Published in final edited form as:

Patient Educ Couns. 2017 May ; 100(5): 805–811. doi:10.1016/j.pec.2016.10.026.

Tracking the Dissemination of a Culturally Targeted Brochure to Promote Awareness of Hereditary Breast and Ovarian Cancer among Black Women

Courtney Lynam Scherr^{a,*}, Linda Bomboka^b, Alison Nelson^b, Tuya Pal^b, and Susan Thomas Vadaparampil^b

^aNorthwestern University Department of Communication Studies Chicago, IL 60611 USA

^bMoffitt Cancer Center Health Outcomes and Behavior Tampa, FL 33612 USA

Abstract

Objective—Black women have a higher rate of *BRCA1* and *BRCA2* (*BRCA*) mutations, compared with other populations, that increases their risk for hereditary breast and ovarian cancer (HBOC). However, Black women are less likely to know about HBOC and genetic testing. Based on a request from a community advisory panel of breast cancer survivors, community leaders and healthcare providers in the Black community, our team developed a culturally targeted educational brochure to promote awareness of HBOC among Black women.

Methods—To reach the target population we utilized a passive dissemination strategy. Using Diffusion of Innovations (DOI) as a framework, we traced dissemination of the brochure over a five year period using self-addressed postcards contained inside the brochure that included several open-ended questions about the utility of the brochure and a field for written comments. Closed-ended responses were analyzed using descriptive statistics and thematic analysis was conducted on the open-ended responses.

Results—DOI captured the proliferation of the brochure among Black women across the US.

Practice Implications—The use of passive dissemination strategies among pre-existing social networks proved to be a useful and sustainable method for increasing knowledge of HBOC among Black women.

Keywords

dissemination; diffusion of innovation; hereditary breast and ovarian cancer; genetics; Black women; health disparities

*Corresponding author at: 701 North Lake Shore Drive, 15th Floor, Chicago, IL 60611, USA, Phone: 1-312-503-7209, Fax: 1-312-503-0896, courtney.scherr@northwestern.edu.

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1. Introduction

Women with a *BRCA1* or *BRCA2* (*BRCA*) mutation have a 40 – 87% risk to develop breast cancer and a 35-65% risk for ovarian cancer [1]. A woman identified with a harmful (or ‘deleterious’) *BRCA* mutation can be provided with more intensive prevention measures to reduce breast and ovarian cancer incidence and mortality [2, 3]. Although testing for such *BRCA* mutations has been available since the 1990's, research consistently indicates Black women, compared to White women, are less likely to participate in genetic counseling [4] and testing [5]. Yet, recent studies conducted found *BRCA* mutation prevalence in Black women in the United States to be double that of non-Hispanic White women [6-8]. These results are consistent with findings about prevalence of *BRCA* mutations in a sample of Nigerian women with breast cancer [9]. Cumulatively, results indicate Black women age 50 or younger with a personal or family cancer history of breast and/or ovarian are particularly good candidates for genetic counseling and testing.

Although numerous systems level barriers (i.e., lack of healthcare provider referral, insurance, access, cost) were identified as preventing Black women from seeking genetic counseling and testing [10, 11], among studies controlling for systemic barriers, Black women were less likely than White women to proceed with genetic counseling and testing [12]. Additionally, when controlling for other factors such as: risk for carrying a *BRCA* mutation, socioeconomic status, risk perception, attitudes, or primary care physician recommendations, Black women were still less likely to participate in genetic counseling and testing compared with their White counterparts [4]. Low rates of genetic counseling service uptake among Black women at risk for hereditary breast and ovarian cancer (HBOC) have been attributed to concern about stigma, discrimination, and a lack of trust in the medical profession [13-16]. However, one study found Black women, after learning about genetic counseling and testing, held positive attitudes regarding the benefits of genetic counseling [13], and another found Black women's attitudes were even more positive than their White counterparts [17]. Therefore, it seems a principle barrier to obtaining genetic services among Black women is a lack of knowledge. To that effect, a recent study identified low levels of familiarity with and knowledge of genetic counseling and testing as the most significant barrier to receiving genetic counseling and testing among Black women at medium and high risk for HBOC [18].

Interventions addressing barriers to genetic counseling participation may be useful in promoting genetic counseling uptake among young Black women with breast cancer [19]. Although recent evidence suggested differences in genetic testing may be partly explained by cultural differences rather than disparities [20], the overwhelming evidence for a lack of knowledge relating to genetic counseling and testing among Black women indicates a need for a culturally appropriate intervention designed to increase knowledge and awareness of genetic counseling and testing [14, 18, 21]. Furthermore, increased knowledge about genetic counseling and testing will allow Black women to make informed decisions regarding genetic counseling and testing.

A history of medical mistrust, cancer fears, and concern for privacy have created challenges to communication about cancer in the Black population [22, 23]. Studies assessing

information seeking behaviors among blacks about cancer revealed sources such as brochures and booklets and information gathered through interpersonal channels including personal physicians, friends, support groups, churches, community fairs, and public health departments were viewed as trustworthy [22, 23]. Voluntary membership to these interpersonal networks increased trustworthiness and the persuasive impact of the messages [24]. Therefore, interventions for Black women should consider brochures or booklets that capitalize on preexisting social network ties as an important strategy to disseminate health related information.

In 2005 a Community Advisory Panel (CAP) of breast cancer survivors, community leaders, and community healthcare providers in the Black community, was established as part of a project called the Breast Cancer Genetics Research and Education for African American Women Team (B-GREAT). The CAP was formed to provide guidance about statewide recruitment efforts of young Black women to genetic counseling and testing studies. In the initial phase of the project, a need for outreach and educational materials focused on increasing awareness about hereditary breast and ovarian cancer (HBOC) among Black women became apparent. As no such validated brochures existed at that time, an original study brochure, developed and tested through a community-based participatory approach and learner verification, [25] was modified, tested in focus groups with the target audience, and revised based on feedback, a process described in an earlier publication [26]. In particular, cultural tailoring was implemented by including pictures, narratives and images representative of Black culture, describing hereditary cancer as a relevant problem for Black women, and using language suggested by community members and focus group participants [26]. The resulting brochure titled *The Family Link between Breast and Ovarian Cancer in Black Women* was well received by target audience members. Consistent with calls for more research exploring dissemination of cancer prevention and control programs [27, 28], this study uses Roger's Diffusion of Innovation Theory (DOI) [29] as a framework to report on the passive dissemination of a culturally targeted brochure to increase awareness of HBOC in Black women. The main outcomes of interest include: (1) the rate at which brochures are disseminated per year, and (2) the number of states where requests for brochures originated. Arguably, if the rate of brochure dissemination is maintained or increases each subsequent project year and if the numbers of states from which requests are initiated increases, then dissemination is successfully occurring.

A reported challenge in dissemination research is a lack of clear definition and conceptualization of dissemination [27, 30]. As this report uses DOI as its framework, Roger's definition of diffusion is utilized: "...the process in which an innovation is communicated through certain channels over time among members of a social system. It is a special type of communication, in that the messages are concerned with new ideas" [31]. In this case, the innovation is genetic counseling and testing and DOI is used to report on the communication (i.e., the brochure) through certain channels (i.e., pre-existing social networks) over time. As indicated by Rogers, there is generally lag time required between knowledge and adoption of the innovation (i.e., genetic counseling and testing) [31]. Communication interventions can accelerate knowledge acquisition processes and may ultimately increase adoption rates. In this case, the communication intervention is designed to increase knowledge diffusion about genetic counseling and testing and HBOC. DOI

specifies four interacting factors including 1) an innovation, 2) communication channels, 3) social systems, and 4) time. Including all but innovation, three of the four interacting factors will be used to provide a description of the diffusion of a brochure for Black women at increased risk for HBOC to promote genetic counseling and testing.

2. Methods

Following institutional IRB approval, all CAP members were notified about the brochure and process for requesting the brochure via email and during annual CAP meetings. In addition, study team members periodically attended and distributed brochures during CAP events. To supplement the targeted efforts with our CAP, we engaged in activities to enhance dissemination of information about HBOC in Black women by expanding our reach throughout Florida. To do this, our team identified additional sites/organizations focused on breast cancer or African American health to disseminate our educational materials statewide. Once these organizations were identified, we contacted organizational representatives to inform them about our efforts in the Black community and the availability of our educational materials. Each brochure included an end user survey related to satisfaction with and utility of the educational brochure. Finally, the brochure was highlighted on our B-GREAT website (<http://bgreatinitiative.net>), developed as a source for information about breast cancer in Black women and includes resources for the public including educational materials and support group information. Anyone requesting the brochure was asked to indicate the quantity of brochures desired, and the study team shipped the brochures at no charge.

Data was collected from organizations or individuals requesting the brochure including: the organization type, state and city, how they learned about the brochure, and distribution plans. Records of the total number of brochures requested by year, were maintained by study staff.

A self-addressed postcard with paid postage was enclosed in the brochure requesting basic and clinical demographic information and how the brochure was received by the individual recipient. To assess the utility of the brochure, participants were asked to respond to the question, “how useful was this booklet in helping you understand more about cancer that runs in families?” on four item categorical scale of “very useful,” “useful,” “somewhat useful,” and “not at all useful.” To assess impact on future behavior, participants were asked to respond to the questions: “After reading the booklet, how likely are you to share information with others about cancer that runs in families?” and “After reading this booklet, how likely are you to discuss your own personal and/or family history of cancer with your healthcare provider?” on a categorical scale of “very likely,” “likely,” “somewhat likely,” and “not at all likely.” Recipients were also given space to write any additional comments regarding the brochure. As an incentive, completion and return of the postcard between 2009 and 2013 entered participants into raffles for Target gift cards in varied amounts (\$25 - \$100) as well as free promotional items. Postcards returned after a specified date listed on the postcard were not entered into a chance drawing.

Closed ended questions were analyzed using descriptive statistics. Given the relatively few and short open ended responses, a single member of the study team constructed the code book. Following an initial reading of all open-ended responses, thematic analysis was

conducted using two stages of coding using MAXQDA to manage the qualitative data. Initially, open coding was conducted by assigning a summative label to each response. In the second stage, selective coding was utilized to collapse alike codes into overarching themes. A second team member independently reviewed and categorized all responses into the themes to assess reliability of the themes. Krippendorff's alpha was calculated and an acceptable level of reliability was achieved ($\alpha = .79$).

3. Results

Overall, 23,756 brochures were distributed between January 2009 - November 2013 (Figure 1). Brochures primarily were requested by support groups ($n = 24$; 22%), followed by hospitals or clinics ($n = 21$; 19%), and other ($n = 21$; 19%; Table 1). The purpose for requesting brochures was mostly dissemination at a community event ($n = 32$; 24%), other ($n = 32$; 24%), and at a health fair ($n = 21$; 15%; Table 2). Initially, dissemination began in Florida but quickly spread to 28 states (Figure 2).

Of those who returned the end user survey ($N = 219$; Table 3), the majority were Black ($n = 192$; 87.7%). The majority was between the age of 50-64 years old ($n = 76$; 34.7%) and did not have a personal history of breast or ovarian cancer ($n = 161$; 73.5%). Of those who did not have a personal history of cancer, the majority ($n = 80$; 49.7%) had a family history of breast or ovarian cancer.

The majority received a copy of the brochure at a community event ($n = 76$; 34.7%). Overall, participants indicated the booklet was very useful ($n = 153$; 69.9%), and since reading the information in the booklet were very likely to share this information with others ($n = 167$; 76.3%), and were very likely to discuss their personal or family history of cancer with a healthcare provider ($n = 162$; 74.0%; Table 4).

Fifty-nine participants provided open ended comments about the brochure, of which 15 were removed as the comments were not relevant to the brochure resulting in a total of 44 comments that were analyzed. The majority of comments were positive; participants found the brochure informative ($n = 27$; 61.4%) and/or were thankful for the material ($n = 17$; 38.6%). For example, "I really appreciate your sharing information that helps me and others as well. I appreciate it. Thank you." A number of individuals ($n = 11$; 25%) indicated this brochure was the first time they saw HBOC information targeted for them, helping them to realize the need to take protective action and talk with their family. "I never knew how susceptible AA [Black] women were to developing breast cancer. I am aware now and will continue seeing my physician and doing my monthly self-checks." Only 2 (4.5%) respondents indicated continued confusion about BRCA. "More information on BRCA1/BRCA2 testing would be helpful, and the difference between the two."

4. Discussion and Conclusion

4.1 Discussion

Although Black women have a lower lifetime incidence of breast cancer compared to White women [32], they have a higher incidence of breast cancer at young ages (i.e., under the age

of 50), and are more likely to die from breast cancer compared to women of all other races [33, 34]. Young age of breast cancer onset is a hallmark of *BRCA* mutations, and independent of other risk factors, was found to be significantly predictive of *BRCA* mutations in Black women [35].

Overall, dissemination occurred consistently throughout the first two years, rose the third year, declined slightly the fourth year and made a significant jump the final year (Figure 1). Dissemination began in Florida with our CAP member organizations, but has since reached organizations in 29 states. As a personal or family history of breast and/or ovarian cancer are clinical features of HBOC, it is of note that only 65 (33.9%) respondents did not have a personal or family history of cancer indicating we were largely successful at reaching this specific population. However, it is important to note, the goal of the brochure was to increase awareness among all Black women, therefore, we were successful in reaching this population as the majority who returned the postcards were Black women. Additionally, participants were appreciative of culturally targeted, simple and easy to understand information.

4.1.1 Communication Channels—Communication channels in DOI are networks by which information about an innovation flows from an individual with knowledge about the innovation to an individual who does not [31]. In the case of innovations related to health promotion, interpersonal networks are particularly effective for disseminating knowledge as trust and rapport are already established in groups likely to share sociodemographic and cultural similarities [31, 36, 37]. Consistently, Black women reported most frequently getting health information from existing interpersonal networks such as church and community health fairs and by “word of mouth,” particularly from those with similar experiences [22]. The current study lends support for the use of pre-existing interpersonal networks for information dissemination among Black women, highlighting the advantage of using pre-existing social networks when employing passive dissemination.

Although our study did not have a control condition, compared to no intervention, some evidence exists suggesting passive dissemination of printed information can be successful in promoting health behaviors [38]. However, some studies found passive dissemination was less successful [39-41], especially when compared with active implementation [42]. Furthermore, two of the aforementioned studies sought to achieve continued behavior change through the development of new networks [39, 40], a more difficult outcome to accomplish compared to increasing knowledge and awareness in existing networks, which was the goal of this study. Additionally, the request for the brochure came directly from members of the target audience, whereas the communication intervention undertaken in the aforementioned study was determined by the researcher and developed by members of a stakeholder group who were not part of the target audience. The success of passive dissemination efforts in this study may be attributed to the use of pre-established communication networks and the request from a CAP. Specifically, research in social work identified the use of existing social networks as an effective means to achieve cultural sensitivity and increase success of health prevention practices [43].

4.1.2 Social System—In addition to the use of pre-existing social networks, other factors in the larger social system may have influenced the rate of adoption, particularly events leading up to the year 2013. First, a grant awarded to the research team allowed their participation in relevant health fairs during the years 2011 – 2012, thus increasing visibility and awareness of the brochures. Second, acting as a celebrity change agent, Angelina Jolie's op-ed piece regarding her journey with *BRCA* was released in the New York Times in 2013, thus significantly increasing public awareness of *BRCA* and HBOC. Finally, in a case brought to the Supreme Court in 2013, Myriad very publically lost their patent of the *BRCA1* and *BRCA2* genes.

On May 14th, 2013 Angelina Jolie announced in an op-ed piece in the New York Times that she carried a *BRCA1* mutation, putting her at a significantly increased risk of developing breast and ovarian cancer [44]. She described her risk, her decision to undergo a preventive double mastectomy, and her intention to bring attention to the issue including empowering women to take control of their health. The use of celebrity status to shed light on health issues is not novel, can be empowering, and oftentimes has positive effects. For example, Katie Couric's decision to undergo a colonoscopy on public television in 2000 raised awareness about colon cancer and prevention resulting in a statistically significant nationwide increase in colonoscopy uptake following her campaign (Cram et al., 2003). Similarly, what has been described as the “Angelina Effect” occurred, where awareness and interest increased regarding the role of genetics in the development of cancer [45]. However, a recent study found more individuals knew about Angelina's situation, but few understood the genetic interpretation related to her *BRCA* mutation and subsequent risk [46]. Studies examining information-seeking behavior on the internet following Jolie's opinion piece found significant increases in web-based searches and traffic to websites with information about genetics and risk reduction resources [47, 48]. Although individuals may not have understood information from Jolie's op-ed piece, it clearly drove information-seeking behaviors, and may partly explain the upsurge in brochure requests.

Finally, in 2013, Myriad Genetics lost their case in the Supreme Court that would have granted an extension of their patent on the *BRCA1* and *BRCA2* genes. The patent held for the past 20 years granted Myriad exclusive rights to test an individual's DNA for these genetic mutations. Furthermore, in the ruling, the US Supreme Court declared naturally occurring genes may not be patented, even in isolation from the rest of the DNA strand, ultimately setting a precedent to prevent future patents of genetic tests. This widely publicized case combined with Jolie's op-ed piece may have increased public awareness of genetic contributions to breast and ovarian cancer, increasing the interest of our target audience in additional information, and subsequently may provide an additional explanation for the increased number of brochures disseminated in 2013.

4.1.3 Time—In addition to the impact of the social system, the natural passing of time may have contributed to the increasing use and adoption of the brochure. Time according to DOI may be measured as the time between learning of an innovation and adopting it, the time relative between the availability of the innovation and adoption compared with others in the system, and finally the rate of adoption within the system [31]. First, one may believe the rate of adoption would have dropped off after 2012 given the trend in the data, but may have

been bolstered by the new information which flooded the social system regarding Angelia Jolie and Myriad's patent as previously discussed. Second, it may be possible the diffusion of the brochure is just speeding up.

4.2 Conclusion

Although passive dissemination efforts have not been established as an effective means for dissemination of information, this case provides an example of effective passive dissemination efforts among Black women, particularly those with a personal or family history of cancer. In particular, the development of a culturally targeted brochure and the use of pre-existing social networks is believed to have contributed to the success of our dissemination efforts. Additionally, elements of the larger social system and the natural passage of time assisted in dissemination efforts as well.

One of the major limitations of this study was that only a fraction of postcards were returned from the total number of brochures disseminated. Women who participated self-selected to participate based on the return of the postcards, therefore we were unable to collect data from those who did not participate. It is possible that we only received responses from those who were most interested in this issue, thus skewing the responses to be primarily favorable, and not representative of all individuals who received the brochure. The size of the postcard limited the number of questions and depth of responses that we were able to gather. For example, we did not collect detailed demographic information, as education, insurance coverage, marital status which have been found to influence knowledge of HBOC in previous studies [49].

Other studies indicated the lack of evidence based behavior change measures to limit the validity of the impact of the intervention [28]. Similarly, our study included only self-report data on the target behavior of discussing personal and family history of cancer with family members and personal physician. However, the breadth and reach of the dissemination presents difficulty in validating self-report data with practice information.

Another limitation of the study was that passive dissemination was the only dissemination mechanism, and therefore we cannot comment on the true reach of the brochure. Although requests for the brochure increased and the geographic area, using an active dissemination strategy may have resulted in greater dissemination of the brochure at a faster rate. However, given limited resources, this report demonstrates the efficacy of utilizing pre-existing interpersonal networks among Black women.

4.3 Practice Implications

A shortcoming of many dissemination studies is that they are limited to a single defined control population, such as a school district or a work place [30]. These studies are often time and labor intensive and require a specific infrastructure to be replicated if disseminated to a different or larger population, however dissemination research may be more effective if it can be demonstrated to be effective in reaching a larger target audience in a sustainable and widely implemented fashion [27]. An advantage to our study is the demonstration of the ability for our intervention to have wide reach, as indicated by the number of states and organizations who have adopted and distribute the brochure, and remain sustainable in the

long term. Although it is currently unclear whether we have reached critical mass, where enough individuals have adopted an innovation to render diffusion self-sustaining [50], it may be that this brochure is leading in that direction and warrants further study. These data lend support for the development of a communication intervention. Identifying methods to improve knowledge of HBOC may lead to increased uptake of genetic counseling, testing, and ultimately, clinical outcomes among Black women.

Acknowledgments

this work was supported by the Florida Breast Cancer Foundation Educational Grants Program. Dr. Courtney L. Scherr was supported by the National Cancer Institute of the National Institutes of Health R25 CA 090312 Behavioral Oncology Education and Career Development grant. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Florida Breast Cancer Foundation Educational Grants Program or the National Institutes of Health.

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Highlights

- Awareness of hereditary breast and ovarian cancer (HBOC) among Black women was low.
- Examined passive dissemination of a culturally appropriate brochure about HBOC.
- Utilized diffusion of innovations to track dissemination over five years.
- Provided example of effective passive dissemination efforts among Black women.

Figure 1. Number of brochures requested by year

Figure 2. Year of initial brochure request by state

Table 1
Requests for brochure by organization type

Organization Type	n	%
School/University	6	5
Religious Group	8	7
Health Agency	14	13
Service Organization	17	15
Hospital/Clinic	21	19
Other (i.e., community outreach organization or business)	21	19
Support Group	24	22
Total	111	100%

Table 2
Anticipated dissemination plans

Dissemination Plan	n	%
Religious Event	14	10
Support Group	18	13
Doctors Office	19	14
Health Fair	21	15
Other	32	24
Community Event	32	24

* Percentages may not add up to 100% due to missing data.

Table 3
Demographic Characteristics (N = 219)

	<i>n</i> (%) [*]
Race/Ethnicity	
African American/Black	192 (87.7)
Asian	1 (0.5)
Native American	2 (0.9)
Hispanic White	5 (2.3)
Non-Hispanic White	7 (3.2)
Other	1 (0.5)
Age	
Under 30	15 (6.8)
31-49	66 (30.1)
50-64	76 (34.7)
Over 65	38 (17.4)
Personal diagnosis of breast or ovarian cancer	
Yes	54 (24.7)
No	161 (73.5)
Family member diagnosed with breast or ovarian cancer	
Yes	114 (52.1)
No	94 (42.9)

* Percentages may not add up to 100% due to missing data.

Table 4Perceived Utility and Impact of the Booklet ($N = 219$).

Survey Question	<i>n</i> (%) [*]
How did you get a copy of this booklet?	
Health fair	57 (26.0)
Support group	25 (11.4)
Doctors office	10 (4.6)
Community event	76 (34.7)
Other (i.e., educational organization, friend)	45 (20.5)
How useful was this booklet in helping you understand more about breast cancer that runs in families?	
Very useful	153 (69.9)
Useful	56 (25.6)
Somewhat useful	3 (1.4)
Not useful at all	1 (0.5)
After reading this booklet, how likely are you to share information with others about cancer that runs in families?	
Very likely	167 (76.3)
Likely	42 (19.2)
Somewhat likely	6 (2.7)
Not likely at all	0
After reading this booklet, how likely are you to discuss your own personal and/or family history of cancer with your healthcare provider?	
Very likely	162 (74.0)
Likely	41 (18.7)
Somewhat likely	8 (3.7)
Not likely at all	1 (0.5)

* Percentages may not add up to 100% due to missing data.