **Cancer worry is similar to those undergoing genetic testing or known to be mutation carriers.**
- **Misconceptions and knowledge gaps suggest educational needs**

Conclusions

- **Taking care of families with hereditary cancer predisposition involves counseling over the lifetime.**
- **Consideration of a more proactive approach to educating/informing daughters of mutation carriers in formats which will engage people of varying ages may reduce morbidity, mortality.**

Conclusions

Without enhanced education, care and prevention activities, young women at high risk will continue to be diagnosed with excessive breast cancers and many will die of the disease, despite genetic advances.

Future Work: The Next Generation

- **Study impact of having a mother die from breast or ovarian cancer on attitudes, actions of 18-24 year old daughters of mutation carriers**
- **Longitudinal studies**
- **Development of interventions and studies of efficacy and impact of intervention**
 - ✦ to assist in information sharing and
 - ✦ encourage early screening



Abstract for the 2013 International Meeting on Psychosocial Aspects of Hereditary Cancer

Presented at the 13th International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC), Sydney, Australia (March, 2013)

Next Generation Education: Daughters of *BRCA1/2* Mutation Carriers Report Preferences for Receipt of Genetic Information and Planning Support through a Psycho-Educational Intervention

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Introduction: Daughters of *BRCA1/2* mutation carriers (DMC) aged 18-24 years are a high-risk group (at 50% risk of inheriting the deleterious mutation) who have important near-term decisions to make about testing and screening, but have received little professional attention. Data about their interest in education about *BRCA1/2* and preferences for effective receipt of genetic information are lacking.

Methods: Funded by a DOD Breast Cancer Research Program grant, 40 daughters, ages 18-24 years, of *BRCA1/2* mutation carriers (DMC) were assessed by mixed methods including in-depth interviewing. Based on subjects' self-report of gaps in *BRCA1/2* knowledge and cancer-related distress, researchers, planned a psycho-educational intervention. Nine additional DMC evaluated pilot intervention pages, detailing preferences for *BRCA1/2*-related content and format. Data from both groups, including illustrative narratives, are reported.

Results: Interest in learning about the heritability of *BRCA1/2* mutations, associated cancer risks and screening/ risk-reduction options from a credible, professional source was high. Web-based intervention was strongly preferred; potential utility of social media utility was described. Different voices of authority (physician, genetic counselor, psychologist, peer) were preferred by women for learning about medical risks versus psychosocial implications of living with *BRCA1/2*. Women wanted definitions of basic genetic concepts, information about locating genetics professionals, discussion of myths and misconceptions about *BRCA1/2*, peer stories, and the opportunity to plot a personal timeline for uptake of counseling, testing and screening. Subjects varied in their desire for medical statistics, suggesting a need for various ports of entry into the intervention depending on individual information style and level of *BRCA1/2*-related fear.

Conclusion: 18-24 year old DMCs are eager to receive targeted, credible genetic information, peer and professional support, and personalized health planning to guide decision-making about their *BRCA1/2* cancer risks. Findings suggest age-targeted, psycho-educational intervention from professional sources geared to young adults' styles of information retrieval would be well-received.

*Presenting author

Young Adult Daughters of *BRCA1/2* Positive Mothers: What Do They Know about Hereditary Cancer and How Much Do They Worry?

Short title: Cancer worry of young adult daughters of *BRCA1/2* mutation carriers

by

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Abstract

Objective: To determine 1) what daughters, ages 18-24 years, of *BRCA1/2* mutation carriers understand about their 50% chance of carrying a *BRCA1/2* mutation and about risk reduction or management options for mutation carriers, 2) the extent and nature of daughters' cancer-related distress and 3) effects of knowing mother's mutation status on daughters' future plans.

Methods: Forty daughters, currently aged 18-24 years, of mothers who tested positive for a mutation in *BRCA1/2* were invited by mail to participate (with contact information supplied by their mothers). Daughters participated in a qualitative telephone interview about the impact of learning their mother's mutation status on their understanding of their own cancer risks, their cancer-related distress, knowledge of screening strategies and risk-reducing surgery, current health status and future plans. Participants also completed a study-specific demographic and family history questionnaire, the Brief Symptom Inventory-18, Impact of Event Scale (with hereditary predisposition to breast/ovarian cancer as the event), and the Breast Cancer Genetic Counseling Knowledge Questionnaire.

Results: Daughters' genetic knowledge is sub-optimal; gaps and misconceptions were common. Over 1/3 of daughters reported high cancer-related distress, despite normal levels of general distress. Disclosed genetic information raised future concerns, especially regarding childbearing.

Conclusion: Targeted professional attention to this high-risk cohort of young women is critical to inform the next generation of daughters of *BRCA1/2* mutation carriers and encourage recommended screening by age 25. Improved uptake of screening and risk reduction options could improve survival and psycho-education could reduce cancer-related distress.

Keywords: *BRCA1/2*, hereditary breast/ovarian cancer, mutation carriers, preventive oncology, psycho-educational intervention, cancer risk

INTRODUCTION

A key motivation for individuals undergoing *BRCA1/2* mutation testing is that their test results may help their children, especially daughters, identify cancer risks before cancer develops [1]. Daughters of mutation carriers (DMC) have a 50% chance of inheriting the parental mutation and, with it, accompanying lifetime cancer risks ranging from 56%-85% for developing breast cancer [2-3] and 10-60% for developing ovarian cancer [4-6]. A striking feature of hereditary breast cancer is the younger age of onset, occurring frequently in the 30's and 40's and even among women in their 20's. *BRCA1/2* mutation carriers ages 20-29 have a relative risk of breast cancer that is 17-19 times that of women in the same age in the general population [7].

Owing to these facts, young women who are mutation carriers or those who are not yet tested but at high risk of being carriers are advised to begin evidence-based, risk management strategies developed for female *BRCA1/2* mutation carriers at age 25 [8]. However, uptake of recommended early screening remains suboptimal among high-risk young women and screening adherence is especially low for 25–40-year-old mutation carriers [9-10].

The cancer genetics community places a high value on protecting individual patient privacy surrounding genetic test results and has, as a result, determined that communication of test results to at-risk relatives should be done by tested index patients or probands [11-13]. Thus, parents are typically the initial conveyors of information to their children about the presence of a familial mutation, related hereditary cancer risks and opportunities for genetic counseling and testing. Data are limited about the effectiveness of this family communication paradigm. Although a high percentage of parents disclose their result to minor children [14-17], many parents report being ill-prepared for this task and would welcome targeted decision aids to support such communication [18-20]. Whether intentional or not, information transmission to family members often omits major components of the relevant genetic information or omits particular first-degree relatives [21, 15]. Family communication of hereditary cancer risk has been compared to a children's "whisper" or "telephone" game, due to the large amounts of misperception, miscommunication and misinterpretation among involved family members [22]. Some question whether this approach is adequate or whether alternate models of professional–family member communication might be better suited to comprehensive care of hereditary cancer families. To determine this, we need data on what family members, especially DMC, understand and feel when informed by parents and how prepared they are to make use of this information in a timely manner for self-care behaviors.

Research on family communication about hereditary cancer has focused largely on perceptions of individuals providing the information, not on the recipients [22-23]. Understanding the needs of high-risk, young DMC is a critical pre-requisite to determining how to approach, empower and support this cohort and encourage uptake of recommended screening at age 25.

PATIENTS AND METHODS

Our project ascertained self-report data from DMC in the critical 18-24 year age bracket between when genetic testing is advised (age 18 or after) and before screening should begin (age 25). Because this is a complex, novel area of inquiry, we relied heavily on qualitative measures to capture the full range of genetic knowledge, related emotions, attitudes, and future plans of this unstudied group of young adult daughters of *BRCA1/2* mutation carriers. We also incorporated several standardized self-report health behavior measures to augment narrative findings.

Participants: Participants were recruited from among age-eligible daughters of *BRCA1/2*-positive women tested at the hereditary cancer centers of the Dana-Farber Cancer Institute (DFCI), Massachusetts General Hospital (MGH), and the Beth Israel Deaconess Medical Center (BIDMC), Boston. Letters, signed by the appropriate clinic director, were sent to all *BRCA1/2*-positive women tested in years 2000-2009 who had indicated willingness to be recontacted for future research participation and had one or more daughters in the eligible age range (18-24 years). Mothers willing to provide daughter(s)' contact information did so by mail for daughters they had informed of the maternal result.

DMC whose mothers provided contact information were invited by letter to participate. If there was more than one age-eligible daughter in a family, project personnel selected the eldest or youngest in a counterbalanced manner. Eligibility criteria for daughters included 1) that they had been informed of the maternal result, 2) had not had cancer, 3) spoke English and 4) were willing to participate. Human subjects approval was received from the Dana-Farber/Harvard Cancer Center Institutional Review Board and the USAMRMC Office of Research Protection, HRPO. Daughters were consented via telephone.

Interview: The qualitative interview was developed by the principal investigator (AFP) and piloted with 5 DMC. Interviews were scheduled at the convenience of the participants and conducted via telephone by 3 female advanced social science graduate students with qualitative interview training. Interviews, which averaged 56 minutes (range 33-96 minutes), were audio-recorded, verbatim-transcribed and thematically coded using Atlas-ti software. Participants were asked about 1) learning their mother's *BRCA1/2* mutation status, 2) the emotional impact over time, 3) their understanding of cancer risks conveyed by positive mutation status and the implications of those risks and 4) health status assessment and planning in consideration of this genetic knowledge.

A code manual was developed for analysis of the interviews based on themes identified in advance from the literature and clinical experience and others derived in a constant comparative method from the review of all the interview material. When codes were added, prior interviews were re-coded. While most interviews were conducted by one research assistant, 10% of the interviews were randomly selected for double-coding (i.e. coding by two assistants). In these cases of double-coding, the percentage of agreement between the assistants on all of the codes was 80%. Thematic analysis was conducted by the Principal Investigator utilizing the methods of Weiss, 1994 [24].

Self-Report Questionnaire: The questionnaire included demographics, daughter's current health status, her prior discussions with professionals about hereditary cancer, interest in and experience with genetic counseling and/or testing, family cancer history, self-reported cancer-related distress and 3 standard psychological measures. **The Brief Symptom Inventory-18 (BSI-18)** [25] is an abbreviated screening version of the well established BSI, a measure of general psychological distress. The standard cutoff score of 63 on the Global Severity Index (GSI) standardized T-score identified clinical levels of distress. **The Impact of Event Scale (IES)** [26] is a widely used, 15-item measure of current subjective distress aimed at assessing avoidant or intrusive thinking during the prior week in reaction to a particular stressor, here, "inherited predisposition to breast/ovarian cancer". A cutoff score of 20 on the IES identified high levels of distress [27]. **The Breast Cancer Genetic Counseling Knowledge Questionnaire (BCKQ)** [28] is a 27-item scale developed from testing of women post-*BRCA1/2* genetic counseling; it has established high levels of content validity and reliability. Questionnaires were completed and returned prior to the telephone interview.

Statistics. For the BSI-18 Global Index Score (GSI), raw scores were converted to standard T scores per scale instructions. The proportions of participants with low and high GSI T scores, “low” scores characterized as scores <63 and “high” scores as those ≥ 63 , were reported with a 95% exact binomial. For the total IES mean score, two-sided, 95% confidence intervals (CIs) were reported so that the mean scores of the daughters could be compared with the mean scores of other groups. Normality assumptions were checked. The 95% CIs were examined for any overlapping qualities: CIs that do not overlap are considered significantly different. To further investigate the IES Total score, “low” scores were characterized as scores <20 and “high” scores were those ≥ 20 . The proportions of participants with low and high IES scores, respectively, were reported. 95% CIs were calculated using the exact binomial distribution. For the BGKQ-27, two-sided, 95% CIs were created so that the mean scores of the daughters could be compared with the published mean scores of counselees. Normality assumptions were checked. BGKQ-27 knowledge scores from our sample and from Erblich et al. [28] counselees ($n=28$), were used to calculate 95% CI levels. Confidence intervals were examined for any overlapping qualities: CIs that do not overlap are considered significantly different.

RESULTS

Participants. Fifty-three mothers who received genetic counseling/testing and tested positive for *BRCA1/2* at one of 3 Harvard teaching hospitals (52,DFCI; 17,BIDMC; 32, MGH) provided contact information for a total of 65 daughters. (There were two age-eligible daughters in 12 families). Of these 65 daughters, we invited 58 to participate. (More than one daughter was invited in five families where a first daughter was either unresponsive or had served as a pilot participant). Nine daughters who were un-responsive to follow-up calls were assumed to be passive decliners. Two daughters actively declined. One daughter became ineligible when her mother died before she completed participation and one additional daughter had incomplete data. Forty-five of the invited and eligible 57 DMC agreed to participate (5 pilot + 40 research participants), resulting a participation rate of 80%.

Participants [see Table 1] averaged 21 years of age, the majority were either college students or college graduates, 90% were single, and 31 daughters (77.5%) had mothers who had cancer.

How Were Daughters Informed and What Did They Hear?

Daughters had learned their mother’s *BRCA1/2* test result an average of 3.1 years previously. None was younger than 12 years of age when informed; about half were told before they were 18 and half between 18 and 21 years [see Table 2]. More than half said they were informed “within hours” or a few days after their mother had received her result. Most others did not recall how long after their mother learned her result they were informed.

For most, the result disclosure was not in a “sit-down”, formal family meeting, but, rather, occurred as a casual encounter. About 10% learned their mother’s result over the telephone; several learned about it while driving in the car with their mother. However, one learned about it in a family meeting where her grandmother did most of the talking and another learned her mother’s result in a genetic counseling session arranged by her mother for herself and her sister.

Almost all the daughters were informed of their mother’s result in a private conversation with their mother. In a few cases, siblings were also present, most commonly a sister. It was rare for both parents to participate in the disclosure. A few fathers conveyed the information. This typically occurred in the context of the mother being ill, having been genetically tested at the

same time she was diagnosed with cancer or had a cancer recurrence. Disclosure of the mother's mutation status to her daughter was also sometimes conflated with news that the mother would shortly be undergoing prophylactic mastectomy or bilateral salpingo-oophorectomy. By DMC report, these double disclosures were particularly emotionally charged, evoking considerable fear about their mother's health. Even in the absence of a second reason for concern, however, many daughters spoke of the receipt of their mother's result information as crystallizing their worry about their mother's health. Typically, daughters worried first about their mothers and, only secondarily, about themselves.

"I was nervous for her [mother] more than myself right away and I was nervous for like a year after when my cousin had it and that just really made me think, like, wow, I could have it too."

Messages Parents Conveyed. Table 3 provides an overview of what daughters reported was the information parents stressed in disclosing the maternal result. Some messages were open and empowering, some attempted to model reassurance for the daughter, others were quite directive, and some conveyed deep parental fears. What daughters reported strongly suggested that they had received their parent's message that the disclosure of the positive maternal test result was information of the highest importance. It was less clear whether daughters understood how or when to act on the information or whether they would take parental advice.

But she had always pushed just how serious it was and that it was kind of a big deal... it kind of scared me. But she also — she wouldn't say it in a scary way— She would just sort of stress it and I sort of preferred not to think about it.

What Daughters Knew about Hereditary Cancer

Name of the Gene. Most daughters, when we asked, knew the gene their mother had a mutation in or a close approximation. Variant responses included: "BRCA 1A or A1", the breast cancer gene", "BA something. I don't really remember", "BRCA-I'm not sure if it's 1 or 2, I just know she said they were all positive." About 15% could not provide any name for genes their mothers were tested for.

Misconceptions. DMC had significant misconceptions. The most common was that genetic testing was not possible until age 25. Another misconception was that a mother who had tested negative for a *BRCA1/2* mutation could still have children who tested positive (i.e. that the hereditary cancer predisposition could skip a generation). There was some confusion about whether separate genes controlled breast and ovarian cancer risk. Cancers associated with mutations were sometimes confused; for example, cervical cancer was not infrequently mentioned as a *BRCA1/2*-related cancer, with some daughters raising subsequent questions about whether they needed more frequent Pap smears. Another daughter thought being a mutation carrier raised one's risk for all types of cancer. One daughter was surprised to learn that she could be tested for *BRCA1/2* mutations; she had assumed that only people who had cancer could be tested. Another young woman said her doctors told her she needed to have her ovaries removed by age 30 which shocked her, as she thought it might then preclude having children.

So that's putting a price, like a time limit, on when I can have kids. I just wanted to be an average 24-year old girl. I didn't want to have to worry about having my kids early, having to have my life sped up from this one test result. To me, it's kind of like put a halt around my life.

Breast Cancer Genetic Knowledge Scores. Knowledge scores further illustrated significant gaps in daughters' understanding. Particularly salient was that many daughters lacked information necessary to understand how much greater their risks are than for women in the general population and why it would be important to undertake screening at age 25. Only 28% of the sample could correctly identify from 4 choices the average risk of breast cancer for a woman in the general U.S. population (12%), a number important for considering the relative risk of hereditary breast cancer. Similarly, more than a third of daughters thought the statement that hereditary breast cancer tends to occur at younger ages than breast cancer in the general population was false.

On average, daughters correctly answered 61.9% (16 of 27) of questions on the BCKQ [28]. All daughters knew *BRCA1/2* mutations convey increased risk for breast cancer and 85% knew they also conveyed ovarian cancer risks. However, many thought *BRCA1/2* mutations also conveyed increased risk for lung cancer (50%) and bladder cancer (43%). Eighty-five percent knew that women can inherit a *BRCA1/2* mutation from their father as well as from their mother. Thirty percent did not know that if a woman has a *BRCA1/2* mutation, her sister has a 50% risk of carrying the same mutation.

Daughters' Awareness of Recommended Screening or Risk-Reducing Options

Table 4 delineates DMC responses to study-specific questions about whether had they had heard of the screening options or risk-reducing surgeries recommended for carriers of *BRCA1/2* mutations. Any, even casual and unexplained statement that the daughter had “heard of” the option was scored as a positive response, indicating awareness of the option. Mammograms were not asked about, as it was expected that all daughters would have heard of mammograms. All daughters knew about breast self-exam, although many told us that they either did not perform self exams regularly or were made very anxious by doing so. Over half had heard of clinical breast exams and roughly two-thirds knew of breast MRIs. Ovarian cancer screening methods were much less in the daughters' awareness; roughly a third had heard of transvaginal ultrasound and only 13% had heard of the CA-125 test. Less than half said they had heard of a “prophylactic mastectomy” and 21% had heard of “prophylactic oophorectomy.”

So, while most daughters clearly conveyed that they had heard their mother's *BRCA1/2* test result and had received their parent's message about the information being important, gaps and misconceptions in these young women's understanding of the relevant facts were common.

DAUGHTERS' CURRENT HEALTH STATUS AND CANCER-RELATED WORRY

Many daughters said they wished they were a bit more careful about their diet and physical exercise patterns, but most described their health as: “it's great”, “no major medical concerns”, “I think I am a really healthy person”. Knowledge of their mother's risk status had not undermined their own sense of being generally healthy and cancer risk did not permeate DMC's assessment of their health status.

Distress: General distress among DMC was not high; only 10% (95% CI: 2.8% – 23.6%) had GSI T scores on the BSI-18 above the clinical cut-off, similar to population expectations [25]. However, levels of cancer-related distress were considerably higher on both the study-specific self-report questionnaire and the IES. In the questionnaire, asked to describe their distress about family members' future cancer risks on a 5-point Likert scale question, 40% chose either a 4 (“a great deal”) or 5 (“worry to an extreme”). Worry about their own cancer risk was similarly high; 37.5% scored 4 or 5. Twenty-three percent of our sample, the vast majority of whom did not yet have children, worried “a great deal” or “to an extreme” about cancer risk to their children.

The mean score on the IES was 16.9; 32% of the daughters (n=13) scored at or above the cutoff score of 20 for high distress related to hereditary breast/ovarian cancer. The 95% CIs of daughters' scores overlapped CIs of published IES scores for a variety of cancer genetics cohorts, including *BRCA1/2* mutation carriers [29-34] [Table 5], indicating that daughters' levels of cancer-related worry weren't significantly different from distress levels of women with known *BRCA1/2* mutations.

Nature of Daughters' Cancer Worries

Daughters reported many foci for worries they associated with knowing their mother's hereditary cancer predisposition. These included worry about their mothers' risks of developing cancer, having a recurrence, developing a second cancer or dying. Before disclosure, many DMC had not previously been aware of the high hereditary risk their mothers had for ovarian cancer or breast cancer, whichever had not occurred in their family. Daughters feared that if/when they were to undergo genetic testing, receiving the results might be "devastating" and could make them "paranoid" or "pessimistic". They worried about the impact genetic knowledge could have on their life plans, especially plans for childbearing. Many were generally aware of the recommendations for prophylactic removal of their ovaries and fallopian tubes, but were often unclear about the age at which this should occur and, thus, they worried whether it might preclude childbearing. Some worried whether, if their children got cancer, those cancers would be "caught in time"; they also worried whether they [the daughters] would live long enough to raise their children. Some worried about using birth control which they had heard could "fuel the risk of cancer." Daughters worried about the health of other family members – aunts, sisters, even brothers. One woman worried about worry, fearing that stress about hereditary cancer risk could further raise her cancer risk.

Trajectories of distress. Daughters described emotional volatility reflected in either, increasing or decreasing concern from the time of disclosure until the time of the interview. For some, fear and worry peaked when they were told about their mother's positive mutation status, but diminished over time as they acclimated to the information and learned risk-reducing steps mutation carriers could take. Other young women said at the time they were told, the implications for themselves seemed distant, but, as they entered adulthood, fears about developing breast or ovarian cancer had increased as they approached the ages at which they thought cancers might occur or they expected they would increase in the future as they thought more about this topic and related decisions. This suggests intervention targeted to the trajectory of the daughter's distress may be more effective.

GENETIC TESTING INTENTIONS

The majority of our sample had had neither genetic counseling nor *BRCA1/2* testing. Untested daughters expressed a wide range of intentions about when or whether they thought they would seek testing. Some said learning their mother's result had immediately made them want to get tested.

I think I want to get tested as soon as possible, even though my mom thinks I don't really need to, just because, why not? Just to, kind of, know. Because I am already assuming I have it. So nothing will change if I do have it, but a lot could change if I don't.

Others had a more distant time in mind: "this summer", in "a few years", when they graduated from college or, for quite a few, when they turned 25 or 30. One said, "...it really depends on my mood and, you know, how my day is going". Others thought they might not want testing until after they began having mammograms or when they were ready to have

children, with several thinking they might decide against having children to prevent passing on the familial mutation or might have to give up having children to have their ovaries removed in time to prevent ovarian cancer.

Daughters said, if found to be carriers, that information could be “dampering” or make them feel “doomed” or “destroy” their life. Several imagined the wait for test results would be very stressful and the maturity a few years could add would make that more bearable. Another worried that if she knew she was mutation positive, she could become a “hypochondriac”, seeing any physical problem as a likely cancer. Many of the daughters expressed ambivalence about genetic testing, saying they wanted it, but reporting barriers which did not seem major, like needing to wait until it was possible to take a half day off from work or worrying “if it cost a ton”. A few felt strongly they did not want testing, either now or at all. One woman worried about upsetting her mother if she were positive. Another said she would seek testing only if she developed cancer; then it would be to know if she was at increased risk for other *BRCA1/2*-related cancer. In contrast, other women condemned views about not wanting testing, saying they thought for a woman at 50% risk never to be genetically tested would be “ignorance”.

DISCUSSION

This paper is the first to describe in depth retrospective experiences young adult daughters of *BRCA1/2*-positive mothers had in learning their mother’s mutation status and the ways in which their emotions and future planning have been affected by this knowledge. These are the next generation of women at risk for hereditary breast/ovarian cancer and the first to grow into adulthood with awareness of the possibility of genetic testing to determine their individual cancer risks and the availability, if positive, of targeted, evidence-based recommendations. Their experiences may well help us to anticipate how upcoming generations learn about and act on genetic information about many conditions, information likely to increase exponentially in coming decades.

An average of 3 years after learning their mothers are mutation carriers, these daughters of *BRCA1/2* mutation carriers were generally faring well in their lives, feeling healthy and not generally anxious, but they reported high levels of cancer-related worry. They had registered the disclosure information and advice parents had delivered; they knew it was important to the mothers and would or should be important to them, but there was not a sense of active engagement for most. Few had specific plans for genetic testing or screening; next steps were not clear. Many misconceptions were reported. While professional attention has been focused on communication of test results to children [14-17], it appears that there are major gaps in what young adult daughters of *BRCA1/2* mutation carriers approaching screening age know about their cancer risks and about screening or risk-reduction options to reduce or minimize the impact of their risks.

As might be expected from a group of late adolescents and young adults, there was a broad range of attitudes towards advice offered by parents. The findings do suggest that parents considering disclosing genetic test results to their adolescent or older children can be assured that the messages are received and that daughters are aware of what parents want them to do with the advice. The ambivalence expressed about following advice from parents strongly suggests the utility of an alternative, accurate information resource for these young women, preferably guided by professionals.

Our data suggest that the traditional “wait until they come to us” stance of the professional community with regard to young women at high risk, rooted in the ethics of respect

for privacy of the parent, may be failing to meet the educational and emotional needs of this population of young, high-risk women. While more study is needed, it is likely that identification of and professional outreach to these DMC and provision of an easily accessible form of education and support would help bring their knowledge about cancer risks and screening and risk reduction options to a level more supportive of entry into screening programs by age 25. Outreach about the availability of genetic counseling and testing prior to age 25 for those who wish to determine their mutation status between ages 18-24 might also enhance timely screening uptake. Counseling approaches to this population may require modification; daughters may need sequential counseling to consider first the importance of starting breast screening at age 25 and then later counseling about ovarian risk around age 30 when that risk increases and later, more in-depth discussion of prophylactic surgeries when they are more likely to be seriously considered than in the mid-20's.

Additionally, psycho-educational support might help daughters cope with high levels of cancer-related anxiety, which may further encourage screening uptake. The multi-faceted worries daughters expressed indicate that even those who eventually test negative for their mother's *BRCA1/2* mutation, have lives affected for many years by fears that hereditary cancer or risk-reducing surgeries might interfere with their childbearing and childraising. Earlier counseling and testing might help the 50% of daughters expected to test negative find earlier relief for their cancer-related distress.

Our findings contrast with those from a recent study of children of parents tested for *BRCA1/2* where the majority of parents were not mutation carriers. In that study, children reacted to disclosure of parental *BRCA1/2* mutation status largely with relief or little affect [17]. Our subjects, all of whom were daughters of mutation carriers, typically experienced learning their mother's mutation status as a highly impactful event, with far-reaching implications and related, strong emotions. Some feared that more intense investigation of the relevant genetic information and risk-reduction recommendations might render them overwhelmed or paralyzed in making decisions about next steps in their own health planning. However, the majority believed that it was important to know this information and for them, as young adults, to be able to use the information to make determinative future decisions. Good decisions cannot be made on inaccurate information. The finding that young women in this age group report considerable cancer-related distress and lack important knowledge about hereditary breast/ovarian cancer strongly suggests this is an underserved population.

Limitations. Like many study cohorts in research on hereditary cancer impact, our sample was not ethnically, geographically or socioeconomically diverse, so our results may not generalize to more heterogeneous samples. Our information was retrospective and one-sided; we cannot match what daughters said to what actually occurred at the time of disclosure. Hence, we do not know where along the chain of family communication, faulty information was introduced. There is prior data suggesting that it is difficult for mothers to accurately take in information about their daughters' hereditary cancer risks in the course of their genetic counseling [35] and it is also well known that this is highly complex, detailed information [36]. All daughters in our study had living mothers; future research should include daughters of deceased maternal carriers and also daughters of paternal carriers, as the psychoeducational needs of both groups may be even greater than those we found. Strengths of this study are its direct assessment of daughters of women who are all *BRCA1/2* mutation carriers, the multi-modal nature of the assessment and the in-depth qualitative material, allowing a nuanced picture of the impact of maternal disclosure.

Ambivalence in young women's plans for genetic testing suggests that practitioners dealing with this age group should be cautious in interpreting stated interest in genetic testing.

Many daughters espoused wanting testing, but, when asked specifically about when, time frames ranged from a few months to more than 10 years. The young women's thinking combines the idealism and exuberance of adolescence with the malleable goals and plans of this age cohort.

Since daughters are expected to initiate screening by age 25, it is critical that they understand more about their cancer risks. Ideally, conversations with medical providers about the most relevant facts concerning hereditary breast cancer would occur early enough in young adulthood to allow adequate time for these women to process the information fully before initiating genetic testing and screening. Accurate genetic information may be difficult to come by for young adults, many of whom have very infrequent visits to physicians. Also, many internists, gynecologists and family physicians lack good information about *BRCA1/2* and recommendations for mutation carriers [37]. A number of daughters mentioned to us that they were still under the care of a pediatrician, professionals even less likely to have knowledge about screening recommendations for hereditary breast/ovarian cancer. Medical providers of many types will need training in talking to young, high-risk women about hereditary cancer risks, including pediatric professionals.

Future research should include larger, dyadic (mother-daughter and father-daughter) samples followed longitudinally from time of disclosure so that both the actual disclosure of the maternal result to the daughter and its impact can be assessed in real time and factors identified which influence daughters' outcomes. These might include the impact of the total family cancer experience and daughters' personal experience of genetic counseling and/or testing in relation to their genetics knowledge and cancer-related distress. Research is needed to develop effective psycho-educational interventions targeted to the worries of these high risk women. Clearly, different approaches are needed for this group, concerned about childbearing, their mothers' health and unborn children, than for the women 10, 20 or 30 years older than they, to which most *BRCA1/2* resources are geared. Our data contributes to the important discussion of the roles and responsibilities of professionals with regard to education of this next generation of high-risk women about hereditary cancer risk. Without improvements in our approach, despite our growing genetic knowledge, young women at high hereditary risk of breast cancer will continue to develop advanced breast cancer and die of tumors which could have been prevented or found at much earlier, more treatable stages.

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Table 1: Characteristics of the Daughters of *BRCA1/2* Mutation Carriers (n=40)

	Median	Range
Age	21	(18 – 24)
	N	%
Race/Ethnicity		
White/Non-Hispanic or Latino	40	100
Education		
High school graduate	3	7.5
Some college	23	57.5
College graduate	14	35.0
Work Status		
Full time student	13	32.5
Both student and employed	7	17.5
Employed	17	42.5
Unemployed and looking for work	1	2.5
Unemployed and not looking for work	2	5.0
Marital Status		
Single	36	90.0
Living as married	2	5.0
Married	2	5.0
Children		
Yes	3	7.5
No	37	92.5
Had Genetic Counseling or Testing?		
No Counseling or Testing	30	75.0
Yes, Genetic Counseling Only	2	5.0
Yes, Genetic Testing Only	3	7.5
Yes, Both Counseling and Testing	5	12.5
<i>Genetic Testing Result was positive: found to be BRCA1/2 mutation carrier</i>	1	2.5
<i>Genetic Testing Result was negative</i>	7	17.5

Table 2. How old were daughters when informed of mother's BRCA1/2 result?

Age in Years When Told	N	%
12-15	9	22
16-17	9	22
18-21	17	43
22 or older	4	10
"teenager"	1	3

Table 3. Daughters' Perceptions of Parental Primary Messages

Individual, Open-ended Responses
She wants me to get testing
She doesn't want me to get testing now.
It's your decision if you want testing.
Wants me to know the family history
Have a good doctor
Live a healthy life. Be proactive
Make sure you know what you need to do
Have mammograms. Take care of ourselves
If you do get cancer, you can get through it
Mother as role model, you can live with risk, dealing with the "beauty of the unknown".
Mother apologetic for passing on the mutation
Don't be scared. It doesn't automatically mean you will get cancer.
(Dad:) Mom, everyone will be OK.
I want you to avoid having cancer as I have had.
You deserve to know.

Table 4. Daughters' Awareness of Screening and Risk-Reducing Options for *BRCA1/2***Mutation Carriers**

Ever Heard of?	N	Yes		No	
		N	%	N	%
Breast Self-Exam	40	40	100	-	-
Clinical Breast Exam	39	22	56.0	17	44.0
Breast MRI	40	27	67.5	13	32.5
Trans-vaginal Ultrasound	40	13	32.5	27	67.5
CA-125	39	5	13.0	34	87.0
Prophylactic or risk-reducing Mastectomy	39	18	46.0	21	54.0
Prophylactic or risk-reducing Oophorectomy	38	8	21.0	30	79.0

Table 5: Impact of Event Scores - Comparison of Confidence Intervals of Daughters of BRCA1/2 Mutation Carriers (n=40) and Published Scores for Cancer Genetic Cohorts

IES Total Mean Score	N	95% Confidence Interval
DFCI : 18-24 year old daughters of <i>BRCA1/2</i> mutation carriers	40	(12.92, 20.88)
Quebec: women, <i>BRCA1/2</i> carriers, 1-month post-disclosure [29] (Dorval et al., 2006)	45	(5.89, 13.71)
Australia; women seeking genetic counseling [30] (Meiser et al., 2001)	218	(13.11, 17.09)
Australia: women <i>BRCA1/2</i> carriers; 12 mos. Post-disclosure [31] (Meiser et al., 2002)	20	(9.57, 22.63)
Belgium: women <i>BRCA1/2</i> carriers; 12 mos. Post-disclosure. [32] (Claes et al., 2005)	34	(6.12, 14.68)
London : women seeking genetic counseling with family hx of breast cancer [33] (Watson et al., 1999)	267	(15.63, 19.41)
Netherlands: women, post-counseling, pre-disclosure for <i>BRCA1/2</i> [34] (van Oostrom et al., 2007)	175	(21.6, 27.0)

QUESTIONNAIRE FOR PARTICIPANTS

**THANK YOU FOR PARTICIPATING IN THIS STUDY.
PLEASE FILL OUT THIS FORM AND RETURN IT IN THE ENCLOSED
ENVELOPE**

Today's Date (please fill in): _____

Demographics

1. Date of birth: Month: _____ Day: _____ Year: 19____

2. Current age: _____ years old

3. Gender: ☐ Male ☐ Female

4. Race: (Check all that apply)

☐ White ☐ Black or African American ☐ Asian

☐ American Indian/Alaska Native ☐ Native Hawaiian/ Pacific Islander

5. Ethnicity: ☐ Hispanic or Latino ☐ Not Hispanic or Latino

Education

6. Highest grade in school: (Check one that applies)

☐ Finished elementary or middle school

☐ High school graduate or equivalent Year graduated: _____

☐ Some college Years attended: _____

☐ College graduate -Year graduated____ Degree____ Major: _____

☐ Post-graduate Degree: Degree _____ Field _____

☐ Other (please explain) _____

Employment

7. Occupation: _____

8. Current employment: (Check all that apply)

☐ Employed full time

☐ Employed part time

- ☐ Full time Student
- ☐ Part time Student
- ☐ Homemaker full time
- ☐ Retired
- ☐ Not employed- seeking work
- ☐ Not employed – not seeking work

Home & Family

9. Do you have sisters? (circle one) Yes No

If yes, how many? _____

If yes, how old are your sisters? _____

10. Do you have brothers? (circle one) Yes No

If yes, how many? _____

If yes, how old are your brothers? _____

11. Marital status:

- ☐ Single
- ☐ Married; Spouse's Occupation _____
- ☐ Living as Married; Partner's Occupation _____
- ☐ Separated
- ☐ Divorced
- ☐ Widow or Widower

12. If currently married: Years Since Marriage _____

13. If currently married: Spouse's **Education**

Highest grade in school: (Check one that applies)

- ☐ Finished elementary or middle school
- ☐ High school graduate or equivalent
- ☐ Some college
- ☐ College graduate

- ☐ Post-graduate Degree:
- ☐ Other (please explain) _____

14. I live most or all of the year: (Check one that applies)

- ☐ With parents, grandparents, brothers or sisters
- ☐ With wife, husband or partner
- ☐ In dorm, with or without a roommate
- ☐ With a roommate in apartment or house
- ☐ Alone
- ☐ Other _____

15. Household income:

- ☐ Under 20,000 per year
- ☐ Between 21,000 and 50,000 per year
- ☐ Between 51,000 and 100,000 per year
- ☐ Between \$101,000-\$149,000 per year
- ☐ Over \$150,000 per year
- ☐ Don't know
- ☐ Don't want to say

16. Do you have children? ☐ Yes ☐ No - If no, please skip to Question **22**.

17. Number of children you have: (Please check one)

- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 or more

18. Current age of daughter(s): _____

19. Current age of son(s): _____

20. Are any of these children step-children?

- ☐ Yes - If yes, please circle age(s) of step-child(ren) above.
- ☐ No

21. Are any of these children adopted?

- ☐ Yes - If yes, please underline age(s) of adopted child(ren) above.
- ☐ No

22. If it were up to you would you plan to have more children than you currently have sometime in your life?
(please answer whether or not you currently have children)

- ☐ Yes
- ☐ No

Family History of Cancer

Please tell us about ANYONE in your family who has ANY type of cancer. We are interested in any cancer in a **blood relative**. A maternal relative is a blood relative on your mother's side of the family. A paternal relative is a blood relative on your father's side of the family.

Relative	Had Cancer? (circle one)	Type(s) of Cancer	Their Age at Diagnosis	Your Age when he/she Diagnosed	Is he/she currently living? (circle one)	If person is not living, did they die of cancer? (Circle one) (DK=Don't know)
Mother	Yes or No				Yes or No	Yes No DK
Maternal grandmother	Yes or No				Yes or No	Yes No DK
Maternal grandfather	Yes or No				Yes or No	Yes No DK
Father	Yes or No				Yes or No	Yes No DK
Paternal	Yes or No				Yes or No	Yes No DK

grandmother						
Paternal grandfather	Yes or No				Yes or No	Yes No DK

23. Please tell us about the following blood relatives.

24. Have any of your sisters ever had cancer? (circle one)

Yes

No

N/A (I don't have a sister)

For each blood-related **sister** who had cancer, list the type(s) of cancer, her age when the cancer was found, your age at that time and answer the other two questions.

Sister	Type(s) of Cancer	Her Age at Diagnosis	Your Age when her cancer was found	Is she currently living? (circle one)	If person is not living, did they die of cancer? (Circle one) (DK=Don't know)
<u>1</u>				Yes or No	Yes No DK
<u>2</u>				Yes or No	Yes No DK
<u>3</u>				Yes or No	Yes No DK
<u>4</u>				Yes or No	Yes No DK

25. Have any of your brothers had cancer? (circle one)

Yes

No

N/A (I don't have a brother)

For each blood-related **brother** who had cancer, list the type(s) of cancer, his age when the cancer was found, your age at that time and answer the other 2 questions.

Brother	Type(s) of Cancer	His Age at Diagnosis	Your Age when his cancer was found	Is he/she currently living? (Circle one) (DK=Don't know)	If person is not living, did they die of cancer? (Circle one) (DK=Don't know)
<u>1</u>				Yes or No	Yes No DK
<u>2</u>				Yes or No	Yes No DK
<u>3</u>				Yes or No	Yes No DK
<u>4</u>				Yes or No	Yes No DK

26. Do you have any other blood relatives who have had cancer? This could include aunts (sisters of your mother or father) or uncles (brother of your mother or father) or cousins.

☐ Yes ☐ No- Skip to Question 27.

For each of your other blood relatives, who had cancer, list how he or she is related to you (your maternal aunt, paternal uncle, maternal first cousin, etc.), the type(s) of cancer, how old he/she was when the cancer was found and your age when their cancer was found.

Relation to you	Type(s) of Cancer	His/Her Age at Diagnosis	Your Age when cancer was found	Is he/she currently living? (Circle one) (DK=Don't know)	If person is not living, did they die of cancer? (Circle one) (DK=Don't know)
1.				Yes No DK	Yes No DK
2.				Yes No DK	Yes No DK
3.				Yes No DK	Yes No DK
4.				Yes No DK	Yes No DK

Insurance

27. I have: (Check one that applies)

☐ Health insurance through my work

- ☐ Health insurance through my spouse's work
- ☐ Health insurance through my parents
- ☐ Health insurance from another source: _____
- ☐ No health insurance

28. I have:

- | | | | |
|----------------------|------------------------------|-----------------------------|-------------------------------------|
| Disability insurance | ☐ Yes | ☐ No | ☐ Don't know |
| Life insurance | ☐ Yes | ☐ No | ☐ Don't know |

29. Do you think you have ever been denied or had difficulty getting any type of insurance due your family history or a known predisposition to cancer?

- ☐ Yes - If yes, please explain below. ☐ No

Personal Medical History

30. Do you have any significant health problems?

- ☐ Yes- If yes, please list below ☐ No

Concerns about Cancer & Heredity

31. Do you think the cancer in your family was due to an inherited predisposition to cancer in your family?

- ☐ Definitely not ☐ Probably not ☐ Don't know ☐ Probably ☐ Definitely was

32. How much do you worry about cancer risk being inherited in your family?

- ☐ Not at all ☐ A little ☐ Quite a bit ☐ A great deal ☐ To an extreme

33. How much do you worry about getting cancer in the future?

- ☐ Not at all ☐ A little ☐ Quite a bit ☐ A great deal ☐ To an extreme

34. How much you would say you worry about whether your child/children (present or future children) will develop cancer in the future?

- ☐ Not at all ☐ A little ☐ Quite a bit ☐ A great deal ☐ To an extreme

Discussion with Professionals

35. Have you ever spoken to any of these professionals about cancer and heredity? (Check all that apply)

- ☐ Internist/Primary Care Doctor
- ☐ Gynecologist
- ☐ Oncologist
- ☐ Other doctor _____
- ☐ Your child's pediatrician
- ☐ Genetic counselor/Geneticist
- ☐ Nurse
- ☐ Social Worker
- ☐ Psychotherapist
- ☐ Others (who?) _____
- ☐ NONE OF THE ABOVE

36. Have you ever:

- | | | | |
|-------------------------------------|-----------------------------------|-----------------------------------|--|
| Had Cancer Genetic Counseling | ☐ Yes | ☐ No | ☐ Don't know |
| Had Genetic Testing for cancer gene | ☐ Yes | ☐ No | ☐ Don't know |
| Gotten cancer genetic test result | ☐ Yes | ☐ No | ☐ Don't know |
| If tested, test result was | ☐ Positive | ☐ Negative | ☐ Indeterminate |

BREAST CANCER GENETICS QUESTIONNAIRE

Please answer all of the questions below. Feel free to say you don't know. Genetic medicine is a new field and many professionals are taking courses to learn about the genetic advances in recent years. So, please do not feel badly if you are not sure of all the answers. But please do try to give one answer for each item.

CIRCLE THE ANSWER YOU BELIEVE IS CORRECT:

	<u>True</u>	<u>False</u>	<u>Don't Know</u>
1. 50% of inherited genetic information (about breast cancer risk) is passed down from a person's mother.	True	False	Don't Know
2. 25% of inherited genetic information (about breast cancer risk) is passed down from a person's father.	True	False	Don't Know
3. There is more than one gene that can increase the risk of breast cancer.	True	False	Don't Know
4. A woman who has a sister with a breast cancer gene mutation has a 1 in 4 chance of having a gene mutation herself.	True	False	Don't Know
5. A father can pass down a breast cancer gene mutation to his daughters.	True	False	Don't Know
6. One in 10 women has a breast cancer gene mutation.	True	False	Don't Know
7. All women who have a breast cancer gene mutation will get cancer.	True	False	Don't Know
If the currently available genetic tests were to indicate that a woman has a breast cancer gene mutation, she is at increased risk for:			
8. Breast cancer	True	False	Don't Know
9. Ovarian cancer	True	False	Don't Know
10. Lung cancer	True	False	Don't Know
11. Bladder cancer	True	False	Don't Know
If a woman who already had breast cancer was found to have a breast cancer gene mutation, she is at increased risk for developing:			
12. Another breast cancer	True	False	Don't Know
13. Ovarian cancer	True	False	Don't Know
14. Lung cancer	True	False	Don't Know
15. Bladder cancer	True	False	Don't Know
16. Women who test positive for breast cancer mutations are generally more likely to develop breast cancer at a young age	True	False	Don't Know
17. A man who carries a breast cancer gene mutation has an increased risk of developing breast cancer himself.	True	False	Don't Know
18. If a woman tests positive for a breast cancer gene mutation, her male relatives' risk for developing prostate cancer are lowered.	True	False	Don't Know

19. A woman may be at greater risk for developing ovarian cancer if she has several close relatives with ovarian cancer.	True	False	Don't Know
20. A woman may be at greater risk for developing ovarian cancer if she has several close relatives with breast cancer.	True	False	Don't Know
21. A woman who has her healthy ovaries removed will definitely not get ovarian cancer.	True	False	Don't Know
22. A woman who has her breasts removed will definitely not get breast cancer.	True	False	Don't Know
23. Screening for ovarian cancer often does not detect a tumor until it is more advanced.	True	False	Don't Know

Directions: Please check one answer for each question #24-27.

24. How many copies of a non-working breast cancer gene must one inherit to be at inherited risk for breast cancer?

- a. 0
- b. 1
- c. 3
- d. Don't know

25. What is the approximate risk that the average women in the United States will develop breast cancer in her lifetime:

- a. 12%
- b. 24%
- c. 58%
- d. 72%
- e. Don't know

26. If a genetic test were to indicate that a woman inherited a breast cancer gene mutation, then how likely is she to develop breast cancer in her lifetime?

- a. Up to 15% chance
- b. Up to 25% chance
- c. Up to 40% chance
- d. up to 50% chance
- e. up to 85% chance
- f. Don't know

27. Select the procedure that is NOT appropriate for the detection of ovarian cancer:

- a. ultrasound
- b. pap smear
- c. CA-125 blood test
- d. pelvic examination
- e. Don't know

Directions:

Indicate how frequently each of these comments was true for you during the past seven days in relation to **inherited predisposition to breast/ovarian cancer**. Please **circle the word that best fits your experience over the past 7 days**.

	<u>Not at all</u>	<u>Rarely</u>	<u>Sometimes</u>	<u>Often</u>
1. I thought about it when I didn't mean to.	Not at all	Rarely	Sometimes	Often
2. I avoided letting myself get upset when I thought about it or was reminded of it.	Not at all	Rarely	Sometimes	Often
3. I tried to remove it from memory.	Not at all	Rarely	Sometimes	Often
4. I had trouble falling asleep or staying asleep because of thoughts about it that came into my mind.	Not at all	Rarely	Sometimes	Often
5. I had waves of strong feeling about it.	Not at all	Rarely	Sometimes	Often
6. I had dreams about it.	Not at all	Rarely	Sometimes	Often
7. I stayed away from reminders of it.	Not at all	Rarely	Sometimes	Often
8. I felt as if it hadn't happened or wasn't real.	Not at all	Rarely	Sometimes	Often
9. I tried not to talk about it.	Not at all	Rarely	Sometimes	Often
10. Pictures about it popped into my head.	Not at all	Rarely	Sometimes	Often
11. Other things kept making me think about it.	Not at all	Rarely	Sometimes	Often
12. I tried not to think about it.	Not at all	Rarely	Sometimes	Often
13. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	Not at all	Rarely	Sometimes	Often
14. Any reminder brought back feelings about it.	Not at all	Rarely	Sometimes	Often
15. My feelings about it were kind of numb.	Not at all	Rarely	Sometimes	Often

THIS PAGE WILL BE SEPARATED FROM THE QUESTIONNAIRE WHEN RECEIVED

Could you please tell us when it would be best for us to try to reach you to schedule our phone interview for this project:

Best times: _____

Best days: _____

Phone numbers: Please give us your phone numbers and tell us if it ok to call that number to reach you

Day: _____ ☐ ok to call

Evening or weekends: _____ ☐ ok to call

Cell: _____ ☐ ok to call

THANK YOU.

**PLEASE RETURN TO US WITH ONE SIGNED COPY OF THE CONSENT FORM IN
THE STAMPED ENVELOPE PROVIDED.**

**Return to: Dr. Andrea Patenaude
Dana-Farber Cancer Institute
450 Brookline Ave. D1029
Boston, MA 02115**

TELEPHONE INTERVIEW SCHEDULE FOR DEVELOPMENTAL INTERVIEW

PARTICIPANT NUMBER: _____ **INTERVIEWER:** _____

DATE: _____

START TIME: _____ **END TIME:** _____

INTERVIEW LENGTH (MINUTES): _____

FIRST, THANK YOU VERY MUCH FOR YOUR WILLINGNESS TO PARTICIPATE IN THIS INTERVIEW.

THE GOAL OF THIS PROJECT IS TO LEARN AS MUCH AS WE CAN ABOUT HOW YOUNG WOMEN WHOSE FAMILIES HAVE BEEN AFFECTED BY CANCER OR THE RISK OF CANCER THINK ABOUT RISKS FOR THEMSELVES AND OTHERS AND HOW THEY THINK ABOUT THEIR OWN HEALTH. WE ARE HOPING THAT YOU CAN HELP US TO PLAN HOW TO TALK TO OTHER YOUNG PEOPLE YOUR AGE ABOUT THESE THINGS.

WE ARE VERY INTERESTED IN YOUR THOUGHTS AND OPINIONS, SO PLEASE TAKE AS LONG AS YOU LIKE TO ANSWER OUR QUESTIONS.

I WOULD LIKE TO SAY AGAIN THAT YOU ARE FREE NOT TO ANSWER ANY QUESTION YOU DON'T WANT TO ANSWER AND YOU CAN ALSO STOP THE INTERVIEW AT ANY TIME. ALSO, FEEL FREE TO SAY I DON'T KNOW AT ANY POINT. WE DO NOT EXPECT THAT YOU WILL KNOW THE ANSWERS TO ALL THE QUESTIONS WE ASK.

BEFORE WE BEGIN, ARE THERE ANY QUESTIONS YOU WOULD LIKE TO ASK ME?

GENERAL INFORMATION- CURRENT STATUS

1. First, Can you please start by telling me a bit about yourself, about your life currently – where are you in school or work, what do you think about for your future, what's most important to you now?
2. How do you think about your own health now?
3. Do you think at all about insurance – health, life, disability? If so, what do you think?, do?
4. Do you do anything in particular to try to stay healthy? If yes, What do you do?

CANCER

1. Would you say that cancer runs in your family?
2. How you would say cancer or the risk of getting cancer has affected your family?

3. How much do you worry about getting cancer yourself?

What triggers your worries?

What is your specific worry, if any?

Do you tell anyone about that worry?

4. How much do you worry about other people in your family getting cancer (or getting cancer again?) Who do you worry about?
5. Who in your family has had genetic testing for cancer genes?

<u>Relationship</u>	<u>gene tested</u>	<u>when done</u>	<u>result</u>	<u>Subject's reaction</u>
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FINDING OUT

1. How did you find out that your mother (or other relatives) had been tested?

Probes, if not clear:

Did you go with your mother when she was tested?

When she got her result?

Whenever daughter was informed:

What exactly were you told?

How old were you?

Do you know what gene she was tested for? And what was found?

How long after your mother knew the result?

Who was present when you were told? Who spoke?

Do you remember what went through your head as you were being informed?

How did you react immediately?

Later?

When has it come up subsequently? How often? What brings it up?

2. Did the person informing you have any particular message they were trying to get across about the meaning of this information either for themselves or for you? If yes, what message? How did you feel about that message?
3. How do you now think about the meaning or importance of this information to you?
Probe: Did this information change how you think about cancer and your family?
(Clarify if not clear, if daughter herself has been tested and, if so, how that changed meaning or importance of the genetic information for her)
4. What type or types of cancer does this information relate to for you or for other members of your family?
5. Did having this information (either mother's result or, if tested herself, mother's and her result), change any of your thinking about your future, either what you might want to do or the timing of what you plan to do?

TALKING WITH OTHERS

1. Were you given any guidelines about people to talk to or not talk to about it?

Whom have you talked with about this information? How have these discussions gone?

Probes:

a. Mother

b. Father

- c. Sisters
 - d. Brothers
 - e. Other relatives
 - f. Friends
 - g. Significant Other
2. Have you talked to any medical professionals about inherited cancer risk?

If no: has it just not come up or did you choose not to speak about it?

If yes: who did you talk to , how did it come up , about what, how did you feel about those conversations?
 3. Have you spoken to anyone else who is in a position similar to yours, i.e. having a tested relative? How was that for you? Would it be helpful?
 4. Was there anyone you wanted to speak to about this who you haven't been able to talk to?

If yes: whom? why wasn't it possible?
 5. Have there been times when you wanted to hear **less** about genetics or genetic testing or related matters, when you wished people didn't talk about it to you so much?

If yes: could you tell us about those times?
 6. Are there things you wish you knew or understood better about this area?

Things you wish you didn't know or feel you would have been better off not knowing?
 7. Based on your own experience, what do you think is the ideal age or time for parents to talk to their children about their own hereditary cancer risk or test results?

THINKING ABOUT COUNSELING AND TESTING

1. How old were you when you learned that there was testing YOU could have at some point in your life which could tell you about your own hereditary cancer risks?

How did you feel about testing then?

How now?

How much do you think about testing?
2. Have your parents given you advice about getting tested, either whether to have it or when to have it?

Has anyone else talked to you about genetic testing for yourself?
3. Have you ever spoken to a genetic counselor?

If yes: how did that come about? Who went? How was it for you? What did you learn?

If no,: did you ever want to? Would you know how to find a genetic counselor?

4. Have you ever seen any ads on TV or in magazines about testing for hereditary cancer genes?

If yes: what effect, if any, did the ads have on you?

5. **If clear subject has been tested, skip to Q. 7.** What do you think now about getting tested?

Do you have a clear idea of what you want to do? If so, what?

What are the pros and cons?

Thoughts about testing later on in life? Never?

Need more info to decide? Where would you get that info?

6. If she decides she wants to be tested, is there an age or a time in a woman's life when it would be ideal for her to get testing?

7. **If not tested, skip to Q. 9b.** How did your testing come about? How did it feel to wait for results? Have you gotten results? What was your reaction to results?

If got results: how did you feel about your result?

If not gotten results: do you have a plan for getting them or just not now?

8. Whom have you told about your test result? Family? Friends? Doctors?

9. a. Is there an age or a time in a woman's life when it would be ideal for her to get testing?

b. **(SKIP TO HERE)** What do you think should be the youngest age at which people with hereditary cancer risk in their family should be able to be tested to see if they carry that increased risk (minimal age)? Why?

10. Do you think there should be genetic counseling for kids before the age when they can usually be tested to answer questions about genetic risk?

If yes: how should it work?

HEALTH BEHAVIORS

1. When do you go to a doctor?

Probes:

How often?

what type?

Do you feel like your doctor really knows you?

Do your doctors know about hereditary risk in your family? your result (**if appropriate**)?

2. Has anyone talked to you about things that you can do to try to prevent cancer either now or in the future?

If no: skip to Q. 3.

If yes:

Who?

What?

When?

How did you feel when these things were brought to your attention? (**Probe:** Hopeful, Avoidant or Other feelings)

How often do you think about these things?

How do you feel when you think about those things now?

3. (**SKIP TO HERE**) Do you do anything to try to prevent cancer that is related to knowledge of hereditary cancer risk?

4. At what age do you think you will start having mammograms?

How often would you plan to have them then?

How would you arrange to have a mammogram?

How do you think they will get paid for?

5. Is there anything else you know of that a woman who might be at hereditary risk for cancer might do to reduce her risk of cancer?

6. Are there/were there things that your mother or other relatives have done/did to try to prevent cancer?

Do you know other people who are doing special screening or other things because of having hereditary cancer risk?

How did you feel about their doing those things?

Does their experience influence your thoughts about what you might do?

7. Have you ever heard of any of the following? **If yes, what have you heard about them?**

Breast MRIs

Clinical breast exams

Breast self-examination

Prophylactic or risk-reducing mastectomy

Prophylactic or risk-reducing oophorectomy

CA-125 test

Transvaginal ultrasound

HEREDITY IN THE NEWS

1. Where do you get most of your information about hereditary cancer or genetic testing?
2. How often do you come upon an article or program about cancer and genetics? Do you typically read it or listen or not? How do you find the level of the information?

FUTURE RESOURCES

1. How much do young people who are from families with increased hereditary cancer risks want to know about the risk and their options? When and how should it be discussed?
2. Would it be helpful if there were an information source geared specifically to young people who might have such hereditary risk?

If not: why not?

If so: what format would be best (written brochure, video, Internet website, other)?

What should it include?

Not include?

Who should deliver the message?

Can you imagine a situation where you might use this information source?

RESPONSE TO PARTICIPATION

Subject Feedback Section

Thank you for taking the time to participate in this interview. Now I would just like to ask you a few more questions about how it was for you to participate in this interview.

1. How have you felt answering these questions today?
2. Did you feel distressed in any way by any aspect of participating in this study?

If yes- Can you tell me a bit about what caused you distress? How distressing was it?

3. Did you find participating in this interview helpful in any way?

If yes- In what way(s)

4. Were there any questions you didn't like or that we could have asked in a better way?

If yes- Which questions?

5. Are there important questions for cancer survivors related to cancer and heredity which we have left out?

6. Is there anything that you would like to know more about that we talked about or touched on today?

Thank you. (Turn off tape recorder).

Confirm address as to where the honoraria should be sent.

END TIME: _____

SAMPLE PAGES FOR PILOT INTERVENTION (TEXT)

HOME PAGE

Main banner: Do you have a parent who carries a *BRCA* mutation?

Program name: 25: Staying Alive and Healthy

Subtitle: A space where young women can learn about inherited cancer risk

- Current information from experts
- What you can do to stay well
- Experiences of other young women

Main navigation

Cancer in my family

My risks

Staying healthy

Feelings about it all

Talking to others

My plan for me

Personalization options

I'd like to get:

- Guidance from a genetic counselor
- Information from a physician
- Stories about their experiences from other young women

Social media icons

Find us on Facebook

Follow us on Twitter

Institutional branding

Dana-Farber Cancer Institute (with logo)

Funded by: Congressionally Directed Medical Research Program –Breast Cancer Research Program Idea Grant BC084061;

Developed by DF/HCC Health Communication Core

GENETIC COUNSELING LANDING PAGE

(Image of a lovely and kind woman]

Genetic counselors are health care professionals trained to help people learn about how cancer has affected their families and what their own risk might be. For example, a genetic counselor can:

- Give you information about how *BRCA1* or *BRCA2* genes are inherited and what the risks are to those in the family who carry a mutation
- Help you find out if you carry a mutation
- Offer guidance for those who are carriers about options for early screening and prevention options you may want to consider
- Advise non-carriers about their risks.
- Help you to organize what you need to do first –especially, if you are a carrier, that by age 25 you would be advised by experts to begin screening

[Listen to a question-and-answer session with a genetics counselor](#)

Here are some topics that young women frequently ask me about. You can read them all to see the “big picture” or just read the sections that feel most useful to you today. Click on the **topic** ([link to list of topics](#)) you’re interested in or [look at some of the additional features](#) ([link to list of features](#)).

What would you like to know more about?

Cancer genes: What are *BRCA1* and *BRCA2* genes? What does gene “mutation” mean?

You can also [hear a doctor explain these genes](#)

[Watch a video about cancer genes and how they work](#)

Cancer risk: What cancers are mutation carriers at higher risk for?

You can also [listen to a genetic counselor talk about cancer risk](#)

[Link to lots of useful resources](#)

Genetic counseling: What’s a genetic counseling session like? How can it help me learn more about the cancer in my family and my own risks.

You can also [find a cancer genetic counselor](#)

[Send a question to a genetic counselor](#)

Family history: What do I need to know about cancer in my family in order to understand about my personal risks?

You can also [fill out an online family history questionnaire](#)

Genetic testing: What is it? What will it tell me? Where is it done?

You can also [listen to a genetic counselor discuss genetic testing](#)

[Watch a slideshow that takes you through the genetic testing process](#)

[Read journal entries from young women before, during, and after genetic testing](#)

Staying healthy: Different ways of **screening for cancer** that experts recommend for women with genetic risk.

You can also [listen to other young women talk about their screening decisions](#)

My feelings about the cancer in my family: What are all these feelings? Who can help me sort them out?

You can also [listen to young women talk about their feelings and experiences](#)

[Talk to a psychologist](#)

My timeline--what steps might be important for me to take and when are the best times for making the right decisions for myself.

You can also look at a [timeline of options and recommendations](#)

[Make a personal plan](#)

DATING: WHAT DO I SAY, WHEN DO I SAY IT?

(This section will appear after the person has read about talking with friends and others about issues related to hereditary cancer.)

(Image of a lovely and kind young woman]

Many of us wonder about when to talk to our boyfriend or girlfriend about the hereditary cancer in our family. What do I say? When do I say it? Will it affect our relationship? Will he or she start worrying about me? Will it scare him or her away?

Most people discover that their relationship is not harmed by talking openly with their partner about hereditary cancer risk. If the relationship is a strong one, the partner is concerned most of all about the safety and health of the person he or she loves. They want to help her do what she can to stay healthy. Both people also may find it helpful to share their worries and hopes about the future with each other!

Here's what other young women had to say:

- "I talk about it when the topic comes up naturally. As we started getting to know each other, I talked about my mom and her cancer and how that has affected me. That led to talking about the fact that the cancer is hereditary and, at some point, to talking about what I think my own risks are." Amanda G.
- "It used to be hard to talk because I wasn't really sure what I was talking about or how I felt about it. I feel much more comfortable about myself now, and much more comfortable with the information. So talking about it is not the big scary deal it used to be." Melissa N.
- "I know it's the right time is when I feel comfortable enough with the other person." Donna S.
- "I like to wait a while to see how the relationship is developing to talk about it." Shirronda A.
- "Don't try to force it as a test of the relationship. This could be misinterpreted in ways that prove hurtful." Jane T.
- "I find it made our relationship closer, because we were talking about issues that affect our lives together." Sheila W.
- Listen to other young women's stories...

TELEPHONE INTERVIEW SCHEDULE FOR PILOT INTERVENTION

Discussion guide
BRCA prototype

Hi and thanks for speaking with us. My name is _____ I'm from the Dana-Farber Cancer Institute in Boston. We're conducting phone interviews with (_____) to get their feedback on the prototype of an online resource we're developing for young women at hereditary risk of cancer.

Participation in this interview is completely voluntary. You can choose to not answer questions, or to end the interview at any time.

With your permission we will be tape recording this session. We are doing this because we want to make sure that we remember everything that you say. Your comments are really important to us. Everything that you say is confidential and will not be shared with anyone other than the research staff. I want to encourage you to speak openly about your ideas. This is not a test - there are no right or wrong answers. You won't hurt my feelings if you tell me you don't like something or if you have an idea about what might work better. Your opinions and experiences are valuable to us, and we really want to hear what you think. Your feedback will help us improve the resource we are developing for other young women.

Can we start the interview now?

Do you have a computer with internet access in front of you?

Please open the email message you see from us and click on the link in the email.

This is a sketch of what the home page of this website might look like. The actual website would be more fully developed. This sketch is intended to give you an idea of what might be included. Please take a minute to look it over.

What is the first thing you noticed on the home page? What did you notice next?

What does this home page tell you about who the site is for and what visitors will find there?

What is your first response to the home page? (Likes? dislikes?)

How does looking at it make you feel?

Does the home page make you feel like this is a website for someone like you--someone your age, with your interests?

What is your response to the main banner, "Do you have a parent who carries a *BRCA1* or *BRCA2* mutation?" Does it get your attention? Turn you off? Draw you in? Should it say something else? Do you have any suggestions?

What do you think about the name of the program: “25: Staying Alive and Healthy”?

What do you think about the description of the website, “A space where young women can learn and talk about inherited cancer risk.” Is it clear? Does it make you feel that this is a good place for you to find information? Find support? If it doesn’t work for you, does a good description come to mind?

Please take a look at the topics on the left-hand navigation buttons.

What would you expect to see in the “Cancer in my family” section?

...In the “My risks” section?

...In the “Staying healthy” section?

...In the “Feelings about it all” section?

...In the “Talking to others” section?

...In the “My plan for me” section?

Do you think the information here would be useful for you?

Should any of these buttons be worded differently?

Is there something additional you would like to see here?

Please look at the right-hand column where you can select different kinds of information from different sources, like a physician or a peer or a genetic counselor. Would you find it useful?

Please look at the social media buttons in the upper right-hand column. Would you link to any of these? Are any missing? How do you think we could use social networking to reach out to other daughters?

Please look at the bottom of the page where Dana-Farber Cancer Institute, the site’s funder, and the site’s developer are identified. Is this information useful? How does it make you feel?

Overall, what do you think about the colors of the home page? (like, dislike, what would be better?)

What do you think about the layout of the home page? (like, dislike, what would be better?)

Overall, does this site look like the information is trustworthy? Yes/why? No/why not? No/what would make it look more trustworthy)

Overall, does this site look appropriate for the topic, which is hereditary cancer risk, and its main audience, which is young women 18-24? Yes/why? No/why not? No/what would make it look more appropriate)

OK, thanks, that’s great. I really appreciate your feedback. There are two other pages that I’d like you to take a look at. Please scroll down to the next screen (Genetic Counseling)

What is the first thing you noticed on this page?

What did you notice next?

This page is the introduction to a section of the site on genetic counseling. Please take a minute to read the page. Nothing on the page is clickable but we've underlined words that could link to other pages or to interactive features like an online tool or a video.

Ok now I'd like to ask you some questions about this page.

What's your response to the image of the woman who is a genetic counselor?

Is her explanation of genetic counselor services clear? Helpful? How does it make you feel?

Would you want to listen to a question-and-answer session with a genetics counselor?

Now let's look at the information below "What would you like to know more about."

Would you be able to find the information you're looking for in this list of topics?

Would you want to:

...Hear a doctor explain *BRCA1* and *BRCA2* genes?

...Watch a video about cancer genes and how they work?

...Listen to a genetic counselor talk about cancer risk?

...Link to resources? What kind of resources would you like there to be here?

...Find a cancer genetic counselor?

...Send a question to a genetic counselor?

.....Fill out an online family history questionnaire?

...Listen to a genetic counselor discuss genetic testing?

...Watch a slideshow that takes you through the genetic testing process

...Read journal entries from young women before, during, and after genetic testing?

...Listen to other young women talk about their screening decisions?

...Listen to other young women talk about their feelings and experiences?

...Talk to a psychologist

...Look at a time line of recommended screening and prevention options?

...Make a personal plan?

Any other thoughts about this page?

Is there too much content, too little, the right amount?

Is the organization confusing or clear?

Did you find it easy to read or hard to understand?

Did the information sound trustworthy and reliable?

How did the information make you feel? Interested, afraid, confused, curious...?

Is there anything here that should be removed?

Ok this is really excellent. There is just one more short page that I'd like your feedback on Your comments are very helpful and I appreciate your willingness to help us out with by sharing your thoughts.

Please scroll down one more page, to the page titled Dating.

What's your response to the image of the young woman? Is she someone you would relate to? Trust?

What's your response to her description of her thoughts about dating and talking about her family's history of cancer? Is it clear? Confusing?

Did you find the quotes from other young women helpful?:

Would you want to listen to other young women's stories?

Excellent, thank you so much. I have a few final questions.

Please scroll down to the final page. This is not part of the website. It shows a few different ways of approaching the graphics on the site. We're not proposing to use these, in fact we've borrowed them from other materials. But we'd like to know if any of them appeals to you.

Now you don't need to look at anything on your computer. Here are some ideas we had of features that could be on the site, we'd like to know if you would find them useful.

Basic definitions

Peer stories told in journal entries.

...Told in audio.

...Told on video.

Advice from mothers, aunts, and grandmothers

How to find a Genetic Counselor

How to find a Cancer Genetics Doctor

Opportunity to talk with a psychologist on the phone

Resources--like websites, research articles

Information For Friends that would help them help you

Frequently Asked Questions

Discussion of Myths and Misconceptions

Finally,

Anything that you think we have left out that should be in a website like this?

That is the end of our questions. How has it been for you to answer these questions today?

Was there anything distressing or upsetting to you in answering them?

Anything interesting or thought-provoking about answering them?

Concluding thank you....We are very grateful to you for sharing your thoughts with us. We will use them to help us plan next steps in the development of this website. Your opinions and reactions are very helpful to us.

I will just turn off the tape recorder now so I can confirm the address to which we will send your gift card.

TURN OFF TAPE RECORDER.

25:

STAYING ALIVE AND HEALTHY

find us on Facebookfollow us on Twitter

A space where young women can learn about inherited cancer risk

Do you have a parent who carries a BRCA mutation?

Learn more. Browse through these links to find out how you can take charge of inherited cancer risk.

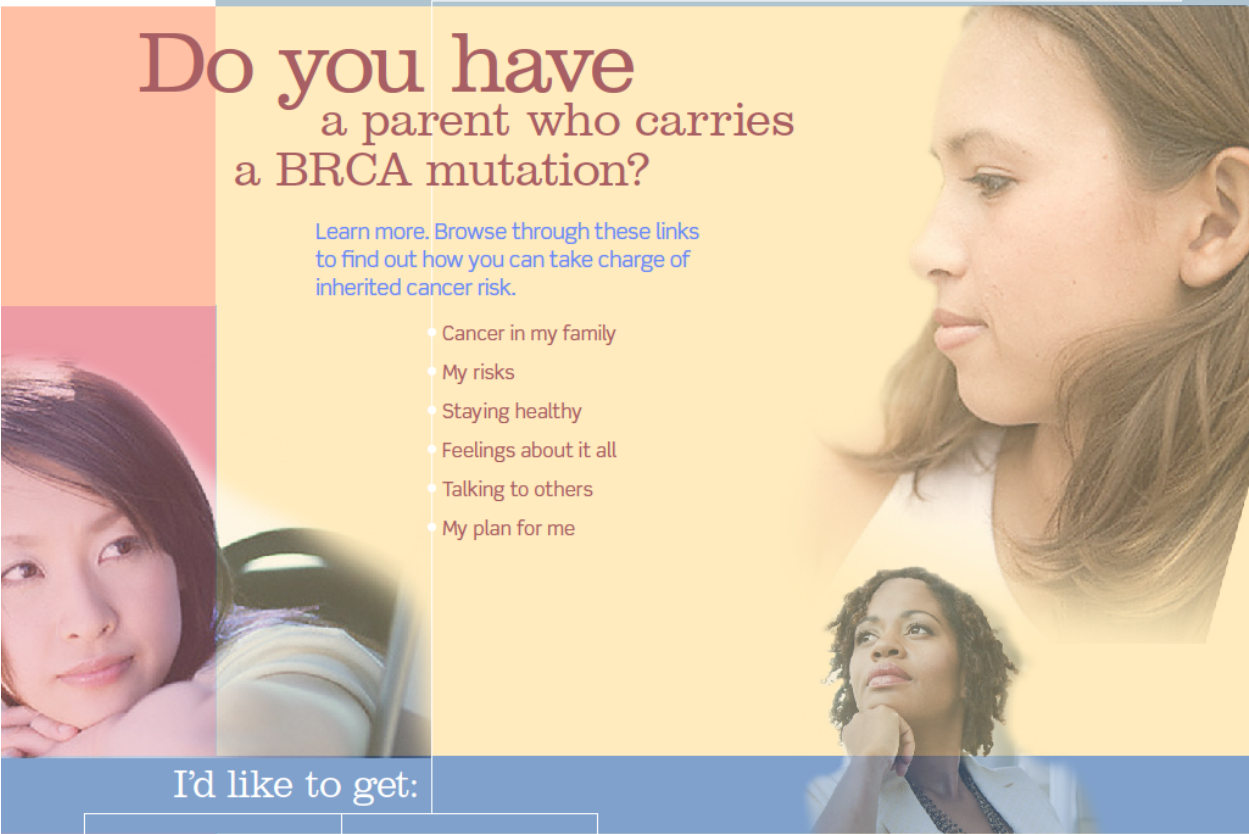
- Cancer in my family
- My risks
- Staying healthy
- Feelings about it all
- Talking to others
- My plan for me

I'd like to get:

• Guidance from a genetic counselor

• Information from a physician

• Stories about their experiences from other young women



Funded by: Congressionally Directed Medical Research Program—Breast Cancer Research
Program Idea Grant BC084061

Developed by DF/HCC Health Communication Core

Genetic Counseling



GENETIC COUNSELORS are health care professionals trained to help people learn about how cancer has affected their families and what their own risk might be. For example, a genetic counselor can:

- Give you information about how BRCA1 or BRCA2 genes are inherited and what the risks are to those in the family who carry a mutation
- Help you find out if you carry a mutation
- Offer guidance for those who are carriers about options for early screening and prevention options you may want to consider
- Advise non-carriers about their risks.
- Help you to organize what you need to do first—especially, if you are a carrier, that by age 25 you would be advised by experts to begin screening

Here are some topics that young women frequently ask me about. You can read them all to see the “big picture” or just read the sections that feel most useful to you today. Click on the topic (link to list of topics) you’re interested in or look at some of the additional features (link to list of features).

What would you like to know more about?

Cancer genes: What are BRCA1 and BRCA2 genes? What does gene “mutation” mean?

Cancer risk: What cancers are mutation carriers at higher risk for?

Genetic counseling: What’s a genetic counseling session like? How can it help me learn more about the cancer in my family and my own risks.

Family history: What do I need to know about cancer in my family in order to understand about my personal risks?

Genetic testing: What is it? What will it tell me? Where is it done?

Staying healthy: Different ways of screening for cancer that experts recommend for women with genetic risk.

My feelings about the cancer in my family: What are all these feelings? Who can help me sort them out?

My timeline: what steps might be important for me to take and when are the best times for making the right decisions for myself.



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Dating: What do I say, when do I say it?

Many of us wonder about when to talk to our boyfriend or girlfriend about the hereditary cancer in our family. What do I say? When do I say it? Will it affect our relationship? Will he or she start worrying about me? Will it scare him or her away?

Most people discover that their relationship is not harmed by talking openly with their partner about hereditary cancer risk. If the relationship is a strong one, the partner is concerned most of all about the safety and health of the person he or she loves. They want to help her do what she can to stay healthy. Both people also may find it helpful to share their worries and hopes about the future with each other!



Here's what other young women had to say:

"I talk about it when the topic comes up naturally. As we started getting to know each other, I talked about my mom and her cancer and how that has affected me. That led to talking about the fact that the cancer is hereditary and, at some point, to talking about what I think my own risks are." Amanda G.

"It used to be hard to talk because I wasn't really sure what I was talking about or how I felt about it. I feel much more comfortable about myself now, and much more comfortable with the information. So talking about it is not the big scary deal it used to be." Melissa N.

"I know it's the right time is when I feel comfortable enough with the other person." Donna S.

"I like to wait a while to see how the relationship is developing to talk about it." Shirronda A.

"Don't try to force it as a test of the relationship. This could be misinterpreted in ways that prove hurtful." Jane T.



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