



Christine Zalewski. *Magnolia I.* Photograph.

*More work is needed to make patient education materials on genetic risk for breast cancer easier to understand.*

## Enhancing the Readability of Materials Describing Genetic Risk for Breast Cancer

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**Background:** *The number of individuals contemplating genetic testing is increasing, but the current materials and overall subject matter remain complex and not easily understood by many. The goal of this project was to evaluate efforts to revise and increase the readability of an existing information packet describing genetic risk for breast cancer.*

**Methods:** *Evaluation was conducted in two stages through two related studies. In Study 1, a focus group of multiethnic breast cancer survivors was assembled to obtain feedback on images included in the revised breast cancer genetics information packet. In Study 2, African American adult students in a literacy program evaluated the revised images (based on the feedback of the focus group in Study 1) and text of the information packet and provided ratings on readability, format, and appearance.*

**Results:** *Responses from Study 1 participants suggested that some of the images created for the packet needed to be clearer in the concepts they were intended to convey. In Study 2, ratings of adult learners suggested difficulty with word comprehension in spite of the inclusion of definitions and a glossary. The reading level achieved was markedly lower than the college reading level required by the original information packet and other patient-directed cancer genetics materials.*

**Conclusions:** *Although efforts to clarify written materials in order to better serve patients with low literacy received generally favorable responses, continued efforts to create more user-friendly patient education materials are warranted.*

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## Introduction

Literacy is a critical yet often overlooked issue in the development and dissemination of printed cancer education materials. Results from the Department of Education National Adult Literacy Survey revealed that approximately 20% to 25% of the US adult population reads at or below a 5th-grade level and lacks the basic reading skills that would enable them to read and understand directions on a map or instructions on a medication.<sup>1,2</sup> Low reading comprehension is associated with lower recall of health-care information and lower satisfaction with the communication of such information.<sup>1</sup> It is not surprising, then, that low literacy levels are consistently associated with poorer health status.<sup>3,4</sup> Although the association between literacy level and cancer-related outcomes has not been examined specifically, reviews have revealed that most cancer education materials are written at a 10th-grade level or higher,<sup>1</sup> which would make such materials too difficult to understand for a significant portion of the population. Therefore, efforts to increase the readability of printed cancer-related information are necessary.

Little attention has also been paid to the literacy level required by materials developed for individuals at high risk for developing breast cancer due to their family history of the disease. It is estimated that 5% to 10% of breast cancer cases are due to mutations in two genes, *BRCA1* and *BRCA2*,<sup>5,6</sup> and testing to identify these mutations is now available commercially. In order to make an informed decision about testing, individuals should have some understanding of complex genetic information as well as the potential positive consequences of testing (eg, improved medical decision-making, increased information about relatives' cancer risk) and the negative consequences of testing (eg, increased worry about one's health status and the health of relatives, negative emotional reactions, and possible insurance or employment discrimination).<sup>7-10</sup> Richards and Ponder<sup>11</sup> assert that a general "genetic literacy" is a prerequisite for appropriate patient use of genetic tests. To date, there is no review of the readability of patient-directed cancer genetics materials in the literature. However, Gribble<sup>12</sup> investigated the readability of informed consent documents for *BRCA1/2* testing obtained from several research institutions. Such consent forms typically include a description of the genetic testing process, as well as the potential consequences of testing. Gribble reported that, on average, these documents were written at a grade level 1 year beyond high school graduation and had reading ease scores similar to those of academic journals. These results are indicative of what has been referred to as a "readability gap" between the language of cancer genetics materials and the reading skills of many people.<sup>12</sup>

The goal of the two studies presented here was to evaluate efforts to revise and increase the readability of an existing information packet describing genetic risk for breast cancer. These efforts were part of an ongoing

research project at the Mount Sinai School of Medicine called Talking About Counseling and Testing (TACT). The primary aim of TACT is to evaluate the impact of culturally targeted genetic counseling vs standard genetic counseling on decisions to undergo *BRCA1/2* testing among African American breast cancer patients. As part of this aim, it was necessary to include supplementary printed materials that review the basic content of the counseling sessions. The readability of the information packet was an area of focus because, although the majority of low-level readers are white, people of color are more likely to perform at the lowest literacy levels.<sup>13</sup>

The current evaluation is unique in two ways. First, the revised information packet was reviewed by lay people who shared key characteristics with the packet's target audience: breast cancer survivors and adults with low literacy skills. Many readability evaluations of cancer education materials are based on objective scores and assessment tools (eg, the Flesch Reading Ease Formula, Flesch-Kincaid Grade Level Formula, the Readability Assessment Instrument, SMOG Readability Formula) that are used by or administered to professional-level reviewers.<sup>14-17</sup> Second, the current evaluation is unique in that it employed a two-stage approach: (1) Multiethnic breast cancer survivors, who met regularly as research subject recruiters for a separate study, participated in a focus group to provide feedback on images included as part of the revision. Members of this group of survivors were asked to participate due to their similarity to the information packet's target group in terms of breast cancer diagnosis and concerns about familial aspects of breast cancer risk. Their feedback was used to revise the images even further. (2) Next, ratings of both the revised images and text of the information packet were obtained from a class of African American adult learners with low literacy skills. These class members were included in our evaluation efforts because they not only shared the target group's ethnicity, but also were representative of the segment of the information packets' target group who are likely to demonstrate low reading comprehension according to national survey data. Both studies were components of educational efforts to increase awareness of genetic risk for breast cancer.

## Study 1

### Methods

In Study 1, a focus group of breast cancer survivors was organized to obtain feedback on images included in the revised breast cancer genetics information packet.

### Participants

The focus group was composed of 7 women who were breast cancer survivors and who also served as Patient

Advocates for Research Participation (PARPs). These survivors recruit breast cancer patients for a separate, ongoing, large-scale case-control study at the Mount Sinai School of Medicine. The PARPs who participated in the current study were enlisted at a regular recruiter meeting and all attendees participated. Participants were 3 African American survivors, 3 white survivors, and 1 Latina survivor, ranging in age from 45 to 54 years. Of these women, 3 had completed high school and 4 had either an Associate's degree or a Bachelor's degree.

### **Materials and Measures**

Participants were presented with the images included in a revised information packet describing genetic risk for breast cancer. The original information packet is part of a separate research study conducted at both the Lombardi Cancer Center at Georgetown University and Mount Sinai School of Medicine called Personal Aid to Health (PATH). The original information packet contains 26 pages of breast cancer genetics information followed by an additional 13 pages of resources. The information packet begins with an overview of the PATH study and provides background information on risk factors for breast and ovarian cancer. It then reviews the inheritance of cancer susceptibility, including a discussion of breast cancer susceptibility genes (specifically, *BRCA1* and *BRCA2*) and the cancer risks associated with alterations in these genes. The information packet also reviews the process of genetic testing and its benefits and limitations. Finally, the information packet includes a discussion of appropriate cancer screening and risk reduction options for breast cancer.

This information packet was revised for the TACT project because it was written at a considerably sophisticated level, the text was dense, and it had few pictures that facilitated comprehension of the text. This assessment is supported by a calculation of the packet's Flesch-Kincaid Grade Level, which is a function of the average length of sentences in a text and the average number of syllables per word. The Flesch-Kincaid Grade Level of the original packet was greater than grade 12. Readability was also assessed through the Flesch Readability Test, which determines reading ease and is based on a formula that yields a score of 0 (ie, extremely difficult to read, average sentence length is 37 words, average word is more than two syllables) to 100 (ie, very easy to read, average sentence length is 12 words, no words of more than two syllables). The original packet had a Flesch Reading Ease score of 39.5. As a score of 65 represents "plain English," a score of 39.5 suggests that the packet was written in fairly complex language.

**Revision of Information Packet Text to Increase Readability** — The existing information packet was revised using several strategies recommended for creating printed health-related materials appropriate for a wide range of reading levels.<sup>1,18-20</sup>

**Word Substitution and Limiting of Sentence Length** — The authors attempted to shorten sentences whenever possible. For example, the PATH heading, "Estimated Cancer Risks Associated with *BRCA1* and *BRCA2* Alterations" was revised as "What Does It Mean if I Have a *BRCA* Mutation?" Also, whenever possible, difficult words were substituted with simpler words. For example, the word *individual* was changed to *person*. However, in some instances, authors chose to retain an advanced word or term if it was commonly used by genetics professionals and there was no alternative word or term that was both succinct and conveyed the same meaning. Examples of such words or terms that were always defined but used repeatedly include *mutation*, *tamoxifen*, *chromosome*, and *variant*.

**Comprehension of Difficult Words** — All difficult words were presented in boldface type and defined in the text. They were also included in a glossary at the end of the information packet along with the pronunciation of the word and a more detailed definition.

**Use of Analogies as Examples** — Wherever possible, the authors used analogies that would be familiar to the information packet's target audience as a way of clarifying concepts.<sup>20</sup> One such example was the explanation of the meaning of specific *BRCA1/2* test results referred to as variants of uncertain significance. This type of result means that a genetic change was found but it is uncertain if this change has an effect on a person's risk for cancer. In certain cases, variant results can be further defined to indicate that the result is either likely or unlikely to be associated with an increased cancer risk. Such test results were explained in the revised information packet using the analogy of a commuter train ride, since this experience is familiar to the urban population from which the majority of participants would be recruited. In this analogy, readers were asked to imagine that they were taking an express train to make an appointment on Main Street. They were then asked to envision different scenarios that might occur during the ride that could each affect whether the rider will make it to the Main Street appointment on time. The likelihood of whether a rider will be on time for their appointment is related to the different types of variant results. For example, a scenario in which the train changes its route and the rider will probably not be on time is related to a variant result.

Other strategies applied to increase readability included the use of large font, use of headings to introduce new ideas, limited use of tables and graphs, and increased use of white space on a page.<sup>1,18-20</sup> After this first revision, the readability of the information packet, which was 23 pages long, was significantly improved with a Flesch Reading Ease score of 63.7 and a Flesch-Kincaid Grade Level of 8.0. Although the packet was still above a 5th-grade reading level, readability scores may have been inflated by the retention of genetic and other medical terms that were multisyllabic. In fact, in exploratory analyses, the deletion

of all genetic terms alone improved readability somewhat (Flesch Reading Ease score = 68, Flesch-Kincaid Grade Level = 7.3). Therefore, it is possible that the information packet may have been easier to read than scores indicated. It was unclear whether the genetic and medical terms would present a significant obstacle to comprehension since all these terms were defined.

### Revision of Information Packet Images

As part of the revision, we limited the use of tables and graphs and increased the number of pictures that accompanied different sections of the information packet as has been recommended to increase readability. Most of these images were cartoons created by a coauthor (N.O.K.). These cartoons accompanied specific text and demonstrated various genetic concepts. The original information packet included three tables and four pictures. The revised information packet included 10 pictures and one simple graph showing how breast cancer risk increases with age.

### Procedures

A rapid focus group was moderated by two coauthors: a certified genetic counselor (K.B.) and a clinical psychologist (H.S.T.). Rapid focus group strategies are detailed by Krueger.<sup>21</sup> A rapid focus group is one adapted to accommodate emerging situations or immediate opportunities and is conducted when there is a need to collect and analyze data quickly.<sup>21</sup> In this instance, the immediate opportunity was a scheduled monthly meeting of the PARP recruiters. Additionally, there was a need to obtain feedback on images quickly in order to continue with evaluations of the complete information packet (images plus text). Rapid focus groups differ from standard focus groups in that they often “piggyback” on existing meetings or conferences and ask questions that are specific and limited in scope. Also, only approximately half of the questions of a standard focus group are used (4 to 7 questions vs approximately 12 questions).

First, the moderators introduced themselves and presented the primary objectives of the TACT project. Next, the objective of the rapid focus group was presented. Participants were informed that an information packet describing genetic risk for breast and ovarian cancer was being revised and

specific feedback on the information packet’s images was desired. Participants were told that because the information packet was intended for breast cancer patients, their opinions as breast cancer survivors were desired. For the purposes of the rapid focus group, we selected 5 of the 10 images that were best representative of the style of all cartoons. Three of these cartoons were presented with the original image they replaced, so that a total of 8 images were presented to the rapid focus group.

The original information packet included a photographic reproduction of chromosomal pairs (Fig 1). A cartoon (Fig 2), developed to replace Fig 1, depicted a pair of chromosomes that were anthropomorphized by giving them eyes, mouths, and arms. Fig 3 was a new image created for the revised information packet that described how chromosomes are inherited from parent to child. Fig 4 was also a new image created for the revised information packet to demonstrate the concept of genetic dominance. In this cartoon, one anthropomorphized mutated gene appeared to dominate a conversation with a normal gene. The mutated gene had a hand placed over the mouth of the normal gene, which had annoyed expression on its face. The original information packet also included an image showing the location of the *BRCA1* and *BRCA2* genes on the chromosomes (Fig 5). Fig 6, developed to replace Fig 5, was a cartoon of a gene living on a chromosome. Fig 7, from the original information packet, and Fig 8, a cartoon developed to replace Fig 7, both demonstrated dominant inheritance of a cancer susceptibility gene.

The images were displayed with an overhead projector. As each image was displayed, a brief explanation of the image was provided by the genetic counselor. Participants

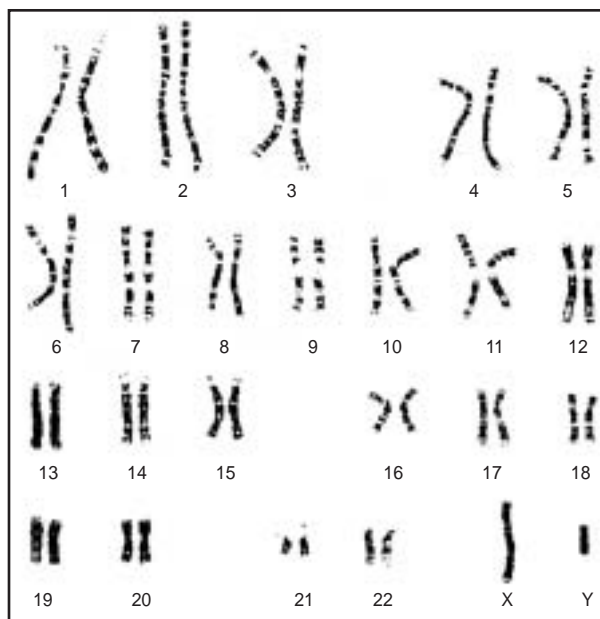


Fig 1. — Photographic reproduction of chromosomal pairs from the original information packet. Courtesy of Brynn Levy, PhD, at Mt. Sinai Medical Center, New York, NY.

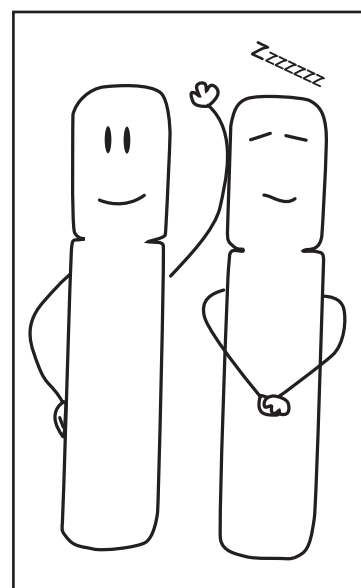


Fig 2. — A cartoon of a pair of chromosomes that were anthropomorphized by giving them eyes, mouths, and arms. This image was intended to replace Fig 1.

were asked (1) whether the image appeared consistent with the explanation provided, (2) their general opinions about how effective the cartoons were in helping to explain concepts, and (3) how appropriate the cartoons were for inclusion in the information packet. This last issue was important because researchers have recommended that developers of print materials use adult-looking visuals and recommend caution in using visuals that may make the materials appear less credible to an adult.<sup>20</sup> A notetaker (A.F.) was present to record responses. Note-based analysis was conducted to identify themes across questions that were asked about each image.<sup>22</sup>

## Results

The two primary themes that emerged based on participants' responses to the images were related to the appropriateness and clarity of the cartoons. First, the majority of participants responded favorably to the new cartoons. Of the 5 new cartoons presented, 3 were well-received (Figs 3, 4, and 8), with participants indicating that these cartoons enhanced comprehension of genetic concepts. For example, several participants indicated that the cartoon in which one mutated gene appeared to dominate a conversation with a normal gene (Fig 4) was a clever and amusing way to illustrate genetic dominance. One participant stated, "I think it's good to have it illustrated." Participants also indicated that the cartoons were appropriate for adult readers. One participant stated, "The cartoons were serious enough."

Although there was a generally favorable response to the inclusion of the cartoons, a second theme that

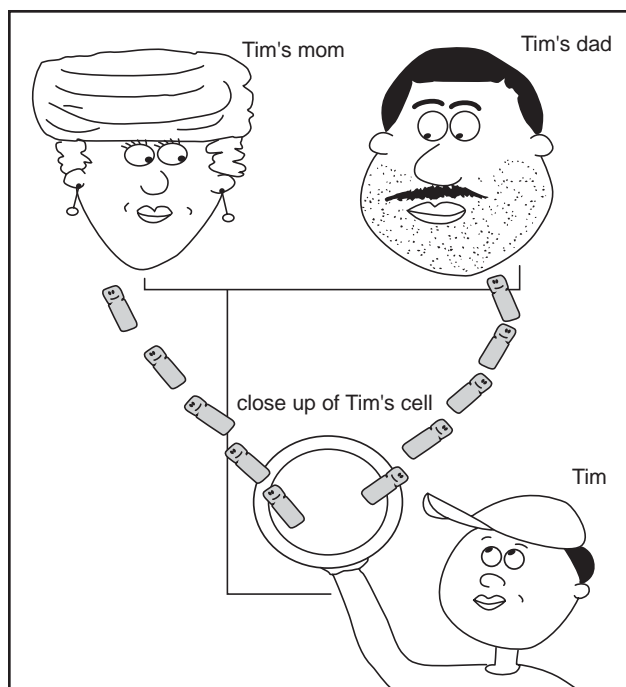


Fig 3. — A new image created for the revised information packet that described how chromosomes are inherited from parent to child.

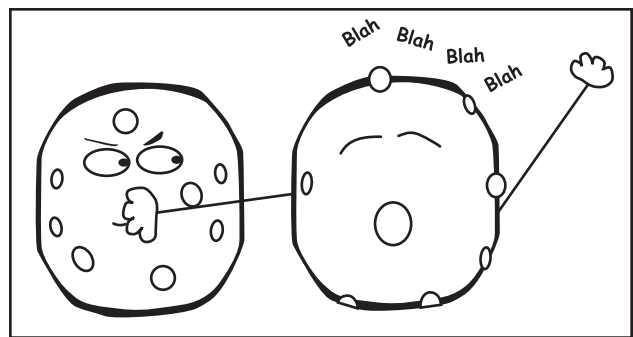


Fig 4. — A new image created for the revised information packet to demonstrate the concept of genetic dominance.

emerged was a need for increased clarity. In some cases, respondents felt that a cartoon could be altered in order to be clearer. For example, when Fig 4 (mutated gene appearing to dominate a conversation with a normal gene) was presented, one participant responded, "The normal gene looks too cross to be dominated. He doesn't look submissive at all." In other instances, participants expressed uncertainty about what the cartoon was supposed to represent as well as its relationship to the accompanying genetic concept, even after hearing the genetic counselor's explanation of the cartoon, because the cartoon was too simple. For example, when Fig 6 was presented, one participant asked, "Does that mean that genes are on top of the chromosome or within?" Participants expressed a preference for simple illustrations that still conveyed the complexity of genetics, as with Fig 8, about which one participant stated, "It's very detailed but simple. It does a good job of explaining it." This desire to get a sense of genetic complexity was also demonstrated when Fig 1 (a photographic reproduction of chromosomal pairs) was presented with Fig 2 (a cartoon of a pair anthropomorphized chromosomes). One participant responded that Fig 1 "looks like it has parts to it but [the second]

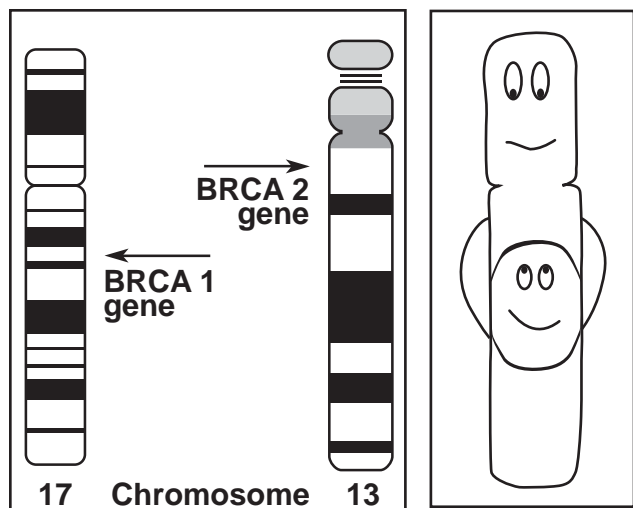


Fig 5. — An image from the original information packet showing the location of the *BRCA1/2* genes on the chromosomes.

Fig 6. — A new image of a gene living on a chromosome. This image was intended to replace Fig 5.

doesn't. I'm fascinated with the first one." Another participant stated that Fig 1 "shows more of a whole picture to me." Another participant felt that Fig 2 "would insult" her intelligence.

### Study 1 Discussion

Rapid focus group methodology enabled the authors to obtain specific information regarding the utility and appropriateness of images for the revised information packet. For the information packet revision, it was particularly important for the authors to know whether the cartoons were appropriate for its intended audience of adult breast cancer patients and inoffensive in light of some humorous elements. There was consensus among focus group participants that cartoons were appropriate but also that the cartoons could be made clearer. The rapid focus allowed the authors to reach a particular objective, ie, obtaining feedback that could be immediately incorporated into revision efforts. As a result of the focus group, several changes were made, including the deletion of Figs 2 and 6. Fig 4 was changed according to the group's responses.

Several limitations of this study must be acknowledged. First, field notes rather than audiotape recordings were used to record participant responses. Reliance on notes may have introduced a bias in the responses recorded and, subsequently, in the interpretation of these responses. Second, a small number of breast cancer survivors were included in the focus group, and it is unclear how representative they were of the information packet's target audience of African American survivors, especially those with low reading skills. Moreover, the educational level of the participants was high, and their level of genetic knowledge before the focus group is unknown. However, these factors may be balanced by the fact that participants did not provide feedback to text but to images, so education and reading level may be less relevant in this case.

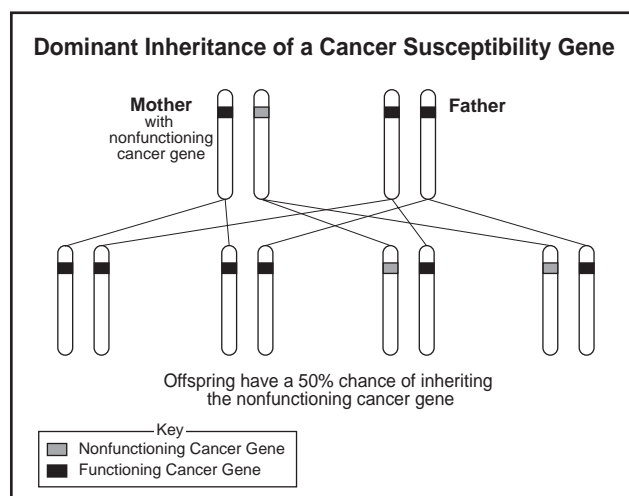


Fig 7. — An image from the original packet demonstrating dominant inheritance of a cancer susceptibility gene.

## Study 2

### Methods

In Study 2, a revised revised information packet that incorporated the feedback of the focus group in Study 1 was reviewed by African American adults with low literacy skills.

### Participants

Participants were adult students in a literacy program sponsored by a local library system based in the Harlem area of New York, NY. The goal of this program is to serve adults who are nonreaders or beginning readers and writers by providing instruction in small groups, facilitated by volunteer tutors who are recruited, trained, and supported by professional staff members. Review of the revised information packet was consistent with the literacy program's goal of general health education.

The revised information packet was reviewed by 5 African American participants (3 men and 2 women) with an age range of 27 to 55 years. All participants were students in the literacy program and attended sessions at the library twice a week.

### Materials and Measures

Participants reviewed the first 6 pages of the information packet. These pages contained sections discussing the major risk factors for breast and ovarian cancer and an introduction to genetics and included 1 graph and 3 cartoons (Figs 3, 4, and 8). This one section was selected for review due, in part, to time constraints within the class. It

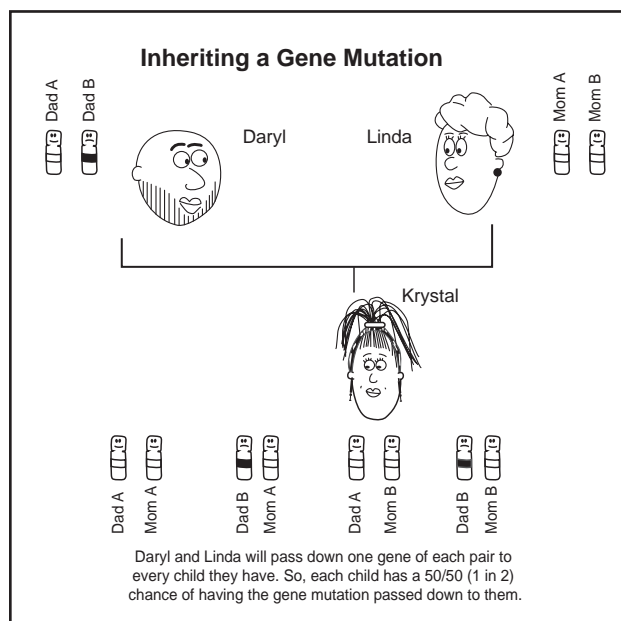


Fig 8. — Also demonstrating dominant inheritance of a cancer susceptibility gene, to replace Fig 7.

was also selected because, as the introduction to genetics, it contained more genetics-related terms and concepts compared with the rest of the information packet. Participants were asked to complete a 6-item evaluation of the information packet based on items in an assessment tool developed by Guidry and colleagues.<sup>17</sup> Although this tool is intended for professional-level reviewers of cancer education materials, in the current study we administered these items to the adult learners whose responses may be the best indicators of the information packet's readability.

## **Procedures**

Copies of the revised information packet were submitted to the literacy program. Each copy began with instructions informing participants of the purpose of the booklet and that they were being asked to read a section of the information packet to make sure that it "is easy to understand and the language is down-to-earth." Through an agreement with the leadership of the literacy program, participants were asked to review the information packet during class time under the guidance of program tutors. Participants were also encouraged to provide general comments about the information packet content.

## **Results**

Four of the 5 participants agreed that the information was presented in a way that was easy to understand and follow, that the font was easy to read, and that images in the information packet were appealing. Additionally, all participants agreed that the print size was easy to read. However, when asked how well they understood the meaning of all the words used in the booklet, all participants reported "a little" or "not at all." Also, when asked how much they liked the way the materials looked, 4 of the 5 participants reported "a little" or "not at all."

## **Study 2 Discussion**

The ratings provided by adult learners provided vital information regarding the effectiveness of applied strategies to increase the readability of the information packet. Although these participants agreed that elements of the format and presentation facilitated comprehension, they largely reported that many words were difficult to understand. It was unclear whether lack of understanding was due to the use of words specific to genetics but clearly defined, or whether there were other, more common words that could have been substituted. In any case, this feedback suggested to the authors that the use of genetic jargon might be reduced and further revision was required. It is important to note that while the adult learners were given the information packet with only a brief explanation of its purpose, the information packet's actual target audience will receive the information packet after

participating in a 2-hour genetic counseling session that will have already introduced all of the medical and genetics-related terms presented in the packet. It is possible that the exposure to these terms in the session will facilitate comprehension when the packet is later read.

Participants also generally did not like the way the materials looked. This may have been due to the fact that the information packet was not in color and did not look like a typical health-related brochure. This remains unclear as more specific feedback was not provided on these aspects. The failure to obtain more detailed feedback from participants is one limitation of this study. A second criticism that may be made of the study is that participants were asked to review only part of the information packet. Had the participants reviewed the entire packet, reports of comprehension may have been different. However, it may be argued that since comprehension of the first 6 pages was low, it is unlikely that comprehension of the rest of the packet would have been greater. A final limitation that may be noted is that there is no information on whether participants' knowledge of breast cancer genetics increased based on review of the information packet section. A pre- and post-test of such knowledge would have provided valuable information about reading comprehension.

Although feedback was somewhat limited, it provided an indication of how others with low reading ability might respond to the revised information packet and warranted continued efforts to improve readability as well as the appearance of the information packet. Based on participants' ratings, the text underwent a second revision. The final information packet was 25 pages long and included 8 pictures and 1 graph. A glossary and listing of patient resources was also included. Even after applying diverse strategies to increase readability, the final packet had a Flesch Reading Ease score of 64.8 and a Flesch-Kincaid Grade Level of 7.7. In exploratory analyses, the deletion of genetic terms and advanced medical terms improved readability somewhat (Flesch Reading Ease score = 70.7, Flesch-Kincaid Grade Level = 6.7).

## **General Discussion**

The two studies reported here are among the first to describe efforts to reduce the readability gap between the advanced language often used in cancer genetics materials and the low literacy levels of a considerable portion of the US population. In the first study, a focus group of breast cancer survivors suggested that while the cartoons created for the packet were appropriate, some needed to be clearer in terms the concepts they were intended to convey. The focus group was a source of detailed responses that enabled the authors to make decisions regarding which images to retain, eliminate, or modify. In the second study, the ratings of adult learners suggested difficulty

with word comprehension in spite of the inclusion of definitions and a glossary. As a result of the evaluation-guided efforts described here, the readability of the final information packet improved significantly. Although the packet was not at a 5th-grade reading level, the 7th-grade reading level achieved is considerably lower than the college reading level required by the original information packet and the reported reading levels of informed consent documents for *BRCA1/2* testing.<sup>12</sup>

Although these studies provided valuable information that guided the revision of the information packet, it is important to reiterate the general limitations of both studies. First, only 3 participants were African American breast cancer survivors, the group that is the information packet's target audience. The inclusion of more constituents of this group might have provided a better indication of how actual TACT participants would evaluate and interpret the information packet. Second, although those who participated in the evaluation shared key characteristics with the packet's target audience, it is unclear how similar their responses were to potential responses from African American breast cancer survivors as a group since there is no published data on education or literacy levels of African American breast cancer survivors. Since limited sociodemographic data were collected from study participants, it is unknown how representative the participants were of the target audience. Also, the sample sizes of both studies were small, so even if the groups included in the evaluation were demographically very similar to the packet's target audience, generalizability is unclear. Finally, although we are collectively experienced in developing and testing cancer-related interventions, these studies are among our first efforts in developing printed materials that are appropriate for a wide range of reading levels. However, it is likely that many professionals developing cancer genetics materials have limited experience in addressing readability issues, and this fact should not preclude efforts among professionals to increase readability.

In spite of these limitations, there were several advantages to the evaluation approach reported here. First, it is common practice for interventionists and researchers to evaluate readability through quantitative methods and formulas rather than through the feedback of individuals.<sup>14-17</sup> Therefore, the approach used in the two current studies is a significant departure from methods used in previous readability evaluations. It is also consistent with a participatory research model that stresses substantive participation by those for whom materials are intended.<sup>23</sup> A second advantage of the studies presented here is the two-stage approach to evaluation in which the information packet's images, which were integral to comprehension, were evaluated first. Only after obtaining feedback on the images was the packet evaluated in its entirety. A third advantage was the use of methods and measures that enabled rapid data collection.

Future efforts to increase the readability of cancer genetics materials may address at least one unresolved issue in the current studies: the inclusion of genetics-related terms that inflate objective readability scores. It seems compulsory to include in such terms in educational materials as the goal of such materials are to increase patient knowledge. Additionally, many of these terms are commonly used by medical professionals. Thus, a patient's familiarity with these terms may assist in making interactions with medical professionals more informative and productive. However, it is possible that these terms may impede a patient's comprehension of materials because they are advanced terms that are more a part of professional jargon vs everyday language. Future studies may carefully assess the extent to which patients' understanding of cancer education materials are enhanced or undermined by the inclusion and exclusion of these terms.

More generally, future efforts to increase the readability of cancer genetics materials may make greater efforts to draw on the perspectives of the constituents who represent the materials' target audience. Such efforts are crucial as those who develop the materials and have expertise in the topic may underestimate the topic's complexity, thus limiting the ability to assume the perspective of a naive reader. Constituent evaluation, therefore, has the potential to identify areas in which further explanation and clarification is necessary. Finally, the studies reported here demonstrate the value of collaboration with formal organizational networks such as literacy programs and cancer patient/survivor groups. These networks may assist in the identification of individuals appropriate for inclusion, and they typically have communication mechanisms in place (eg, regular meetings, mailings) that facilitate actual data collection.

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