



Published in final edited form as:

*J Cancer Educ.* 2015 June ; 30(2): 327–332. doi:10.1007/s13187-014-0721-z.

## African Americans' and Hispanics' Information Needs About Cancer Care

**Teresita Muñoz-Antonia,**

Molecular Oncology Department, H. Lee Moffitt Cancer Center and Research Institute, MRC 3044, 12902 Magnolia Drive, Tampa 33612, FL, USA. Department of Oncologic Sciences, University of South Florida, College of Medicine, Tampa, FL, USA

**Danielle Ung,**

Department of Health Outcomes & Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, USA

**F. Alejandro Montiel-Ishino,**

Department of Health Outcomes & Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, USA

**Alison Nelson,**

Department of Health Outcomes & Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, USA

**Jorge Canales, and**

Department of Health Outcomes & Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, USA

**Gwendolyn P. Quinn**

Department of Oncologic Sciences, University of South Florida, College of Medicine, Tampa, FL, USA. Department of Health Outcomes & Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, USA

Teresita Muñoz-Antonia: Teresita.Antonia@moffitt.org

### Abstract

Few studies have reported on African American and Hispanic (AA and H) populations' informational needs when seeking cancer care at an institution that offers clinical trials. Moffitt Cancer Center (MCC) sought to identify and examine the decision making process, the perceptions, and the preferred channels of communication about cancer care services for AA and H communities in order to develop a list of marketing recommendations. Five focus groups ( $N=45$ ) consisting of two AA and three H were conducted in four counties of the MCC catchment area in Tampa, FL. Participants were asked about their perceptions, knowledge, attitudes, and beliefs about cancer care and MCC. Focus groups were audio-recorded and verbatim transcripts

**Conflict of Interest** The authors of this article have no conflicts of interest to disclose.

**Financial Disclosure** No financial disclosures were reported by the authors of this paper.

Electronic supplementary material The online version of this article (doi:10.1007/s13187-014-0721-z) contains supplementary material, which is available to authorized users.

were analyzed using content analysis. Similarities in responses were found between AA and H participants. Participants received general health and cancer information from media sources and word of mouth and preferred to hear patient testimonials. There were concerns about costs, insurance coverage, and the actual geographic location of the cancer center. In general, H participants were not opposed to participating in cancer clinical trials/research, whereas, AA participants were more hesitant. A majority of participants highly favored an institution that offered standard care and clinical trials. AA and H participants shared similar concerns and preferences in communication channels, but each group had specific informational needs. The perceptions and preferences of AA and H must be explored in order to successfully and efficiently increase cancer clinical trial participation.

### Keywords

Minority groups; Cancer care; Access to health care; Marketing; Health promotion

---

### Introduction

It is vitally important to develop strategies to reduce cancer health disparities in minority populations. Access barriers to cancer care remain one of the key impediments to receiving timely and evidenced-based cancer treatment. Improving minority access to cancer care is also of benefit to the institution, especially in the area of clinical trials, where minority representation is often low. While many strategies to improve minority accrual to clinical trials have been published, the challenge remains to first improve access to the cancer center itself; access barriers to cancer care affect enrollment in clinical trials particularly in racial and ethnic minority and under-served populations who represent less than 15 % of all adult participants in National Cancer Institute (NCI) treatment trials [1–3]. Although data indicate the incidence rates for many cancer sites are lower among ethnic minority groups than among non-Hispanic Whites, African American and Hispanic (AA and H) have a higher risk of mortality and shortest survival rate after a cancer diagnosis than any racial and ethnic group in the USA for most cancers [4, 5]. Given the urgent need to decrease cancer incidence and mortality rates in AA and H populations, understanding the barriers that hinder cancer care seeking behaviors is critical and the necessary first step.

An important aspect of quality cancer care is identifying contributing factors to cancer health disparities that can be influenced by the quality of health communication. For example, with commercial marketing strategies for health promotions, efforts are made to design successful ways to assist at-risk underserved populations' access to health promotions [5]. Within social marketing, audience segmentation is frequently used to understand the needs and preferences of minority and underserved populations [6]. Participants from a larger pool are divided into smaller groups based upon factors such as similar demographics, location, and experiences so that researchers can explore if these factors are predictors of response patterns [7]. The results of this technique can be used to convey messages in the specified communication channel and to the specific audience, increasing the persuasiveness and acceptance of the message [6].

Recent research has identified several factors contributing to racial and ethnic disparities in seeking cancer treatment and clinical trial enrollment [1] that should be addressed when designing communication strategies. Cognitive (e.g., emotional) and structural (e.g., economic issues) barriers commonly reported by AA and H populations include a lack of education about cancer care and facilities, perceived harms of seeking treatment (e.g., side effects), inadequate health insurance, low personal income, lack of transportation, study design barriers (e.g., studies that are exclusive rather than inclusive), cultural and linguistic barriers, and mistrust of health care providers and of research studies due to previous history with discrimination and provider bias [1, 2, 8, 9]. Of particular concern to underserved populations are the costs associated with cancer care. More often than not, immediate survival needs such as food, clothing, and shelter are placed at a higher priority than costs associated with preventative care and treatment of health problems [8, 9], resulting in more frequent reports of a lack of health insurance and access to health care among minorities [10]. For many individuals within the Hispanic population, language and communication barriers with health care providers and in cancer advertisements have resulted in a lack of adequate knowledge about cancer care and a reluctance to seek care and participate in clinical research [11].

To improve the quality of health communications, researchers have implemented a number of key strategies to spark interest in AA and H populations and to improve awareness of cancer clinical trials/research including: group/individual educational sessions, use of educational booklets and audiovisual materials, media campaigns, and church-based project sessions [7]. For example, a recent study interviewed Hispanics to create audiovisual materials in the form of a Spanish-language DVD and accompanying booklet [7]. Such strategies have been successful at increasing cancer clinical trial recruitment rates of minorities [1, 12].

The present study aimed to examine the informational needs and preferred channels of communication of minority individuals when seeking cancer care and to develop a list of recommendations based upon these observations that could be used to promote care to AA and H populations.

## Methods

### Design and Setting

The target audience of this project was AA and H men and women residing in the Moffitt Cancer Center (MCC) catchment area. Five focus groups were conducted, two were comprised of AA community members and three were comprised of H community members, of which two were conducted in Spanish. All focus groups were conducted in a community setting. Each focus group ranged from six to twelve participants.

This study received approval from the Institutional Review Board and a waiver for signed informed consent was obtained. Focus groups were conducted using a guide based on a review of the current literature and previous focus group guides used in similar health services research projects (see Supplemental Material). During each 90 min focus group, led by a trained moderator, participants were asked a series of questions on their perceptions,

knowledge, attitudes, and beliefs about cancer care and MCC. The focus groups were audio-recorded and transcribed verbatim. Spanish focus groups were translated into English. All transcripts were reviewed for accuracy and systematically coded. Transcripts were systematically coded using the constant comparative [13]. A codebook was developed to define each of the themes and to classify and organize data. Key themes and subtopics were selected from the entire transcription based on our study goals and the focus group guide questions. Data were coded independently by at least two researchers, and an inter-rater reliability rate of 90 % was achieved. These methods have been used successfully in a number of research studies [14]. Participants received a US\$25 gift card for their participation.

### Participant Recruitment

Individuals for the focus groups were recruited through flyers, mailings, and community events in the targeted geographic areas. Interested participants called a study toll-free telephone to see if they qualified. Participants who met all eligibility criteria and gave verbal consent were scheduled for one of the five 90-min focus groups.

A total of 45 AA and H individuals were recruited. Eligibility criteria included the following: (1) individuals who were greater than 18 years of age; (2) had no observable psychiatric or neurological disorders that would interfere with study participation (e.g., dementia, psychosis); (3) capable of speaking and reading standard English or Spanish; (4) had a previous cancer diagnosis; (5) had any family member or loved one with a previous cancer diagnosis; (6) not a past or current MCC employee; and (7) did not receive care nor had a relative receive care at MCC. Participants who had associations with Moffitt were excluded from participation to remove any personal bias that may influence the opinions of other participants in the focus group. All study procedures and data analyses were conducted between October 2012 and July 2013.

### Statistical Analyses

Demographic characteristics were summarized using descriptive statistics. Results from the qualitative interviews were analyzed using the interview transcripts and a combination of hand coding and Atlas TI® computer program to identify themes. Interview data was analyzed using content analysis procedures [15]. Transcribed texts for each interview were read and coded by two members of the study team. Excellent inter-rater agreement was established. Transcribed texts for each interview were read and coded by two members of the study team and agreement between the two coders was evaluated using a Kappa statistic. Excellent inter-rater agreement was established ( $k=1.0$ ).

### Results

The majority of participants were between the ages of 30 and 49 years, self-identified as H, and female (Table 1). The original study design included three groups each for AA and H; however, despite focused efforts, recruitment of participants for the third AA focus group was not successful. In the following sections, a summary of the results is provided along with representative quotes from the participants.

## Knowledge and Attitudes Toward General Health Care and Health Promotions and Marketing

Participants indicated that they received most of their health and cancer information from TV commercials, billboards, the Internet (e.g., Web MD, YouTube, blogs), family and friends, and their health care providers. However, participants reported seeing cancer advertisements for only breast, cervical, and prostate cancer. Although participants felt cancer advertisements were informative and necessary for preventative purposes, they noted TV commercials and billboards were not memorable and preferred advertisements that caught their attention with catchphrases and flashy appearances.

In addition, participants favored advertisements on the radio, community events (e.g., fairs; sporting events), DVDs/CDs, newspapers, support groups, and by mail. Older participants preferred physical mail, whereas, younger participants preferred the use of social media and audiovisuals. Almost all participants felt it was very important to be represented in images for advertising. They noted that if the faces in the promotions were similar to them in socioeconomic status and ethnicity, they could relate more to the advertisement and it would provide a catalyst to seek cancer care. AA participants reported wanting someone who was race concordant and had similar socioeconomic status. However, many H felt this was not an issue. They reported that since cancer did not “discriminate”, they did not feel it was necessary for advertisements to be race concordant. Almost all H participants preferred to receive cancer care information in Spanish or have someone who was bilingual convey this information. However, if the person was not bilingual, they wished to have an interpreter who was patient and could explain the information in a comprehensible manner. Furthermore, participants stated that on these advertisements, they would like to hear testimonials of individuals recalling their experiences with cancer and the quality of cancer care they received.

AA participants reported wanting someone who was race concordant and had similar socioeconomic status.

“But on the whole, on the real I think I would rather see somebody look like me, somebody who can relate with me” (AA participant)

However, many Hispanics felt this was not an issue. They reported that since cancer did not “discriminate”, they did not feel it was necessary that the advertisements be race concordant,

“No, no it doesn’t have anything to do with it being Mexican, Puerto Rican, Cuban, Afro-Americans or American... doesn’t matter... as long as the message is in Spanish.” (Hispanic participant)

## Cancer Care Information Needs and Choosing Cancer Care

Many participants reported that they would like to receive the following information about cancer care: education about cancer (e.g., cause of cancer, types of cancer, prevention, cure), treatment options and process (e.g., treatment expectations and the pros and cons of receiving certain treatments), and statistics and general information of specific institutions (e.g., specialization, success rate, availability, support opportunities, and transportation options).

Participants frequently reported that the quality of care, support for the family members (e.g., seminars, workshops), provision of equal care (i.e., providing cancer care regardless of socioeconomic status, age, gender, and ethnicity), and cost and insurance coverage were most important to them and their family when discussing cancer care. Among H participants, the need for documentation and immigration status was frequently mentioned as a reason they were hesitant to seek care at hospitals and clinics. There were concerns among participants about deportation and/or not receiving help. One H participant indicated, *“I have heard many times from the hospital they are going to deport you and due to this, one is afraid and one doesn’t go to the doctor even if one is feeling ill... even if you feel ill you don’t go because of the documents... Because of that some people are afraid that we are undocumented we can be dying and we do not go because we don’t want them to send us back to Mexico because it is difficult to return.”*

### Community Knowledge and Perceptions of MCC

Very few participants reported they had no knowledge of MCC prior to the focus group. Those who were aware of the cancer center reported learning about MCC from TV commercial advertisements, word of mouth, and billboards. A few participants reported they knew MCC conducted research and clinical trials. However, they did not have any basic information about MCC such as its location, qualifications, population served, access to care, and services provided (e.g., transportation, family support services). Despite their lack of information about MCC, many participants expressed interest in going to MCC to receive cancer care because of remarks from community members who had described being satisfied with the care they received from MCC. A participant reported,

“I think if we go to Moffitt, they do not discriminate anyone, Moffitt takes in everyone because I have seen it...” (Hispanic participant)

### Perceptions and Informational Needs for Cancer Research

All participants shared favorable opinions toward cancer research and institutions that conducted research and administered care. Many H participants stated that research gave them hope in finding the cure. When asked if they would participate in cancer clinical trials for research, both groups were open to the idea of participation. H participants reported they would participate as long as it contributed to finding a cure. However, many AA participants reported being more hesitant to “go first” because they did not want to be “first round guinea pigs”.

Despite these reservations, many AA and H participants were in support of being involved in research if it helped other people. For example, a participant stated, *“... If you can use me to maybe help somebody else, the next person you may learn something from me being that guinea pig, so maybe it will help somebody else”*. (AA participant)

### Discussion

The present study examined the perceptions and preferred channels of communication regarding cancer care of AA and H populations. Interestingly, they share many similarities in preferences and concerns. Similar to previous findings [8], participants preferred

receiving health care and cancer care information from the television, the radio, billboards, the Internet, and print media. More specifically, H participants stated that they preferred to have cancer care information presented in a culturally sensitive manner, preferably in Spanish, and explained using lay terms, as opposed to medical terminology. These concerns and preferences are in concordance with recent studies [1, 14].

Access barriers to cancer care and knowledge of clinical trials commonly reported in previous studies were also observed in our study [1, 2, 8]. These barriers included cost, transportation, health insurance coverage, and lack of cancer care knowledge. In particular, H participants in our focus groups were frequently concerned about issues related to lack of documentation and deportation. These fears can influence their decision about when and/or where to seek general health care and cancer care. At times, respondents indicated they often opted not to seek immediate medical treatment even when they were not feeling well. This is problematic given that early detection is one of the most important determinants of patient prognosis for many cancer sites [16]. These barriers must be addressed if disparities in cancer care treatment in the overall H population are to be reduced.

Two frequent concerns across all focus groups were the cost and health insurance coverage of cancer care, which have been commonly reported in past studies [1, 17]. In 2009, over 50 million people were reported to be without health insurance [18] and recently, H were reported to be the least likely to have health insurance of any racial or ethnic group [5]. This is alarming given that in the USA, health insurance coverage is closely linked to access to cancer screening and treatment [19]. Consequently, individuals who are uninsured or have minimum coverage are more likely to be diagnosed at a later stage than those with private insurance and have an increased risk of death after diagnosis compared to patients with private insurance [20].

A majority of participants were willing to participate in clinical trials and looked favorably upon institutions that ran clinical trials and offered cancer care; however, these findings have not always been supported in past studies [21], suggesting that minorities are beginning to have more positive attitudes toward research despite past beliefs that they would be mistreated [10, 22]. Some participants stated that they would not like to be seen as “guinea pigs” but would participate in cancer clinical trials if it helped to find a cure and benefited others. This suggests that recruitment among minority participants in clinical trials may be more effective by correcting misconceptions, reminding individuals of the contribution they can make in finding a cure for cancer, and highlighting the positive contributions of cancer research.

Based upon this study’s results, recommendations for health care providers, researchers and institutions are presented in Table 2. Specifically, in future cancer advertisement endeavors, institutions may best capture the attention of these populations by providing more information regarding the cancer care institutions (e.g., location, specialization, population treated, comparability), providing testimonials of cancer survivors with consideration of race/ethnicity/socioeconomic status, advertising cancer care in the preferred language and using lay terminology, focusing on preferred avenues of communication (e.g., billboards and television advertisements versus booklets and pamphlets), and alleviating these population’s



fears regarding cancer care and research. Similar to previous reports [23], participants relied heavily on word of mouth from family members and friends when making decisions about when and where to seek cancer care. This suggests that one of the most effective ways for cancer education outreach for a cancer care institution may be through local events (e.g., fairs, festivals, church) where individuals and their families can engage in conversations about cancer care and/or through frequently visited websites (e.g., Facebook, medical websites, blogs). This study highlights the need for cancer prevention programs and institutions to be culturally sensitive and relevant to all populations. Health promotion messages must be tailored to meet the needs of the specific for groups and not to be assumed that they are the same across all racial and ethnic groups.

### **Limitations of the Study**

This study is not without limitations. The majority of the participants were female, self-identified as H, and were between the ages of 30 and 49 years old. As with all qualitative research, results are not generalizable to all AA and H populations. Data were collected in one geographic area in west Florida and questions center around an NCI-designated cancer to center; thus, the recommendations may not be applicable to of other areas of the USA. Furthermore, although, outreach attempts were made to AA communities, there was one less AA focus group than originally intended. Some AA individuals complained they perceived these attempts were for marketing purposes and often were not interested to learn about the study.

### **Conclusion**

Barriers to cancer care for minority and underserved populations continue to remain a roadblock to preventative cancer care, treatment, and enrollment in cancer clinical trials. There is a great need to explore the perceptions and preferences of minorities and underserved populations regarding cancer care before strategies are explored and implemented to efficiently and successfully recruit these populations for clinical trials. This study's data suggest that targeted advertising and promotions that provide the information potential consumers need will be more effective in motivating this population to seek care at MCC or another cancer facility; compared to promotions that are expert driven and promote accomplishments or statistics that are less likely related to how consumers make health care decisions.

### **Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

### **Acknowledgments**

This project was supported by an institutional grant from the Division of Clinical Science at Moffitt Cancer Center. Study sponsors have no role in the study design.



## References

1. Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer*. 2008; 112:228–242. [PubMed: 18008363]
2. Carpentera WR, Tyreec S, Wuc Y, et al. A surveillance system for monitoring, public reporting, and improving minority access to cancer clinical trials. *Clin Trials*. 2012; 9:426–435. [PubMed: 22761398]
3. Tisha Moniek F, Pena GD, Chapital BF. Peer reviewed: disparities in cancer clinical trials: an analysis of comprehensive cancer control plans. *Prev Chron Dis*. 2009; 6:1–9.
4. Byers TE, Wolf HJ, Bauer KR, et al. The impact of socioeconomic status on survival after cancer in the United States. *Cancer*. 2008; 113:582–591. [PubMed: 18613122]
5. Society AC. Cancer facts & figures for 2013. Am Cancer Soc. 2013 2013.
6. Rodgers S, Chen Q, Duffy M, et al. Media usage as health segmentation variables. *J Health Commun*. 2007; 12:105–119. [PubMed: 17365354]
7. Quinn GP, Jessica MI, Gonzalez LE, et al. Improving awareness of cancer clinical trials among Hispanic patients and families: audience segmentation decisions for a media intervention. *J Health Commun*. 2013; 18:1–17.
8. Rivers D, Euna M, August IS, et al. A systematic review of the factors influencing African Americans' participation in cancer clinical trials. *Contemp Clin Trials*. 2013; 35:13–32. [PubMed: 23557729]
9. Dignan M, Evans M, Kratt P, et al. Recruitment of low income, predominantly minority cancer survivors to a randomized trial of the I Can Cope cancer education program. *J Health Care Poor Underserved*. 2011; 22:912–924. [PubMed: 21841287]
10. Richardson LD, Norris M. Access to health and health care: how race and ethnicity matter. *Mount Sinai J Med: J Transl Personal Med*. 2010; 77:166–177.
11. David G, Shea JA, Katrina A. Perceived community commitment of hospitals: an exploratory analysis of its potential influence on hospital choice and health care system distrust. *J Health Care Organ Prov Financ*. 2013; 50:312–321.
12. Dew A, Khan S, Babinski C, et al. Recruitment strategy cost and impact on minority accrual to a breast cancer prevention trial. *Clin Trials*. 2013; 10:292–299. [PubMed: 23321266]
13. Glaser, Barney G.; Strauss, Anselm L. The discovery of grounded theory: strategies for qualitative research. New York: Aldine De Gruyter; 1967.
14. Luque JS, Quinn GP, Montel-Ishino FA, et al. Formative research on perceptions of biobanking: what community members think. *J Cancer Educ*. 2012; 27:91–99. [PubMed: 21927867]
15. Kreuter MW, Wray RJ. Tailored and targeted health communication: strategies for enhancing information relevance. *Am J Health Behav*. 2003; 27:227–232.
16. Horner, MJ.; Ries, LAG.; Krapcho, M.; Neyman, N.; Aminou, R.; Howlader, N.; Altekruse, SF., et al. *Seer Cancer Statistics Review, 1975–2006*. National Cancer Institute; Bethesda, MD: 2009.
17. Ellington L, Wahab S, Martin SS, et al. Factors that influence Spanish and English speaking participants' decision to enroll in cancer randomized clinical trials. *Psycho-Oncology*. 2006; 15:273–284. [PubMed: 15973647]
18. De Navas-Walt Carmen; Proctor, Bernadette D.; Smith, Jessica C. *Income, poverty, and health insurance coverage in the United States: 2009*. Washington (DC): 2010.
19. Robinson JMM, Shavers V. The role of health insurance coverage in cancer screening utilization. *J Health Care Poor Underserved*. 2008; 19:842–856. [PubMed: 18677074]
20. Kwok J, Scott M, Langevin AA, et al. The impact of health insurance status on the survival of patients with head and neck cancer. *Cancer*. 2010; 116:476–485. [PubMed: 19937673]
21. Advani AS, Benjamin A, Brown CL, et al. Barriers to the participation of African-American patients with cancer in clinical trials. *Cancer*. 2003; 97:1499–1506. [PubMed: 12627515]
22. Evans KR, Jane Lewis M, Hudson SV. The role of health literacy on African American and Hispanic/Latino perspectives on cancer clinical trials. *J Cancer Educ*. 2012; 27:299–305. [PubMed: 22203466]

23. Meade, Cathy D.; Calvo, Arlene; Rivera, Marlene A.; Baer, Roberta D. Focus groups in the design of prostate cancer screening information for Hispanic farm workers and African American men. Paper presented at the Oncology nursing forum; 2003.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 1**

Race, ethnicity, and age of focus group participants

<b>Eligible participants who took part in focus groups</b>			
<b>Participants</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
African American/Black (AA/B)	9	6	15
Hispanic (H/L)	7	23	30
Total (N=45)	16	29	45
Age			
30–39	5	11	16
40–49	7	12	19
50–59	4	5	9
60+	0	1	1
Total (N=45)	16	29	45

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 2**

## Recommendations for cancer institutions promotions of cancer care

- 
- 1 Provide specific information about the cancer care institution: where it is located, the types of cancer or treatment in which the center specializes; the populations it can treat (e.g., newly diagnosed, preventive care, relapsed/refractory cancers; what types of insurance or charity care offered).
  - 2 Provide testimonials from cancer survivors, specifically from individuals with similar race/ethnicity/socioeconomic status.
  - 3 Advertise cancer care in the preferred language (e.g., Spanish) using lay terminology.
  - 4 Use preferred avenues of communication (e.g., radio and television advertisements versus booklets and pamphlets).
  - 5 Address the population's fears about cancer care and research; identify if standard treatment is available, emphasize the *choice* of clinical trials as opposed to promoting trials as if they were the only option.
  - 6 Recognize that minority communities often rely heavily on word of mouth from family members and friends combined with their own Internet research from consumer sites when making decisions about when and where to seek cancer care. Thus, an effective way for cancer education outreach for may be through local events (e.g., fairs, festivals, church that are not health related) where individuals and their families can engage in conversations about cancer care.
  - 7 Frequently visited social websites (e.g., Facebook, medical websites, blogs) are also a source of information for minority communities and are often used to seek recommendations from others about where or how to access cancer care. This highlights the need for cancer prevention programs and institutions to be aware the cancer health care seeking information is often "triangulated." Individuals make choices when they see positive information about an institution from a variety of course.
-