Media Exposure and Genetic Literacy Skills to Evaluate Angelina Jolie's Decision for Prophylactic Mastectomy

Leah R. Abrams^a Laura M. Koehly^b Gillian W. Hooker^c Ryan S. Paquin^d
Joseph N. Capella^e Colleen M. McBride^f

^aUniversity of Michigan School of Public Health, Ann Arbor, Mich., ^bSocial and Behavioral Research Branch, National Human Genome Research Institute, Bethesda, Md., ^cNextGxDx, Franklin, Tenn., ^dRTI International, Washington, D.C., ^eAnnenberg School for Communication, University of Pennsylvania, Philadelphia, Pa., and ^fRollins School of Public Health, Emory University, Atlanta, Ga., USA

Key Words

BRCA genetic mutations · Genetic literacy · Media · Prophylactic mastectomy · Public opinions

Abstract

Purpose: To examine public preparedness to evaluate and respond to Angelina Jolie's well-publicized decision to have a prophylactic mastectomy. **Methods:** A consumer panel (n = 1,008) completed an online survey in November 2013, reporting exposure to Jolie's story, confidence applying genomic knowledge to evaluate her decision, and ability to interpret provided genetic risk information (genetic literacy skills). Linear and logistic regressions tested mediating/moderating models of these factors in association with opinions regarding mastectomies. **Results:** Confidence with genomics was associated with increased genetic literacy skills and increased media exposure, with a significant interaction between the two. Confidence was also associated with favoring mastectomies for women with BRCA mutations, mediating the relationship with media exposure. Respondents were more likely to form opinions about mastectomies if they had high genetic literacy skills. **Conclusion:** These find-

ings suggest that having higher genetic literacy skills may increase the public's ability to form opinions about clinical applications of genomic discovery. However, repeated media exposure to high-profile stories may artificially inflate confidence among those with low genetic literacy.

© 2016 S. Karger AG, Basel

Introduction

In May 2013, actress and filmmaker Angelina Jolie wrote an op-ed in the New York Times about her unusually high risk for breast cancer due to a BRCA1 genetic mutation and her resulting decision to have both breasts surgically removed [1]. She encouraged women to seek information, explore options, and take action regarding their own cancer risk – messages she reiterated in March 2015 when announcing her decision to have her ovaries and fallopian tubes surgically removed as well [2]. Widespread media coverage [3] of Jolie's initial decision brought genomics to the forefront of public discourse, opening a discussion that was continued by her second announcement.

This increased public attention on genetic risk provides an ideal context for evaluating the public's capacity to use genomic information in everyday situations and the impact of such information on health decision-making. The Risk Information Seeking and Processing (RISP) model provides a framework for considering factors that influence the public to take an active role in acquiring and applying information [4]. The concepts in this model guide our current work exploring the role of genetic literacy in how the public evaluated Angelina Jolie's decisions to surgically reduce her risk for breast cancer.

There is a long history of celebrities' health experiences influencing related public awareness, opinions, and behaviors, both with health enhancing and detrimental effects. For example, Nancy Reagan's mastectomy in 1987 was associated with subsequent improvements in cancer screening and treatment [4, 5]. More recently, Jenny McCarthy's outspoken condemnation of vaccines has promoted distrust in this public health practice [6]. In the realm of breast cancer, women credit the media more often than friends, family, or medical professionals when asked to cite the sources of memorable messages about breast cancer [7]. In the RISP model, the influence of pop culture contributes to 'informational subjective norms' that shape what the public considers to be important to learn and sufficient to know regarding a given risk [8, 9]. Angelina Jolie's outspoken medical choices had unique potential to influence public norms considering the difficult decisions that accompany *BRCA* genetic mutations.

On average, 55–65% of women with the *BRCA1* genetic mutation will develop breast cancer before age 70, compared to a 12% lifetime risk for those without the mutation [10]. However, *BRCA1* and *BRCA2* genetic mutations are responsible for only 5–10% of all breast cancer cases [10]. Several studies have shown both mastectomies and oophorectomies to be effective in cancer risk reduction, though the relative benefit of mastectomy compared to less invasive methods (i.e. intensive screening, chemoprevention) remains uncertain and long-term survival benefits need confirmation [11–13]. As these elective surgeries come with significant risk, financial cost, and personal sacrifice, they are not universally recommended by the United States Preventive Services Task Force (USPSTF) or the National Comprehensive Cancer Network. Therefore, managing the genetic risk for breast cancer depends on the patient's values, and as often the physician's values [14], both of which can be influenced by the mass media.

Several blogs and editorials [15–17] quickly reacted to the news of Jolie's mastectomy, expressing concern that

misunderstanding or misinformation about genomics in the media might lead to confusion. Exploring the legitimacy of worries about the public effect of Jolie's announcement, Borzekowski et al. [18] conducted a nationally representative study in 2013 and found that awareness of Jolie's news was not associated with increased understanding and may have actually confused conceptions of familial breast cancer risk. While that study did not detect behavior changes, research conducted in the UK in 2014 found an increase in monthly referrals to breast cancer family history clinics and genetics centers and a doubling in demand for testing following Jolie's announcement, though other factors potentially contributed to the trend [15]. In December 2013, the USPSTF published a warning against *BRCA* genetic testing for women at low risk, who are unlikely to benefit [19].

With Jolie's second announcement again gaining widespread media coverage, the questions remain – how prepared is the public to use genomic information in everyday situations like watching the nightly news? And how does their confidence influence their use of information gained through media exposure? Previous research on genetic literacy has highlighted public confusion and misunderstanding by assessing what respondents know about genes [20–22]; in Borzekowski et al.'s [18] study, this entailed reciting the population risk for breast cancer as compared to the risk of those with *BRCA* mutations. However, the RISP model suggests that many factors besides gaps in knowledge could influence information seeking and processing [23]. The ability to properly interpret genetic information is likely to be especially important considering the dramatic increase in online information seeking about genetic breast cancer and preventive mastectomies that followed Jolie's first editorial [24, 25]. Therefore, we focused on a specific facet of genetic literacy – the skills to comprehend provided information about genetics. We posit that those with high genetic literacy skills would be more capable of incorporating genomic information from the media into their assessments of Jolie's decision.

Unlike many encounters with genetic risk information, Jolie's media blitz occurred outside the clinical realm. Therefore, in addition to objective skills, we were interested in individuals' *perceived* confidence to apply their genomics knowledge, in this case, to assess the soundness of Jolie's decision. Recent research into the similar construct of genetic self-efficacy has called for further investigation into the general population's perceived ability to use genomic information [26]. The importance

of measuring the public's confidence with using genomic information cannot be ignored considering the proliferation of genomic health information in consumer settings and online [27, 28]. Both outlets call on individuals to evaluate genetic information without an expert or clinician. Of course, high confidence will be most useful for decision-making if it is properly informed by knowledge and skills [29]. Similar to the role of perceived capability in the RISP model, we considered confidence as a potential mechanism that links media exposure and genetic literacy skills to opinions about prophylactic mastectomies. In this sense, confidence may supplement knowledge by enabling one to apply what they know to make judgments and take action. We thus ask whether those who lack the confidence to apply what they know about genomics are able to benefit from their genetic literacy skills when forming opinions.

To answer these questions, we modeled the main effects and possible interaction of genetic literacy skills and media exposure, while testing for mediation by confidence, in association with the formation and direction of opinions about prophylactic mastectomies. The aim of this analysis was to employ an innovative approach to measuring genetic literacy, with a focus on applied skills and perceived confidence. In capturing this widespread media event, we hoped to enhance understanding of the potential benefits of informed confidence and capable information processing alongside the potential harms of misinformation.

Materials and Methods

The Genetic Literacy Survey was conducted in November 2013 to gather information about how adults in the United States understand genomics and apply this knowledge in everyday situations. The protocol was deemed exempt by the National Institutes of Health Office of Human Research Protections as well as by the University of Pennsylvania Institutional Review Board.

Sample

Approximately 6 months following Angelina Jolie's first op-ed in the New York Times, a total of 1,008 men and women completed our electronic survey. Responses were collected by GfK (market research company) through a heterogeneous consumer panel designed to represent the U.S. adult population, with wide variation in geographic region, education level, age, and household income. The sample over-represented Black non-Hispanic adults.

Survey

The questionnaire was designed to take less than 30 min to complete and included 122 items on genetic literacy and applications of genomic knowledge. The key measures for this report include the following:

Exposure to Angelina Jolie's Media Story. Respondents reported whether or not they had read Jolie's op-ed entitled 'My Medical Choice' in the New York Times and how often they had heard about this story from someone they knew or from media sources (TV, radio, magazines, newspapers, or the Internet) – questions designed based on a validated measure of encoded exposure [30]. The number of times each respondent had read or heard about this story was summed into one composite variable. We used the median value when respondents selected a range, so that a response of '2–4 times' was given the value of 3 when summing total media exposure. If respondents did not provide an answer for one or two of the three questions, it was entered as 0 when summing. If they did not respond to all three questions about media exposure, they were considered missing on this variable and were not included in the analyses. Total media exposure scores ranged from 0 to 21.

Genetic Literacy Skills. Respondents were presented with facts about the genetic risk for breast cancer and a pictograph illustrating the relative risk for those with and without the rare *BRCA* genetic mutations (online suppl. fig. 1; for all online suppl. material, see www.karger.com/doi/10.1159/000447944). This information sheet was derived from the state of the science regarding optimal risk communication strategies [31–33]. Respondents could refer back to this information to answer six multiple choice and fill-in-the-blank questions, such as 'About how many women out of 100 who do not have a *BRCA1* or *BRCA2* mutation will get breast cancer?' Respondents received a point for each correct answer and no points for incorrect and unanswered questions, resulting in scores ranging from 0 to 6. Respondents who answered none of the six questions were considered missing on this variable and were excluded from the analyses. This original measure of genetic literacy was designed to focus on respondents' ability to interpret and apply provided information to align with trends in increasing user control in seeking and processing risk information [23] and expanding opportunities to encounter genomics outside the clinical setting. We have previously found this genetic literacy skills instrument to be more difficult for the general public than recognizing genomic terms, but easier than true/false questions about the biology of genomics [34].

Confidence. Respondents were presented with a hypothetical scenario in which a celebrity decided to have both breasts removed after learning that she carried a 'faulty' gene that greatly increased her risk for breast cancer. Respondents were asked how confident they were to apply what they knew about genomics to evaluate the justification of this decision, ranging from 1 (not at all confident) to 7 (completely confident). This question was derived from previous measures of genetic self-efficacy [26, 35].

Opinionation about Prophylactic Mastectomies. Respondents were asked how much they agreed with the statement: 'Women who have a harmful *BRCA1* or *BRCA2* gene mutation should get a mastectomy.' We first created a variable to capture 'opinionation', whether respondents chose a side in this difficult health scenario or remained neutral. Respondents who strongly, mostly, or somewhat agreed or disagreed were considered to have decisively formed an opinion. Those who said they did not know or selected to neither agree nor disagree (neutral option number four on the seven-point scale) were considered to not have formed an opinion on the issue.

Opinions about Prophylactic Mastectomies. A separate variable used this same question to capture the direction of opinions based on respondents' level of agreement with prophylactic mastecto-

Table 1. Sample characteristics (n = 1,008)

Characteristics	Percentages (n)
Gender	
Male	47.9 (483)
Race	
White non-Hispanic	58.6 (591)
Black non-Hispanic	27.0 (272)
Hispanic	8.2 (83)
2+ races non-Hispanic	3.8 (38)
Other	2.4 (24)
Age	
18–29	16.1 (162)
30–44	23.6 (238)
45–59	36.2 (365)
60+	24.1 (243)
Mean age (SD)	47.41 (14.26)
Education level	
Less than high school	9.0 (91)
High school	31.3 (316)
Some college	29.6 (298)
Bachelors or higher	30.1 (303)
Household income	
Less than USD 24,999	19.0 (192)
USD 25,000–49,999	23.2 (233)
USD 50,000–99,999	31.6 (319)
USD 100,000+	26.2 (264)

mies for women with *BRCA* mutations, with 1 indicating ‘strongly disagree’ and 7 indicating ‘strongly agree’ with having the surgery. Respondents who selected ‘do not know’ (n = 63) were coded as missing when this variable was used in linear regressions.

Demographics. Respondents self-reported demographics such as gender, race, age, education level, and household income.

Analysis

We used SPSS statistical software to conduct our analyses. Respondents with missing data on media exposure, genetic literacy skills, confidence, or opinionation were dropped from our analyses, and those who selected ‘do not know’ were considered missing when modeling opinions. All models were adjusted for gender, race, age, education, and household income. Age, education level, and household income were entered as continuous variables in the models.

First, we computed descriptive statistics on key variables. Then, we modeled the main effects and interactions of media exposure and genetic literacy skills in association with the formation and direction of opinions about prophylactic mastectomies, and tested whether such associations were mediated by confidence (online suppl. fig. 2). We used logistic and linear regressions in the first four-step process to assess (1) the associations of media exposure and genetic literacy skills with the binary outcome of opinionation about prophylactic mastectomies, (2) the associations of these independent variables with the mediating variable of confidence, (3) the association of confidence with the outcome of opinionation, and (4) the best model of independent variables from step one while adjusting for confidence.

Fig. 1. Interaction of genetic literacy skills and media exposure in association with confidence (n = 1,008).

This four-step procedure was repeated using linear regressions for the outcome of opinions about prophylactic mastectomies, with higher values indicating more agreement with the surgery. In both sets of tests, we began steps one and two with testing main effects of media exposure and genetic literacy skills and then built up by adding their interaction. We dropped insignificant interactions, using corrected Akaike information criterion values to determine which model best fit the data without unnecessary complexity.

Results

The characteristics of the sample of 1,008 respondents are presented in table 1. Respondents had heard about Angelina Jolie’s news story an average of 3.5 times (SD = 4.21). Genetic literacy skills were moderate, with an average score of 3.94 correct responses (SD = 1.89). All six of the genetic literacy skills questions were answered correctly by more than half of the respondents. Sixty-three percent of the sample were considered to have ‘high genetic literacy skills’ by scoring above average (at least four correct responses). Fifty-eight percent of respondents were at least somewhat confident in using their knowledge of genomics to assess the decision to have a mastectomy, with an average response of 4.66 (SD = 1.69).

When asked whether women with *BRCA* mutations should get mastectomies, about 51% of respondents neither agreed nor disagreed, while 6% did not know. These

Table 2. Binary logistic and linear regressions of four-step mediation test for factors associated with opinionation (n = 1,008)

Step	Outcome	Variables	Estimate	SE	Wald χ^2	Significance
1	Opinionation	Exp. GLS	0.009 0.162	0.0159 0.0390	0.322 17.308	0.571 <0.001
2	Confidence	Exp. GLS Exp.*GLS	0.152 0.175 -0.018	0.0312 0.0359 0.0069	23.803 23.660 6.531	<0.001 <0.001 0.011
3	Opinionation	Confidence	0.070	0.0387	3.249	0.071
4	Opinionation	Exp. GLS Confidence	0.006 0.157 0.045	0.0162 0.0393 0.0402	0.117 15.999 1.263	0.732 <0.001 0.261

Models are adjusted for gender, education, income, race, and age.
Exp. = Media exposure; GLS = genetic literacy skills.

respondents (57%) were grouped as ‘indecisive’ for having not formed an opinion about this risk-reducing strategy. The remaining ‘decisive’ respondents were relatively evenly split, with about 19% agreeing and about 24% disagreeing that women with *BRCA* mutations should have mastectomies.

Factors Associated with Opinionation about Mastectomies

In the first step of this mediation procedure (table 2), logistic regressions revealed that genetic literacy skills were significantly associated with forming an opinion about mastectomies ($B = 0.162$, $p < 0.001$), while media exposure and interaction were not significant. In the second step, linear regressions showed that media exposure and genetic literacy skills were both positively related to the mediating variable – confidence applying genomic knowledge to assess the justification of Jolie’s choice ($B = 0.152$, $p < 0.001$, and $B = 0.175$, $p < 0.001$, respectively). Media exposure had a greater impact on confidence for those with lower genetic literacy skills (interaction: $B = -0.018$, $p = 0.011$) (fig. 1). This interaction shows that when media exposure was very high, the expected confidence score for those with low genetic literacy skills was higher than the expected confidence of those with high genetic literacy skills. In the third step, confidence was not associated with opinionation ($B = 0.070$, $p = 0.071$), indicating no evidence for mediation in this case. When confidence was entered into the model with the independent variables, genetic literacy skills remained the only

significant association with forming an opinion ($B = 0.157$, $p < 0.001$).

Factors Associated with Agreeing with Mastectomies

We repeated the four-step mediation process using linear regressions for the outcome of opinions agreeing with mastectomies (table 3). Complete data for this outcome were available for 945 respondents. In the first step of this mediation procedure (table 2), the best fit model showed a significant association of media exposure with opinions favoring mastectomies ($B = 0.027$, $p = 0.011$), though the overall model was not significant ($F = 10.060$, $p = 0.435$). Genetic literacy skills were not associated with opinions and did not interact with media exposure. Modeling confidence revealed the same pattern as seen above – media exposure had a greater impact on confidence for those with lower genetic literacy skills. In step three of the mediation test, we found that increased confidence was significantly associated with opinions favoring mastectomies ($B = 0.191$, $p < 0.001$). When confidence was entered into the model with the independent variables, confidence remained significant ($B = 0.189$, $p < 0.001$) while the effect size for media exposure dropped and was no longer significant ($B = 0.012$, $p = 0.244$). Therefore, confidence to apply genomic knowledge mediated the association between media exposure and opinions about mastectomies. In addition, there was an indirect effect of genetic literacy skills on opinions through the pathway of increased confidence (Sobel test effect = 0.026, $p < 0.001$).

Table 3. Multiple linear regression of four-step mediation test for factors associated with opinions favoring mastectomies (n = 945)

Step	Outcome	Variables	Estimate	SE	Wald χ^2	Significance
1	Opinions favoring mastectomies	Exp. GLS	0.027 -0.007	0.0106 0.0257	6.398 0.071	0.011 0.790
2	Confidence	Exp. GLS Exp.*GLS	0.157 0.191 -0.019	0.0334 0.0377 0.0073	22.256 25.747 0.6816	<0.001 <0.001 0.009
3	Opinions favoring mastectomies	Confidence	0.191	0.0254	56.287	<0.001
4	Opinions favoring mastectomies	Exp. GLS Confidence	0.012 -0.032 0.189	0.0105 0.0252 0.0262	1.357 1.645 52.106	0.244 0.200 <0.001

Models are adjusted for gender, education, income, race, and age.
Exp. = Media exposure; GLS = genetic literacy skills.

Discussion

The occurrence of high-profile individuals publicizing health decisions related to genomics is inevitable and likely to increase with new testing capabilities. Our results provide insight into the public's preparedness to evaluate and respond to such media coverage.

Our results suggest that the most important factor in forming an opinion was the objective ability to use genomic information. This association between genetic literacy skills and opinionation is consistent with that reported by Lillie et al. [36]. Those with higher health literacy preferred to have more control in making medical decisions rather than deferring to their doctor. Thus, higher genetic literacy skills may enable more thoughtful consideration of genetic cancer risk to form an opinion regarding whether women with *BRCA* mutations should have risk-reducing surgery. However, in this cross-sectional study, directionality is unclear. It is also possible that our measures of genetic literacy skills and opinionation were capturing engagement with the topic of genomics; those who carefully referred to the information sheet also may have more extensively considered their opinion about prophylactic mastectomies rather than remaining neutral.

Repeated exposure to Jolie's media story was associated with greater confidence even for those less skilled with, or engaged with, the topic. Such effects could be problematic considering the viral nature of modern mass media coverage and its tendency to frame genetic re-

search in misleading ways in the past. Our models suggested that very high media exposure resulted in higher expected confidence for those with lower genetic literacy skills. With Jolie's story featured in the main section of elite newspapers as well as front cover stories [3], this finding raises concerns about the potential of high-profile news stories to artificially inflate confidence among those least prepared to use genomic information. Future research should prospectively evaluate confidence with genomics and information seeking.

Increased confidence applying genomics was associated with favoring mastectomies, a relationship that overrode the main effect of media exposure. These findings align with the RISP model's emphasis on 'perceived information gathering capacity' [8]. For example, 'Internet self-efficacy' has been shown to mediate the association between web use experience and attitudes towards the quality of information through overcoming barriers of online information seeking [37]. Similarly, confidence applying genomics may play a crucial role in fostering greater processing of information in the media to promote favorable opinions about this preventive surgery. These findings also align with those that have shown perceived knowledge about genomics to be a greater driver of attitudes and decisions than actual genomic knowledge [29].

Despite significant health and psychological implications, prophylactic mastectomies can be risk-reducing for those at highest risk of breast cancer [11, 13]. Therefore, the link between confidence and opinions favoring mas-

tectomies implies a potential benefit of *appropriately* improving confidence with genomic information. In our study population, the majority appear to have appropriate confidence in that 70% of those with above average confidence also had above average genetic literacy skills. Learning more about the remaining 30% and the gaps between what they actually know and what they think they know will be important [29]. For example, future research should consider whether confidence operates differently for individuals with and without objective genetic literacy. Longitudinal or experimental research could help decipher directionality, as the observed association likely partially captures how previously favoring mastectomies might promote confidence in evaluating Jolie's decision. In addition, the potential benefits of confidence to apply genomic knowledge should be explored in other relevant scenarios, such as assessing DNA evidence on jury duty, genetically modified food labels, and claims of ancestry testing.

The strengths of this study include the large sample size that relatively accurately represents the U.S. adult population. Our panel over-represented Black non-Hispanic respondents, which means that the data do not reflect the exact demographics of the United States. However, this sample captured the opinions of a group that is often underrepresented in genomics research and provided the opportunity to investigate racial differences in future analyses. We did not weight our data based on race because doing so would have involved losing much of our sample and reducing its statistical power while inferring responses, which would have led to more complex results. We instead adjusted for race in our models. The limitations of the study include cross-sectional data collection. However, the survey was designed to capitalize on a news event, and thus collecting baseline data beforehand was not a possibility. While our study does not account for individuals' breast cancer risk/diagnosis or experiences with genetic testing or cancer screening, it is reasonable

to expect such influences to reflect those of the general population, and the goal of this study was to characterize the public rather than a patient sample. It is still possible that genetic literacy skills, confidence, opinionation, and attitudes are partially driven by previous experiences with breast cancer or genomic risk and other contextual factors not captured by the survey. Future research should consider how such personal experiences affect the patterns we observed.

Our study was able to capture the public after a viral news story had brought genomics into the mainstream media, revealing the link between exposure to such media coverage and confidence applying genomic knowledge. We found this association to be exacerbated for those with low genetic literacy skills, while having high skills was the only factor that facilitated forming an opinion regarding mastectomies. These findings reveal a subset of the population whose confidence with genomics is more vulnerable to the influence of mass media, suggesting the importance of utilizing media coverage to educate the public. Properly improving the public's confidence applying genomic knowledge is critical considering its role moving from media exposure to shaping opinions about risk reduction.

Acknowledgments

This work was supported by the Intramural Research Program of the National Human Genome Research Institute (NHGRI). Its content is solely the responsibility of the authors and does not necessarily represent the official views of the NHGRI or the National Institutes of Health.

Disclosure Statement

Gillian W. Hooker is employed by NextGxDx. There are no patents, products in development, or marketed products to declare.

References

- 1 Jolie A: My medical choice. *The New York Times*, May 14, 2013, p A25.
- 2 Jolie Pitt A: Angelina Jolie Pitt: Diary of a surgery. *The New York Times*, March 24, 2015, p A23.
- 3 Kamenova K, Reshef A, Caulfield T: Angelina Jolie's faulty gene: newspaper coverage of a celebrity's preventive bilateral mastectomy in Canada, the United States, and the United Kingdom. *Genet Med* 2014;16:522–528.
- 4 Nattinger AB, Hoffmann RG, Howell-Pelz A, Goodwin JS: Effect of Nancy Reagan's mastectomy on choice of surgery for breast cancer by us women. *JAMA* 1998;279:762–766.
- 5 Lane DS, Polednak AP, Burg MA: The impact of media coverage of Nancy Reagan's experience on breast cancer screening. *Am J Public Health* 1989;79:1551–1552.
- 6 Kata A: Anti-vaccine activists, Web 2.0, and the postmodern paradigm – an overview of tactics and tropes used online by the anti-vaccination movement. *Vaccine* 2012;30:3778–3789.
- 7 Smith SW, Nazione S, Laplante C, Kotowski MR, Atkin C, Skubisz CM, Stohl C: Topics and sources of memorable breast cancer messages and their impact on prevention and detection behaviors. *J Health Commun* 2009;14:293–307.

- 8 Griffin RJ, Dunwoody S, Neuwirth K: Proposed model of the relationship of risk information seeking and processing to the development of preventive behaviors. *Environ Res* 1999;80(2 Pt 2):S230–S245.
- 9 Yang ZJ, Aloe AM, Feeley TH: Risk Information Seeking and Processing model: a meta-analysis. *J Commun* 2014;64:20–41.
- 10 National Cancer Institute: BRCA1 and BRCA2: cancer risk and genetic testing. National Cancer Institute Fact Sheet, 2014. <http://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>.
- 11 Heemskerk-Gerritsen BA, Menke-Pluijmers MB, Jager A, Tilanus-Linthorst MM, Koppert LB, Obdeijn IM, van Deurzen CH, Collee JM, Seynaeve C, Hooning MJ: Substantial breast cancer risk reduction and potential survival benefit after bilateral mastectomy when compared with surveillance in healthy BRCA1 and BRCA2 mutation carriers: a prospective analysis. *Ann Oncol* 2013;24:2029–2035.
- 12 Kurian AW, Sigal BM, Plevritis SK: Survival analysis of cancer risk reduction strategies for BRCA1/2 mutation carriers. *J Clin Oncol* 2010;28:222–231.
- 13 Domchek SM, Friebel TM, Singer CF, Evans DG, Lynch HT, Isaacs C, Garber JE, Neuhausen SL, Matloff E, Eeles R, Pichert G, Van t'Veer L, Tung N, Weitzel JN, Couch FJ, Rubinstein WS, Ganz PA, Daly MB, Olopade OI, Tomlinson G, Schildkraut J, Blum JL, Rebbeck TR: Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. *JAMA* 2010;304:967–975.
- 14 Bouchard L, Blancquaert I, Eisinger F, Foulkes WD, Evans G, Sobol H, Julian-Reynier C: Prevention and genetic testing for breast cancer: variations in medical decisions. *Soc Sci Med* 2004;58:1085–1096.
- 15 Evans D, Barwell J, Eccles D, Collins A, Izatt L, Jacobs C, Donaldson A, Brady A, Cuthbert A, Harrison R, Thomas S, Howell A, Miedzybrodzka Z, Murray A: The Angelina Jolie effect: how high celebrity profile can have a major impact on provision of cancer related services. *Breast Cancer Res* 2014;16:442.
- 16 Nolte SM: Missed opportunities: media, celebrities, and BRCA1 screening. *Signals* 2014. <http://www.signalsblog.ca/missed-opportunities-media-celebrities-and-brca1-screening/>.
- 17 Pravettoni G, Gorini A, Bonanni B, Veronesi U: The role of heuristics and biases in cancer-related decisions. *Ecancermedicalscience* 2013;7:ed26.
- 18 Borzekowski DL, Guan Y, Smith KC, Erby LH, Roter DL: The Angelina effect: immediate reach, grasp, and impact of going public. *Genet Med* 2013;16:516–521.
- 19 U.S. Preventive Services Task Force: BRCA-related cancer: risk assessment, genetic counseling, and genetic testing. U.S. Preventive Services Task Force Published Recommendations, 2013. <http://www.uspreventiveservicestaskforce.org/Page/Document/Update-SummaryFinal/brca-related-cancer-risk-assessment-genetic-counseling-and-genetic-testing>.
- 20 Christensen KD, Jayaratne TE, Roberts JS, Kardia SL, Petty EM: Understandings of basic genetics in the United States: results from a national survey of Black and White men and women. *Public Health Genomics* 2010;13:467–476.
- 21 Durant J, Hansen A, Bauer M: Public understanding of the new genetics; in Marteau T, Richards M (eds): *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*. Cambridge, Cambridge University Press, 1996.
- 22 Lanie AD, Jayaratne TE, Sheldon JP, Kardia SL, Anderson ES, Feldbaum M, Petty EM: Exploring the public understanding of basic genetic concepts. *J Genet Couns* 2004;13:305–320.
- 23 Dunwoody S, Griffin RJ: Risk Information Seeking and Processing model; in Cho H, Reimer T, McComas KA (eds): *The Sage Handbook of Risk Communication*. Thousand Oaks, Sage Publications, 2014, p 376.
- 24 Juthe RH, Zaharchuk A, Wang C: Celebrity disclosures and information seeking: the case of Angelina Jolie. *Genet Med* 2015;17:545–553.
- 25 Noar SM, Althouse BM, Ayers JW, Francis DB, Ribisl KM: Cancer information seeking in the digital age: effects of Angelina Jolie's prophylactic mastectomy announcement. *Med Decis Making* 2015;35:16–21.
- 26 Carere DA, Kraft P, Kaphingst KA, Roberts JS, Green RC: Consumers report lower confidence in their genetics knowledge following direct-to-consumer personal genomic testing. *Genet Med* 2016;18:65–72.
- 27 Bernhardt JM, McClain J, Parrott RL: Online health communication about human genetics: perceptions and preferences of Internet users. *Cyberpsychol Behav* 2004;7:728–733.
- 28 Dutta MJ, Pfister R, Kosmoski C: Consumer evaluation of genetic information online: the role of quality on attitude and behavioral intentions. *J Comput Mediat Commun* 2010;15:592–605.
- 29 Pearson YE, Liu-Thompkins Y: Consuming direct-to-consumer genetic tests: the role of genetic literacy and knowledge calibration. *J Public Policy Mark* 2012;31:42–57.
- 30 Southwell BG, Barmada CH, Hornik RC, Maklan DM: Can we measure encoded exposure? Validation evidence from a national campaign. *J Health Commun* 2002;7:445–453.
- 31 Hawley ST, Zikmund-Fisher B, Ubel P, Jancovic A, Lucas T, Fagerlin A: The impact of the format of graphical presentation on health-related knowledge and treatment choices. *Patient Educ Couns* 2008;73:448–455.
- 32 Zikmund-Fisher BJ, Fagerlin A, Ubel PA: Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer* 2008;113:3382–3390.
- 33 Tait AR, Voepel-Lewis T, Zikmund-Fisher BJ, Fagerlin A: The effect of format on parents' understanding of the risks and benefits of clinical research: a comparison between text, tables, and graphics. *J Health Commun* 2010;15:487–501.
- 34 Abrams LR, McBride CM, Hooker GW, Cappella JN, Koehly LM: The many facets of genetic literacy: assessing the scalability of multiple measures for broad use in survey research. *PLoS One* 2015;10:e0141532.
- 35 Kaphingst KA, McBride CM, Wade C, Alford SH, Reid R, Larson E, Baxevanis AD, Brody LC: Patients' understanding of and responses to multiplex genetic susceptibility test results. *Genet Med* 2012;14:681–687.
- 36 Lillie SE, Brewer NT, O'Neill SC, Morrill EF, Dees EC, Carey LA, Rimer BK: Retention and use of breast cancer recurrence risk information from genomic tests: the role of health literacy. *Cancer Epidemiol Biomarkers Prev* 2007;16:249–255.
- 37 Rains SA: Seeking health information in the information age: the role of Internet self-efficacy. *West J Commun* 2008;72:1–18.