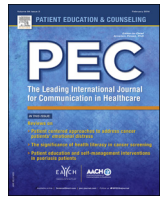




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Tracking the dissemination of a culturally targeted brochure to promote awareness of hereditary breast and ovarian cancer among Black women

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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.

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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 *BRCA* mutations has been available since the 1990s, research consistently indicates Black women, compared to White women, are less likely to participate in genetic counseling [4] and testing [5]. Yet, recent studies 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 history of breast and/or ovarian cancer are particularly good candidates for genetic counseling and testing.

Numerous system 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]. However, 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 White female equivalents [4]. Low rates of genetic counseling service uptake among Black women at risk for hereditary breast and ovarian cancer (HBOC) have been attributed to concerns 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

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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 Black community members 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 pre-existing 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. This process is described in an earlier publication [26]. 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, lag time is generally 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, we notified all CAP members 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 within our CAP, we engaged in activities to enhance dissemination of information about HBOC in Black women by expanding our reach throughout the state of 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. The brochure also was highlighted on our B-GREAT website (<http://bgreatinitiative.net>), developed as a source for information about breast cancer in Black women that includes resources for the public such as 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

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