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A Pilot Program in Collaboration with African American Churches Successfully Increases Awareness of the Importance of Cancer Research and Participation in Cancer Translational Research Studies among African Americans

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Abstract

African Americans are underrepresented in cancer research. We evaluate whether collaboration with African American churches can improve cancer awareness and increase participation in translational research protocols among African Americans. From February to April 2010, the Mayo Clinic partnered with African American Jacksonville churches to provide educational programs focused on cancer research and healthy behaviors. Education on multiple myeloma and on-site access to a translational cancer research pilot project evaluating the prevalence of monoclonal gammopathies and t(14,18) in African Americans was offered. Seventy-four percent, 236 out of 318 participants, returned the questionnaires. The majority of participants had never received information on multiple myeloma (67%), had never received clinical research study information (57%), and were enrolled in the translational research studies (55%). Partnerships with African American churches in community education projects that bring research to church venues are effective in improving cancer awareness and in increasing research participation among African Americans.

Keywords

Healthcare disparities; Minority health; Cancer; Multiple myeloma; Monoclonal proteins; t(14,18); African Americans

Introduction

African Americans are underrepresented in cancer clinical research studies [1]. Reasons for underrepresentation in clinical trials include a lack of awareness about research, lack of access to trials, fear and distrust, cultural beliefs, and racial/ethnic discrimination [1, 2]. Lack of access to trials is due to multiple factors including lack of access to facilities that are performing research, been cared for at facilities that are not involved in research, and presence of multiple comorbidities in a higher percentage of patients that make them ineligible for research participation among others.

Despite the fact that African Americans have a greater incidence of monoclonal gammopathies and of multiple myeloma [3, 4], community education programs on these conditions have not been performed in northeast Florida (Duval County) and other regions of our country. In order to increase awareness, access, and participation in cancer clinical research studies and myeloma studies for African Americans in Jacksonville, FL, the Mayo Clinic collaborated with several local African American churches and the Northeast Florida Chapter of the Leukemia and Lymphoma Society to develop a feasibility study evaluating whether a program that brings education on the importance of cancer prevention and cancer research to the African American churches is successful. Understanding that myeloma is a

relatively rare condition and that large-scale efforts to increase knowledge about myeloma as the sole reason for community outreach would not be practical, we decided to incorporate education on cancer prevention with a focus of five simple behaviors that will decrease the risk of common cancers. These behaviors included regular exercise, adequate nutrition with avoidance of obesity, avoidance of excessive alcohol consumption, avoidance of smoking, and promotion of lactation among childbearing females. At the same time, we evaluated if this program would facilitate participation in a myeloma translational research study. The objectives of this project were to: (1) assess the level of knowledge and understanding about multiple myeloma and the importance of research among African American in northeast Florida and (2) determine if adequate participation in a myeloma translational research project is feasible, if this is offered as part of a community education program that focuses on cancer prevention and myeloma in African American churches.

Methods

A total of 12 educational programs focused on multiple myeloma and five behaviors that reduce cancer risk. These behaviors include proper nutrition, adequate fitness, tobacco cessation, breastfeeding, and limited alcohol consumption. The programs were completed from February through April 2010. A majority of the events took place at African American churches located in health zone 1 of Duval County (7 of 12 events). Health zone 1 is the urban downtown area of Jacksonville, and has the highest minority population (83% African Americans) as well as one of the greatest cancer mortality rates in Duval County [5]. The staff met with each pastor, and members from each congregation gave an overview of the educational program and study. The programs were developed in collaboration with a Community Research Advisory Board (CRAB), which is composed of local community and church leaders. The CRAB is charged with ensuring that research is culturally competent and beneficial to the community. Partnerships with the African American churches were facilitated by church leaders from the CRAB. Local fitness and nutrition experts participated by providing interactive demonstrations for the audience. There were additional resources available for participants to find out their BMI, breast and colorectal cancer risk (using the GAIL Breast Cancer Risk Assessment and the NCI Colorectal Cancer Risk Assessment). After each program, participants were surveyed on health, multiple myeloma knowledge, and on their willingness to participate in research. Demographic data (age, race, residential zip code, insurance status, physician access) were also collected.

An IRB-approved translational cancer research pilot project evaluating the prevalence of t(14,18) and monoclonal proteins in African Americans and other racial/ethnic minorities was offered to all participants. Translational research participation was facilitated by a mobile research unit (MRU), a converted RV that has sample collection, processing, and storage capabilities. At each educational program, clinical research coordinators from Mayo Clinic were on location to provide additional study information, administer a study questionnaire, and go through the informed consent process with study participants. Phlebotomists from Mayo Clinic were on location to collect blood samples. All samples were collected, stored, and transported back to Mayo Clinic in the MRU. Demographic information was collected through the study questionnaire. Study enrollees were also surveyed on their willingness to allow their samples to be used for other health research and their willingness to allow other research institutions to use their samples.

Results

A total of 236 out of 318 participants (74%) returned written questionnaires provided during the education events (Table 1). Forty-three percent resided in a health zone of Jacksonville (health zone 1) that has worse health outcomes compared to any other sections of the city

[5]. A majority of the event attendees were over the age of 50, which was the targeted age group for the translational research projects. Eighty-three percent responded that they had some type of health insurance, and 88% had a primary care provider. Sixty-seven percent had never received any information on multiple myeloma, and 57% had never received information about clinical research studies. Sixty percent responded that they would participate in research studies, and 61% indicated that they would participate if the research focused on health issues that impacted African Americans.

A total of 175 out of 318 participants (55%) were enrolled in the translational research feasibility study (Table 2). Seventy-two percent of the research study participants were female, and 77% were African American. Ninety-three percent of all study participants agreed to have their samples used for research of other health conditions, and 85% agreed to have their samples shared with other research institutions. Five of the 175 patients (2.9%) had a detectable monoclonal protein in their serum, all of them consistent with a monoclonal gammopathy of unknown significance (MGUS). Two of the five patients were followed by the Mayo Clinic investigators for management of their MGUS. The other three patients were followed by their primary care physicians. The t(14,18) prevalence study is in progress at this time.

Discussion

Significant disparities in cancer care outcomes and cancer research participation among racial and ethnic minorities exist in the USA. In Duval County, disparities in cancer care outcome have been shown in areas with a higher percentage of lower socioeconomic status families and higher minority percentage [5]. This pilot project demonstrated that there is a need for increasing the awareness about the importance of cancer research and for community education programs focusing on diseases that have a greater incidence among African Americans, like multiple myeloma. Despite the majority of event participants having a primary care physician and health insurance, most participants had never received information/education on the importance of cancer research nor on multiple myeloma. This project also showed that most of the participants were willing and interested in participating in cancer research, if the research is of relevance to their population and is accessible.

There were several components that facilitated the successful completion of this project. First of all, the involvement and collaboration with African American churches and the CRAB in the development and execution of the project were critical. Historically, African American churches have promoted social change and healthy behaviors, in addition to being a place for members and their families to congregate, network, and obtain support [6]. Involving church leaders in the planning stages of the project and consulting with them about the execution of the project facilitated the implementation of the project. Initial attempts at bringing an education program on multiple myeloma as the only subject were not enthusiastically received since most leaders were not aware of the disease. The incorporation of a general cancer prevention topic for the education program increased the interest in the programs and also facilitated their successful implementation. This demonstrates the successful incorporation of efforts at educating communities on less common diseases as part of education programs that address more common health issues. It also demonstrates that participation in research that addresses these less common medical conditions among underserved populations is feasible if incorporated into an education program that takes place within the underserved communities.

The staff met with the pastors of each church and attended church services weeks before the scheduled event. This showed the church leaders and members the commitment of the staff to build trust with the church congregation. CRAB is an important part of engaging

communities in research. The local CRAB was developed to serve as an advisory board that would assist local researchers with ensuring research is culturally competent and provide strategies to include minorities and underserved populations in the research. The CRAB served an important role by evaluating all components of the project. They also served as champions for the project and encouraged community members in their area to participate in the events and the study. When communities are consulted and engaged in the research project, this greatly increases the success of the project [7].

A second important determinant of the success of this project was the incorporation of the translational research study into a single event that brought the research to the community. The focal point of this project was to increase awareness and knowledge about multiple myeloma, overall cancer risk factors, and clinical research. Communities provided with health education can lead to positive behaviors, including early detection, lifestyle changes, and, in the case of this project, participation in clinical research. Prior to this project, a significant number of event participants had not received information regarding clinical trials and/or multiple myeloma. Interaction with clinicians and providing health education via a presentation increased the likelihood of participation in the research study that was offered.

Finally, the use of an MRU physically brought research into communities where access has been noted as a barrier to research participation. Many racial and ethnic minorities are willing to participate in research, but lack of access is a major barrier to participation [8]. Strategies need to be developed to increase access in order to recruit and retain minority research participants [9]. The MRU that was used in this project is a converted 50-ft recreational vehicle that has collection, storage, and processing capabilities. Consenting and phlebotomy staff members were also at each event. The participation rate was greatly increased by providing immediate study access at the time of the event.

Amelioration of cancer care disparities requires educating communities on the importance of cancer research and engaging communities in research projects. The ultimate success of these efforts requires a partnership between the research institutions and the community with carefully planned programs that incorporate education and research access in the community setting.

Conclusion

Lack of knowledge about cancer clinical research and lack of access to research pose significant barriers to research participation among African Americans. The lack of knowledge about cancer, specifically cancers like multiple myeloma, leads to the observed disparities in cancer outcomes. In this project, a high rate of participation in a blood collection translational research project was observed among this predominantly African American population because the research study was incorporated with educational programs that explain the nature of the problem and the benefits of clinical research. Most participants expressed a positive attitude towards research participation. Partnerships with African American churches in projects that provide community education and bring research to church venues with an MRU are effective in improving knowledge about the importance of research and in increasing translational research participation among African Americans. Expansion of this pilot program into other regions of the USA is likely to translate into amelioration of these significant disparities.

Acknowledgments

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Table 1Demographic and health-related characteristics of program attendees ($n=236$)

Characteristics	Frequency, n (%)
Residential health zone	
Zone 1 (urban core)	103 (43)
Zone 2 (Greater Arlington Area)	19 (8)
Zone 3 (Southeast Duval County)	5 (2)
Zone 4(Southwest Duval County)	13 (6)
Zone 5 (outer rim of Duval Co.)	32 (14)
Zone 6 (beaches area)	7 (3)
Outside of Duval Co. health zones	3 (1)
Not reported	54 (23)
Age range	
Less than 30 years	15 (6)
Between 30 and 39 years	11 (5)
Between 40 and 49 years	39 (17)
Between 50 and 64 years	101 (42)
Over 65 years	59 (25)
Not reported	11 (5)
Health insurance status	
Insured	196 (83)
Not insured	38 (16)
Not reported	2 (1)
Primary care provider	
Yes	208 (88)
No	24 (10)
Not reported	4 (2)
Fruit and vegetable consumption	
Eat at least 5 servings each day	70 (30)
Do not eat at least 5 servings each day	160 (67)
Not reported	6 (3)
Physical activity	
Exercise (at least 30 min/3 times a week)	105 (44)
Exercise less than (30 min/3 times a week)	127 (54)
Not reported	4 (2)
Ever received nutrition and physical activity information	
Yes	188 (80)
No	38 (16)
Not reported	10 (4)
Ever received information about breastfeeding (as it relates to breast cancer risk reduction)	
Yes	87 (37)
No	116 (49)

Characteristics	Frequency, <i>n</i> (%)
Not reported	33 (14)
Ever received information on tobacco usage and its relation to increased cancer risk	
Yes	167 (71)
No	53 (22)
Not reported	16 (7)
Ever received information about multiple myeloma	
Yes	47 (20)
No	158 (67)
Not reported	31 (13)
Ever received information about clinical research studies	
Yes	68 (30)
No	132 (57)
Not reported	30 (13)
Interest in clinical research study	
Yes	142 (60)
No	63 (27)
Not reported	30 (13)
Interest in clinical research studies with a focus on AA health issues	
Yes	144 (61)
No	35 (15)
Not reported	57 (24)

Table 2Demographic and health-related characteristics of study enrollees ($n=175$)

Characteristics	Frequency, <i>n</i> (%)
Gender	
Female	126 (72)
Male	49 (28)
Race/ethnicity	
African American	134 (77)
Asian	4 (2)
Caucasian	34 (19)
Hispanic/Latino	3 (2)
Smoking status	
Nonsmokers	94 (53)
Ex-smokers	33 (19)
Current smokers	15 (9)
Unknown	33 (19)
BMI calculation	
Underweight (<18.5)	1 (1)
Normal weight (18.5–24.9)	42 (24)
Overweight (25–29.9)	49 (28)
Obesity (30–39.9)	61 (35)
Extreme obesity (>40)	18 (10)
Unknown	4 (2)
Permission to use sample for other health-related research	
Yes	163 (93)
No	12 (7)
Permission to share samples with other research institutions for health-related research	
Yes	150 (86)
No	25 (14)