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## Prevalent Health Concerns among African-American Women belonging to a National Volunteer Service Organization (The Links, Incorporated)

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### Abstract

**Objective**—African American women bear a disproportionate burden of cardiovascular disease (CVD) and cancer. The purpose of this study was to identify prevalent health concerns among African American women who are members of The Links, Incorporated (Links), a large national service organization with health programming for communities of color.

**Methods**—Survey data (n=391) were collected during the 2012 Links National Assembly. Twenty-six health issues were presented within five groups: cancer, CVD, pulmonary disease, chronic conditions, and behavioral health. For each issue, women indicated if it was a concern for “you/your family” or “the African American community” via check-boxes. Differences in the proportions for “you/your family” and “the African American community” were evaluated using the McNemar test.

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**Ethical approval:** All procedures performed in studies involving human participants were in accordance with the ethical standards of the Mayo Clinic Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Compliance with Ethical Standards:** All authors have declared that they have no conflict of interest. Informed consent was obtained from all individual participants included in the study.

**Results**—Hypertension was the most frequently endorsed concern for you/your family (79%); 73% indicated this was a concern for the African American community. Sick cell anemia was the most frequently endorsed concern for the African American community (77%). Melanoma was the least endorsed health issue overall (15% you/your family, 55% community). Breast was the most frequently endorsed cancer concern, while lung was among the least. For 23 out of 26 health issues, the proportion concerned was greater for the “African American community” than for “you/your family” (all  $p < 0.05$ ).

**Conclusion**—CVD and breast cancer were salient concerns; both are topics for which national awareness campaigns and Links health programming exist. Comparatively lower concern was observed for melanoma, a cancer with known survival disparities, and for lung cancer, a leading cause of death in women.

### Keywords

women; health priorities; health disparities; African American; cardiovascular diseases; cancer

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## INTRODUCTION

In the United States (U.S.), African Americans experience earlier morbidity and mortality than whites including two leading causes of death: cardiovascular disease (CVD) and cancer [1–3] African American women have a higher prevalence of CVD risk factors and mortality than their white counterparts [4] and a lower level of heart disease awareness despite a national increase in awareness rate for women [5]. Moreover, African American women have higher death rates for nearly all cancers than white women, with the racial disparity widening between 1999–2011 for colorectal [6] and breast cancer [7, 8]

Effective mobilization of education and interventions focused on disease prevention or early detection relies in part on recognition and concern regarding the major health issues faced by an individual or his/her community. Recognition and concern may influence the actions taken (or not taken) to mitigate the health threat. If individuals are not concerned about a particular health issue, it is unlikely they will attend to information about it or accurately identify signs to seek care for themselves or a family member. Efforts have been made to create awareness of major health issues affecting African Americans. However, it is unknown whether these efforts are successful in increasing the concerns that African American populations may have for particular health issues. Furthermore, known cognitive biases can complicate the process of awareness and concern, particularly in the area of health. These include *availability bias*: [9] overestimating what is easy to retrieve in memory due to a recent occurrence/event or emotional impact; *confirmation bias*: [10] tendency to focus on information that conforms to one’s own preconceptions; or *optimistic bias*: [11, 12] thinking that one’s own chance of experiencing a negative outcome or event are lower than that of one’s peers [13–15]. Rather than flaws in thinking, these biases can be viewed as common heuristics or “mental shortcuts” (e.g., “people with darker skin pigmentation do not need to be concerned about melanoma”) or efforts to protect oneself from threatening thoughts (e.g., “I do not need to be concerned about lung cancer because I don’t use tobacco.”).

Recognizing that effective efforts to prevent the major causes of morbidity and mortality in African Americans begin with acknowledging bias and capturing concern regarding these diseases, the purpose of this study was to identify prevalent health concerns among a large, national organization that is dedicated to serving communities of color. The Links, Incorporated (Links) is a volunteer service organization whose membership consists of over 12,000 professional African American women across the U.S. The Health and Human Services (HHS) facet of the organization addresses issues salient to the African American community by implementing programs through strategies such as public information and education, economic development, and public policy campaigns. Thus, identifying what Links members see as key health issues can inform health programming efforts within the organization and ultimately determine which programs will reach African American communities across the U.S. through Links service initiatives and volunteering.

## METHODS

### Study Population

This descriptive study is part of a larger investigation that surveyed Links members regarding their perceptions, practices, and attitudes toward health-related research. The study was approved by the Mayo Clinic Institutional Review Board and Links leadership and was performed in accordance with the ethical standards outlined in the Belmont Report. Informed consent was obtained from all individual participants included in the study. Specific procedures surrounding the development and distribution of the survey have been previously described [16, 17]. Briefly, data were gathered through a cross-sectional, self-administered survey made available to over 2,000 registrants at the 2012 Links National Assembly. At the Assembly, staff provided registrants with packets containing study information, an oral consent script and a self-administered, anonymous survey. Participants were instructed to return their completed survey to a member of the study staff in the research booth located in the exhibit hall and receive a thank you gift. The survey assessed demographics, research participation attitudes and experiences, general health status, health concerns, sources of health information, and knowledge and willingness to participate in various types of research studies.

### Measures

Socio-demographic characteristics included age, marital status, current employment, educational attainment, and health insurance coverage. The health concerns assessment used methods adapted from Bishop and colleagues [18]. Specifically, women were presented with a list of 26 health issues, two columns of check-boxes labeled “You/Your family” and “African American community” and the instructions: “*Please indicate if the following are health concerns for you/your family, or the African American community by checking the appropriate box or boxes. A concern does not necessarily mean that individuals suffer from these conditions, just that you are concerned. If something is not a concern, just leave it blank.*” The 26 health issues included: cancer (breast, prostate, colon, ovarian, lung, pancreatic, skin [melanoma]), cardiovascular disease ([CVD], hypertension, high cholesterol, stroke, coronary heart disease, heart attack), pulmonary disease (asthma, chronic obstructive pulmonary disease [COPD]), behavioral health (tobacco use/dependency,

obesity, physical inactivity), and chronic health conditions (diabetes, arthritis, gout, fibromyalgia, kidney disease, lupus, glaucoma/eye diseases, dementia/Alzheimer's disease, sickle cell anemia). An option for "other" was provided for participants to write in health concerns not included in the list. Survey questions underwent initial pilot-testing among 18 women in the organization who were attending a Links community event several months prior to the National Assembly. The pilot-testing informed our choice to reduce three response columns ("You," "Your family," "the African American Community") in the health issues section of the survey to two columns, one for the "African American Community" and a second for "You/Your family."

### Data Analysis

Descriptive statistics are presented, including frequency (n) or means and standard deviations ( $M \pm SD$ ), median and range to present the demographic characteristics of the sample. Responses indicating concern for the various health issues are presented as frequency and percentage (%) of the total sample. A McNemar test was used to examine differences between health concerns for "You/Your family" and "the African American Community." Statistical significance was declared at  $p < 0.05$ . Data analysis was performed using SPSS (version 20, IBM SPSS).

## RESULTS

A total of 391 African American women returned a completed survey. The socio-demographic characteristics of the survey respondents reflected the membership of Links: a majority (84%) was 50 years of age or older ( $M = 57.9$  years  $\pm 9.9$ , median = 59, range 20–87), employed (67%), married or in a committed relationship (66%) and had achieved a graduate or professional degree (84%). Over 63% of respondents reported an annual household income of \$100,000 or greater. Additional details regarding the sample are reported elsewhere [16, 17].

The proportion of women (out of 391) who marked a particular health issue as a concern for "You/Your family" and for the "African American Community" is shown in Table 1. The proportion of respondents indicating concern for the African American community was greater than the proportion for oneself/one's family for 23 out of 26 health issues (all  $p < 0.05$ ); differences were not observed for arthritis ( $p = 0.89$ ), high cholesterol ( $p = 0.52$ ), or hypertension ( $p = 0.10$ ). Hypertension was the only health issue where the pattern of proportions was reversed, that is, a higher proportion of respondents indicated concern for "You/Your family" as compared to the "African American Community."

With regard to the African American community, the highest frequency concern was sickle cell anemia (77.2%); the least prevalent concern was melanoma (54.7%). Concern about all types of CVD was more prevalent than concern for any of the cancers. Other higher frequency concerns for the African American community included obesity (73%), breast cancer (71.6%), and diabetes (71.4%).

With regard to oneself and one's family, hypertension was the most prevalent concern (79%) and melanoma the least, with only 15% of respondents indicating concern. Similar to the

pattern observed for the African American community, CVD concern was more prevalent than concern about any of the cancers. Among the cancers presented, breast cancer was the most frequent cancer concern (47.3%) followed by prostate, colon, ovarian, lung, pancreatic, and skin. Obesity, diabetes, and arthritis were concerns for oneself or one's family in more than 60% of respondents.

Sixty-four women checked "other" concerns for oneself/one's family (n=19), the African-American community (n=29), or checked "other" and marked both columns (n=16). The most commonly listed "other" health concerns encompassed mental health issues including depression, mental illness, drug dependency/addiction, and stress. Other concerns noted by fewer individuals included liver cancer and blood cancers (i.e., leukemia, lymphoma, myeloma), autoimmune (Crohn's disease), endocrine (thyroid disease), and neurologic diseases (MS, ALS, Parkinson's), and issues related to reproductive or sexual health (fibroids, cervical cancer, pre-teen pregnancy, HIV/AIDS).

## DISCUSSION

This study identified prominent health concerns among a sample of educated, professional African American women who are members of a large, national volunteer service organization. In this study, diseases of the cardiovascular system, including heart attack, stroke, and hypertension, were identified as health concerns for the African American community by greater than 70% of respondents. This finding is significant, as heart disease is widespread among African Americans [19–21] and correlates with excess disease burden in this minority population [22, 23]. Importantly, heart disease is the leading cause of death among African American women in the U.S. [3] and despite significant increase in awareness rates among women in general there are still racial differences [5]. The comparatively high concern regarding CVD observed in this sample may reflect overall health awareness, the impact of heart related public awareness campaigns (e.g., the National Heart, Lung Blood Institute's Heart Truth® campaign [24], American Heart Association's Go Red For Women® [25], and Association of Black Cardiologists initiatives [26]), an increase in preventative services provided by a variety of organizations (e.g., The CDC's Wisewoman™ [27] for low income, un-insured/underinsured women), experiential knowledge, and/or Links HHS programming efforts, which currently include a signature program "HeartLinks to Heart Health" that implements healthy-heart activities among other cardiovascular risk-reduction programs in African American communities.

A majority (23 out of 26) of the health issues demonstrated a pattern suggestive of optimistic bias, as women more frequently endorsed concerns for others in their referent group (African Americans, in general) than for themselves or their family. This finding is consistent with other studies showing that African Americans perceive themselves to be at lesser risk to ascribed behaviors and/or diseases than individuals in the broader community [28–31]. Why this pattern was not seen with hypertension, arthritis, or high cholesterol remains open for further investigation. The difference in percent concerned between self/family and community was largest for lung cancer, COPD, sickle cell anemia, lupus, and tobacco use. This may reflect a combination of the good health status of our sample [17] and

knowledge among this educated group of women that sickle cell anemia and lupus are commonly diagnosed in African Americans.

Though informative about health concerns among African American women, the findings from this study have limitations for generalizability. Links members may not be representative of the broader African American community; most of the study participants have a high educational attainment and income, are insured, and likely have access to a variety of health information resources. However, by virtue of being a member of The Links, Incorporated, these women have a wide social network, connectedness through a formal organizational structure, health programming, and a commitment to service. These characteristics provide a platform for potentially influencing African American communities across the nation. In addition, the list of health conditions provided in the survey was not comprehensive; therefore, there may be an omission bias. Inclusion of a write-in option lessens this concern, although it is possible that if options written-in as “other concerns” were included in the list, a greater proportion of women would have endorsed those health concerns. This may be particularly true for uterine fibroids, which was written-in by only one individual but is a more prevalent and aggressive condition among African American women than white women [32]. Likewise, depression, which has lower prevalence but greater severity in African Americans than whites [33–35], was written-in by many participants in the space for “other concerns.” Both of these important health issues were inadvertently omitted from the pre-populated list of health conditions and reflect unfortunate oversights; nonetheless, our survey was still able to capture these concerns within our sample by including a write-in option. Finally, the large venue and method of survey distribution hindered our ability to calculate an actual response rate, as we could not guarantee that every registrant at the Assembly received a survey packet, actually opened it, and made a decision about whether or not to complete it. Survey packets were available at the registration desk and at the research booth in the main assembly hall to ensure wide distribution. Survey return at the research booth confirmed each woman only responded once, and received one thank you gift. We are careful to describe our sample as a convenience sample that is neither generalizable to the entire organization nor to the general population of African American women.

Acknowledging the potential influence of the availability bias, our findings suggest that health programming likely has the intended effect of raising awareness and/or concern regarding those issues. For instance, Links programming and national awareness campaigns on heart disease and breast cancer were in existence at the time of the survey, and concern for these conditions was evident for a high proportion of the sample. Additionally, general public-health promotion campaigns have recently focused on heart disease and breast cancer, while much remains to be done for many other health conditions.

Relative to other health issues, lung cancer had lower endorsement of concern despite being the leading cause of cancer death among women [36]. Smoking history and exposure to secondhand smoke among Links membership are unknown; heightened awareness of lung cancer mortality among African American women may be beneficial. Furthermore, concern was lowest overall for melanoma, the deadliest form of skin cancer. This finding could reflect a confirmation bias that individuals with darker skin pigmentation do not need to be

concerned about melanoma. While this cancer is indeed uncommon among African Americans, it is often detected at more advanced stages and has lower survival rates in this group [37–39]. Our data reveal patterns suggestive of availability, confirmation and optimistic biases; these observations, taken together with published epidemiologic findings, suggest that focused educational campaigns around lung cancer and melanoma in African Americans may be beneficial.

## CONCLUSIONS

This study describes health concerns for the African American community, as perceived by women who are members of an African American organization that is characterized by dedicated health programming, a national presence, and a commitment to community service. The data showed CVD, breast cancer, and sickle cell anemia to be prominent health concerns, while lung cancer, a leading cause of death for women, was among the lowest cancer concerns for “you/your family.” The Links organization and others similar to it are positioned to disseminate information and resources regarding health conditions and issues affecting communities of color and potentially reduce disparities in health. In order to maximize this potential, it is important to periodically assess the concerns and priorities of the membership, evaluate health programming efforts against epidemiologic trends and mortality data, and recognize the potential for cognitive biases and heuristics to influence the process of setting priorities.

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**Table 1**

Frequency of Health Concerns Reported by African American Female Survey Respondents (N = 391)

Health Concern	Concern for You or Your Family n (%)	Concern for the African American Community n (%)
<b>Cancer</b>		
Breast	185 (47.3)	280 (71.6) ***
Prostate	162 (41.4)	269 (68.8) ***
Colon	145 (37.1)	260 (66.5) ***
Ovarian	103 (26.3)	246 (62.9) ***
Lung	89 (22.8)	262 (67.0) ***
Pancreatic	84 (21.5)	237 (60.6) ***
Skin (melanoma)	60 (15.3)	214 (54.7) ***
<b>Cardiovascular Disease</b>		
Hypertension	308 (78.8)	285 (72.9)
High Cholesterol	273 (69.8)	283 (72.4)
Stroke	221 (56.5)	287 (73.4) ***
Coronary Heart Disease	220 (56.3)	290 (74.2) ***
Heart Attack (MI)	214 (54.7)	293 (74.9) ***
<b>Pulmonary Disease</b>		
Asthma	154 (39.4)	256 (65.5) ***
COPD	87 (22.3)	251 (64.2) ***
<b>Other Chronic Health Issues</b>		
Diabetes	241 (61.6)	279 (71.4) *
Arthritis	238 (60.9)	241 (61.6)
Dementia or Alzheimer's Disease	194 (49.6)	267 (68.3) ***
Glaucoma or other eye disease(s)	181 (46.3)	248 (63.4) ***
Kidney Disease	135 (34.5)	263 (67.3) ***
Gout	113 (28.9)	227 (58.1) ***
Sickle Cell Anemia	80 (20.5)	302 (77.2) ***
Lupus	79 (20.2)	269 (68.8) ***
Fibromyalgia	67 (17.1)	219 (56) ***
<b>Behavioral Health</b>		
Tobacco Use and Dependency	102 (26.1)	268 (68.5) ***
Physical Inactivity	209 (53.4)	279 (71.4) ***
Obesity	247 (63.2)	286 (73.1) *

*COPD* Chronic Obstructive Pulmonary Disease; *MI* Myocardial Infarction

\* denotes  $p < 0.05$ ;

\*\*\* denotes  $p < 0.001$