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The role of numeracy on client knowledge in BRCA genetic counseling

David B. Portnoy[a,*], **Debra Roter**[b], and **Lori H. Erby**[b]

[a] Cancer Prevention Fellowship Program, National Institutes of Health, Bethesda, MD, USA

[b] Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

Abstract

Objective—To assess the impact of numeracy and health literacy on client's ability to learn information orally communicated during a BRCA 1/2 genetic counseling session.

Methods—Fifty-nine videotaped simulated genetic counseling sessions were shown to 246 analogue clients (AC) recruited to imagine themselves as the client in the genetic counseling session. AC numeracy, genetic literacy, state and trait anxiety, and decisional conflict were assessed. The primary outcome was AC learning about BRCA1/2.

Results—Health literacy and numeracy were moderately correlated, and each independently predicted learning. Higher numeracy was associated with higher knowledge scores only among ACs with adequate literacy. Decisional conflict was not related to literacy, numeracy, or knowledge acquisition. It was, however, inversely related to state anxiety so that the higher post-session state anxiety, the lower the AC's decisional conflict.

Conclusion—Numeracy and health literacy are associated with learning of orally communicated information during genetic counseling. It appears that numeracy can facilitate learning for literate subjects; it does not, however, make any difference in learning ability of clients with significant literacy deficits.

Practice Implications—Numeracy plays an important role in client's ability to learn information communicated during medical sessions, especially among clients who are otherwise regarded as literate.

Keywords

Numeracy; Patient–provider interaction; Genetic counseling; Patient learning

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* Corresponding author at: Cancer Prevention Fellowship Program, National Cancer Institute, Executive Plaza North, MSC 7365, 6130 Executive Boulevard, 4th Floor, Bethesda, MD 20892-7105, USA. Tel.: +1 860 490 8993, fax: +1 270 638 0417. portnoydb@mail.nih.gov (D.B. Portnoy).

1. Introduction

Although genetic testing can be useful in determining an individual's risk of disease, appropriate action can only be taken if the patient can understand and interpret the information they receive. The risk concepts that underlie this information are difficult to grasp without familiarity with the concepts of probability and risk. Few low literate women have mastery of these concepts. As described in a study by Schwartz and colleagues [1], one-third of the 500 women in their study were unable to accurately predict how many of 1,000 fair coin flips would land on the same side. Not surprisingly, the majority of these women misinterpreted risk reduction data provided to them in regard to mammography. The authors conclude that quantitative information about risks and the benefits of screening in terms of risk reduction may be meaningful only to individuals who have facility with the concepts from which the meaning of probability is derived. In a similar vein, Davis and colleagues (1996) found that women with reading skill at or below the fifth grade level were three times more likely than those reading at or above the ninth grade level to fail to understand the value of preventive screening tests in terms of risk reduction.

A number of studies specific to genetic screening have also documented less than optimal understanding of tests among women being offered screening. Furthermore, it is the least educated women that have the poorest scores [2-4]. Although a number of knowledge-based interventions have successfully increased women's capacity to recall basic information pertinent to genetic screening, the challenge is much more complex than the delivery of simple facts and the raising of knowledge scores. Coupled with the heightened anxiety of uncertainty and vulnerability attending the first visit, the conversation regarding genetic risk can be cognitively and emotionally overwhelming. It is in this circumstance that the medical dialogue provides the translational link between the new technologies of genetics and **a** client's ability to use the information to engage in a process of meaningful, informed decision making with her doctorregarding subsequent health actions.

Along with literacy, numeracy has also been shown to be associated with **a** patient's ability to accurately interpret food labels [5], but this relationship has not been examined in potentially high stakes encounters such as genetic counseling. As genetic counseling information presents both risk and probability concepts as well as health terms, both numeracy and health literacy may play a role in their understanding. An analysis of the content of genetic counseling sessions about familial breast cancer risk revealed the presentation of an average of four risk concepts per session [6,7]. These concepts are often the crux of a genetic counseling session and used to formulate decisions based on personal risk [8]. Patients who are unable to understand risk information because of numeracy deficits may fail to benefit from genetic counseling, or even worse, make screening or treatment decisions based on a faulty understanding of their risk. The lack of knowledge and inaccurate risk estimates may also lead to decisional conflict. Positively related to anxiety, decisional conflict represents difficulty in making a decision, especially when it involves uncertainty and high stakes [9]. While the impact of literacy on learning and decision making has been examined, we are unaware of any research that distinguishes the effect of literacy and numeracy on these processes in genetic counseling. Based on previous research, we predict that both literacy and numeracy will have an independent effect on client learning of orally presented information and decisional conflict.

2. Methods

2.1. Study participants and procedures

This sample was drawn from the Genetic Counseling Video Project, the details of which have been reported in detail elsewhere [10,11]. Eighty-one genetic counselors (GC)

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recruited during the National Society of Genetic Counselors meetings in 2003 and 2004 conducted videotaped cancer genetic counseling sessions with **one** of six female simulated clients (SC), and in half the cases, a simulated spouse. The SC portrayed a woman with a family history of breast and ovarian cancer seeking information about BRCA1/2 genetic testing, **with** or without a simulated male spouse present.

A total of 246 subjects, referred to as Analogue Clients (AC), were recruited in Baltimore, MD and Salt Lake City, UT through various community **sources**. AC serve as a proxy for actual genetic counseling clients by viewing the videotaped session and imagining themselves as the client (female subjects) or client's spouse (male subjects). Approximately four AC were recruited to independently view each of the 59 videotapes (M = 4.17 AC per videotape) which averaged just under one hour of face-to-face counseling time (M = 51.57 minutes, SD = 15.23).

Eligibility criteria were set to enhance the AC identification with the simulated client and spouse in the videotape. These criteria included having a personal or family history of cancer but no prior genetic counseling experience. Because female ACs were used to rate sessions conducted with the client alone as well as those with a client and spouse, the majority of ACs were female (77.5%) and were on average 37.08 years old (Range: 18 -76). The sample was ethnically diverse; half of the AC (50.0%) sample was Caucasian and over a third (36.2%) was African American. Although the sample was recruited nearly evenly from the two sites (52% from Baltimore), almost all (96.6%) of **the** African American subjects in the study were recruited from Baltimore. The study was approved by the IRBs of the Johns Hopkins Bloomberg School of Public Health and the University of Utah. All GCs and ACs gave full informed consent for study participation.

2.2. Study Measures

Numeracy was measured using a three-item measure that asks participants to estimate a simple probability, convert a percentage into a number, and convert a number into a percentage in which the number of correct items was summed with a possible range from 0 to 3. Previous studies have found this scale to have adequate reliability [12].

To measure genetic literacy, ACs completed the Rapid Estimate of Adult Literacy in Genetics (REAL-G) [13]. The REAL-G, fashioned after the Rapid Estimate of Adult Literacy in Medicine (REALM), assesses ability to read multisyllabic words commonly used in genetic counseling sessions The REAL-G has been validated against the REALM and has been shown to be predictive of knowledge gain [13].

Knowledge about the genetic basis for breast cancer, BRCA 1/2 mutations, and BRCA 1/2 genetic testing was assessed using an eight **item** true/false **measure** adapted from Lerman **et al** [14,15]. The percentage of correct answers comprised the knowledge score. The measure had an acceptable level of internal consistency (Cronbach's α = .69). Assuming equivalent baseline knowledge about BRCA 1/2 among all ACs, questionnaire scores are assumed to reflect learning of information communicated during the genetic counseling session. This assumption is based on the eligibility criteria of having a family history of breast cancer, but having no previous experience with genetic counseling. To control for other factors possibly related to baseline knowledge, site of recruitment and age are controlled for in the analyses[1].

[1]No individual-level data on AC's education were collected. However, due to the large difference in average level of education by area of recruitment (% adults that are high school graduates: 68.4% for Baltimore [32] vs. 83.4% for Salt Lake City [33]) among other differences (Table 1), controlling for site of recruitment in the analysis will help to control for the effect of general education on learning or knowledge about BRCA 1/2.

Decisional conflict was measured by a modified version of the decisional conflict scale [9]. Participants indicated how hard or easy it would be for them to make the decision to get BRCA 1/2 genetic testing if they were the client **(or spouse)** in the videotape. On a 5-point Likert-type scale, participants agreed or disagreed with 13 statements such as "I'm unsure what to do in this decision". Items were scored so that higher number**s** indicated **a** greater amount of decisional conflict (e.g., having a harder time making a decision).

AC Anxiety was measured both before and after watching the videotaped session using the State-Trait Anxiety Inventory [16]. Trait anxiety was measured prior to viewing the video and state anxiety was measured both before and after viewing the video. Each scale consists of twenty statements (e.g., I feel calm) to which subjects indicate on a 4-point scale ranging from *Almost Never* to *Almost Always* how often they currently (state) or generally (trait) feel that way.

Session length and dialogue interactivity, defined as the rate of speaking turns per session minute and described in detail elsewhere [17,18], w**ere** used to characterize the session dialogue because these variables have been previously found to be related to oral literacy demand.

2.3. Analysis Strategy

Statistical analyses were conducted using SPSS version 14.0.0 [19]. Although each video was viewed by multiple AC, creating a nested structure of data whereby AC data were nested in videotape "clusters", multi-level modeling was not performed. The intraclass correlation (ICC) using the main outcome of cancer knowledge was quite low (ICC = .04). Using this ICC and the mean number of AC who viewed the same tape (4.17), the corresponding design effect was only 1.12, well below the threshold requiring multi-level modeling. According to Maas and others [20,21], if the design effect is less than two, not using multilevel modeling with nested data should not produce overly inaccurate estimates. Therefore, for ease of interpretation the data were analyzed using stepwise multiple linear regressions using Generalized Linear Model (GLM) procedures.

There were no differences found on any key variable by AC gender, including numeracy t (242) = −.503, p = .616; knowledge t (239) = −.690, p = .491; or anxiety t (241) = .830, p = .408. Because of this equivalence on key variables, and the relatively small number of men in the sample (n=55, 22.4%), gender was not included in the analyses. However, the influence of site and age **were** controlled for due to **their** relation to key variables as described below.

3. Results

3.1. Summary of key variables related to demographic factors

Descriptive statistics for key variables as they relate to AC demographic factors and differences by site are presented in Table 1. Numeracy for this sample was fairly high on the three-item scale (M = 2.16, SD = 1.09), however the Utah sample exhibited much higher scores than the Baltimore sample, t (242) = 9.77, p < .001. Numeracy and age were significantly negatively correlated, r (244) = −.218, p = .001.

Genetic literacy as measured by the REAL-G [13] was adequate for the sample as a whole (M = 59.27 out of 63, SD = 7.96), but significantly higher in the Utah sample than the Baltimore sample, t (242) = 5.91, p < .001. The REAL-G score was also significantly negatively correlated with age, r (244) = −.256, p < .001. Learning of genetic information assessed after viewing the videotaped session was adequate but varied widely (M = 68.28%, SD = 25.10). Again, differences were found between the two sites; ACs from Utah showed higher levels of learning than did ACs from Baltimore, t (238) = 7.25, p < .001. In addition, cancer knowledge and age were significantly negatively correlated, r (240) = −.163, p = .012.

The Baltimore sample was lower on numeracy, cancer knowledge and genetic literacy, and these variables were significantly correlated with age (Table 1). The Baltimore site also accounted for nearly all the African American subjects. To control for these potential confounding effects, both site of AC recruitment and age were controlled for in the analyses.

3.2. Numeracy, genetic literacy and learning

Numeracy and literacy were significantly related, r (244) = .50, p < .001. Low literate subjects, defined as scoring 3 or less on the 8-item Short REAL-G [13], also had lower numeracy scores (M = 1.06, SD = 1.09) than subjects with adequate literacy skills (M = 2.37, SD = .936), t (236) = −7.09, p < .001.

To assess the relationship between numeracy and learning, a stepwise multiple linear regression was performed with four steps. Step 1 included the age and site variables to control for possible confounding, as well as the main predictor of numeracy; step 2 included the REAL-G score; step 3 included the session characteristics of session length and interactivity; step 4 included the interaction terms of session length by interactivity and numeracy by REAL-G score.

Each step of the regression was significant (Table 2), and the final model accounted for 30.1% of the variance in knowledge scores. In the first step, numeracy positively predicted learning, consistent with hypotheses. In the second step, genetic literacy also positively predicted learning and numeracy remained a significant independent predictor. After including session length and interactivity in the third step, both numeracy and REAL-G remained significant. Session length was also a significant positive predictor of learning after controlling for numeracy and genetic literacy. Adding the interaction terms in step 4 did not significantly improve the model (p = .137). However, in that step, the interaction of numeracy and REAL-G was marginally significant, p = .061 (Table 2). Holding all other variables constant, an increase in numeracy predicted knowledge scores for ACs with adequate literacy (Figure 1). Among ACs with restricted literacy, increased numeracy did not significantly increase learning. **After** rerunning the analysis stratified by site, a similar general pattern of results was found. **T**he relationship was weaker for the Utah sample as the effect of numeracy became non-significant in step 3.

3.3. Decisional Conflict and Anxiety

Decisional conflict was unrelated to literacy, numeracy and learning. However, it was inversely correlated with ACs' state anxiety measured after viewing the video, r (238) = −.154, p = .017. Higher state anxiety was related to less decisional conflict. This effect was most pronounced for AC with low levels of trait anxiety.

There was a significant increase in AC anxiety after exposure to the counseling session video. After watching the video, anxiety averaged 10.78; pre-viewing state anxiety averaged 5.06; t (236) = −26.49, p < .001. This change in state anxiety was more pronounced for those subjects who scored above the mean in trait anxiety at baseline; AC that were above the mean in trait anxiety increased more (M = 21.1) than did those below the mean (M = 14.4), t (234) = −5.05, p < .001.

Using repeated-measures ANCOVA with state anxiety as the within-subjects variable, age and site as covariates, and numeracy, genetic literacy, knowledge, decisional conflict, session length, and interactivity as between-subjects variables, produced no significant effects, F (1, 105) < 2, p > .10 other than the change in anxiety from pre to post assessment.

4. Discussion and conclusion

4.1. Discussion

The main findings supported the study predictions; both numeracy and genetic literacy were independent predictors of learning from videotaped genetic counseling sessions These findings echo Rothman [5] who found that understanding of a food nutrition label was related to both numeracy and health literacy As in their study, we found that numeracy and literacy were only moderately related, so that differences in numeracy skill were evident even among subjects with adequate literacy. This suggests that genetic literacy and numeracy work in concert to aid learning. In addition, the differential effect of numeracy by literacy level suggests that for those with adequate literacy, higher numeracy is more of an aid to learning than it is in those with low genetic literacy.

Longer sessions were associated with greater knowledge, but more interactive sessions were not. As noted elsewhere, longer and less interactive sessions convey more information [17]. Longer sessions may also allow for more time for clients to process information, and may allow for the repetition of key information that shorter sessions do not.

Contrary to predictions, decisional conflict was not related to knowledge gain or literacy. AC with more information on which to base their hypothetical decision to get BRCA testing found it no easier to make a decision than ACs who learned less from the session. This may be related less to the amount of knowledge a client possess**es** when making a decision for testing, and more to the persuasiveness of the knowledge they do have. In fact, more information, which presents both positives and negatives of a decision, may be more cognitively difficult to process and synthesize, especially if some information is contradictory. In fact, other studies have found that decision-makers often constrain the amount of knowledge they consider when making a decision [22] to avoid this cognitive overload.

It also appears that decisional conflict and state anxiety were related in the opposite direction than predicted [9], and found previously [23]. State anxiety increased for ACs after watching the videotaped session, suggesting that the presentation of risk information raises state anxiety. There is a caveat to this finding; baseline levels of trait anxiety were associated with the amount of change in state anxiety. Generally anxious clients were most likely to experience an increase in state anxiety, perhaps as a result of exposure to risk information. The ACs had not seen a genetic counselor prior to the study, and had some family experience with cancer; the increase in anxiety may be similar to a client who has been referred to genetic counseling for the first time. Like first time clients, AC entered the study with little, if any, information about their own risk. At the end of the study, they had a better picture of their risk, which may have facilitated hypothetical decision making, but nonetheless experienced some increase in state anxiety, especially among those with generally high levels of anxiety.

4. 2. Limitations

This study used analogue clients who watched a simulated genetic counseling session. Consequently, the ACs were unable to participate in the genetic counseling session or obtain true personalized risk information. However, the majority of (73.2%) of ACs reported that it was “Easy” or “Extremely Easy” to imagine themselves as the client in the videotape, and the sessions approximated the length of real genetic counseling sessions [7]. In addition, AC's level of education was not directly assessed. However measures of numeracy and genetic literacy that were used are thought to be more sensitive than measures of years of education, because they assess functional skills [24,25]. In addition, assessing education would not have given information about baseline levels of BRCA 1/2 knowledge.

Although we assumed equivalence of BRCA knowledge at baseline and attempted to control for potential differences, "learning" of information as defined in the study may reflect both pre-counseling levels of BRCA knowledge and learning during the session. Even if this were the case, the results showing the independent and interactive effects of numeracy and genetic literacy would still hold with respect to overall BRCA knowledge, all of which was learned at one point.

4. 3. Conclusion

Numeracy is an important correlate of health outcomes [26] as well as decision process variables in risk perceptions [1]. In this study, we showed that numeracy, independent of genetic literacy, was related to knowledge gleaned from a genetic counseling session for breast cancer risk. Strategies often used to present risk information may address some issues related to numeracy, such as through the use of visual aids [27]. Our results show that clients' level of numeracy may have important implications for their ability to make informed testing, screening and treatment decisions. Numeracy's effect may not be constant; in fact, it appears that variation in numeracy is associated with learning only for those with adequate literacy. The need to tailor genetic counseling information to a client's expectations and affective state has been established [28]. To this we must also add that the presentation of risk information must be tailored to the client's ability to understand and use it.

These results also suggest an inverse relationship between anxiety and decisional conflict such that heightened anxiety may be the price of lessened decisional conflict. We hope that future studies will examine this issue in more detail. We do not know if numeracy deficits impede learning of information that is presented using numbers or if restricted numeracy affects all types of information, but our finding**s** suggest that its effect may be broader than simply numeric. It may speak to the ability of individuals to engage in abstract and conceptual reasoning at higher levels than needed to mechanically decode text.

4.4. Practice Implications

The practice implications of this work are clear. Numeracy, as well as health literacy, should be assessed along with other factors that may influence clients' ability to make sense of and use risk information. If possible, domain-specific forms of health literacy such as genetic literacy should be used to provide a more accurate assessment of competency to understand the risk information. In addition, it should not be assumed that simply because a client requests risk information in numbers that they can understand those numbers as they appl**y** to personal risk. Similarly, low health **or genetic** literacy should not be equated with numeracy. Health literacy deficits have been widely documented [29,30], however the research on numeracy is still emerging. Consequently, genetic counselors and other**s** presenting quantitative risk information must be aware of the potential of numeracy to impede client understanding.

Measures of numeracy that take little time to administer, such as the one used in this study [12], or subjective measures of numeracy [31] may help to inform health care providers of a patient's level of numeracy which can then be used to tailor the delivery of risk or other numerate information. In conclusion, health care providers should be cognizant of their patient's numeracy and health literacy in order to ensure that risk or other numerate information can be both comprehended and used by their patients.

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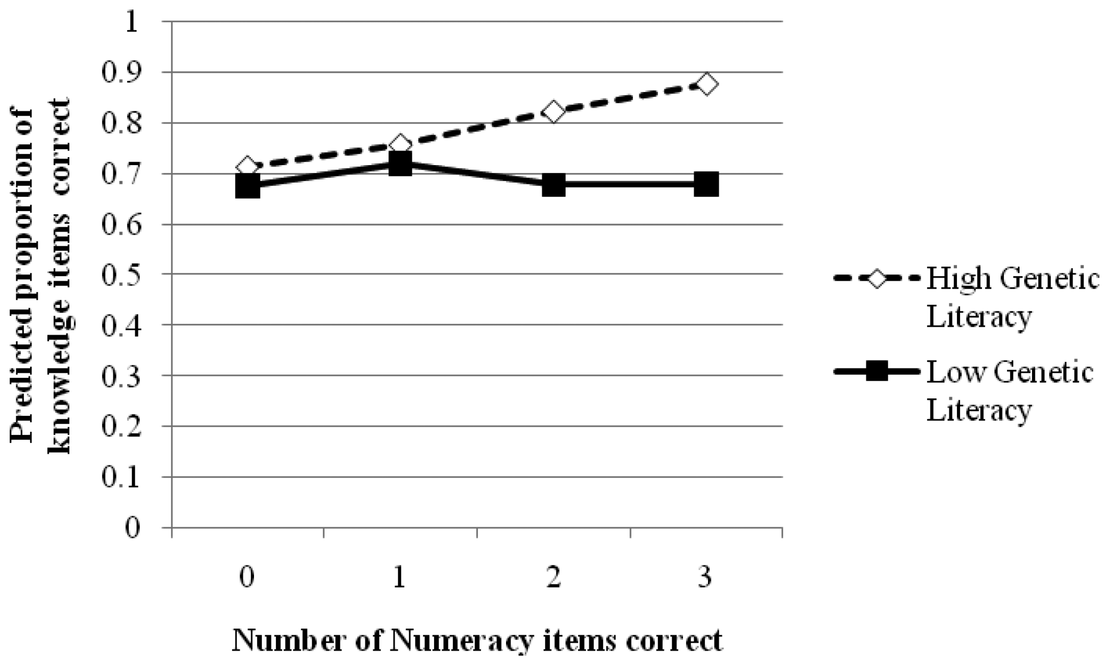

Note: High genetic literacy (REAL-G) = 63 (Scale max.), Low genetic literacty (REAL-G) = 52 (-2SD from Mean).

Analyses are controlling for age, site, session length, interactivity, and session length X interactivity.

Figure 1.
Interaction of genetic literacy (REAL-G) and numeracy on knowledge

Table 1

Summary of key variables related to demographic factors

	Overall		Utah		Baltimore				
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	**p-value**	**correlation with age**	**p-value**
Numeracy	2.16	1.09	2.71	0.631	1.56	1.16	<.001	−0.218	0.001
Knowledge	68.28%	25.1	78.50%	19.74	57.20%	25.65	<.001	−0.163	0.012
REAL-G	59.27	7.96	61.98	4.02	56.33	9.91	<.001	−0.256	<.001

Note: Numeracy score is out of 3, REAL-G score is out of 63.

Table 2

Regression results for knowledge score

Step	Variables	Beta	p-value	p-value for step	Adjusted R^2	R^2 change	p-value for change
1	Age	−0.018	0.775	< .001***	0.243	0.254	< .001***
	Site*	−0.228	0.020				
	Numeracy***	0.344	< .001				
2	Age	0.003	0.966	< .001***	0.261	0.021	0.016*
	Site**	−0.211	0.003				
	Numeracy***	0.278	< .001				
	REAL-G*	0.168	0.016				
3	Age	0.005	0.939	< .001***	0.301	0.046	0.002**
	Site***	−0.226	0.001				
	Numeracy***	0.275	< .001				
	REAL-G*	0.16	0.018				
	Session Length***	0.202	0.001				
	Interactivity	−0.057	0.340				
4	Age	0.006	0.917	< .001***	0.301	0.014	0.137
	Site**	−0.194	0.007				
	Numeracy	−0.562	0.216				
	REAL-G	0.051	0.570				
	Session Length	0.29	0.091				
	Interactivity	0.046	0.816				
	Numeracy × REAL-G†	0.916	0.061				
	Session Length × Interactivity	−0.146	0.552				

* $p < .05$

** $p < .01$

*** $p \leq .001$

† $p < .07$