Black and African-American Outreach Guide

NHPCO
National Hospice and Palliative
Care Organization

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I. OVERVIEW

Introduction

The historic 2008 version of this African-American Outreach Guide begins with a quote from Langston Hughes (1902-1967), "There is no color line in death."[1] In this present climate, one could hear this statement as a plea for hospice and palliative care providers to work aggressively towards the goal of making an impact on decades old statistics.

The National Hospice and Palliative Care Organization's (NHPCO) 2018 Edition of its "Facts and Figures" report, informs that of the 1.49 million Medicare beneficiaries that received hospice care, only 8.2% of those beneficiaries were Black/African-Americans.[2] Moving ahead to the organization's 2020 Edition, of 1.55 million Medicare beneficiaries, Black/African-American utilization remained the same.[3]

In the setting of the COVID-19 pandemic, social unrest, racial health disparities and socioeconomic determinants of health — the year 2020 has demanded a structural shift within the healthcare system and the United States as a whole.

Black/African-American essayist and novelist James Baldwin (1924-1987) said, "The world is before you and you need not take it nor leave it as it is."[4] As the infrastructure of our society modernizes and redefines itself, so must the hospice and palliative care organizations servicing this same social network.

II. HEALTHCARE DISPARITIES

Snapshot of Black/African American Health

Top 5 Leading Causes of Death for Black AA (1980/2017)
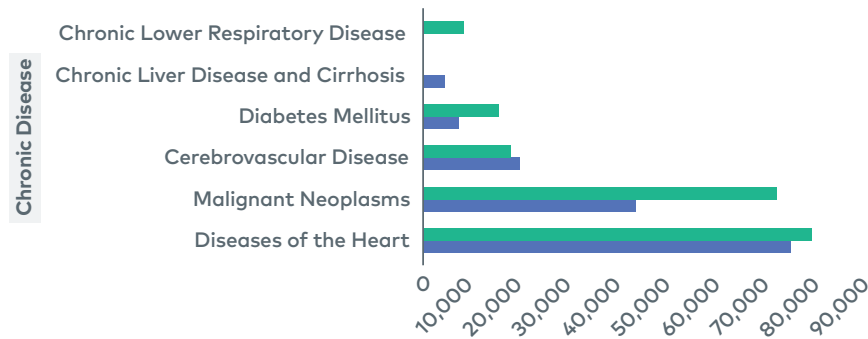
	Diseases of the Heart	Malignant Neoplasms	Cerebrovascular Disease	Diabetes Mellitus	Chronic Liver Disease and Cirrhosis	Chronic Lower Respiratory Disease
■ **2017**	79,318	70,747	19,305	14,989	0	11,365
■ **1980**	72,956	45,037	20,135	5,544	4,790	0

Figure 1. Deaths from malignant neoplasms, and diabetes mellitus increased significantly between 1980 and 2017. Chronic liver disease and cirrhosis was not a top 5 leading cause of death in 2017. Similarly, chronic lower respiratory disease did not rank in 1980.[5]

1   Marchioli, J. (2019, August). African American Outreach Guide. Retrieved November 07, 2020, from https://www.nhpco.org/wpcontent/uploads/2019/08/African_American_Outreach_GuideFull.pdf
2   Ibid.
3   *NHPCO Facts and Figures* (pp. 1-26, Rep. No. 2020 Edition). (2020). Alexandria, VA: National Hospice and Palliative Care Organization.
4   Baldwin, J. (1993). In Search of a Majority. In *Nobody knows my name*. New York: Vintage Books.
5   *Leading causes of death and numbers of deaths*, by sex, race, and Hispanic origin: United States, 1980 and 2017 (Rep.). (2019, October). Retrieved November 9, 2020, from Centers for Disease Control website: https://www.cdc.gov/nchs/data/hus/2018/006.pdf

Top 5 Leading Causes of Death Black AA Men (2017)

Legend:
- Diseases of the Heart
- Malignant Neoplasms
- Cerebrovascular Disease
- Diabetes Mellitus
- Chronic Lower Respiratory Disease

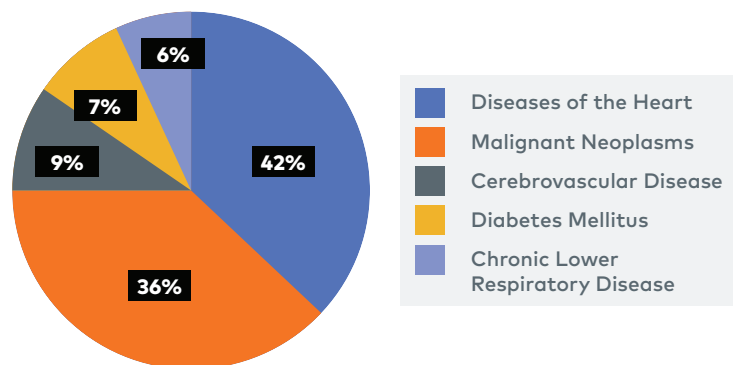Pie chart values: 42%, 36%, 9%, 7%, 6%

Figure 2. Diseases of the heart and malignant neoplasms led all chronic illness deaths for Black AA Men in 2017.[6]

Top 5 Leading Causes of Death Black AA Women (2017)

Legend:
- Diseases of the Heart
- Malignant Neoplasms
- Cerebrovascular Disease
- Diabetes Mellitus
- Alzheimer's Disease
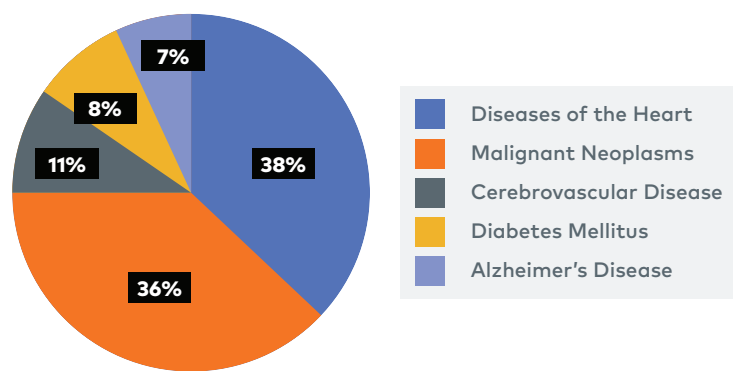
Pie chart values: 38%, 36%, 11%, 8%, 7%

Figure 3. In 2017, Black AA Women also experienced deaths from diseases of the heart and malignant neoplasms at a higher rate than other chronic illnesses. Note Alzheimer's disease appears for the first time among top 5 leading causes of death.[7]

The Concept of Outreach

Community outreach has become a common phrase for organizations looking to invest in the health equity of their communities and decrease health disparities. However, researchers believe that the concept of community health outreach begs further evaluation based on the parameters of programs and the targeted community.[8] A solid understanding of community health outreach can be a useful tool for organizations committed to building relationships with the Black/African-American population.

Although defining the concept of community health outreach presents challenges, providers can operate within the paradigm of a temporary, mobile project in collaboration with the community to promote an intentional health intervention that extends to a targed underserved population — such as Black/African-Americans.[9] It is important to bring attention to the word "temporary" in this definition as it does not speak to launching an initiative for a specified time-frame then disengage. Efforts should be measured for quality and efficacy as hospice and palliative care organizations work towards sustainability while delivering dynamic community outreach programs to Black/African-American stakeholders.[10]

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6   Ibid.
7   Ibid.
8   Young Shin, H., Young Shin, K., & Kang, P. (2020, May 13). Concept analysis of community health outreach. Retrieved November 09, 2020, from https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-020-05266-7
9   Ibid.
10   Sustaining the Work or Initiative. (n.d.). Retrieved November 10, 2020, from https://ctb.ku.edu/en/sustaining-work-or-initiative

Quality: Standard of Practice and Care

Outreach to Black/African American communities should be a Standard of Practice and indicator of an organization's commitment to promoting access to quality care via inclusion. There is a significant population of persons whose health care needs go underserved. According to blackdemographics.com, a website meant to be a single resource for Black/African-American statistics, the 2019 Black/African-American population in the U.S. was 44,075,086.[11] The site also lists the 2020 Census Bureau count for 2019 as 41,147,488.[12] The Medicare distribution of Black/African-American beneficiaries in 2019 was 5,830,500.[13] By investing in community health outreach programs, hospice and palliative care organizations can become preferred providers and known for quality in Black/African-American communities.

NHPCO published a professional development and resource series, "Standards of Practice for Hospice Programs," which includes a section on "Inclusion and Access." For providers interested in offering excellence to Black/African-American stakeholders and the network of organizations that support them — the Standards of Practice recommendations for inclusion and access provides helpful outliers for hospice and palliative care programs:[14]

- **IA 1:** The hospice ensures that patient care and services provided are responsive to the needs of the population.
- **IA 2:** The hospice facilitates access to care by providing services as well as clinical and management staff that are sensitive to the culturally diverse needs of the community it serves.
- **IA 3:** A periodic community needs assessment that examines both private and public resources, with special attention to securing access to care for underserved populations in the community, informs the development and implementation of hospice services.
- **IA 4:** Bereavement education and supportive services are offered to the community at large.

Excellence is to Standard of Practice as quality is to Standard of Care. A hospice and palliative care organization that is intentional about reaching out to the Black/African-American community delivers a Standard of Care relative to the unique health needs of Black/African-Americans. Black/African American culture greatly influences Black health. Cultural competency is crucial to providing quality care while achieving excellence. Standardization of Practice and Care as providers position themselves for health outreach in the Black/African-American community will be key to success and organizational longevity.

Building outreach into hospice and palliative care business strategies is an efficient way to bring about social change, financial sustainability and profitability. Execution of diversity, equity and inclusion (DEI) strategies by diverse executive teams increases the likelihood for an organization to financially outperform its peers.[15]

Consider conducting a Case Story to become inspired to innovate. Following the techniques outlined in this outreach guide, as well as other publications offered by NHPCO's Diversity Advisory Council, can assist your organization with developing strategies commensurate with the needs of its community. The next section of this guide will utilize a significant case story to highlight the theories and procedures discussed in the remainder of this text.

11   POPULATION. (2020, July 12). Retrieved November 08, 2020, from https://blackdemographics.com/population/
12   Ibid.
13   Distribution of Medicare Beneficiaries by Race/Ethnicity. (2020, October 23). Retrieved November 08, 2020, from https://www.kff.org/medicare/state-indicator/medicare-beneficiaries-by-raceethnicity/?dataView=1
14   Standards of Practice for Hospice Programs: Professional Development and Resource Series (pp. 1-206, Rep.). (2018). Alexandria, VA: National Hospice and Palliative Care Organization.
15   Dixon-Fyle, S., Hunt, V., K. D., & S. P. (2020). Diversity Wins: How Inclusion Matters (Publication). Retrieved November 27, 2020, from McKinsey & Company website: https://www.mckinsey.com/~/media/McKinsey/Featured%20Insights/Diversity%20and%20Inclusion/Diversity%20wins%20How%20inclusion%20matters/Diversity-wins-How-inclusion-matters-vF.pdf

In 2020, amid the death of George Floyd and the COVID-19 pandemic, the Black/African-American community also lost the popular, contemporary actor and Howard University alum, Chadwick Boseman. Prior to his death at age 43, Boseman was known for his roles as real-life figures Jackie Robinson in the film "42", James Brown in "Get on Up" and perhaps his most notable role as King T'Challa, ruler of the fictional technologically advanced African nation Wakanda, in the blockbuster, "Black Panther."[16]

African Americans were shocked at the announcement of Boseman's death after a four-year, private battle with colon cancer. "Black Panther" made a significant cultural impact as persons of color across generations witnessed a super-hero that reflected their own likenesses. Furthermore, Wakanda represented a thriving African nation safe from colonizing forces. Through Boseman's role, the film rejuvenated marginalized Black/African-Americans; yet his death alarmed the population about the threat of colorectal cancer in the Black/African American-community.[17]

According to the American Cancer Society, colorectal cancer disproportionately affects Black/African-Americans as the group is 20% more likely to receive the diagnosis and rates are higher than among any racial/ethnic group in the U.S. Roughly 40% of Black/African-Americans with colorectal cancer are expected to die more than other groups as well.[18] As with most health disparities, access to care, cultural risk factors and socioeconomic barriers contribute to colorectal cancer prevalence, timeliness of care and prevention education.[19]

Case stories allow hospice and palliative care providers to pinpoint meaningful events to communities of color and provide context for how business and health outreach strategies might be implemented.

III. STRATEGIES FOR REACHING OUT TO BLACK/AFRICAN-AMERICAN COMMUNITIES

A. GET ORGANIZED

The aforementioned case story provides significant insights about cultural values:

- Despite societal status, Black/African-Americans consider a decline in health as a private, personal journey.
- Cultural icons, historically significant persons or community faith leaders influence acceptance of reality — especially illness, death and grief.
- During a time of communal mourning, related health outreach and education efforts can be a venue for solid relationship building.
- Brainstorm about why specific events may impact the community as a whole and what this can tell you about its values. Research the validity of your perceptions.

Connecting with any community is vital and key to the equitable advancement of the community as a whole. Make sure that all are valued and victorious in receiving access. Connect to the greater community and engage the patient, family and friends and ask what is important to them. The value of observing and listening gives you the opportunity to consider avenues you may not have thought of or even realize were available.

Within the Black/African-American community there are many sensitive and rooted issues that have created a historical pain point for many. Take this into consideration when interacting with individuals or groups within this community:

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16   Chin, A., Taher, A., Thomas, A., Bigham, B., Thoma, B., & Woods, R. (2018, December 26). HiQuiPs: Implementation Part 2 - Which Strategy to Choose: PDSA, Lean, or Six Sigma? Retrieved November 01, 2020, from https://canadiem.org/which-strategy-to-choose-pdsa-lean-or-six-sigma/
17   Pisapia, T. (2020, September 30). The history of Wakanda explained. Retrieved November 28, 2020, from https://www.looper.com/249086/the-history-of-wakanda-explained/
18   ACS Medical Content and News Staff. (2020, September 03). Colorectal Cancer Rates Higher in African Americans, Rising in Younger People. Retrieved November 28, 2020, from https://www.cancer.org/latest-news/colorectal-cancer-rates-higher-in-African-Americans-rising-in-younger-people.html
19   Ibid.

- Clearly define the expected outcome of your strategy.
- Designate the right person to accomplish desired outcomes – Please refer to the Resource Guide as there are certain articles that can provide insight to identifying a Liaison for this area. The Right Person could be:

  - One that is understanding of the issue at hand
  - Respectful of the communities they will be working with
  - Have a genuine interest in decreasing this disparity in End-of-Life Care
  - Will work toward accomplishing these goals to impact and make a difference in the communities they are serving, while representing your organization
  - This person could possibly already exist in your organization or you may have to do an external search

- Conduct one-on-one informational interviews or organize small focus groups to gather data specific to your community.

B. LISTEN TO YOUR COMMUNITY

In supporting the Black/African-American community, it is essential that you do so with a genuine intent and positive approach to building the community up. In short, meet the community where they are!

- Learn to listen more than talk. This is your organization's opportunity to grow a long-lasting relationship with the community it serves.
- When educating, keep in mind that the community will most likely have an idea of what hospice is. Ask questions about one's understanding of comfort care and assist with processing "the big picture" and provide culturally competent information when needed.
- Perhaps a community-based palliative care program might better meet patient and/or family needs.

C. LET YOUR MESSAGE BE HEARD

Whenever and with whomever you engage, do so consistently, with a clear voice that sends the same message every time — "We care, and we are here to support you in all of your needs." Your words and message are critical as you strive to be heard. Referencing the Boseman case story, the following actions would be appropriate:

- Initiate a colorectal cancer outreach effort. Perhaps collaborate with cancer related community organizations, Black/African-American medical providers, social workers and the faith community.
- Use current events to show knowledge of what impacts the Black/African-American community with current patients, families — this will help establish trust.

D. CONSIDER MARKETING

Marketing is just one aspect of outreach and community engagement along with education, public/community relations and sales. If you don't get your message out, who will? Remember that there are many misconceptions about hospice within the Black/African-American community. This is an opportunity to dispel those myths and spread the word about what hospice is and is not!

- **Revise existing collateral or create new materials.** Collaborate with your communications team and be sure that all of your public relations and marketing materials – brochures, newsletters, annual reports, and training manuals – anything that the public will see – offer an accurate representation of your demographics and a thorough understanding of the population you seek to serve. Images that Black/African-Americans will connect with include extended family gathered around the bedside of a loved one, families sitting together and holding hands, and a faith leader praying over a patient with family present.

  It is important to have not only those that are responsible for print to review the materials but ask team members that are Black/African-American how they view the images, as well as your focus group that you assembled to support you in your endeavors. This will save a considerable amount of funding before you go to print as you do not want to put anything out that can offend the community.

- **Work within your systems.** If your hospice is part of a wider healthcare system in which all public relations and marketing are managed by a separate department, communicate well before any advertising is submitted. Don't let anything go out until many eyes have viewed it, especially your own, checking for accuracy of language and appropriateness of images. Since you are the one delivering the message, be sure that the actual materials are ones that are suitable and present the right ideas to draw in the Black/African-American community.

E. BUILD PARTNERSHIPS

The foundation of all outreach is relationships, built over time on deep trust and understanding. Seek them out in both obvious and obscure areas. Commit to fostering meaningful, life-long partnerships with a wide variety of Black/African-American groups in your community. Nurture them and continually re-examine them to be sure they are thriving and mutually beneficial.

- **Engage the entire community.** As discussed in the "Get Organized" section of this Guide, it is imperative to gather support. Your planning team can be comprised of staff and volunteers (with all interdisciplinary team members represented), as well as a wide range of Black/African-American community leaders. Don't leave anyone out! Invite local faith leaders, healthcare professionals, business leaders, academics and students to be a part of the team that will guide your outreach. Invite members to attend meetings and encourage them to consider committing to meeting regularly to provide guidance, suggestions, focus and oversight.
- **Learn about Black/African-American organizations.** There are numerous groups, committees, organizations and coalitions within your community geared specifically towards Black/African-American interests and needs. Some are nation-wide, and others are based right in your own community and serve the needs of your population. Gather this information by simply asking anyone in a position to know, scouring local media, noting community events, surfing the Internet, etc. When you have a fairly comprehensive list and have done the necessary research to learn about their priorities and interest, start reaching out. (Suggestions for how to do this may be found in the next two sections, "Embrace the Faith Community" and "Participate in and Host Community Events.")
- **Link up.** Hospice can be linked to so many causes in your community, presenting perfect partnerships for collaboration. An example is the Balm in Gilead programs, which focus primarily on African-American HIV/AIDS awareness and cervical cancer (ISIS Project). Often, their events will be co-sponsored by local churches. (See the "Embrace the Faith Community" section of this Guide.) By pooling resources on projects and events, the benefits can be enormous.

F. EMBRACE THE FAITH COMMUNITY

Within Black/African-American communities, faith can carry more weight than medicine. Many Black/African-Americans are deeply connected to their faith community and will turn there for support before seeking help from other agencies. The church serves as the bedrock of spiritual activity, a center of social engagement, an indispensable source of information on all topics and a critical foundation of support in times of crisis.

- **Faith is "It."** Studies suggest that Black/African-Americans are willing to participate in health education programs such as smoking cessation, blood pressure and cancer screenings when they are held at their churches, mosques, and synagogues. And since the place of worship is often the primary source of information on a wide range of subjects, it offers one of the best ways to reach the widest audience in a safe, trusted environment.
- **Find your "In."** Begin by identifying the person who handles health-related issues. This might be a lay leader, member of the Diaconate (deacon or deaconess), parish nurse, the head of the congregational care ministry or a social worker who serves as bereavement coordinator. He/she can be your conduit to the pastor (unless you are able to meet with the pastor from the outset). Set up a time to meet and find out the needs of the congregation. If appropriate at the first meeting, offer to host an advance directive or a hospice session. If the church holds its own health fairs, ask to set up an exhibit.

Consider attending services regularly. Come early and stay late for personal introductions and to distribute materials if appropriate. Become a presence in the church. In time, congregants will know you as the hospice contact, and may start coming to you with their needs.

Research shows that there are more than 1,700 church-sponsored outreach programs providing for the spiritual and physical well-being of African-Americans. These programs cover basic needs such as food, clothing and shelter; financial aid and counseling for personal problems; health-related concerns such as HIV/AIDS and substance abuse; and recreation and fellowship for youth and families. So, within this spectrum of faith-based support, be aware that you may be competing with many requests from other groups and simply emphasize that hospice can also be a part of those conversations.

● **The Pastor's role is a critical one.** Not all clergy and faith leaders have the skills to advise families on end-of-life decisions. Be aware that many families will keep their pastor intimately involved in discussions and decisions about their care. Some families will even ask their pastor to be present for at least the initial meeting with hospice admissions staff. Welcome his/her presence and encourage the family to keep that relationship strong.

Generally, pastors emphasize the duality of spirituality and proper medical care, and when serious illness is involved, it is important that he/she understands the wide range of hospice services, and how they can support his/her congregants. Be aware that some families see the pastor's job as praying for healing, first and foremost. While the pastor him/herself will acknowledge that he/she cannot work miracles, the mere suggestion of hospice might be of concern to a family who will perceive it as a pastor turning away from faith and more towards medicine.

Pastors often find themselves negotiating the delicate balance between continuing to pray for hope and healing, but also encouraging the supportive network and resources of hospice.

● **Celebrate life and living, and the role of faith and hope!** Explain that hospice is not about giving up and ending life prematurely, but instead about celebrating life and making the time remaining as meaningful as possible. Hospice's focus is appropriately on life and living, with the ever-present acknowledgement of the role that faith plays. Because faith and healthcare are inextricably linked within Black/African-American communities, your team will be unsuccessful if you avoid spirituality and talk only about medicine. But do emphasize that accepting hospice does not mean the patient must give up faith and hope for healing. Hope is always a part of hospice.

Dr. Bernice Catherine Harper, MSW, MSc.PH, LLD, *shares this perspective on the need to recognize death and dying and views on hospice within African-American communities: "Be aware that African-Americans, like most of us, are not into death and dying; they are into life and living! As a general rule, they see death as going home, and going away from a world of discrimination and hardship. So, they can't get too excited about hospice. To them, hospice is a white, middle class movement, and not one they view as personally applicable. So, we need to help them understand it and be aware of it and present it to people of color in the appropriate cultural context. Be prepared to address the underlying concerns of the patient and family who will respond with, 'Where have you been my whole life? When I needed clothes? Or food? Now you come when I'm dying. But I'm going home. I don't need this now.' We need to break those barriers to healthcare and hospice for African Americans."*

G. PARTICIPATE IN AND HOST COMMUNITY EVENTS

To help make hospice a household term in your community, participate in local community events, especially ones organized by and for Black/African-Americans, or ones that target issues of interest to the Black/African-American community. Organize events and invite everyone to participate. These can be held in conjunction with existing events or independently. Either way, find the appropriate focus and work collectively to plan successful gatherings that energize, inform and bring your diverse groups together.

As with many other elements of your outreach, the key is to take your time and do your research before rushing into things. While most event planning strategies can be effective regardless of your audience, some will be more successful depending on the specific community you are trying to reach. The following essential elements are geared specifically for participating in and hosting events for Black/African-American audiences.

● **Team up.** Don't try to do it alone! As mentioned in the "Build Partnerships" section of this guide, there are many other organizations with whom you can partner and host joint events. Hospice can play a role with health prevention groups focusing on HIV/AIDS, diabetes and cancer, or offering bereavement support to families of accident, suicide or homicide/gang-related victims.

Families affected by homicide or gang violence are a natural outreach for hospice since staff members are experts at loss. Bereavement support to families experiencing loss bridges a gap and shows hospice as an inclusive caring group of experts who seek to help all those who are facing death and dying. However, when referring to what might be perceived as a stigmatizing topic for Black/African-American communities, be sure to avoid the suggestion that the issues are solely Black/African-American problems; homicide, gang violence and crime are universal societal concerns.

H. CONNECT WITH BLACK/AFRICAN-AMERICAN MEDIA

The opportunities to get your message out are plentiful and consider the media outreach as an extension of your outreach plan. Research your local media and determine which are targeted to Black/African-Americans. There are often daily, weekly or monthly periodicals, published by and for the Black/African-American community, as well as radio and television stations (both secular and religious) geared specifically to the same.

- **Research media outlets.** While you may have already done a good amount of market research on your community, as described in the "Get Organized" section of this Guide, do some specific digging to gather all of the information you can on your local media, learning which demographics they target. Turn on your radio and television and tune into their stations. Listen to the advertisements and make lists of popular topics and personalities. This may give you some insight into what's being advertised – by whom and to whom.

   However, because many people not of African descent rely too heavily on the media for research into the Black/African-American community, be appropriately cautious of the information you come across. Many Black/African-Americans will tell you that their community is much different than even the black media portrays them. A good comparison is the representation of Italian-Americans in literature and film, where an almost fantasy version is concocted with its emphasis on mafia ties. The best way to research real Black/African-Americans is to go into their communities and participate in their everyday activities.

- **Make contact.** As you have with all other groups or individuals, make formal and sincere introductions. Explain your intent. But before asking about advertising or articles, get to know key staff members – reporters, publishers, DJs. Invite them to join your advisory group or come to a specific event. As with all of the strategies, a personal relationship will take you much further than throwing collateral at a media representative and expecting it to lead to a prominent feature.

IV. CONCLUSION

NHPCO's Diversity Advisory Council has released a plethora of resources to help make achieving Diversity, Equity and Inclusion attainable for hospice and palliative care organizations. Relevant recourses include:

- "Standards of Practice for Hospice Programs: Professional Development and Resource Series." See section on "Inclusion and Access."[20]
- The position paper, "COVID-19 and Supporting Black Communities at the End-of-Life."[21]
- "Inclusion and Access Toolkit."[22]

All resources are meant to equip organizations with knowledge to develop business strategies, contribute to health equity, and build health outreach programs that represent organizational excellence, quality care delivery and social responsibility.

V. RESOURCE GUIDE

Articles

ACS Medical Content and News Staff. (2020, September 03). Colorectal Cancer Rates Higher in African Americans, Rising in Younger People. Retrieved November 28, 2020, from https://www.cancer.org/latest-news/colorectal-cancer-rates-higher-in-african-americans-rising-in-younger-people.html

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21 McCann-Davis, N., Weiss, T., Harper, D., Duncan, R., Gonzalez, B., Hasan, M. B., Stokes, S. (2020, August). COVID-19 and Supporting Black Communities at the End-of-life. Retrieved December 01, 2020, from https://www.nhpco.org/wp-content/uploads/DAC_Position_Paper.pdf
22 NHPCO Inclusion and Access Toolkit. (2020, November 09). Retrieved December 01, 2020, from https://www.nhpco.org/nhpco-diversity-advisory-council-releases-inclusion-and-access-toolkit/

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Dixon-Fyle, S., Hunt, V., K. D., & S. P. (2020). Diversity Wins: How Inclusion Matters (Publication). Retrieved November 27, 2020, from McKinsey & Company website: https://www.mckinsey.com/~/media/McKinsey/Featured%20Insights/Diversity%20and%20Inclusion/Diversity%20wins%20How%20inclusion%20matters/Diversity-wins-How-inclusion-matters-vF.pdf

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