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What Do Young Adult Daughters of *BRCA1/2* Positive Mothers Know About Hereditary Risk? How Much Do They Worry?

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Abstract

Background and Objectives: Daughters of *BRCA1/2* mutation carriers have a 50% chance of inheriting cancer risks of up to 85% for breast cancer (often early onset) and 60% for ovarian cancer. Genetic testing and uptake of enhanced screening remains suboptimal, especially for 25–40-year-old mutation carriers [1,2]. 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 and risk-reduction measures as well as about their anxiety related to hereditary cancer. These data are needed for the development of targeted educational materials to improve timely screening initiation and risk-reducing interventions that could reduce morbidity and, ultimately, mortality in this high-risk group. A health educational intervention providing high-risk women 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.

Methods: Forty daughters (ages 18–24 years) of living *BRCA1/2*-positive mothers (previously tested at one of three Harvard Medical School-affiliated hospitals) completed written questionnaires including the Brief Symptom Inventory-18 (BSI-18), Impact of Event Scale (with hereditary cancer as the event), and the Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ-27) and qualitative telephone interviews about their knowledge of hereditary breast or ovarian cancer risk and screening and risk-reduction surgeries, worry about hereditary cancer, and the effect of their mother's genetic status on their future planning, including plans for genetic testing.

Results: To date, 40 daughters have enrolled and completed participation. Participation rate is 78%. Participants were an average of 21 years old; the majority were either college students or college graduates. Of the participants, 90% were single. Nine had mothers with no cancer history, 7 with ovarian cancer, 21 with breast cancer, and 1 with breast and ovarian cancer. Phone interviews averaged 56 minutes in length. Daughters' knowledge of hereditary breast or ovarian cancer genetics was significantly less than 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 that knowledge is limited about screening and risk-reduction options, including about the age at which cancer screening should be initiated. Worry about hereditary breast or ovarian cancer was high among daughters; 40% said they worried a great deal or to an extreme about hereditary cancer.

Conclusion: Young, high-risk women have inadequate 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 or ovarian cancer and ultimately improve their participation in effective screening and risk-reducing interventions that improve survival and quality of life.

References:

1. Botkin JR, Smith KR, Croyle RT et al. (2003). Genetic testing for a BRCA1 mutation: prophylactic surgery and screening behavior in women 2 years post testing. Am J Med Genet A118, 201-209.
2. Claes E, Evers-Kiebooms G, Decruyenaere M, et al. (2005). Surveillance behavior and prophylactic surgery after predictive testing for hereditary breast/ovarian cancer. Behav. Med 31, 93-105.

Introduction

Early adulthood may be an untapped teachable moment in the lives of at-risk women when, with targeted assistance, many can increase the likelihood they will appropriately adopt targeted, potentially life-saving breast cancer screening and prevention options when they reach screening age. The specific needs of this group of 18-24 year old high-risk women – informational, emotional, medical, insurance-related, or motivational- are unknown. This project will be the first directly assessing the needs, concerns, knowledge and views of young adult daughters of *BRCA1/2* mutation carriers regarding living with hereditary breast cancer risk.

What We Don't Know:

- What daughters **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.

Aims and Hypotheses

Goals:

1. To 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. To define specific health educational, psychological, insurance and medical needs of this population.

Hypotheses:

1. 18-24 year old, high risk women have significant misconceptions regarding their hereditary breast cancer risks and the implications of those risks for health planning and life choices
2. Having an educational intervention targeted to the identified needs of 18-24-year-old daughters of *BRCA1/2* mutation carriers will improve screening rates at age 25 and, ultimately, reduce mortality and morbidity.

Methods

PROCEDURE:

Contact Mothers → Contact Daughters → Consent Daughters → Questionnaires Returned → 40 Interviews Conducted → Transcription, Analysis, Reports

Eligibility Criteria:

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

66% of Mothers provided daughter contact information
78% Participation Rate for Invited Daughters

Measures

Qualitative Interview:
A semi-structured interview was constructed for this project based on literature review and clinical experience. Interviews were conducted by telephone by advanced graduate students.

The Interviews focus on:

- Impact of family cancer experience
- Current health behaviors and insurance
- Cancer related distress
- Learning about maternal *BRCA1/2* result
- Understanding personal risk and implications of risk
- Knowledge of and attitudes towards screening, risk reduction options
- Impact of family genetic information on life plans
- Interest in genetic counseling/testing
- Educational intervention preferences and expected utility by young adult women

Quantitative Measures:

Brief Symptom Inventory-18 (BSI-18) *Derogatis LR (2000). Brief Symptom Inventory 18: Administration, Scoring, and Procedures Manual (3rd Ed.) Minneapolis: National Computer Systems.* A questionnaire that measures the level of general psychological distress. Has community reference norms.

Impact of Events Scale (IES) *Horowitz M.J., Wilner N.R. & Alvarez W. (1979). Impact of Event Scale: A measure of subjective stress. Psychosom Med 41, 209-218.* The IES Is a 15-item pre-validated scale that measures intrusive thoughts and avoidant thinking about a specific event. Here, "inherited predisposition to breast or ovarian cancer" was the event.

Breast Cancer Genetic Counseling Knowledge Scale (BGKQ-27) *Erblich J, Brown K, Kim Y, et al. (2005). Development and validation of a breast cancer genetic counseling knowledge questionnaire. Patient Education and Counseling 56, 182-191.* This 27-item scale assesses knowledge of information typically included in genetic counseling for breast cancer.

Results

Demographic and Testing Information (N=40)

Age	Mean	21.15 years
	Range	18-24 years
Race	White	100%
Education	High School Graduate	7.5%
	Some College	57.5%
	College Graduate	5.0%
Work Status	Full-time student	32.5%
	Employed	42.5%
	Unemployed and looking for work	2.4%
	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%

		N
Participant had genetic counseling?	Yes	8
	No	32
Participant had genetic testing?	Yes	7
	No	33
Participant's genetic test result	Positive	1
	True Negative	6
	Not Tested	33

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.

How Much Do You Worry About Getting Cancer Yourself?

"**A lot!**" 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." 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!" 22 year old

"**I worry** I think 'cause even if I don't have the gene, I think it's what, 1 in 4 women end up with breast cancer. So I know it is a high risk type of thing."21 year old

"**I tested negative for it**. Since then I've tried to realize that there are other genes involved and all sorts of things and 1 in 10 or 2 in 10 women still get breast cancer, but it's something I've tried not to think that much about anymore." 24 year old

Results Cont'd

Cancer-Related Distress
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)

Suggests cancer-related distress of daughters is similar to that of people undergoing genetic testing or of women found to be *BRCA1/2* gene mutation carriers in most studies

General Distress (BSI-18)

10% of daughters scored above the clinical cut-off score of 63.

Cancer Worries (from questionnaire):
% Scoring; 4 = a great deal or 5 = to an extreme

How much do you worry about:

- Cancer risk being inherited in your family? **40.0%**
- Getting cancer in the future? **37.5%**
- Your present or future child(ren)'s cancer risk? **23.0%**

Impact of Event Scale
Event = Inherited predisposition to breast or ovarian cancer
Proportion of high (>19)Total IES Mean Score

Group	n	Percent	95% CI of Percent
Daughters	**13**	**32.5%**	**(18.6%, 49.1%)**
Counselees, fam hx CRC or BR/OV	51	**23.9%**	(18.5%, 30.4%)

Suggests 1/3 of daughters have cancer related distress above IES cutoff; higher than cancer related distress of individuals seeking genetic counseling

Genetic Knowledge
Results of BGKQ-27 by Group

Group	n	Mean Score	Standard Error	Standard Deviation	95% CI
Daughters	**40**	**16.7**	**0.59**	**3.76**	**(15.52, 17.93)**
Counselees	28	20.7	1.2	-	(18.3, 23.1)

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

More than 75% know:

- Fathers can pass down *BRCA1/2* gene mutation.
- *BRCA1/2* mutation carriers have a higher risk for ovarian cancer.
- Not all *BRCA1/2* mutation carriers develop cancer.
- A mutation carrier who has had breast cancer has a higher risk of contralateral breast cancer.

50% or more do not know:

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

My mom's had breast cancer 4 times... at 10-year intervals. She just got a double mastectomy and reconstructive surgery. When my aunt got ovarian cancer she-my mom-immediately went in and got her ovaries out. It makes me worry because I don't understand genetic cancer all that much but . . . will the cancer move somewhere else? I don't know. But it makes me, like, worried more about her than myself. I kind of am the type of person where, like, if I'm going to get cancer, like, I'm going to get cancer and I'll deal with it when I get it. Like the whole point of getting genetic testing is to know that you could and probably will get it, but I already kind of feel that I will. I'm going to get the test anyway, but you know I just kind of live my life assuming I'm going to have cancer at some point just because everyone in my family has. ..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 who will, like, love me. " 22 year old

Conclusions

- Daughters of *BRCA1/2* mutation carriers have high cancer-related distress.
- Daughters have inadequate knowledge about options for managing their cancers risks.
- Daughters' worry about hereditary cancer affects future life planning.
- Consideration of a more proactive approach to educating/informing daughters of mutation carriers may reduce morbidity, mortality.
- Taking care of families with hereditary cancer predisposition involves counseling over the lifetime.
- 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 Research

Development and testing of educational interventions aimed at young adult daughters of *BRCA1/2* mutation carriers in formats appealing to young women will, hopefully, provide better genetic information and preparation for future genetic counseling, testing and, especially initiation of breast and ovarian cancer screening at appropriate ages. Assessment will evaluate efficacy of these interventions in reducing daughters' anxiety about hereditary breast/ovarian cancer and, ultimately, improve daughters' participation in effective screening which can improve survival and quality of life.

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