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African American Women's Perspectives on Donating Healthy Breast Tissue for Research: Implications for Recruitment

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ABSTRACT

African American women die of breast cancer at a higher rate than any other racial group. The Komen Tissue Bank (KTB) is an ongoing clinical trial that collects healthy breast tissue from women of all racial groups to use as controls in research and represents a critical tool in efforts to treat and prevent breast cancer; however, African Americans display reticence toward donating breast tissue to the KTB. Through the lens of the Integrated Behavioral Model, this study recruited African American women to share their perspectives on donating breast tissue for research purposes. Seventy-one ($N = 71$) eligible Black women who were previous tissue donors to the KTB responded to an online questionnaire. Findings revealed that (a) participants had positive instrumental attitudes or reasons for donating; (b) participants felt generally supported in their decision to donate, but revealed that the lack of Black women participating in the KTB meant that they themselves were setting the norm for others; and (c) their race was an important element in their donation decision. While acknowledging the negative history of African Americans in medical research, they offered their perceptions regarding the importance of involving themselves in medical research, and suggested that health communication strategies to recruit African Americans into research should embrace race as part of the message. The findings from this study have important implications for other those who work in applied clinical settings and are interested in addressing racial disparities in medical research through more effective and targeted recruitment messaging.

Breast cancer is the most common cancer among women globally, regardless of race or ethnicity, and is the second leading cause of cancer death in African American women (Centers for Disease Control and Prevention, 2014). Despite the incidence of breast cancer being higher for White women, the mortality rate is greater for Black¹ women (Office on Women's Health, 2012). Breast cancer research has been extremely successful in discovering better detection and treatment methods over the last 30 years, and clinical trials are a large part of that success (National Breast Cancer Coalition, 2015). One clinical trial in particular, the collection of healthy breast tissue at the Susan G. Komen[®] Tissue Bank at the IU Simon Cancer Center (hereafter referred to as Komen Tissue Bank, or KTB), represents a critical tool in the continuing efforts to find new approaches for the treatment and prevention of breast cancer (Sherman et al., 2012). As the only collection site and repository of healthy breast tissue in the world, the Komen Tissue Bank offers a unique opportunity to study the oncogenesis, or causation, of breast cancers.

African Americans, however, are not donating healthy breast tissue to the KTB in any great number or with any regularity. This may have roots in feelings of distrust deriving from the negative history and treatment of Black people in clinical trials

and medical research in the past (Ford et al., 2013). Lack of representation of women and minorities in medical research, including clinical trials, is a common problem, but ethical and scientific integrity demand that clinical research include appropriate representation of African American participants (Branson, Davis, & Butler, 2007). Therefore, the purpose of this study is to better understand African American women's perceptions of donating their breast tissue for research purposes, and the potential influence of their race on the decision to donate.

African American Women and Breast Cancer

The highest mortality rates and shortest survival times of any racial and/or ethnic group in the United States for most cancers are held by African Americans, a statistic that is also applicable to breast cancer (American Cancer Society, 2016). Recent statistics show that Caucasian women (128.1 per 100,000) and Black women (124.3 per 100,000) are diagnosed with breast cancer at about the same incidence rate, much higher than other racial groups. Despite this, Black women (31.0 per 100,000) are more likely than White (21.9 per 100,000), and in fact all other races, to die from breast cancer (Elledge, Clark, Chamness, & Osborne, 1994; National Cancer

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¹For purposes of readability and versatility, and in reflection of reality, the authors have chosen to use the terms "African American" and "Black" interchangeably throughout this article (Adams-Campbell et al., 2016; Landrine & Corral, 2015).

Institute, 2016), and their tumors often are found at a more advanced stage, which narrows the choice of treatments (Office on Women's Health, 2012). African American women also have a higher breast cancer incidence rate before age 45 years compared to other racial groups (American Cancer Society, 2015; Johnson, 2002). In addition, one study found that Black women are three times more likely to develop triple-negative breast cancer than White women (breastcancer.org, 2015). This type of breast cancer spreads more quickly than others, and currently has no targeted treatment, although it typically responds to chemotherapy (American Cancer Society, 2015).

It has long been hypothesized that these noted disparities may be determined more by socioeconomic standing than solely by minority status (Lantz et al., 2006). Interestingly, however, most studies to date suggest that although the statistical gaps between the racial (predominantly Black and White) differences in breast cancer stages have narrowed somewhat, they still remain statistically significant after socioeconomic variables are taken into account (Lantz et al., 2006). Due to these factors, it is increasingly important that researchers looking for better treatment or a cure have access to tissue from African Americans and other minorities. However, access to breast tissue from racial minorities can only be realized if these women volunteer to participate in tissue donation studies.

Lack of African American Participation in Research

African Americans' unwillingness to participate in research revolves around the historic medical exploitations of Blacks in the past—in particular, the Tuskegee Study of Untreated Syphilis, often called the Tuskegee Trials (Ford et al., 2013; Harris, Gorelick, Samuels, & Bempong, 1996; Roberson, 1994). In the Tuskegee study, which ran from 1932 to 1972, public health researchers gathered data from 399 syphilitic men who were left untreated to die from the disease, even after penicillin was widely available. The African American population has regarded this as indefensible and unforgivable, and suspicion remains, more than four decades later (King, 1992; Russell, Robinson, Thompson, Perryman, & Arriola, 2012).

More recently, Skloot and Turpin (2010) wrote a hugely popular research study unveiling another act of exploitation. *The Immortal Life of Henrietta Lacks* read like a novel, and told the story of a poor African American woman diagnosed with cervical cancer in 1951. Without her knowledge, a physician at Johns Hopkins Hospital harvested a tissue sample from her tumor and used it to develop HeLa cells, the first viable human cell line. Henrietta Lacks died 8 months after her cells were taken. Her descendants lived in poverty, never knowing that HeLa cells were commercialized and have played pivotal roles in research ever since (Landecker, 2000). The Henrietta Lacks story brought attention to the unethical practice of doing human subjects research without informed consent, with particular concern for the poor and powerless. The story's popularity has also helped reveal the breadth of the lack of trust still held by members of the African American population (Luebbert & Perez, 2015).

Mistrust of research and researchers is one of the most commonly identified barriers to clinical trial participation for Black people (Hughes, Varma, Pettigrew, & Albert, 2015; Luebbert & Perez, 2015). Hughes et al. (2015) report that beliefs about medical disparities and abuse have been passed down from generation to generation, perpetuating widely held distrust for research and leaving little room for openness to new or contradictory information. Even the human studies precautions that have been put into place in the last decade can be reviewed with suspicion by African Americans, some of whom may perceive the informed consent language and process to be a mechanism to protect the researchers from legal responsibility rather than as a document focused on safeguarding the participant (Luebbert & Perez, 2015; Otado et al., 2015). These kinds of psychological barriers are considerably more likely to be identified as a problem in the African American communities than in the general population (Tanner, Kim, Friedman, Foster, & Bergeron, 2015).

Research and clinical trials are so important in finding early detection and treatment advances, yet the research must represent all types of people to best be able to serve them. Added to this, in order for research to be wholly ethical and scientifically reliable, any sample population must represent the population as a whole (Branson et al., 2007). In the case of most racial and ethnic minorities, however, it is proving to be difficult to recruit enough participants to satisfy this need.

Since the 1950s racial/ethnic groups have been underrepresented in experimental medical studies such as cancer clinical trials (Roberson, 1994). In addition, despite suffering disproportionately from poor health (Abrams, 2006; Kjellstrom, Mercado, Sami, Havemann, & Iwao, 2007; LaVeist, Gaskin, & Richard, 2011), the Black population is exceptionally underrepresented in DNA biobanks. In order for clinical applications of individualized therapies to be made available to everyone, it is vital that the collections of genetic data be diverse according to bio-geographical ancestry (DNA origins). This means encouraging people of African, Latino, and Asian ancestry to donate. Unfortunately, at this point in time, those who contribute to biobanks have largely been White (Buseh, Stevens, Millon-Underwood, Townsend, & Kelber, 2013). Researchers seem unable to successfully enroll African Americans as donors to biobanks with any regularity (Buseh, Underwood, Stevens, Townsend, & Kelber, 2013; Holloway, 2011; Lemke, Halverson, & Ross, 2012), and information about what Black people think about biobanks and the ethical questions surrounding them is also insufficient (Lemke et al., 2012).

Focus-group research has shed some light specifically on clinical trial participation reticence. Data that emerged from one focus group study showed that the primary barrier to participation in clinical trials was fear of being treated as an experiment (Brooks, Paschal, Sly, & Hsiao, 2008). Focus-group participants espoused the view that health workers in clinics and emergency departments do not uphold the same standard of care for African Americans as for Whites (Brooks et al., 2008). There is some documented progress, however, in African Americans' attitudes toward participation in research. Despite their fears about being treated like guinea pigs (Hughes et al., 2015; Otado et al., 2015), a majority of the African American participants in one focus group felt that clinical trials and

medical research were important or necessary. These participants recognized the importance of clinical research, but some freely admitted a lack of knowledge about clinical trials (Brooks et al., 2008), results that are upheld in several other current studies (Hughes et al., 2015; Luebbert & Perez, 2015; Otado et al., 2015). Thus, it is possible that a tension exists for African Americans: They mistrust medical researchers, but they recognize that these medical studies are important. The current study seeks to explore this “tension” and provide useable knowledge to address it through better messaging about African Americans’ participation in clinical trials.

Current Study

The Susan G. Komen® Tissue Bank at the IU Simon Cancer Center (hereafter, KTB) is the only biorepository in the world in which healthy breast tissue is collected from female donor volunteers as normal controls for breast cancer research (Sherman et al., 2012). The KTB donation process is set up as a clinical trial under the IU Institutional Review Board; women having no evidence of breast cancer self-select into the study, consent to participate, and then donate normal tissue to the KTB. Researchers from around the world use these samples as normal controls in breast cancer studies. This sample collection process is representative of a relatively new area of breast cancer research concentrating on prevention and treatment. There is no shortage of available donors but the vast majority of these women are Caucasian, which is a concern (Doherty, MacGeorge, Gillig, & Clare, 2015). As previously discussed, breast cancer affects women of different genetic heritage in different ways; it is important to study the various types of normal tissue among diverse racial and ethnic populations (Komen Tissue Bank, 2015). Although the KTB database of healthy breast tissue is growing steadily, the relatively low number of continued African American donors presents challenges for having sustainable and representative samples of tissue from this racial group.

According to the U.S. Census Bureau, 13.2% of the U.S. population is African American (U.S. Census Bureau, 2015). The samples currently stored in the KTB are 16.1% African American (Komen Tissue Bank, 2015). See Figure 1. On the surface these numbers seem comparable if not well within the appropriate percentage needed to be representative of the general population (Branson et al., 2007). However, that impression is somewhat misleading in this situation. In addition to continued efforts to match donors to the population percentage, the KTB has also established the goal to over-sample African American donors such that they comprise 25% of the tissue samples (A. Storniolo, personal communication, August 1, 2015). This is due in part to the prediction that a large percentage of breast cancer research in the near future will be focused on triple negative breast cancer, which most commonly affects Black women, and also because the amount of African American participation at the current level took repeated, focused attention on prospective participants, which is not sustainable in the long run for the limited staff and resources at the KTB (A. Storniolo, personal communication, August 1, 2015).

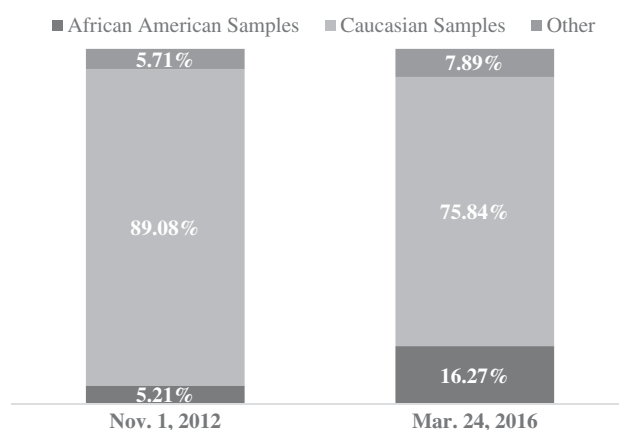


Figure 1. Percentage of of breast tissue donations at the Komen Tissue Bank by race. Chart displays percentages of tissue samples in the Komen Tissue Bank for two time points: November 1, 2012, before any minority recruitment efforts began; and the most recent numbers on March 24, 2016.

Instead, the KTB needs to develop more effective and efficient recruitment strategies for African American women through targeted health communication messaging. Unlike their Caucasian counterparts, potential Black donors who demonstrated some interest in donation, but who for whatever reason either could not or would not donate at the upcoming event, would make no moves to follow up to donate at future events. This could perhaps be significantly increased by applying proactive retention strategies (Kim, Hickman, Gali, Orozco, & Prochaska, 2014). Hence, there is a need for the KTB to develop more effective methods for sustained recruitment of African American women, and communication research is needed to define the messaging that will attract Black women to this type of research and keep them coming. The Integrated Behavioral Model, which is described next, provides a particularly useful lens for the study of this health behavior.

Theoretical Framework

The Integrated Behavioral Model (IBM) is a health behavior model comprised of fundamentals from the theory of reasoned action, the theory of planned behavior, social cognitive theory, the theory of interpersonal behavior, and the health belief model (Kasprzyk, Montañó, & Fishbein, 1998), and is determined by three construct categories: attitude toward the behavior, perceived norm, and personal agency (Montañó & Kasprzyk, 2008). A person’s attitude toward a particular behavior is determined by whether the behavior is considered to be generally favorable or unfavorable. Perceived norm refers to the social pressure one feels to perform or not perform a particular behavior, and personal agency, which is divided into self-efficacy and perceived control, refers to one’s ability to influence one’s own environmental occurrences (Montañó & Kasprzyk, 2008). These variables in the model are shown to predict behavioral intention, which serves as the precursor to actual behavior.

The specific purpose of this study was to examine the perspectives of African American women toward donating breast tissue to the KTB for research purposes, especially in light of their racial heritage. Using the IBM as a framework, this study investigated the attitudes, norms, and aspects of personal control that may influence an African American woman to decide to donate breast tissue. Findings from this study would serve as input in the design of more targeted and potentially effective messaging about healthy breast tissue donation targeted toward the Black community. In sum, the following two research questions guided this study:

RQ1: What are the perceptions of Black women toward donating healthy breast tissue for research purposes?

RQ2: What are the important racial and social influences voiced by Black women when donating healthy breast tissue for research purposes?

Methods

Participants and Recruitment

Participants for this study were 71 African American women who had previously donated to the KTB. An e-mail containing the request to complete an online survey was sent to eligible participants; women were eligible for the study if they had donated breast tissue to the KTB and if, at the time of their donation, they had identified themselves as Black/African American. The text of the e-mail included a thorough description of the project. The informed consent statements for both the KTB itself, which they had previously signed and which allowed for some follow-up communication from KTB researchers, and for this study were included and reminded participants about the stated limitations on how many times per year and for which purposes any researcher would be allowed to further contact the women. The e-mail informed the past tissue donors that (a) they would not receive any follow up e-mail reminders about this project, and (b) they would have 2 weeks from the date the e-mail was sent to complete the survey. Interested women followed a link embedded in the e-mail that directed them to an online survey.

The Komen Tissue Bank allows donors to choose more than one race when they complete their medical history questionnaire. Thus, the e-mail recruitment message was sent to any previous donor who had identified that they were Black/African American, even if they selected other races. Originally, 88 participants self-selected into this study. However, 17 of those women were ultimately excluded from data analysis because they indicated they were Asian, Eurasian, mixed (with no further definition or clarification), or multiracial (with no further definition or clarification). Only women who identified themselves in this online study as Black/African American or “bi-racial” where “White/Black” was specified were included in the analyses. Other than race, no demographic information was collected.

Data Collection

The collection and analysis of data in this study were carefully executed using a deductive process guided by the chosen theoretical framework. Each respondent completed a survey questionnaire hosted by Survey Gizmo consisting of seven open-ended questions focused on their feelings and perceptions about having donated breast tissue, the attitudes of family and social circle members with regard to the participant’s tissue donation, the role race played in their decision to donate tissue, and perspectives on how to effectively recruit more Black women into medical research in general, and to this project in particular. Participants could write as much as they wanted for each question and could skip any question they preferred not to answer.

Data Analysis

After the online survey was closed, the collected data were exported to an Excel spreadsheet, after which the process of primary-cycle coding began. Tracy (2012) describes primary-cycle coding as beginning “with an examination of the data and assigning words or phrases that capture their essence” (p. 189). After determining the final participant criteria (i.e., racial groups), all ineligible respondents were removed from the data set. Using IBM as a guide, we engaged in primary-cycle coding by first immersing ourselves in the data and reading through it several times to become familiar with the sound and the feel of the responses (Tracy, 2012). Next, using cell and column coloring in Excel as a tool to help identify distinctive categories, both researchers began coding using the procedures learned from Tracy (2012) and Saldaña (2012). The constant comparative method was used to examine data related to each code, and the researchers modified codes to make room for new ones. This process resulted in first-level codes informed by IBM, which could already begin to be allocated to themes (Saldaña, 2012).

Once the first-level coding was completed, both coders independently performed second-level coding through the lens of IBM. While doing this, the researchers continued the use of a deductive, “top-down” approach and looked for responses that would solidify and help narrow the loosely formed general thematic ideas. For example, as one component of IBM, a researcher must examine a participant’s attitude toward a behavior. Our primary level of coding focused simply on identifying whether or not the women’s attitudes could be categorized as positive or negative. As our analysis developed, it became clear that overall, the women felt positive about the donation experience. It was through second-level coding, however, that the breadth and depth of these positive attitudes was revealed, making it possible to identify specific types of instrumental attitudes espoused by these women. We could then easily apply these same processes to the other components of IBM, perceived norm and personal agency.

Once this second level of analysis was complete, the coding results from both authors were compared and contrasted, and appropriate similarity of results was determined (Saldaña, 2012). Any discrepancies were resolved through discussion and returning to the data and coding scheme. After solidifying the themes and interpreting the data, the researchers were

able to record their findings. Finally, the first author returned to the coded data and selected representative examples to highlight the findings for each theme, and those are presented in the following.

Findings

The results of this study revolve around three main themes, all derived from examining the data through the lens of the IBM. The first identified theme focuses on the attitudes of the participants toward their donations. In the second theme, perceived normative influences on donation are discussed, but also participants discuss their role in “creating” norms for this behavior. The third theme highlights the ways in which these participants’ racial heritage affected their desire to participate in the KTB clinical trial and how that racial heritage was actually a driving force (i.e., personal agency), rather than a deterrent, to their desire to donate.

Positive Instrumental Donation Attitudes

Consistent with the IBM, participants in this study expressed both experiential (i.e., emotional response to performing the behavior) and instrumental attitudes (i.e., beliefs about the outcomes of performing the behavior) toward donating breast tissue for research. The experiential attitudes expressed were mostly unremarkable, ranging from women who found their tissue donation experience to be commonplace (“I was nervous”; “The procedure didn’t hurt”) to outliers who had negative experiences (“I experienced a problem. They had a hard time to stop me from bleeding”). Given that both authors have previously donated themselves and have talked to many women who have also donated, we concluded that these experiential attitudes were not unique to Black women and thus we do not present them as a major finding. The instrumental attitudes expressed by these women, however, were nuanced and revealed unique perspectives; we present these instrumental attitudes as three separate types in the following.

First, many participants expressed that they thought it was important to help with breast cancer research in general. This was evidenced by Donor 27, who said, “I felt like I was a part of the solution or [was helping to] find a cure when I donated breast tissue,” and Donor 88, who stated, “I am proud to be able to contribute to the research.” It is significant that 14 other tissue donors taking part in this study echoed her use of the word “proud.” Donor 8 explained her outlook at length:

I wish everyone would donate. This research is so important to help find a cure. If a treatment is found to help breast cancer it maybe could be used to cure other cancer. I pray that any and all research is a [potential] cure for all cancer, not just breast cancer. I wish more people realized just how important this is.

Second, participants demonstrated positive instrumental attitudes toward their desire to help Black women specifically, and the importance of having the African American race represented in breast cancer research. Sometimes this desire to participate to help their race overcame their anxiety about donating. “I was nervous at first,” stated Donor 15, “but being

an African American female, I wanted to help out as much as I could.” Some of the women, like Donor 89, showed knowledge about the significance of low levels of participation of minorities in clinical trials. “I’m very open to donating because I know how few women of color participate in studies AND how often studies don’t reflect the needs of women of color, which may be different from white women.”

Third, participants expressed a desire to honor or support someone who has or had breast cancer. Emotion runs deeply through this third subtheme as participants speak of their family members and close friends who were affected by the disease: from Donor 2, “It was a way to honor my sorority sister who died”; from Donor 50, “I have had several family members diagnosed with breast cancer and I wanted to do my part”; and from Donor 29, “My grandmother passed away from breast cancer before I was born. I have her name.” Hope is also evident in some of the responses. Donor 73 was “thankful that I can help other women. Several friends have died from breast cancer.” When she wrote “It was a wonderful experience. My aunt, cousins, and my mom’s best friend have/had breast cancer” Donor 41 expressed only optimism and positive energy. In sum, women expressed very positive outlooks about their decisions to donate their healthy breast tissue and believed firmly that the outcomes of them donating was that others would be helped.

Influencing Others More Than Being Influenced

The second theme concerns the influences of others that may or may not have been felt by the participants. These influences are a combination of two parts: the prevalence of a behavior (in this case, donation) referred to as descriptive norms, and the pressures these donors experience to conform to or perform this behavior, which are called injunctive norms. The data in this study show that these injunctive normative influences were expressed in a unique way by these women. In the following, we describe the role of normative influences chronologically, from predonation, to donation, to postdonation.

During the time of predonation, more than half the women did feel supported verbally for making the choice to participate. The support came from various sources: family, friends, and even strangers. Some women felt strongly reinforced, like Donor 1, who stated, “Everyone was supportive of my decision to donate my breast tissue!,” and pride again presented itself in this subtheme, as mentioned by Donor 2 with noticeable simplicity: “They were proud of me.” Donor 87 wrote that her “family and social circle were very supportive” of her decision. “I posted it on Facebook and got nothing but positive feedback,” Donor 13 revealed.

In the second subtheme, donation (which includes the day of donating and immediately after), we uncovered that participants felt that the norm was actually created by the donor herself, through telling others about the KTB, and then stimulating postdonation support for what she did. Donor 31 said of her support team, “They all would like to have the opportunity to donate tissue in the near future,” and Donor 83 had a similar experience: “I had so many people asking me how was it and how can they donate.” Donor 47, who wrote, “I will continue to advocate to AA women to become breast

cancer donors. I've received a commitment from my sister to strongly consider it next year," seems to be committed for the long haul. Women like Donor 60, although they may not realize it, can be particularly important to the mission of an organization like the KTB. "I had a lot of support and encouragement from family and friends, and several contacted me to get additional information about the KTB," she responded. This type of advocacy can reap long-term benefits for an organization.

The postdonation subtheme yielded a new idea that does not really fit the description of either the descriptive or the injunctive norm. Labeled "legacy norm" by the authors of this study, it drives a motivation for these women to participate as a tissue donor in order to help other women in the future. They feel like their actions will be good for, and result in better outcomes for, their daughters, granddaughters, and future members of their race. The passion felt by Donor 47 for this cause is made clear through her written response:

Looking around and seeing a minimal number of African American women donating [made me] become passionate in spreading the word to my fellow sistahs and encouraging them to at least consider becoming a donor. I also share with them the disparity in donating tissue as well as that of the death rate between Caucasian and AA women to breast cancer.

Donor 29 demonstrated the breadth of this outlook when she responded, "Honestly, I felt like it was . . . a duty/responsibility to help others," and the eloquence of Donor 41, who wrote, "It was a wonderful experience. My aunt, cousin, and my mom's best friend have/had breast cancer and it was important to me to donate to help our future generations."

In summary, the data indicate a unique and exciting new examination of perceived normative influences; these women felt supported in their decision, but also became strong forces in advocating others (i.e., creating norms) to donate.

It Is All About Race

The third and final theme hinges on the fact that the participants in this study identify as African American females who have decided to participate in medical research by donating their breast tissue. As the data within this theme were examined, three subthemes developed that, at their core, concentrated on what would encourage or prevent the involvement of Black women in this type of study.

First, many women acknowledged that history had not been kind to Black people involved in medical research. Some even mentioned that when there was a lack of family support for the choice they had made to donate, it was usually because of familiarity with that negative history. This outlook was shown through both external negativity (e.g., from family, husband, or society) and internal negativity (e.g., from the donor's own personal knowledge of the history of her people.) In response to a question about the outlook of family members and social circles with regard to her choice to donate her breast tissue, Donor 7 replied, "Well, I'm Black. Henrietta Lacks, Tuskegee experiments. They were extremely apprehensive." Donor 23 delved into her own knowledge and subsequent viewpoint:

I am very much aware of the history of exploitation in the U.S. with Black women's bodies (e.g., slavery and breeding, medical experimentation, test subjects, etc.). So that was definitely in the forefront of my mind (i.e., why contribute to medical research that has damaged us in the past, and may not benefit us in the future?). The exploitative history has caused a deep-rooted, distrustful sentiment about the medicine/doctors/hospitals in Black culture.

This finding reveals importantly that the history of African Americans in medical research in the United States was at the forefront of these women's minds when deciding to donate. In other words, they are fully aware of the "elephant in the room" when deciding to volunteer to donate their own breast tissue; thus, any messaging aimed at recruiting more African American women to donate should fully acknowledge this "elephant."

The second race-oriented subtheme revealed that participants' positive feelings about the importance of being involved in this research, coupled with their negative feelings about women in their community suffering from breast cancer, were important motivators to donation. Many participants were aware that breast cancer disproportionately affects Black women and there was widespread agreement that as Black women they shared a responsibility to be a part of this kind of study. Donor 3 expressed a simple yet strong opinion in her response to a question about race: "Minority women need minority advocates to encourage and support the donation of breast tissue." Donor 7 brought up an important fact when she said that "Breast cancer for Black women tends to be more aggressive and caught later," and then continued with her reasoning, "so by donating my tissue hopefully they can find a cure." Donor 38 expressed what motivated her decision to donate very clearly: "I hope my donation can help all women, but if it can help Black women especially, it makes me feel proud to know that my little contribution could have such far reaching effects."

In the third and final subtheme, participants suggested that in recruiting and educating Black women with regard to the need for them to be a part of this research, the KTB (and others doing research where African Americans are needed) should make it about race. These women say they want and need to hear specifically and in detail why they should actively take part in the research. Here is Donor 36:

The Black community does not know about donating. Now if you would like more studies of African American women, please advise, communicate, and educate. Every Black women I have spoken to, [including] women preachers who have traveled the world, state they did not even know that they could donate [their breast tissue.]

In this sense, highlighting that African American women, rather than just women in general, are specifically needed for these studies can be an effective motivating force to drawing these women in.

Echoing this sentiment, Donor 23 contributed the following:

I think it's always important to communicate to minority groups how their participation can benefit not just women in general but their communities in particular. It's important to communicate the cause and effect. How does their contribution directly impact

their daughters, sisters, and friends? Be honest about the bad history surrounding their past “participation” in research to dispel the myths, be honest about the truths, and explain the differences (i.e., this is safe, confidential, important, you won’t be taken advantage of) ... build confidence and trust by acknowledging the past and the current distrust and worry so that minority women can see their role in positively impacting the future.

The overall message of this third theme is that political correctness can be a hindrance here. Race is important in the context of this clinical trial in that Black women, in particular, are needed. These participants are expressing that race is important and it should be acknowledged up front. In sum, the women made it clear that in order to promote forward progress of African Americans taking part in medical research, they need to have conversations with medical researchers and those promoting that research about the elephant in the room—race.

Discussion

The purpose of this study was to examine African American women’s perspectives on donating their healthy breast tissue for research, and to identify the normative influences to which they are exposed. The responses of these tissue donors indicated that they experienced very positive instrumental attitudes; most women expressed they had yielded to an internal pressure to do the “right thing” and had experienced subsequent feelings of pride. Normative factors were in play, as was the discovery that for these women being Black and being involved in this research were connected; it was important to them. Being African American was a central factor in the decision these women made to donate their tissue. Using the IBM as a framework, implications of these findings are discussed in the next few paragraphs.

Instrumental Attitudes

The participants of this study demonstrated overwhelmingly positive instrumental attitudes about donating healthy breast tissue for research. The sense of altruism stemming from being in a position to help others was so important to these women that it outweighed any actual or perceived negative experiential attitudes. Godsken, Hansson, Nygren, Nordin, and Kihlbom (2015) collected data by questionnaire from 88 cancer patients who were participating in clinical trials, asking why they were participating. The two most significant responses were that they hoped for a cure, and they wanted to help others in the future. Altruism as a motivating force for participation may be a particularly effective messaging component for recruitment into clinical trials. People seem to have a predisposition toward participation in clinical trials resulting from an inclination to help others and exacerbated by an idea that they can also help themselves as a bonus (McCann, Campbell, & Entwistle, 2010). It appears this phenomenon is not restricted to one race or ethnicity, but is present across all cultures and colors. An implication of this finding is that a possibly effective strategy for increasing tissue donorship in African American women revolves around comprehending and appealing to this existing sense of selflessness.

Positive Norms

Overall, the women felt supported in their decisions and reported positive normative influences. When they mentioned their intentions to donate tissue, their families and social circles reinforced this behavior or, at the very least, were neutral in their reactions. A significant factor of this finding, however, is not that the participants experienced and may have been influenced by this support, but rather that they themselves became the influencers. Not only did they convert their intentions to actions, these women broadcast their decision through varied media and interpersonal channels. They became opinion leaders, sometimes purposefully encouraging others to join them, and inviting friends and family members to come along for support or because it was the right thing to do. Often, however, simply announcing their intentions seemed to be all the influence needed to stimulate additional, unsolicited participation. While there is research finding that normative pressures may not have much impact on health behavior (De Vries, Kok, & Dijkstra, 1990; Kok, De Vries, Mudde, & Strecher, 1991; Lechner & De Vries, 1995), this is not exactly the case here. These early adopters made internal decisions independently of normative pressures, not because of or despite them. Focusing, sharpening, and channeling their convictions and sending them into the community to relay their opinions would make them excellent ambassadors for health research.

Another important element of this finding is the discovery of the “legacy norm,” which fits into neither of the existing IBM categories of descriptive and injunctive norms. The legacy norm is consistent with perceptions through history about African American women and their propensity toward sacrifice for their families: teachings that have been handed down from mother to daughter for centuries (Fouquier, 2011; Greene, 1990; Williams, 2006). In an article published when she was editor of *Ms. Magazine*, Pulitzer prize-winning author Alice Walker (1972) wrote of the folkloric identity of Black women as “the mule of the world,” referring to their collective role as the carrier of everyone else’s burdens. Our research shows this is also applicable to health behaviors, and recognizes an opportunity to examine the communication involved in recruiting Black women into research that helps others, now and in the future.

Race

Although many participants freely discussed the negative history of medical research and its abuse of African Americans, having this knowledge was not enough to serve as a deterrent to donating for this group of participants. In fact, for many women who were more educated about health research, this awareness even acted as a motivator. They expressed that African Americans might be nervous about research or not understand its importance to Black people, who must be involved in research to be able to benefit from it. According to the women who felt this way, making it about race is the key to increasing self-efficacy and perceived control, and will open the door to encouraging Black people to participate in medical research. Applying cultural tailoring, information

strategies intended to reach a certain group of people and that are based on characteristics unique to that group (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003), offers practical implications for clinical trials such as the KTB. Relatedly, this approach moves beyond culturally sensitive health communication to be more in line with what Dutta calls the “cultural-centered approach that puts culture at the core of health communication practices” (Dutta, 2007, p. 304). Recommendations for increasing the involvement of African American women might include these strategies:

- Hold information sessions about unethical studies like the Tuskegee Trials and discuss the changes and safeguards in place in current research.
- Educate communities about the purposes of culturally focused medical research, making sure to clarify that benefit for particular groups comes only through participation.
- Get the word out through trusted channels. Gatherings at churches and community venues are good opportunities for informing the Black community about applicable medical research opportunities.

These and other messaging strategies gleaned from this study are currently being tested by the KTB to recruit more African American donors and to ensure sustainable and representative samples from Black women in the future. However, more research is needed to evaluate these health communication tactics to determine whether they will contribute to the increased and sustained recruitment of African American women to the KTB.

Limitations

Data for this study were gathered by Web-based questionnaire, which, while ensuring anonymity of the participants, created important methodological limitations. This survey was sent out to all African Americans who had donated tissue to the KTB at the time of this study, and included respondents from four cities in Indiana—Indianapolis, Lafayette, Fort Wayne, and Bloomington—as well as Louisville, KY, and Chicago, IL. While this did potentially allow for some geographic diversity in our answers and a potentially more representative sample, conducting interviews instead would have possibly provided more in-depth answers and offered the researchers a chance to implement the use of follow-up questions, allowing for more clarity and depth of the responses. In addition, at the time the data was collected, these were all of the cities in which the KTB had held collection events, and represent only a segment of the Midwestern region of the United States. Finally, we did not collect geographical information on these women, so within these six cities we have no data on geographic representation.

The authors also realize that recruiting only women who have previously donated can limit the perspective. The choice was made to focus only on this cohort because these women had previously practiced the behavior (i.e., donating) that this study hopes to address with future health communication efforts. The findings from these

“early adopters” can help us better understand how women from this population think and feel about donating tissue, and these findings be used to inform targeted message design to educate and persuade other women to perform the behavior (Rogers, 2002). In addition, research also shows that early adopters have the potential to influence action themselves, serving as opinion leaders or examples to their peers (Haider & Kreps, 2004; Rogers, 2002). As noted by Haider and Kreps (2004), “Communication of messages concerning new ideas involves the active creation and sharing of information among people to reach mutual understandings” (p. 4) and “behavior change processes . . . rest on the idea that one should try to accelerate the filtering of innovations from the innovators to the laggards as quickly and precisely as possible” (p. 5). However, future work could focus on African American women who had decided not to donate and could uncover barriers to donation.

Conclusions

This study sought to identify how African American women feel about donating breast tissue, how they talk about it, and what barriers and motivators may be in place that affect their desire to perform this behavior. We administered a Web-based survey questionnaire and discovered that African American women who were previous donors spoke about: a) strong instrumental attitudes toward donating, b) perceived normative influences and creating their own norms, and c) personal agency related to their racial heritage and the desire to participate in research. Each of these findings has important implications for health communication scholars interested in effective message design, but also for medical researchers seeking to better recruit racial minorities into clinical research, for people working at the KTB and other donation organizations (e.g., blood, tissue, marrow, etc.), and for others working with African American people who seek to get them involved in any kind of research.

Continuing to understand how minority groups feel about health research is important because their participation in medical studies will lead to better health outcomes for their racial groups. Some of the findings of this study, such as altruistic leanings and the interesting effects of normative pressures, or lack thereof, are cross-cultural. Other conclusions, however, such as the important discovery of the legacy norm and the broadly expressed desire to talk freely about what Black people need to do to help Black people, are distinctively representative of the group’s race. Perhaps the major finding from this study should not be surprising: Clearly communicating about the fact that if African American women participate in this research, they benefit more from this research, is an important step in making sure that this racial group no longer has to suffer disproportionately from breast cancer.

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References

- Abrams, D. B. (2006). Applying transdisciplinary research strategies to understanding and eliminating health disparities. *Health Education & Behavior, 33*, 515–531. doi:10.1177/1090198106287732
- Adams-Campbell, L. L., Dash, C., Palmer, J. R., Wiedemeier, M. V., Russell, C. W., Rosenberg, L., & Cozier, Y. C. (2016). Predictors of biospecimen donation in the Black Women's Health Study. *Cancer Causes & Control, 27*, 797–803. doi:10.1007/s10552-016-0747-0
- American Cancer Society. (2015). *Breast cancer facts & figures 2015–2016*. Atlanta, GA: American Cancer Society, Inc.
- American Cancer Society. (2016). *Cancer facts & figures for African Americans 2016–2018*. Atlanta, GA: American Cancer Society, Inc.
- Branson, R. D., Davis, K., & Butler, K. L. (2007). African Americans' participation in clinical research: Importance, barriers, and solutions. *American Journal of Surgery, 193*, 32–39. doi:10.1016/j.amjsurg.2005.11.007
- breastcancer.org. (2015). *Who gets triple negative breast cancer?* Retrieved from http://www.breastcancer.org/symptoms/diagnosis/trip_neg/who_gets
- Brooks, M. M., Paschal, A. M., Sly, M. J. R., & Hsiao, T. (2008). African American women and clinical trials: Perceived barriers to participation and potential solutions. *American Journal of Health Studies, 24*, 298–305.
- Buseh, A. G., Stevens, P. E., Millon-Underwood, S., Townsend, L., & Kelber, S. T. (2013). Community leaders' perspectives on engaging African Americans in biobanks and other human genetics initiatives. *Journal of Community Genetics, 4*, 483–494. doi:10.1007/s12687-013-0155-z
- Buseh, A. G., Underwood, S. M., Stevens, P. E., Townsend, L., & Kelber, S. T. (2013). Black African immigrant community leaders' views on participation in genomics research and DNA biobanking. *Nursing Outlook, 61*, 196–204. doi:10.1016/j.outlook.2012.10.004
- Centers for Disease Control and Prevention. (2014). *Breast cancer statistics*. Retrieved from <http://www.cdc.gov/cancer/breast/statistics/index.htm>
- De Vries, H., Kok, G., & Dijkstra, M. (1990). Self-efficacy as a determinant of the onset of smoking and interventions to prevent smoking in adolescents. *European Perspectives in Psychology, 2*, 209–222.
- Doherty, E. F., MacGeorge, E. L., Gillig, T., & Clare, S. E. (2015). Motivations, concerns, and experiences of women who donate normal breast tissue. *Cancer Epidemiology Biomarkers & Prevention, 24*, 105–110. doi:10.1158/1055-9965.EPI-14-0941
- Dutta, M. J. (2007). Communicating about culture and health: Theorizing culture-centered and cultural sensitivity approaches. *Communication Theory, 17*, 304–328. doi:10.1111/comt.2007.17.issue-3
- Elledge, R. M., Clark, G. M., Chamness, G. C., & Osborne, C. K. (1994). Tumor biologic factors and breast cancer prognosis among White, Hispanic, and Black women in the United States. *Journal of the National Cancer Institute, 86*, 705–712. doi:10.1093/jnci/86.9.705
- Ford, M. E., Siminoff, L. A., Pickelsimer, E., Mainous, A. G., Smith, D. W., Diaz, V. A., ... Tilley, B. C. (2013). Unequal burden of disease, unequal participation in clinical trials: Solutions from African American and Latino community members. *Health & Social Work, 38*, 29–38. doi:10.1093/hsw/hlt001
- Fouquier, K. F. (2011). The concept of motherhood among three generations of African American women. *Journal of Nursing Scholarship, 43*, 145–153. doi:10.1111/j.1547-5069.2011.01394.x
- Godskesen, T., Hansson, M. G., Nygren, P., Nordin, K., & Kihlbom, U. (2015). Hope for a cure and altruism are the main motives behind participation in phase 3 clinical cancer trials. *European Journal of Cancer Care, 24*, 133–141. doi:10.1111/ecc.12184
- Greene, B. A. (1990). Sturdy bridges: The role of African-American mothers in the socialization of African-American children. *Women & Therapy, 10*, 205–225. doi:10.1300/J015v10n01_18
- Haider, M., & Kreps, G. L. (2004). Forty years of diffusion of innovations: Utility and value in public health. *Journal of Health Communication, 9*, 3–11. doi:10.1080/10810730490271430
- Harris, Y., Gorelick, P. B., Samuels, P., & Bempong, I. (1996). Why African Americans may not be participating in clinical trials. *Journal of the National Medical Association, 88*, 630–634.
- Holloway, K. F. (2011). *Private bodies, public texts: Race, gender, and a cultural bioethics*. Durham, NC: Duke University Press.
- Hughes, T. B., Varma, V. R., Pettigrew, C., & Albert, M. S. (2015). African Americans and clinical research: Evidence concerning barriers and facilitators to participation and recruitment recommendations. *Gerontologist*. Advance online publication. doi:10.1093/geront/gnv118
- Johnson, E. T. (2002). Breast cancer racial differences before age 40—Implications for screening. *Journal of the National Medical Association, 94*, 149–156.
- Kasprzyk, D., Montaño, D. E., & Fishbein, M. (1998). Application of an integrated behavioral model to predict condom use: A prospective study among high HIV risk groups. *Journal of Applied Social Psychology, 28*, 1557–1583. doi:10.1111/j.1559-1816.1998.tb01690.x
- Kim, R., Hickman, N., Gali, K., Orozco, N., & Prochaska, J. J. (2014). Maximizing retention with high risk participants in a clinical trial. *American Journal of Health Promotion, 28*, 268–274. doi:10.4278/ajhp.120720-QUAN-355
- King, P. A. (1992). The dangers of difference. *Hastings Center Report, 22*, 35–38. doi:10.2307/3562948
- Kjellstrom, T., Mercado, S., Sami, M., Havemann, K., & Iwao, S. (2007). Achieving health equity in urban settings. *Journal of Urban Health, 84*, 1–6. doi:10.1007/s11524-007-9192-4
- Kok, G., De Vries, H., Mudde, A. N., & Strecher, V. J. (1991). Planned health education and the role of self-efficacy: Dutch research. *Health Education Research, 6*, 231–238. doi:10.1093/her/6.2.231
- Komen Tissue Bank. (2015). *Susan G. Komen® Tissue Bank at the IU Simon Cancer Center*. Retrieved from <http://komentissuebank.iu.edu/>
- Kreuter, M. W., Lukwago, S. N., Bucholtz, D. C., Clark, E. M., & Sanders-Thompson, V. (2003). Achieving cultural appropriateness in health promotion programs: Targeted and tailored approaches. *Health Education & Behavior, 30*, 133–146. doi:10.1177/1090198102251021
- Landecker, H. (2000). *Immortality, in vitro: A history of the HeLa cell line*. Bloomington, IN: Indiana University Press.
- Landrine, H., & Corral, I. (2015). Targeting cancer information to African Americans: The trouble with talking about disparities. *Journal of Health Communication, 20*, 196–203. doi:10.1080/10810730.2014.920061
- Lantz, P. M., Mujahid, M., Schwartz, K., Janz, N. K., Fagerlin, A., Salem, B., ... Katz, S. J. (2006). The influence of race, ethnicity, and individual socioeconomic factors on breast cancer stage at diagnosis. *Journal Information, 96*, 2173–2178.
- LaVeist, T. A., Gaskin, D., & Richard, P. (2011). Estimating the economic burden of racial health inequalities in the United States. *International Journal of Health Services, 41*, 231–238. doi:10.2190/HS.41.2.c
- Lechner, L., & De Vries, H. (1995). Starting participation in an employee fitness program: Attitudes, social influence, and self-efficacy. *Preventive Medicine, 24*, 627–633. doi:10.1006/pmed.1995.1098
- Lemke, A. A., Halverson, C., & Ross, L. F. (2012). Biobank participation and returning research results: Perspectives from a deliberative engagement in South Side Chicago. *American Journal of Medical Genetics Part A, 158A*, 1029–1037. doi:10.1002/ajmg.a.v158a.5
- Luebbert, R., & Perez, A. (2015). Barriers to clinical research participation among African Americans. *Journal of Transcultural Nursing, 27*, 456–463. doi:10.1177/1043659615575578
- McCann, S. K., Campbell, M. K., & Entwistle, V. A. (2010). Reasons for participating in randomised controlled trials: Conditional altruism and considerations for self. *Trials, 11*, 31–41. doi:10.1186/1745-6215-11-31
- Montaño, D. E., & Kasprzyk, D. (2008). Theory of reasoned action, theory of planned behavior, and the integrated behavioral model. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (4th ed., pp. 67–96). San Francisco, CA US: Jossey-Bass.
- National Breast Cancer Coalition. (2015). *Outcome measures or endpoints for clinical trials*. Retrieved from <http://www.breastcancerdeadline2020.org/breast-cancer-information/understanding-research/outcome-measures-or-endpoints.html?referrer=https://www.google.com/>
- National Cancer Institute. (2016). *SEER Stat Fact sheets for female breast cancer*. Retrieved from <http://seer.cancer.gov/statfacts/html/breast.html>

- Office on Women's Health. (2012). *Minority women's health: African Americans*. U.S. Department of Health and Human Services. Retrieved from <https://www.womenshealth.gov/minority-health/african-americans/index.html>
- Otado, J., Kwagyan, J., Edwards, D., Ukaegbu, A., Rockcliffe, F., & Osafo, N. (2015). Culturally competent strategies for recruitment and retention of African American populations into clinical trials. *Clinical and Translational Science*, 8, 460–466. doi:10.1111/cts.12285
- Roberson, N. L. (1994). Clinical trial participation: Viewpoints from racial/ethnic groups. *Cancer*, 74, 2687–2691.
- Rogers, E. M. (2002). Diffusion of preventive innovations. *Addictive Behaviors*, 27, 989–993. doi:10.1016/S0306-4603(02)00300-3
- Russell, E., Robinson, D. H., Thompson, N. J., Perryman, J. P., & Arriola, K. R. J. (2012). Distrust in the healthcare system and organ donation intentions among African Americans. *Journal of Community Health*, 37, 40–47. doi:10.1007/s10900-011-9413-3
- Saldaña, J. (2012). *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage.
- Sherman, M. E., Figueroa, J. D., Henry, J. E., Clare, S. E., Rufenbarger, C., & Storniolo, A. M. (2012). The Susan G. Komen for the Cure Tissue Bank at the IU Simon Cancer Center: A unique resource for defining the “molecular histology” of the breast. *Cancer Prevention Research*, 5, 528–535. doi:10.1158/1940-6207.CAPR-11-0234
- Skloot, R., & Turpin, B. (2010). *The immortal life of Henrietta Lacks*. New York, NY: Crown.
- Tanner, A., Kim, S.-H., Friedman, D. B., Foster, C., & Bergeron, C. D. (2015). Barriers to medical research participation as perceived by clinical trial investigators: Communicating with rural and African American communities. *Journal of Health Communication*, 20, 88–96. doi:10.1080/10810730.2014.908985
- Tracy, S. J. (2012). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. Malden, MA: John Wiley & Sons.
- U.S. Census Bureau. (2015). *QuickFacts United States*. Retrieved from <https://www.census.gov/quickfacts/table/PST045215/00>
- Walker, A. (1972). *In search of our mother's gardens*. New York, NY: Harcourt.
- Williams, D. S. (2006). Womanist theology: Black women's voices (1986). In L. Phillips (Ed.), *Womanist Reader* (pp. 117–125). New York, NY: Routledge.