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Does Family Communication Matter? Exploring Knowledge
of Breast Cancer Genetics in Cancer Families

Sarah Harmon Davis

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Does Family Communication Matter? Exploring Knowledge of Breast Cancer Genetics in Cancer Families

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Purpose: Knowledge of breast cancer genetics is critical for those at increased risk who must make decisions about breast cancer screening options. The purpose of this study was to explore cognitive and emotional variables that might influence knowledge of breast cancer genetics.

Methods: This descriptive, exploratory study analyzed theory-based relationships among variables related to knowledge of breast cancer genetics in cancer families. Participants included first-degree relatives of women with breast cancer who had received genetic counseling and testing; participants themselves did not have breast cancer and had not received genetic counseling or testing. Data were collected by telephone interview and survey. Variables analyzed include numeracy, health literacy, cancer-related distress, age, education, and the reported amount of information shared by the participants' family members about genetic counseling.

Results: The multiple regression model explained 13.9% of variance in knowledge of breast cancer genetics ($p = 0.03$). Best fit of the multiple regression model included all variables except education. Reported amount of information shared was the only independently significant predictor variable ($p = 0.01$).

Conclusion: Participants who reported higher levels of information shared by a family member about genetic counseling also demonstrated increased knowledge about breast cancer genetics.

Keywords: knowledge, breast cancer, genetics, communication, precision medicine

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Does Family Communication Matter? Exploring Knowledge of Breast Cancer Genetics in Cancer Families

Genetic disease plays a role in nine of the ten leading causes of death in the United States (National Human Genome Research Institute, 2016) and affects an entire family, not just the individual presenting with disease. Therefore, patients and family members need information about genetic disease. Knowledge about genetic disease and personal risk helps individuals make informed decisions about how to proceed with screening and prevention measures as well as treatment options to minimize effects of disease.

When a disease is known to have a strong heritable component, people may attend genetic counseling (as counselees) to gain further information, including personal and familial risk. For example, women with early-onset breast cancer may attend genetic counseling to learn information to help them understand their own risk for cancer recurrence as well as their family members' risk for developing cancer. Genetic counselors teach counselees about breast cancer genetics and encourage them to share information with family members who may have increased risk. Consequently, the amount of information shared by a counselee may affect whether at-risk family members understand their risk and are prepared to make informed decisions about prevention and screening. Indeed, a greater amount of information shared about genetic counseling increases the accuracy of risk perception of unaffected family members (Himes et al., 2016). Therefore, family communication plays an important role in helping family members who did not attend genetic counseling.

While it has been demonstrated that family communication improves accuracy of risk perception among women with a close relative diagnosed with breast cancer, less is understood about the role of family communication in increasing knowledge about breast cancer genetics.

Genetic knowledge is critical for women who may be at risk for heritable breast disease. In fact, women at risk for breast cancer make decisions about prevention and screening based on both their risk perceptions and their knowledge about breast cancer (Haas et al., 2005; Tilbert et al., 2011). Knowledge about breast cancer genetics is a complex concept influenced by information obtained as well as an individual's ability to comprehend that information, which involves health literacy and numeracy.

In addition, a person's level of emotional distress is known to influence risk perception (van Dooren et al., 2004; Gibbons & Groarke, 2016). However, it is not known whether emotional distress also influences knowledge about breast cancer genetics. Theory suggests strong connections between cognitive and emotional responses to illness (Levanthal, Brissette, & Levanthal, 2003). Therefore, cognitive and emotional factors may be important to consider when evaluating knowledge of breast cancer genetics.

The purpose of this study was to explore cognitive and emotional variables that may influence family members' knowledge of breast cancer genetics. The principle aim was to explore the relationship between the perceived amount of information shared by a counselee about her genetic counseling and her sister's or mother's knowledge about breast cancer genetics while controlling for other factors believed to influence knowledge outcomes.

Background

This research is based on the Common Sense Model (CSM) of Self-regulation as presented by Levanthal et al. (2003) which describes cognitive and emotional responses influenced by a personalized health threat. According to the CSM, when faced with health threats, people take actions that result from their cognitive representations of danger and their emotional representations of fear, often with the goal of achieving or maintaining a healthy life.

These actions are taken with the intent of controlling danger and fear and are considered parallel actions—occurring simultaneously and interacting with one another (Leventhal et al., 2003).

Building on the Common Sense Model, Marteau and Weinman (2006) present an interpretation of the CSM where DNA risk information is a stimulus that can lead to coping actions.

When faced with a health threat, such as receiving DNA risk information, peoples' behaviors are based on both cognitive and emotional responses to the threat. Subsequent thoughts and actions are then directed towards optimizing a healthy lifestyle, which encompasses reducing the potential burden of genetic disease and minimizes its impact on achieving a healthy and satisfying life. Therefore, how people understand and respond to DNA risk information also affects other areas of life. For example, an overweight woman may increase her physical activity to lower her risk of breast cancer based on DNA risk information, which may in turn improve other aspects of her life.

In our study, DNA risk information is operationalized as information shared by family members about their genetic counseling sessions. Cognitive representations may include perceptions of personal risk for disease as well as knowledge about disease, including disease identity, cause, timeline, consequences, and an individual's ability to control the disease (Marteau & Weinman, 2006). Thus, knowledge of breast cancer genetics can be viewed as a cognitive representation of the disease. Because cognitive representations influence behavior in parallel with emotional responses, it would be incomplete to evaluate the cognitive response without simultaneously considering the emotional response to receiving DNA risk information.

We analyzed several factors that may influence knowledge of breast cancer genetics. Initial regression model variables were based on theory and previous research. These variables

included cognitive factors, an emotional factor, and demographic factors that may influence knowledge about breast cancer genetics.

Cognitive Factors

Health literacy and numeracy skills are cognitive factors that may influence patients' and family members' understanding of complex health information. Health literacy is the ability to understand, use, and interpret basic health information necessary to make decisions (Nielsen-Bohlman, Panzer, & Kindig, 2004). Literature suggests that health literacy is an important skill in relation to communicating genetic information. (Lea, Kaphingst, Bowen, Lipkus, & Hadley, 2011). Numeracy is defined as "the ability to access, use, interpret, and communicate mathematical information and ideas," (Centers for Disease Control and Prevention, 2015, para. 3). Low numeracy skills are associated with poor health outcomes, including a higher prevalence of comorbidities and a 20% increase in prescription medications (Garcia-Retamero, Andrade, Sharit, & Ruiz, 2015). Conversely, strong numeracy skills influence one's ability to interpret complex information related to cancer risk (Lea et al., 2011), essential to making decisions about prevention and treatment. Furthermore, genetic information is often conveyed in terms of *odds ratios* and *lifetime risk* which can be difficult to understand without strong numeracy skills.

Emotional Factor

Familial cancer involves strong emotions in both affected and non-affected family members. Receiving personalized genetic risk information can cause emotional reactions such as fear, worry, and distress (Marteau & Weiman, 2006). Literature has demonstrated that higher levels of distress correlate with higher and inaccurate levels of risk perception (van Dooren et al., 2004; Gibbons & Groarke, 2016). If distress interferes with the cognitive action of accurately assessing risk, it is possible that higher levels of cancer-related distress may be related to the

cognitive task of understanding genetics. Indeed, a recent study of daughters of *BRCA1/2* positive mothers found that 32% of daughters had high cancer-related distress and low levels of genetic knowledge (Patenaude et al., 2013). Therefore, we included cancer-related distress as a covariate to represent emotional response to a health threat.

Demographic Factors

Because of the potential influence of age and education on knowledge of breast cancer genetics these demographic factors were included in our initial regression model. Practical and experiential knowledge generally increase with age. However, knowledge of genetics is significantly lower among older individuals, likely attributable to recent advancements in genetics and educational methods (Ashida et al., 2011; Haga et al., 2013). Generally, more education implies additional learning and knowledge. Individuals with a high level of education tend to know more about genetic disease (Haga et al., 2013).

Methods

In this descriptive, exploratory study, we analyzed theory-based relationships among variables related to knowledge of breast cancer genetics. This study was a secondary analysis of data collected for a prior study. Recruitment methodology is described elsewhere (Himes et al. 2016).

Inclusion Criteria

Adult women who are sisters or daughters of women diagnosed with breast cancer were recruited for this study. All participants had a first-degree family member with cancer who received genetic counseling and testing with uninformative negative *BRCA1/2* test results. No participants were affected by breast cancer or received genetic counseling or testing themselves.

Measures

Knowledge about breast cancer genetics. Knowledge of breast cancer genetics, the outcome variable of interest, was measured using the 27-item Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ) (Erblich et al., 2005). The BGKQ is an objective instrument developed to evaluate knowledge of information typically gained during genetic counseling. This measure has been used to assess knowledge about breast cancer genetics in daughters of women who had received genetic counseling for breast cancer (Patenaude et al., 2013). Internal reliability is high (Cronbach's alpha of 0.92). Possible scores range between 0 and 27.

Numeracy. The Rasch-based numeracy scale (Weller et al., 2013), an eight-item measure of objective numeracy, was used in this study. This composite instrument asks participants to solve math equations to assess their knowledge about principles necessary to interpret genetic knowledge. For example, "If the chance of getting a disease is 10%, how many people would be expected to get the disease out of 1000?" (Weller et al., 2013, p. 203). Internal reliability for this scale is acceptable with a Cronbach's alpha of 0.71 (Weller et al., 2013). Possible scores range from 0 to 8.

Health literacy. Chew, Bradley, and Boyko's Set of Brief Questions (2004) was used to assess self-reported health literacy. Each of the three items ask participants about their comprehending both written and verbal information in health care settings and was presented as a 5-point Likert scale ranging from "never" to "always." During development, each item was compared to the Short Test of Functional Health Literacy in Adults (STOHFLA), a 36-item reading comprehension test designed to measure health literacy. Although the Set of Brief Questions is a measure of self-report rather than an objective measure, when compared to the STOHFLA, the set of brief questions achieved area under the receiver operating characteristic

curve (ROC curve) scores of 0.87, 0.80, and 0.76 indicating the self-measures may be reasonable proxies for the objective measure (Chew et al., 2004). Further, most primary care offices that assess health literacy in patients use self-report measures rather than objective testing. Overall score of the three items combined can range from zero to 15 with higher scores indicating higher self-reported levels of literacy.

Cancer-related distress. Cancer-related distress was measured by an adaptation of the 15-item Impact of Events Scale (IES) with a stated stress-inducing scenario of having a known risk of heredity breast cancer. The scale asks participants to report the frequency of their psychological, physiological, and behavioral responses to an event as follows: not at all = 0, rarely = 1, sometimes = 3, and often = 5. The IES has a Chronbach's alpha of 0.91 (Thewes, Meiser, & Hickie, 2001). Possible overall scores range from 0 to 75 points.

Reported amount of information shared. The variable "reported amount of information shared" was measured by the statement "Please rate on a scale of 0-5 how much information your sister/mother shared with you about what she learned in her genetic counseling session." Answers ranged from "shared nothing" (0) to "shared a great deal" (5). This measure was developed for the parent study and was effective in describing amounts of information shared within families (Himes et al., 2016).

Data Analysis

Data were analyzed using SPSS 22.0 (IBM Corp., Chicago, IL). Demographics and amount of information shared were analyzed using univariate statistics. Two missing values out of a possible 595 were imputed using means substitution. Relationships between knowledge of breast cancer genetics and factors believed to influence knowledge were analyzed using multiple regression. Cancer-related distress and health literacy were transformed to normalize their

distributions. Initial predictors in the regression included age, education, cancer-related distress, numeracy, health literacy, and reported amount of information shared. All statistical assumptions were met.

Results

The sample included 85 women who were mostly married (80%), non-Hispanic white (98.8%), and had received some college education (84.7%). Average participant age was 52.2 years old (see Table 1). Most women reported low levels of cancer related distress and high levels of self-reported health literacy. Participant means for the Rasch Based Numeracy Scale and the Knowledge about Breast Cancer Genetics instrument were close to the median possible score for each instrument. Instrument performance, including range of scores, means and estimates of internal consistency reliability are reported in Table 2. Most women reported very little information from genetic counseling sessions was shared with them by their mother or sister who attended genetic counseling (see Figure 1).

The best fit of the multiple regression model included all proposed variables except education. The overall multiple regression model was significant ($p = 0.03$) and explained 13.9% of the variance in knowledge of breast cancer genetics. The only predictor variable that was statistically significant was reported amount of information shared ($p = 0.01$). Beta weights, a measure of the relative importance of each variable, and p -values for each variable are shown in Table 3. Although the variables treated as covariates were insignificant, they were necessary to explain overall variance in knowledge of breast cancer genetics. The final model is presented in Figure 2.

Discussion

Lack of knowledge can be a barrier to appropriate cancer screening (Ashida et al., 2011; Schapira et al., 2011; Patenaude, et al., 2013). Conversely, knowledge of breast cancer genetics is asserted to be a positive indicator of health (Haga et al., 2013). This exploratory study found that the reported amount of information shared by a mother or sister about her genetic counseling experience accounted for 28% of the variance in knowledge of breast cancer genetics. In families where more information was shared about genetic counseling, family members (who had not attended counseling) had a greater understanding of breast cancer genetics. These results underscore the importance of family communication in transferring knowledge about breast cancer genetics.

Unfortunately, few participants reported a high amount of information was shared by their sister or mother about her genetic counseling (see Figure 2). Most families are not taking advantage of this effective means of transferring personalized information. Sixteen women (nearly 19%) reported that their mother or sister shared nothing about their genetic counseling experience. Therefore, although family communication is a preferred method of disseminating genetic information in a family, it does not happen very often.

While it is not known what kind or quality of information was shared, women who perceived a higher amount of information shared by their mother or sister also knew more about breast cancer genetics. Because of the cross-sectional nature of this study, we are unable to determine causality in the relationship between information shared and knowledge.

Theoretical Significance

The Common Sense Model suggests an interplay between emotional and cognitive factors. We suspected that higher levels of distress (an emotional factor) may interfere with

knowledge of breast cancer genetics (a cognitive factor). However, no significant association was found between knowledge of breast cancer genetics and distress. This finding is similar to study results by Kelly et al. (2014), where no significant relationship was found between distress and a variety of cancer-related knowledge outcomes in women at risk for breast cancer. Therefore, distress may interfere with some, but not all, cognitive factors related to disease. Further research is needed in this area.

Clinical Significance

Although it seems logical that health literacy and numeracy might correlate with women's knowledge of breast cancer genetics, the fact that these variables were not related is important for healthcare providers to understand. People who perform well on literacy or numeracy evaluations may not understand complex genetic principles well enough to make informed decisions about prevention and screening. Healthcare providers should not assume people with high numeracy or self-reported health literacy understand complex genetic information.

Because family communication is a common method for disseminating information about family genetics, it is helpful to understand the relationship between amount of information shared within a family and knowledge outcomes. Healthcare providers may incorrectly believe that if their patient has a family member with cancer who has received genetic counseling, then their patient will have personalized knowledge about breast cancer. This is not always the case. As this study demonstrates, many counselees do not share information learned in genetic counseling (see Figure 1). In addition, overall knowledge scores were low. With an average score of 10.26 (out of a possible score of 27) on the breast cancer genetics knowledge instrument

(see Table 2), there is room for improvement. Thus, even in families where genetic counseling has been provided, non-counseled family members need more information.

This study illustrates one benefit of family communication following genetic counseling. It is promising to find that when more information was shared by counselees, women had increased knowledge about breast cancer genetics. Future research should focus on improving methods of sharing genetic information within families and on sharing familial genetic information with healthcare providers. Healthcare providers can assist at-risk women to make lifestyle changes (smoking cessation, increased activity, and improved nutrition) to decrease their likelihood of developing breast cancer and other significant health threats.

Conclusion

It has been said that knowledge is power. Knowledge about breast cancer genetics can improve breast cancer prevention and screening decisions. Our study found that when more information was shared with family members by counselees, family members had higher levels of knowledge. Unfortunately, few counselees shared a lot of information about their genetic counseling sessions. More research is needed to improve family communication. Healthcare providers should encourage women to talk to family members about what was learned in genetic counseling. Healthcare providers can also help women interpret and utilize personalized genetic information to make lifestyle changes directed towards prevention and to participate in appropriate screenings.

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Table 1
Demographics

Category	participants	
	<i>n</i>	(%)
Age		
40-49	37	(43.5)
50-59	29	(34.1)
60-69	14	(16.4)
70-74	5	(5.9)
Race/ ethnicity		
Non-Hispanic White	84	(98.8)
Asian	1	(1.2)
Education		
High school/ GED	13	(15.3)
Some college/ technical school	32	(37.6)
College graduate and beyond	40	(47.1)
Marital status		
Married or living as married	68	(80.0)
Separated or divorced	13	(15.3)
Widowed	2	(2.4)
Never married	2	(2.4)
Total	85	(100.0)

Table 2

Instrument Performance: Range, Mean (SD) and Estimates of Internal Consistency Reliability

Variable	[range]	<i>mean</i>	(<i>SD</i>)	Cronbach's Alpha
Distress (Impact of Events Scale)	[1-46]	8.20	(11.1)	0.890
Knowledge about Breast Cancer Genetics	[1-24]	10.26	(5.5)	0.854
Numeracy (Rasch Based Numeracy Scale)	[2-8]	4.48	(1.5)	0.530
Health Literacy (Set of Brief Questions)	[6-12]	10.91	(1.3)	N/A

Note: $n=85$ for all instruments except numeracy. One participant declined to answer all numeracy questions and was excluded from analysis of that instrument.

Table 3
Results of Multiple Regression Analysis

Predictors	β	(<i>p</i>)
Age	-0.13	(0.25)
Distress	0.07	(0.55)
Numeracy	0.11	(0.31)
Health Literacy	-0.08	(0.45)
Amount of information shared*	0.28	(0.01)

Overall model $R^2 = 0.14$, $p = 0.03$

Figure 1. Reported amount of information shared

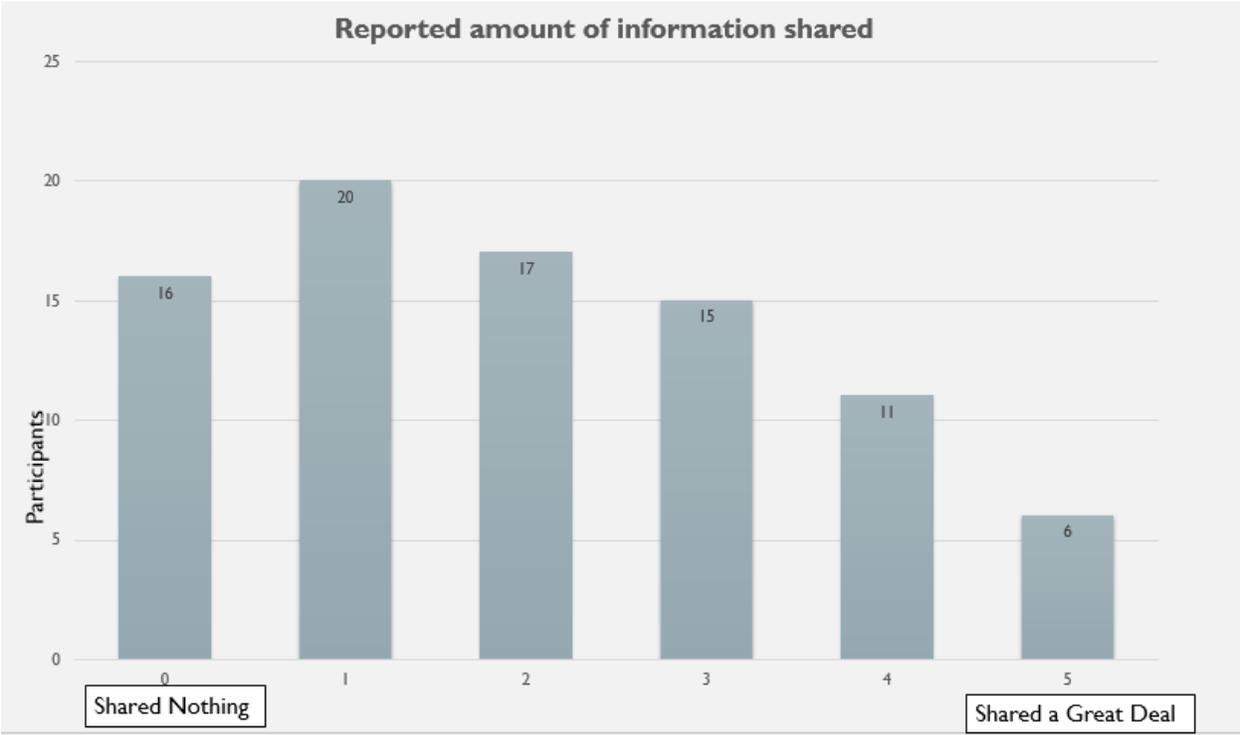
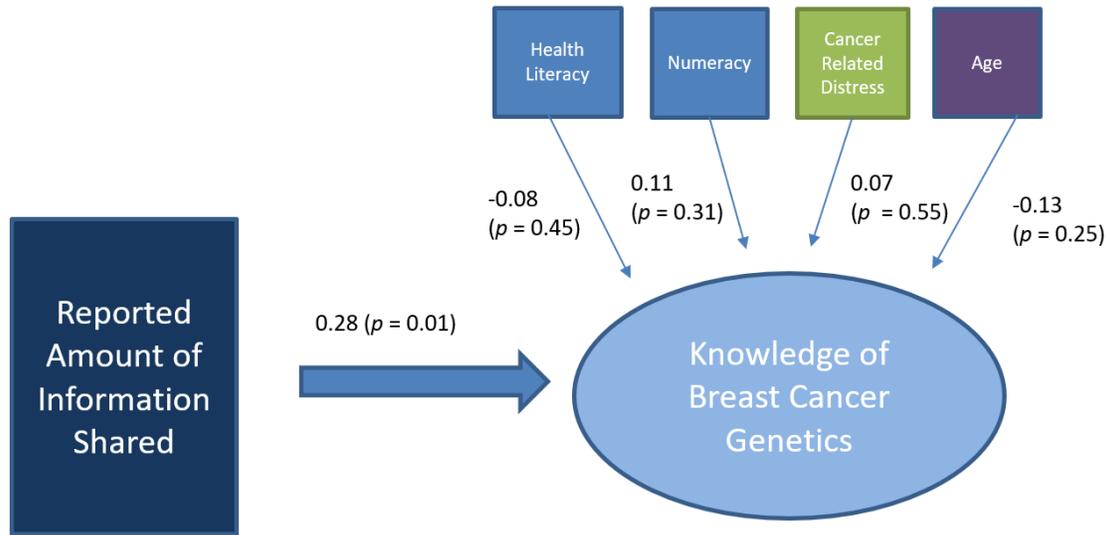


Figure 2. Final multiple regression model

Influence of reported amount of information shared about genetic counseling on knowledge of breast cancer genetics, while controlling for cognitive (blue), emotional (green), and demographic (purple) factors. Overall model fit: R-squared = 0.139, $p < 0.05$